we all hold the keys

A Report to the Community on Phase Two Activities of the Alzheimer's Challenging Behaviors Task Force

December 2012
This report is dedicated to those who care for and about people who are affected by Alzheimer’s disease and other dementias.
we all hold the keys

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Alzheimer’s Challenging Behaviors Task Force

December 2012

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This report represents the work of literally hundreds of people who, in a variety of ways, care for and about people whose lives are impacted by the challenging behaviors associated with Alzheimer’s disease and related dementias.

It recounts the tragic story of one elderly gentleman from Milwaukee whose death led to the formation of the Task Force on Challenging Behaviors. This story is all too familiar to the estimated 110,000 people in Wisconsin affected by Alzheimer’s. The initial report of the Task Force, entitled Handcuffed, was released in December of 2010 and has since influenced local and national thinking on this important issue. The Handcuffed report pointed to four specific questions that needed detailed and comprehensive answers.

1. How can we assure that people on the front lines of dementia care have the tools and skills they need to intervene and de-escalate behaviors so that legal interventions are not required?

2. What, if any, is the appropriate role for psychotropic medications in the treatment of challenging behaviors?

3. In the aftermath of the Helen E.F decision, what legal interventions can be designed for persons with difficult behaviors that will get them needed treatment in competent facilities while respecting their rights and dignity?

4. How can we assure that police and other first responders know the best ways to respond when they are called to the scene to deal with a person with dementia and difficult behaviors?

The current report, We All Hold the Keys, represents the product of the Task Force’s four work groups which attempted to answer those questions over the last year and a half. It includes the full reports of each of the groups including resources they identified, as well as success stories, data, case studies, recommendations, opportunities to move forward, and challenges to the community.

At the same time, the Task Force worked on the statewide level. Meetings with state associations led to the identification of collaborative opportunities; and the Wisconsin legislature, at the Alzheimer’s Association’s request, established a Legislative Council Committee to study the issue of legal interventions for persons with dementia.

On November 1, 2012, the four work groups presented their recommendations to a Summit attended by more than 150 people. Individuals from all disciplines and walks of life joined to review the reports, comment on the recommendations and receive updates. Key recommendations confirmed at the Summit are summarized inside. Also included are updates on related efforts, a chronology of events both nationally and locally, and a summary of relevant evidence-based and promising practices. Each of these helps depict the growing attention to this nationwide problem.
One thing is certain: this report cannot sit on the shelf. The problem of responding to challenging behaviors is complex and cannot be addressed by a single entity, institution or approach. Helping to assure that these recommendations are implemented will require the collaboration of many people from diverse perspectives. The good news is, as the Task Force itself has demonstrated, those people are ready and willing to get to work.

**call to action**

As part of overall systemic efforts to treat persons with dementia-related behaviors in place and avoid care transitions, we can work together to make Wisconsin more dementia-capable. This report is based upon the realization that “We All Hold the Keys.” Here are just a few suggestions to help put your key to use.

**Training Organizations**
- Incorporate the “Key Concepts in Dementia Training” into your programs (see Resources in the Appendix).
- Provide opportunities for multidisciplinary group problem-solving related to challenging behaviors during your training sessions.

**Direct Care Staff**
- Learn more about Alzheimer’s and other forms of dementia.
- Encourage your employer to invest in training which incorporates the “Key Concepts”.
- Read up on and try out new approaches to person-centered care.

**Residential Care Administrators**
- Commit to following the recommendations of the Training Work Group to your facility and in how you deal with challenging behaviors.
- Set goals and outcomes and explore how dementia training can help you meet them. Look for the Dementia Training Content Inventory on alz.org/sewi/ in 2013.

**Health Care Practitioners, Provider Systems, and Health Care Educators**
- Change current practices in your organizations that may rely too heavily on prescribing psychotropic medications before ensuring that non-pharmacologic interventions have been tried and exhausted.
- Remember that behavior is communication - always consider pain and infection as potential underlying causes.
- When medications are warranted, set the expectation that the dosage will be low and that there is a plan for gradual dose reduction.
- Create continuing education opportunities on the topic. Collect data on the use of all psychotropic medications. Develop more geriatricians, particularly for underserved populations.
Legal System and Law Enforcement Organizations
- Encourage your clients to develop a Power of Attorney for Health Care long before it is needed.
- Continue to advocate for legislative changes to improve the way we treat people with dementia in our legal system.
- Create continuing education opportunities on the topic of dementia.
- Expand dementia-related education and training programs for law enforcement and first responder staff.
- Collect data on the frequency and response to dementia-related calls.
- Continue to strengthen relationships between law enforcement and first responders and the Alzheimer’s Association.

Provider Associations:
- Continue to develop opportunities to share best practices and training modalities in dealing with challenging behaviors.
- Continue to work with other associations, especially hospitals and health care systems, to improve care transitions for people with dementia and the practice of treating in place.

Family Caregivers
- Tell your stories – you have a lot to share. This Task Force was initiated because of one family’s story.
- Learn more about your role as an advocate.
- Use the resources of the Alzheimer’s Association and others in supporting your role as caregiver.

State and Local units of Government and Aging and Disability Services:
Work together to:
- Increase the skill level of crisis team members in responding to dementia-related behaviors, and expand mobile crisis teams to respond to dementia-related calls in both community and facility settings.
- Build crisis capacity by identifying, designating, and adequately funding emergency protective placement facilities all over Wisconsin. Identify barriers and gaps in establishing these facilities and report to the legislature.
- Seek legislative approval for an Alzheimer’s Medicaid waiver program to develop new models of service delivery for higher-cost persons with dementia, including those who have been protectively placed for longer periods of times in psychiatric or medical facilities and become very difficult to discharge to nursing homes or other long term care settings.
- Make Alzheimer’s and dementia education and outreach a central component of State and local public health plans and efforts.
Community Members
• Educate yourself about Alzheimer’s disease.
• Volunteer with the Alzheimer’s Association.
• Become a legislative or policy advocate.
• Contribute financially.

Public and Philanthropic Funders
• Support the expansion of mobile crisis teams and enhance the skills of mobile crisis personnel to recognize and respond to dementia-related behaviors.
• Invest in training for law enforcement and first-responder personnel statewide to help them better respond to calls involving persons with dementia-related behaviors.
• Encourage and fund pilot projects to establish dementia-capable emergency protective placement facilities in settings other than inpatient psychiatric facilities.
• Provide resources to develop models that successfully manage care transitions of persons with dementia from community and long-term care settings to hospitals; and discharges from hospitals back to these settings.
• Increase funding for Alzheimer’s research and care and support initiatives in the federal budget.
• Provide funding to establish models of new residential care settings for persons with dementia who have been protectively placed for longer periods of times in psychiatric facilities and cannot be successfully transitioned to currently available nursing homes or other long term care settings.
• Support the development of “Caregiver as Advocate” education and training tools to better equip family members in this regard.

All
• Continue to collaborate, share ideas, develop new partnerships, strengthen existing partnerships and work toward finding a better way.

We all hold the keys.
the beginnings of the task force

On November 1st, 2012, more than 150 people from all disciplines and perspectives arrived at the Medical College of Wisconsin to take part in a day-long interactive Summit convened by the Alzheimer’s Challenging Behaviors Task Force. The room was filled with physicians, lawyers, nurses, discharge planners, family caregivers, state and county human service personnel, advocates, legislative staff, and public and private long-term care providers. One issue united the diverse Summit attendees: the desire to improve care, support and treatment outcomes for people with dementia who experience difficult behaviors – behaviors that are challenging to everyone who cares about people with Alzheimer’s disease and related disorders.

The Summit represented the culmination of almost two years of work conducted by the Task Force, and was designed to obtain the final set of inputs and recommendations that would go into the report you are reading. Why these people came together and the work that was done to prepare for this day began with a sad story from early 2010.

The Task Force was originally convened following the tragic death in March 2010 of Mr. Richard “Stretch” Petersen. Mr. Petersen was a long-time Milwaukee resident who developed difficult behaviors in a long-term care facility. His family sought help for him at a local hospital, but instead of having the issues resolved, they embarked on a troubling journey that took them through the Ch. 51 legal system and several hospitalizations, finally resulting in Mr. Petersen’s death from pneumonia.

Richard Petersen’s experience was not an isolated incident. The Alzheimer’s Association of Southeastern Wisconsin had consulted over the years with many families who had experienced similar situations and negative outcomes. In order to reach a better understanding of the factors contributing to these situations, the Association convened the first meeting of the Challenging Behaviors Task Force in April of 2010.

From its beginning, the Task Force has been a collaboration between the Alzheimer’s Association and the Planning Council for Health and Human Services, funded at first by the Helen Bader Foundation, and in the second phase by three additional funders; the Greater Milwaukee Foundation, Extendicare Foundation, and the Faye McBeath Foundation. The Task Force began by establishing several founding principles and adhered to those throughout the work. The purpose of the Task Force was to bring different perspectives together to find a common understanding of key issues. It was established as a working body aimed at finding solutions and not at pointing fingers or finding blame. It assumes that all are motivated to find better solutions to this complex problem.

The work of the Task Force over the first year led to the release of an initial report to the community in December, 2010. The report title, Handcuffed, was chosen to reflect not only the handcuffs on an elderly gentleman being transported to the Behavioral Health Complex
in the back of a squad car, but also to the systemic rules and regulations which “handcuffed”
nursing homes and other facilities from treating behaviors in place. The report drew national
attention and influenced the outcome of the Helen E.F. case when the Court of Appeals incor-
porated Task Force findings and recommendations in its decision, which was later upheld
by the Wisconsin Supreme Court.

Defining Challenging Behaviors

Challenging behaviors as identified by the Alzheimer’s Association include “Irritability,
anxiety, depression, sleep disturbances, physical or verbal outbursts, emotional distress,
restlessness, pacing, shredding paper or tissues, yelling, delusions, hallucinations.”

According to the American Geriatrics Society, dementia-related behavioral problems include:

- Repetitive vocalizations
- Psychomotor hyperactivity
- Physical aggression
- Self-neglect
- Resisting help with personal care
- Anger and irritability
- Manic-like behavior
- Disturbance of sleep cycle
- Psychosis
- Depression
- Inappropriate sexual behavior
- Pacing or wandering

In the context of medicine, challenging behaviors are categorized under “Behavioral and
Psychological Symptoms in Dementia (BPSD),” an umbrella term used to describe a group
of non-cognitive symptoms and behaviors that occur in people with dementia. In reference
to BPSD, the Alzheimer’s Association reports, “Studies have found that more than 90 percent
of people with dementia develop at least one BPSD with a significant percentage of these
individuals having serious clinical implications.” This figure is supported by The Alzheimer’s
Society (UK) as well.

2 American Geriatrics Society “Geriatrics Evaluation and Management: Dementia-Related Behavioral Problems,” developed as a resource for clinicians to use as they work through the evaluation and management of geriatric conditions, AGS 2012.
Basic Data

1. More than 5.4 million people living in the United States are affected by Alzheimer’s disease.6

2. Alzheimer’s is the most common type of dementia, accounting for 60-80% of total dementia cases.

3. Alzheimer’s disease is under-diagnosed, and as many as half of those who would meet the diagnostic criteria may not know they have it.

4. Nearly two thirds of people with Alzheimer’s in the United States are women.

5. Older African Americans and Hispanics are proportionately more likely than older whites to have Alzheimer’s disease and other dementias.

6. The majority of people living with dementia are living in the community with an estimated 15% living alone.

7. In Wisconsin, the number the number of people living with Alzheimer’s is estimated at 110,000 people. Approximately 16,800 people live in Milwaukee County and approximately 8,700 in Waukesha County.7

8. The baby boomers will change these numbers dramatically. By 2030 the number in Milwaukee will grow to 21,700, and in Waukesha to 12,700.8

9. Between 60 and 90% of people with dementia experience behavioral or psychological symptoms at some time during the course of their illness.9

10. More than 90% of nursing home residents with dementia experience at least one behavioral disturbance10

11. Two-thirds of people displaying behavioral symptoms related to dementia can be successfully managed with appropriate staff training.11

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7 State of Wisconsin, Department of Health Services
8 ibid
11 Malaz Boustani, MD et al.,”Characteristics Associated with Behavioral Symptoms related to Dementia in Long term Care Residents,” The Gerontologist 45 (2005): 56-61
National and State Efforts Gain Momentum

As the work of the Task Force progressed, other efforts converged to further leverage and reinforce the work of the Task Force.

• In May 2011 the Inspector General of the U.S. Department of Health and Human Services issued a report outlining massive inappropriate drug use among older adults in general and psychotropic medication among those with dementia in particular. The United States Senate Special Committee on Aging held a hearing on the Inspector General’s report on November 30, 2011 titled “Overprescribed: The Human and Taxpayer’s Cost of Antipsychotics in Nursing Homes.” Task Force convener Tom Hlavacek provided invited testimony at this hearing.

• Subsequently, the Centers for Medicare and Medicaid Services (CMS) launched a nationwide initiative to address the medication issue directly. Task Force members played roles on the national Advisory Committee that launched this initiative, and now a Wisconsin effort, the Partnership to Improve Dementia Care is also underway.

• Based on the request of the Alzheimer’s Association, the Wisconsin State Legislature established a Legislative Council Study Committee on Legal Interventions for Persons with Alzheimer’s Disease and Related Disorders. The goal of the Study Committee is to provide clarity on the complex issues of involuntary commitment and treatment of persons with dementia in the aftermath of the Helen E.F. decision. (Additional information may be found in the full report of the Legal Intervention’s Work Group.)

• More generally, this timeframe has been marked by the passage of National Alzheimer’s Project Act and the first-ever National Alzheimer’s Plan as well as the Wisconsin State Alzheimer’s Plan process (see update on page 25), based on input gathered around the state through the Hand in the Plan effort. These are charted on the timeline below.

Chronology of Related Local and National Events

APRIL 2010
Over 50 people attend the first Challenging Behaviors Task Force meeting called by the Alzheimer’s Association after the death of Richard “Stretch” Petersen in March.

DECEMBER 2010
Handcuffed: A Report of the Alzheimer’s Challenging Behaviors Task Force is released to the community at the Helen Bader Foundation.

JANUARY 2011
President Obama signs the National Alzheimer’s Project Act (NAPA) into law.

APRIL 2011
The Wisconsin Court of Appeals finds in the case of Fond du lac County vs. Helen E. F. that Alzheimer’s disease is not a qualifying mental condition under Wisconsin statute Ch. 51 and so people suffering from Alzheimer’s cannot be detained or treated under that statute. The Court finds that Ch. 55 is the appropriate legal venue to use for protective placement and treatment. The Court quotes extensively from Handcuffed in reaching its decision.

MAY 2011
The Inspector General of the U.S. Department of Health and Human Services issues a report revealing extensive inappropriate prescription of drugs for older adults in general and antipsychotic medication for those with dementia in particular.
Setting the Stage for Phase Two

In order to improve outcomes for people with dementia who exhibit difficult behaviors, the Handcuffed report pointed to four specific questions that needed detailed and comprehensive answers.

1. How can we assure that people on the front lines of dementia care have the tools and skills they need to intervene and de-escalate behaviors so that legal interventions are not required?

2. What, if any, is the appropriate role for psychotropic medications in the treatment of challenging behaviors?

3. In the aftermath of the Helen E.F. decision, what legal interventions can be designed for persons with difficult behaviors that will get them needed treatment in competent facilities while respecting their rights and dignity?

4. How can we assure that police and other first responders know the best ways to respond when they are called to the scene to deal with a person with dementia and difficult behaviors?

Throughout the first year of the Task Force, whether by interviews with experts, during conversations with state professional associations, or in reviewing the literature, there was one concept with which everyone was in agreement, and two key over-arching issues that subsequently came into play. The fundamental concept with which everyone agreed is that every effort should be made to subject the fewest people with dementia to legal procedures such as the involuntary commitment system.

Two related over-arching themes stem from this position. The first is the importance of making every possible effort to ensure that people with dementia who exhibit challenging behaviors...
behaviors are treated in place. This means recognizing the challenging behavior as a form of communication and using a person-centered approach to determine the best method of dealing with the behavior. Resources, strategies and training are required to equip people to treat in place and avoid moving individuals, especially when it is against their will. The second overarching theme is that even when every effort is made to treat in place, when transitions are necessary, they must be managed with the greatest care possible. Data indicates that the presence of challenging behaviors is the leading cause for a change in setting. And yet care transitions, whether from the community to a nursing home, from a nursing home to a hospital, or from the hospital to another facility, can exacerbate the challenging behaviors and induce transfer trauma. Health care and rehabilitation systems, and their associated reimbursement systems, are closely examining the issues related to unsuccessful care transitions because they are a leading cause of hospital readmissions and negative outcomes for the care recipient. And yet to date, the successful management of care transitions involving persons with dementia has not been widely studied.

In addressing these issues, Task Force members also met with several State-level groups including LeadingAge Wisconsin, the Wisconsin Health Care Association, the Wisconsin Hospitals Association, and the Wisconsin Assisted Living Association. The purpose of these meetings was to discuss care transitions, and to identify the types of facilities that may be better prepared to deal with the medical and behavioral assessment and treatment of people with dementia who are in need of such care.

Finally, a review of best practices and a search for evidence based practices was undertaken. Key promising and evidence-based practices that resulted from this review are summarized in the Appendix and links to additional resources are provided.
Task Force Phase Two Launches Four Work Groups

On May 12, 2011, with support from the Helen Bader, Faye McBeath, Greater Milwaukee, and Extendicare Foundations, phase two of the Task Force officially launched operations. Four work groups were established and charged with examining the issues in greater detail. The original charge and scope of each work group is presented below and their full reports are included later in the document.

**Legal Interventions** See page 31 for the full report.
Original charge: *Analyze the implications of the recent Helen E.F court decision and track the progress of any proposed legislation, producing recommendations on future guardianship and protective placement issues for people with Alzheimer’s disease.*

**Law Enforcement** See page 41 for the full report.
Original charge: *Increase awareness and training for law enforcement personnel in more municipalities on the topic of challenging behaviors among people with dementia.*

**Psychotropic Medications** See page 45 for the full report.
Original charge: *Make recommendations to reduce the inappropriate use of antipsychotic medications for residents with dementia and promote alternate approaches to behavior management.*

**Training** See page 63 for the full report.
Original charge: *Identify or develop training models and curricula that promote a broad-based understanding of Alzheimer’s disease and related disorders, associated behaviors, and the factors which can influence their occurrence. The group will identify training resources, models, and curricula that have the potential to meet the needs of a) family members, b) community providers of residential and adult day care services, c) emergency responders, d) caregivers and administrators in nursing homes and other skilled care facilities, e) in-home care and hospice staff.*

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**MAY 15, 2012**
The CMS initiative, now titled the **Partnership to Improve Dementia Care** is launched nationwide. Later, a Wisconsin Partnership Initiative is also launched.

**MAY 18, 2012**
The **Wisconsin Supreme Court** issues its decision in the Helen E.F case, and **affirms the Appeals Court ruling** that found that Helen was not a proper subject for treatment under Chapter 51 of the Wisconsin Statutes, and that Chapter 55 is the appropriate avenue to utilize.

**JULY 31, 2012**
The **first meeting of Legislative Council Study Committee** is held.

**NOVEMBER 1, 2012**
The **Challenging Behaviors Task Force Summit** is held at the Medical College of Wisconsin to receive input on Task Force Work Group reports.
The four work groups met many times for over a year under the capable direction and coordination of consultant Sue Kelley to develop the reports and recommendations that follow. In addition to the original charges to the groups, they also identified resources and gaps and made recommendations that would eventually be shared with the participants in the interactive process at the Summit.

While the Work Groups were meeting, more intensive discussions were conducted with the State-level groups. The discussions focused on the issue of care transitions, but also expanded into the concept on integrating mobile crisis teams in the response to difficult behaviors. In addition, several members of the State-level groups were appointed as public members to the Legislative Council Study Committee on Legal Interventions.
At the interactive Summit that took place on November 1, 2012, Dr. Joseph Kerschner, the Dean and Executive Vice President of the Medical College of Wisconsin (MCW) welcomed the group and thanked them for their leadership and dedication to this important issue. Dean Kerschner expressed his appreciation for the important funding provided to MCW researchers which comes from the national Alzheimer’s Association Research Grants Program. He also described how his own family had been affected by Alzheimer’s disease and stated his hope that the Medical College could continue to work with community groups to advance progress on care and treatment initiatives such as this.

Tom Hlavacek, Executive Director of the Alzheimer’s Association of Southeastern Wisconsin, and convener of the Task Force welcomed the many participants and acknowledged the value of the partnership with the Medical College, the support of the local foundations and the amazing contributions of the volunteer Work Group chairs. He also acknowledged the Planning Council for Health and Human Services and Sue Kelley for their excellent consultation services, and the many volunteer members of the Task Force and work groups.

In addition to those who have been involved from the onset, the Summit attracted a diverse number of practitioners and various people from other communities who had not previously been involved with the Task Force. Their perspectives and reactions to the work was warmly welcomed and served to enhance and strengthen the recommendations of the group.

The Summit also provided participants the opportunity to receive timely updates on related issues and efforts. These included: an update on the Legislative Council Study Committee on Legal Interventions provided by Committee member Tom Hlavacek; an update on integrating a crisis response to treat behaviors in place, presented by Wanda Plachecki and Jim Kubicek; and an update on the Committee for Wisconsin Response to Dementia: Wisconsin’s Alzheimer’s State Plan Process, presented by Cynthia Ofstead and Kristen Felten.
Updates on Related Issues and Efforts

Legislative Council Study Committee on Legal Interventions

The Study Committee was requested by the Alzheimer’s Association and with the assistance of Task Force member State Representative Sandy Pasch, was created to examine legal interventions for individuals who have Alzheimer’s disease and related dementias. The scope of the Study Committee is to review and develop legislation related to guardianship, protective placement, involuntary commitment and involuntary treatment for adults with a dementia diagnosis who may or may not have a co-occurring psychiatric diagnosis. The Legislative Council Committee has been meeting since August of 2012 and two Task Force members, Tom Hlavacek and Rob Mueller, Corporation Counsel for Waukesha County, serve on the Committee. Activity to date centers around three draft legislative proposals which involve changes to State Statutes (Chapters 51 and 55), changes to laws pertaining to the administration of medication, and changes to the law regarding power of attorney for health care. Advocacy groups are developing positions on these proposals and a work group has been established to rework the proposals with an expected completion date of December, 2012.

The continued work and progress of the Study Committee can be followed at:
http://legis.wisconsin.gov/lc/committees/study/2012/ALZ/index.html

Integrating a Crisis Response to Treat Behaviors in Place

A second update was provided by Wanda Plachecki, Associate Administrator of Lakeview Health Center in West Salem, WI, and Jim Kubicek, LCSW, Deputy Administrator of the Milwaukee County Behavioral Health Division. Wanda and Jim described local and regional efforts to integrate mobile crisis teams and crisis intervention specialists when difficult behaviors are encountered in facility and community situations. They also discussed issues arising from incorporating dementia-specific information and approaches into mental health crisis teams, and the importance of continuing to train and collaborate with law enforcement and other first responders in these efforts.
Committee for Wisconsin Response to Dementia

A third update on the Committee for Wisconsin Response to Dementia: Wisconsin’s Alzheimer’s State Plan Process was presented by Cynthia Ofstead, Director of the State of Wisconsin Office on Aging, and Kristen Felten, Dementia Specialist in the same office. Cynthia and Kristen stressed that given the demographics, Alzheimer’s disease and related dementias will continue to be a high priority in the State of Wisconsin planning process for older adults. Kristen described the overall goals, progress to date and next steps of the Committee for a Wisconsin Response to Dementia, which eventually will produce a series of reports that will describe what is needed to respond to dementia from its earliest stages all the way through end-of-life care and support.

The identified goals are:
1. People are able to obtain a diagnosis early in the disease process
2. People have access to a variety of services in the community
3. Family caregivers are supported in their role
4. People have access to quality dementia care from paid care providers
5. People with dementia are protected from abuse
6. Increase knowledge base to improve care and find a cure

Summit participants were urged to contact Kristen Felten with any questions regarding the proposed topics or if they have interest in participating in the development of the plan.
Case Studies

The final activities at the Summit were a series of Case Studies based on real-life situations, and an opportunity for all Summit participants to vote on the top priorities that would go into this report. Eight groups of 15–20 participants were created for the purposes of reviewing four different challenging behavior case studies and creating outcomes and approaches based upon a prescribed set of questions and a facilitated discussion. The make-up of the groups was pre-determined to assure the representation of diverse disciplines in each group (e.g., direct care staff, medical practitioners, administrators, and others). The scenario described below serves as an illustration of the case study process.

Sample Case Study

Jenny has resided at an assisted living facility’s dementia unit for the past seven months. She can become upset at times, but is easily redirected. Last week, Jenny struck out and injured another resident; as a result, staff sent Jenny to the hospital where she was evaluated, medically cleared, and returned to the facility. Since Jenny has been back, she has hit two additional staff members and another resident. Staff contacted the police but they stated they would not be involved in this situation, and asked the facility to find a solution. The facility called an ambulance to have Jenny taken back to the emergency room where she was again medically cleared. At this point, the facility feels that Jenny is too much of a danger to other residents and will not accept her back.

1. What is the best outcome we want to come from this case? How would we proceed to achieve this?

The best outcome for Jenny is a smooth transition back to the same facility, while addressing the underlying cause of her behavior. We would seek answers to the following questions to determine why she is striking out at others:

• What’s happened in her world during the last week? If Jenny is able to communicate, start by asking her as well as staff and family members.
• What did the other person do that may have caused her to act this way?
• Did anything change or happen in the environment? Also look at time of day/where/who else was present
• Was there a change in health status -- medications, sleep patterns, possible UTI or pain as a result of a fall?

One possible approach is to create a “safe room” or “safe space” at the facility for Jenny to use when behaviors start to escalate (since she is capable of being re-directed, separate area or living “safe space” in her room may be helpful)
2. What resources do we have in place to accomplish this?

- There are many assessment tools and resources to draw upon
- Training programs are available to help develop a person-centered approach to care
- Potential resource people at the facility to help determine answers include housekeepers, beauticians, and other residents
- Depending upon the county, there may be access to Mobile Crisis, Adult Protective Services, or Family Care Case Managers
- Primary Care Physician
- Ombudsman from the Board on Aging and Long Term Care

3. What is missing or keeping us from achieving this best outcome?

- The incentive for the facility to take challenging residents back; fear on the facility’s part, resident safety and being afraid of liability; or negative publicity
- Need to change the default from “getting the person out of here” to “what can we do to keeping this person in place?”
- Can staff accompany Jenny to the ER? Or someone familiar to her?
- Has her medication list been communicated to all, including the primary care physician, facility, hospital, family members?
- Follow up with a geriatrician or a geropsychiatrist (shortage is especially acute of those who are bilingual)
- At some point, a medication could be appropriate
- Access to a mobile crisis team or a ch. 55 facility for protective placement
- Designation within facilities of “safe spaces” for residents like Jenny
- Adequate training
- Best practice protocols
- A “culture of care”

In reporting their findings to the large group, participants in this Case Study scenario noted that the process of convening a group of diverse staff around a specific resident’s behavioral issue could be replicated at their organizations. There was agreement that it was helpful to hear from a number of perspectives and that problem-solving is often easier (and quicker) when done by a group.
Priority Setting at the Summit

The work group recommendations were vetted by the full group of Summit attendees in facilitated discussion, and oral and written feedback was provided. This input was intended to influence and improve the final set of recommendations and priorities. Specifically, participants were asked to identify what stood out in the presentations that should be emphasized and highlighted in this report to the community; what additional information is needed, and what issues are priorities and most important to work on first. Based on this feedback, Summit participants were asked to assign priorities to a set of eight recommendations that emerged from the discussion.

On a scale of one to four, with one being the lowest and four being the highest priority, participants at the Summit rated the recommendations stemming from the presentations and discussion as follows.

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<tr>
<th>RATING</th>
<th>RECOMMENDATION</th>
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<tr>
<td>3.6</td>
<td>1. Fund training on non-pharmacological care and support institutional culture change to assure that behavioral approaches are the preferred mode of treatment.</td>
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<td>3.5</td>
<td>2. Non-pharmacological approaches to treatment should be the default for people exhibiting challenging behaviors due to Alzheimer’s. Emphasize, develop and train on effective practices.</td>
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<tr>
<td>3.4</td>
<td>3. When psychotropic medications are used, dosage should begin at a minimum level and a care plan should be established for regular review and reduction.</td>
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<td>3.4</td>
<td>4. Develop a mobile response service specific to dementia, including care for those with early onset and dual diagnosis.</td>
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<td>3.3</td>
<td>5. Continue to work collaboratively to define key services and characteristics of a Chapter 55 facility.</td>
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<td>3.3</td>
<td>6. Designate an emergency protective placement facility for use by each county.</td>
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<td>3.3</td>
<td>7. Pilot the recommendations of the work groups by implementing, collecting data, and evaluating results. Assess for replicability and sustainability.</td>
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<tr>
<td>2.9</td>
<td>8. Fund training for law enforcement and expand to include other first responders in Milwaukee and throughout the State.</td>
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work group reports

This section brings together the detailed reports submitted by the four work groups: **Legal Interventions, Law Enforcement, Psychotropic Medications, and Training**. Each report provides detailed background information to set the context and identifies the work group leadership, their original charge, a short chronology of their activities, key findings, identified barriers and difficulties encountered in their work, their recommendations, useful resources, a success story and their challenge to the community. Each report also includes the reaction and response of the Summit participants, following the summary presentation and small group discussion.
LEGAL INTERVENTIONS AND LAW ENFORCEMENT WORK GROUPS:
background

Wisconsin Legislative Council Special Study Committee
Currently, there is statewide attention directed to the legal interventions available to handle some of the challenging behaviors exhibited by people with Alzheimer’s disease. In addition to the Legal Interventions and Law Enforcement Work Groups of this Task Force, there is a State Legislative Council Special Committee on Legal Interventions for Persons with Alzheimer’s Disease and Related Dementias, which was first convened in July 2012. Its scope:

"The Special Committee is directed to review and develop legislation to clarify the statutes regarding guardianship, protective placement, involuntary commitment, and involuntary treatment as they apply to vulnerable adults with a dementia diagnosis who may or may not have a co-occurring psychiatric diagnosis."

The case of Fond du Lac County v. Helen E.F.
This Legislative Special Committee was convened at the request of the Alzheimer’s Association of Southeastern Wisconsin, following the release of its 2010 Alzheimer’s Challenging Behaviors Task Force report, Handcuffed, and made more urgent by a Court ruling which removed the use of one particular legal intervention because it was judged to be inappropriate for people with dementia. Specifically, in May of 2012, the Wisconsin Supreme Court upheld the ruling of the Court of Appeals in the case of Fond du Lac County v. Helen E.F in which the Court looked at legal avenues for the involuntary care of someone with Alzheimer’s disease. Two state statutes were examined for their appropriateness in this case: ch.s 51 and 55. The Helen E.F ruling, in brief, held that “a person with Alzheimer’s disease who does not also have a ‘ch. 51 qualifying illness’ is more appropriately treated under the provisions in ch. 55, Stats. than those in ch. 51, Stats., and therefore may not be involuntarily committed...” The Court of Appeals had determined that ch. 51 was inappropriate for the involuntary commitment of Helen E.F because Helen’s diagnosis was Alzheimer’s disease, a degenerative brain disorder -- not a mental illness. The Court noted that this type of brain disorder is not included in the authority of ch. 51, but is included under ch. 55 which covers emergency protective placements. Furthermore, the Court of Appeals stated that ch. 51’s purpose is to provide rehabilitative treatment, however since Alzheimer’s disease is not treatable, ch. 51 again does not apply. The Court went on to highlight two specific provisions of ch. 55 which makes it a more suitable vehicle in the case of people with Alzheimer’s disease: placement options and the appointment of a guardian ad litem.

One problem left open by the Supreme Court is that what to do with people who have dual diagnoses of Alzheimer’s disease and a mental illness or another ch. 51 qualifying illness.

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Brief summary – ch. 51 and its provision for emergency detention
According to the Staff Brief prepared for the Legislative Council Study Committee,:\[13\] Ch. 51 establishes the procedures and criteria under which an individual who is mentally ill, drug dependent, or developmentally disabled may be involuntarily detained and subsequently committed for treatment…Under the emergency detention process, an individual may be detained only if they meet all of the conditions for detention. These are as follows: a) the individual is mentally ill, drug dependent, or developmentally disabled; b) the individual is a proper subject for treatment; and c) the individual is believed to be dangerous because he or she has exhibited any of the following behavior:

- Behavior demonstrating a substantial probability of physical harm to self or others, such as threats, suicide attempts, or violent behavior.
- Behavior demonstrating a substantial probability of physical impairment or injury to self from impaired judgment.
- Behavior demonstrating that, due to mental illness or drug dependency, the individual cannot satisfy his or her own basic needs of medical care, shelter, or safety, which will cause imminent death, injury, debilitation, or disease without prompt treatment. [s.51.15 (1) (a) and (b), Stats.]” (p.8)

Brief summary – ch. 55 and its provision for emergency and temporary protective placement
According to the Legislative Council Staff Brief cited above, “A sheriff, police officer, fire fighter, guardian, or representative of a county department may take an individual into custody and transport them [sic] to an appropriate medical or protective placement facility for emergency protective placement if all of the following are true:

- It appears probable that an individual is so totally incapable of providing for his or her own care or custody that if he or she is not immediately placed, a substantial risk of serious physical harm to the individual or others will occur.
- The individual’s inability to provide for his or her own care is a result of developmental disability, degenerative brain disorder, serious and persistent mental illness, or other like incapacity.
- The person making the emergency protective placement either personally observed the individual’s behavior, or received a reliable report of the behavior from a person who identified himself or herself to the person making the emergency protective placement.” (p.16)

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13 Matthias, Mary and Larson, Brian Staff Brief Legal Interventions for Persons with Alzheimer’s Disease and Related Dementias Wisconsin Legislative Council, SB-2012-05, July 25, 2012.
“Protective placement services may include

- Outreach
- Identification of individuals in need of services
- Counseling and referral for services
- Coordination of services
- Tracking and follow-up
- Social services
- Case management
- Legal counseling or referral
- Guardianship referral
- Diagnostic evaluation
- Any services that, when provided to an individual with developmental disabilities, degenerative brain disorder, serious and persistent mental illness, or other like incapacity, keep the individual safe from abuse, financial exploitation, neglect, or self-neglect, or prevent the individual from experiencing deterioration, or from inflicting harm on himself or herself or another person [s 55.01 (6r), Stats.] (p. 19)

At the time a petition for protective placement is filed, an attorney is appointed to serve as the guardian ad litem for the individual. Without a special order, protective placement takes place in an unlocked unit and cannot take place in a unit for acutely mentally ill people, e.g., a psychiatric hospital. It is worth noting that there is no emergency protective placement facility designated in Milwaukee County, nor in many counties throughout the state.

Ch. 55 allows for a greater degree of protection for an individual with Alzheimer's disease given the requirement that a guardian ad litem be appointed to provide long-term protection for the individual; this is not a provision in ch. 51. In addition, the use of ch. 55 for someone with Alzheimer's disease is consistent with the principle of “least restrictive setting possible”, given the alternative of a locked psychiatric facility used for ch. 51 emergency detentions.

**Brief summary – ch. 155**

The Legal Interventions Work Group also examined the Power of Attorney for Health Care (POAHC) as another legal vehicle to use with individuals with dementia. This document, under ch. 155 of the State Statutes, allows an individual to designate an “agent” to make health care decisions on his or her behalf in the future, consistent with the desires of the individual or “principal”. In order for a signed POAHC to be used, it must be activated by two physicians (or a physician and a licensed psychologist) specifying that the principal is incapacitated. With an activated POAHC, an agent can agree to the voluntary provision of psychotropic medications to the individual, however when the individual does not want to take the medications, the POAHC’s authority is limited.

Changes to ch. 155 to allow for greater authority for the Power of Attorney for Health Care agent are controversial. The balance between the individual's rights and protections is sometimes difficult to navigate.
The Helen E.F. Ruling and its impact on law enforcement
The Helen E.F. ruling changed the ability of law enforcement personnel to place a person with Alzheimer’s disease in emergency detention under ch. 51. Police officers, fire fighters, paramedics, and other first responders were left without an alternate plan, outside of assessing the individual for a ch. 51 qualifying condition or informing callers to handle the situation on their own. This has left law enforcement officers in a difficult situation, given their lack of expertise and training in determining what dementia is and what may be something more than dementia. It is safe to say that education and training efforts related to dementia and challenging behaviors for first responders have not kept pace with changes in the application of legal interventions.
WORK GROUP REPORT: legal interventions

Original charge to work group:
Analyze the implications of the recent Helen E.F. court decision and track the progress of any proposed legislation, producing recommendations on future guardianship and protective placement issues for people with Alzheimer’s disease.

Short chronicle of work group activities:
The work group met twice in 2011 (November 9th and December 15th), and five times in 2012 (January 23rd, February 27th, June 27th, July 23rd, and August 29th). Work group members also attended three full Task Force meetings (November 9th, February 8th, and June 6th) during this time period.

Participating in the work group were representatives from the Wisconsin Public Defender’s Office, Waukesha County Corporation Counsel, Waukesha County Adult Protective Services, current and former staff from the Milwaukee County Behavioral Health Division, attorneys in private practice, skilled nursing facilities and assisted living facilities, a representative of a health care system, the Guardianship Support Center of the Coalition of Wisconsin Aging Groups, Disability Rights Wisconsin, the Alzheimer’s Association of Southeastern Wisconsin, former caregivers, and other advocates.

By consensus, the group agreed to the following working philosophy to guide its recommendations.

Minimizing care transitions for people with dementia is highly desirable. We need to create a system where involuntary administration of medication is the last resort. When it becomes necessary, medication should be administered on-site to the extent possible.

Work Group Co-Chairs:
Attorney Rob Mueller,
Corporation Counsel Office of Waukesha County
Attorney Dennis Purtell
Wisconsin State Public Defender’s Office
Key Findings

• Interpretation as to how ch. 51 should/should not be used varies among counties throughout the state.

• More attention should be directed to getting people to complete advance directives before it’s too late.

• The Supreme Court ruling on Helen E.F differs from the Court of Appeals ruling in that it does not say that Alzheimer's disease is not a commitable illness under ch. 51. Instead the Supreme Court ruling focuses on the issue of treatability. The work group noted that in the future, Alzheimer’s disease could be considered a treatable disease.

• The Supreme Court did not decide what course should be taken, i.e., ch. 51 or ch. 55, when the subject has a dual-diagnosis.

• Current law allows for psychotropic medications to be administered in residential settings which would minimize care transitions. However two barriers limit this from occurring: 1) facilities have limited access to a psychiatrist or geriatrician needed to administer the medication; and 2) the overall reluctance on the part of facilities to administer psychotropic medications due to the “chemical restraint” issue.

• Mobile crisis programs are useful in minimizing unnecessary care transitions because of their proven cost-effectiveness and their ability to treat-in-place.

Barriers and difficulties in achieving work group outcomes

• The Helen E.F Supreme Court decision was not issued until May 18, 2012.

• The lack of statewide uniformity in terms of education, training, and responses to dementia-related crises made it difficult to develop a consistent approach from the group, i.e., the resources vary from county to county.

• Lack of funding designated for emergency placement and mobile crisis teams across counties limits our ability to make recommendations re: appropriate levels of care, although these interventions are recognized as being effective.

• In the current system, temporary guardianships are often filed without regard to a person’s need for a permanent guardian.
Work Group Recommendations

A. Revise ch. 51,
   1. to include the following bolded statement in ch. 51.01 (13) (b),
      
      (b) “Mental illness,” for purposes of involuntary commitment, means a substantial disorder of
      thought, mood, perception, orientation, or memory which grossly impairs judgment, behavior,
      capacity to recognize reality, or ability to meet the ordinary demands of life, but does not include
      alcoholism or people with degenerative brain disease.

   2. to provide a definition of “dual diagnosis”.

B. Revise ch. 55,
   1. so that law enforcement should be required to contact the County of Responsibility
      to approve the detention, in a manner similar to ch. 51;
   2. so that every County designates an emergency protective placement facility or facili-
      ties with three levels of care: protective placement, stabilization/transition, and return
      to the community. The facility (ies) should have the capacity to provide medical evalu-
      ation as well as psychological expertise to assess incapacity.
   3. Individuals whose cases are converted from ch. 51 to ch. 55 should be moved to a Ch.
      55-approved facility within 72 hours of the conversion.
   4. In order to comply with the Olmstead Decision, more funding should be designated
      for ch. 55 placements.

C. Revise ch. 155,
   1. to incorporate language that allows for the Agent of a person with a degenerative
      brain disease to consent for necessary care, including admitting the Principal to a facil-
      ity for psychiatric or psychological evaluation and treatment, which could include the
      administration of psychotropic medication.
   2. to require that Counties ensure that necessary protective placements and guardianships
      are filed;
   3. to ensure that if temporary guardianship or protective placement proceedings are filed,
      the filing attorney is required to file for permanent placement or guardianship, unless
      the Court excuses her/him from doing so;
   4. to add under the "powers" provisions, a checkbox with language allowing an Agent to
      admit the Principal to acute psychiatric care, including a notation that the admission
      procedure and reviews requirements of 51.10 (4m) apply. This is recommended along
      with a modification to ch. 51.10(8) so that in addition to persons under guardianship,
      it includes persons with an activated Power of Attorney for Health Care that gives
      the Agent the authority to admit to acute psychiatric care, as long as said admissions
      are subject to the admission provision 51.10(4m)(a)1 and that section’s review provi-
      sions in 51.10(b), (c) and (d). (Note: the intention of this recommendation is to enable an
      Agent to follow the same review process as a Guardian if approval has been indicated by the
      Principal in the Power of Attorney for Health Care document).
D. Other recommendations

1. Every County should establish mobile crisis teams trained in responding to people with dementia.

2. Training should be required of Adult Protective Service workers, Mobile Crisis Team members, ADRC staff, and others who come into contact with people with dementia in order to ensure that members of this vulnerable population retain their rights and are served in the least restrictive environments.

3. The funding of emergency protective placements is an unaddressed issue that needs further analysis. The State and counties should work together to establish an adequate system of funding for emergency placements in county designated facilities.
Success story:

Anne and Bob Smith, both in their early nineties, lived independently in the community for many years. For most of their retired years they have been active with their church, their grandchildren, and in various community volunteer roles. Over the past two years, however, Anne’s health has declined. She fell in their driveway, hit her head and fractured a hip. She completed a rehab stay at a local nursing home and returned home, however she was no longer interested in or capable of doing many of the things she previously enjoyed. Consequently, Bob assumed the role of serving as her primary caregiver. As her physical health continued to decline, Anne needed more hands-on care. She also began having significant mood changes; she was verbally aggressive and uncooperative with the care her husband tried to provide at home. She began having episodes of sleeplessness, confusion, and paranoia. She became both verbally and physically abusive of her husband and their children when they tried to intervene. The police were called one night when she tried to leave home.

The family contacted Waukesha County the day after the wandering incident and the case was referred to Adult Protective Services (APS) staff. When APS intervened, there were serious concerns that Anne was dehydrated and had a urinary tract infection. She had not been eating or taking her medications as prescribed. Her husband felt he was unable to provide for her care or safety. Anne’s Power of Attorney for Health Care had not yet been activated, and Anne was not agreeable to going to see the doctor or a hospital on a voluntary basis. APS called emergency medical personnel to the home; they completed the ch. 55 emergency protective placement assessment and paperwork. Anne was then taken to the hospital for medical clearance and held in Waukesha’s ch. 55 protective placement facility. Her Power of Attorney for Health Care was activated. Waukesha County pursued a temporary guardianship and temporary protective placement that would allow the guardian the ability to place Anne in a facility that could meet her escalating physical and behavioral needs. Anne was safely transitioned to a community-based residential facility closer to her home.

Despite her initial protest about placement, within three weeks her overall physical status, cognitive status, and mood had greatly improved; she no longer contested the placement. Bob decided to move to the same facility to be with his spouse of seventy years. He was greatly relieved that he was no longer isolated in the community. Permanent guardianship and protective placement were not pursued as the activated Power of Attorney for Health Care was sufficient to gain access to the appropriate medical and placement services for Anne.
Opportunities to move this issue forward:

Two work group members have been named to a State Legislative Council Special Committee on Legal Interventions for Persons with Alzheimer’s Disease and Related Dementias, which was first convened in July 2012.

Challenge(s) to the community:

- Each County is called to establish a therapeutic ch. 55 facility(ies)
- The State should adequately assess and fund these facilities
- Ch. 55 facilities should share information and learn from best practices

Summit Response to the Report of the Legal Interventions Work Group

Participants at the Summit indicated they were pleased to see that legislative changes were being proposed and considered. They suggested that it will be important to include several components in the proposed legislation. Specific recommendations made by Summit participants were to:

- Develop comprehensive protocols and procedures on protective placement facilities that can be followed throughout the state;
- Provide a clear description of what services are required in ch. 55 placements, including guidelines and regulations;
- Recognize the urgency of the immediate need to have a place where people can go now; Consider the use of existing facilities, regional centers, and families;
- Develop the resources to equip facilities and train staff; and
- Recognize the importance of minimal standards, best practices, criteria, and capacity and the full continuum of care that is required.
WORK GROUP REPORT:

law enforcement

Original charge to work group:
Increase awareness and training for law enforcement personnel in more municipalities on the topic of challenging behaviors among people with dementia.

Short chronicle of work group activities:
The work group met twice in 2011 (November 9th and December 6th), and four times in 2012 (January 17th, February 28th, April 19th, and June 25th). Work group members also attended three full Task Force meetings (November 9th, February 8th, June 6th) during this time period.

Work group members included representatives from the Alzheimer’s Association of Southeastern Wisconsin, the Milwaukee Police Department, the Milwaukee Fire Department, the Milwaukee County Department on Aging, assisted living facilities and skilled nursing facilities.

The work group reviewed existing law enforcement training efforts and resources, looked at additional resources, sought additional training opportunities, and developed a set of recommendations.

Key findings:

• Law enforcement officers were largely unaware of the change in State statutes ending the use of ch. 51 for emergency detention of people with dementia. This change in the statutes eliminates an option for law enforcement in dealing with challenging behaviors.

• Law enforcement officers are not in a position to determine if someone is exhibiting challenging behaviors solely due to dementia, making it difficult to know if ch. 51 does or does not apply.

• Milwaukee lacks an adequate mobile response capacity specific to dementia and challenging behaviors; the existing Mobile Urgent Treatment Team (MUTT) does not respond between the hours of 4pm – 8am.

• Law enforcement officers lack awareness of key resources available to help deal with challenging behaviors situations, e.g., Milwaukee County Department on Aging’s Adult Protective Services (APS) staff, and the resources of the Alzheimer’s Association.

• The Milwaukee Police Department has trained approximately 400 officers in dementia approaches (via the Alzheimer’s Association and Milwaukee County Department on Aging) in its Crisis Intervention Training (CIT) Program, and has trained an additional number of new recruits in the Police Academy. This training has now been “institutionalized” in new CIT Training, CIT in-service training, and Police Academy training.
Barriers and difficulties in achieving work group outcomes:

• Loss of work group representation from the Milwaukee Fire Department due to a change in work schedule
• For Emergency Medical Technicians, dementia training is not provided; EMTs are expected to do training on their own time since there is no budgeted staff time
• While quality dementia training materials tailored to law enforcement are available, providing it to the general police population is hampered by other required training and the lack of feasibility of using roll call as a training venue
• A separate group (including the Milwaukee County Department on Aging and the Alzheimer’s Association of Southeastern Wisconsin) had begun meeting with the suburban police departments to bring dementia training to more municipalities, so the work group did not want to duplicate their efforts, which are still ongoing.

Work Group Recommendations:

• Use the 2012 Helen E.F. ruling on ch. 51 as a window of opportunity for providing training to law enforcement entities in Milwaukee County municipalities re: alternative approaches for dealing with challenging behaviors.
• If a challenging behavior cannot be handled using the approaches suggested in the dementia training, law enforcement personnel should offer to take the person and their caregiver to a hospital to determine if there is an underlying medical issue. If the caregiver is unable or unwilling to accompany the person, the Milwaukee County Department on Aging should be contacted for assistance.
• Milwaukee County should develop a mobile response capacity specific to people with dementia. The Milwaukee Police Department should be involved in planning this capacity.
• Milwaukee County should create a ch. 55 facility in order to provide an immediate resource for officers to bring people who do not fit ch. 51 but are unable to be cared for in their current living situation.
• Ensure that all law enforcement personnel are given information about the Alzheimer’s Association 24/7 Helpline, and Milwaukee County’s Department on Aging/Adult Protective Services staff.
• Begin tracking calls and follow-up responses within law enforcement agencies re: challenging behaviors

Resources identified to share with others:

• Medic Alert and Alzheimer’s Association Safe Return
• Milwaukee County Department on Aging’s Aging Resource Center
• Alzheimer’s Association 24/7 Helpline availability
• “Approaching Alzheimer’s”, a DVD developed by the National Alzheimer’s Association specifically for staff working in law enforcement
Success story:

Gladys is an 80 year old with Alzheimer’s disease, who was living with relatives in the Sherman Park neighborhood. She often wandered from home, and the family called the Milwaukee Police Department to track her down. Because they had frequent contact with the relatives, the Police began to suspect that the family situation was unsafe, and called the Milwaukee County Department on Aging to make a referral re: elder abuse and neglect. Staff from the Department evaluated the situation and made the determination that another relative’s house would be safer for Gladys. That same night, she again wandered from the home. The police found her and conferred with the Department on Aging. They were able to bring Gladys to the home of the other relative, resulting in a better and safer care situation.

Opportunities to move this issue forward:

Work group member Ramona Williams of the Milwaukee County Department on Aging is working with Milwaukee County Law Enforcement Agency group to expand training opportunities to suburban municipalities.

Challenge(s) to the community:

In order to handle more cases of challenging behaviors on-site and minimize the trauma for the person with dementia, a mobile response capacity should be developed. Mobile response staff need training specific to dementia approaches, and must be able to respond to calls from law enforcement within twenty to thirty minutes in order to be effective.

Similarly, when someone with dementia who exhibits challenging behaviors is unable to be cared for in their residence, a Ch. 55 facility is needed for emergency protective placements.
Summit Response to the Report of the Law Enforcement Work Group:

Summit participants praised the work group’s report and reacted favorably to the collaborative approach that made it possible. The active presence of law enforcement further demonstrated the importance of engaging multiple players in addressing the complex problem of people with Alzheimer’s disease who exhibit challenging behaviors. Building on the work, attendees at the Summit made several recommendations including the following:

• Recognize the urgency of the problem from the perspective of law enforcement. With no option to use Ch. 51, what can be used as a Ch. 55 placement?;

• Heighten awareness of available resources such as the 24/7 hotline available from the Alzheimer’s Association;

• Begin immediately to expand training for suburban and rural officers and other responders in addition to those in the City of Milwaukee;

• Assure that all counties in Wisconsin have access to a trained crisis intervention team;

• Train all members of a Crisis Response Team. With the 72 hour discharge rule and the lack of available facilities, the need for communication practices, protocols and collaboration between county officials, law enforcement, facilities and care givers is imperative;

• Assure that the Crisis Intervention Team is available during evening hours, when much of the challenging behaviors occur. Explore options for funding this service;

• Recognize that a call to police is a call for help, not necessarily a call for removal. Use the call as an opportunity for following up with training on the part of the family, caregiver, facility and officer;

• Establish data tracking mechanisms that document the extent of the problem and successful approaches to addressing the challenging behaviors;

• Launch a public awareness campaign to educate families, caregivers and others about approaches to reducing challenging behaviors;

• Study documented best practices for successful behavioral interventions and learn what other states are doing to address this problem;

• Training for law enforcement should address mechanisms for dealing with cultural barriers and language issues, as well as the need to consider the possible cause of the behaviors, including medical issues, early onset Alzheimer’s and a dual diagnosis of dementia and mental illness; and

• The State has to be involved in incentivizing, creating and funding training and regional placement centers, and more active communication and sharing of successes across counties.
PSYCHOTROPIC MEDICATIONS WORK GROUP:

background

Discussion of challenging behaviors

In Phase Two of the Alzheimer’s Challenging Behaviors Task Force, the Psychotropic Medications Work Group discussed several issues related to the pharmacologic treatment of challenging behaviors. First and foremost, the Work Group emphasized that non-pharmacologic approaches are preferable and should always be the starting point in treating challenging behaviors. The Work Group also agreed that each case is different; there is no “one size fits all” in terms of when it is appropriate to use medications or which specific medications to use.

For the purposes of our Task Force, the term “challenging behaviors” was selected because it reflects not only the behaviors that may be exhibited by a person with dementia, but also because these behaviors are challenging to address by everyone associated with the person, including family members, paid caregivers, and health care personnel. In the context of medicine, the behaviors exhibited by the person with dementia are categorized as Behavioral and Psychological Symptoms of Dementia (BPSD).

According to the Alzheimer’s Association, Individuals living with dementia may experience behavioral and psychotic symptoms (BPSD) during the course of their disease due to the alteration in processing, integrating and retrieving new information that accompanies dementia. Studies have found that more than 90 percent of people with dementia develop at least one BPSD with a significant percentage of these individuals having serious clinical implications. Depression, hallucinations, delusions, aggression, agitation, wandering and “sun-downing” are hallmark behavioral and psychotic symptoms of dementia, commonly manifested in moderate- to severe stages of disease. These symptoms cause considerable caregiver stress, and frustration is often the breaking point prior to institutionalization in long-term care facilities. Many of these (BPSD) are also the impetus to falls, weight loss, infection and incontinence in individuals with dementia.14

Psychotropic medications

As defined in Wisconsin state statutes, a “psychotropic medication refers to a prescription drug that is used to treat or manage a psychiatric symptom or challenging behavior. Some psychotropic medications fall into specific medication classes like antipsychotics or antidepressants. In other cases, the medications may be primarily used for other diseases but have been found effective in controlling behaviors thus making that specific use a psychotropic medication.”15

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15 Psychotropic Medications as defined in Chapter 55.01 of State of Wisconsin Statutes <www.dhs.wisconsin.gov/r1_dh//.../psychMed.pdf> accessed on October 1, 2012.
Potential underlying reasons for challenging behaviors

Many practitioners have come to understand that challenging behaviors are a form of communication, especially for those who have lost their ability to communicate and regulate their emotions. The American Geriatrics Society cites three categories of potential triggers for challenging behaviors: physiologic, environmental, and caregiver communication. It is also possible that current medications (including over-the-counter) can exacerbate challenging behaviors. According to the Alzheimer’s Society (UK), more than ninety-percent (90%) of people with dementia will experience BPSD as part of their illness. The organization also notes that, “Sudden emergence of BPSD often has a physical trigger.”

About delirium

Delirium is a relatively common condition among older adults, and one that is highly comorbid with dementia. According to the American Geriatrics Society, delirium is found in one-third of hospitalized medical patients over age 70 and in one-third of patients over age 70 presenting to emergency department. Delirium is diagnosed when the following characteristics are present, using the Confusion Assessment Method rating scale:

1. Acute change in mental status and fluctuating course.
2. Inattention
3. Disorganized thinking
4. Altered level of consciousness

*note: the diagnosis requires that both characteristics 1 and 2 are present and either 3 or 4*

Delirium is worth special attention because of its prevalence in people undergoing a “care transition”, i.e., a move from one setting to another, such as from a hospital to a skilled nursing facility. The condition is often treated with psychotropic medication, and the Work Group’s concern is twofold: 1) that these medications are often prescribed unnecessarily, i.e., before non-pharmacologic interventions are used, and 2) that people remain on these medications beyond their usefulness, putting people at risk for complications. The Work Group is singling out the treatment of delirium as a critical area where the default practice must be changed, looking first at non-pharmacologic interventions and in cases where these are ineffective or when a person exhibits severe aggression or psychosis that place them and those caring for them at risk of imminent harm, using psychotropic medications with gradual dose reduction.

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17 Alzheimer’s Society, 10.


Another area of concern is the need to assess the underlying cause(s) of delirium. In Review: Delirium in the Elderly: A Comprehensive Review by Mittal et al (2011), the authors conclude,

Although not fully understood, it appears that delirium develops due to a complex interplay between various predisposing and precipitating factors… Increasing age and pre-existing cognitive deficit are thought to be the 2 most common predisposing factors for delirium.

A study by Inouye demonstrated that a simple predictive model based on 4 predisposing factors—vision impairment, severe illness, cognitive impairment, and BUN/creatinine ratio—can identify at admission older persons at greatest risk for delirium.

Inouye and Charpentier identified 5 independent precipitating factors for delirium in the elderly: use of physical restraints, malnutrition, more than 3 medications added, use of bladder catheter and any iatrogenic event.”

Young et al, summarizing recommendations from the National Institute for Health and Clinical Excellence (NICE), lists the following interventions in order to prevent delirium:

Within 24 hours of admission, assess people at risk for the following clinical factors that might precipitate delirium:

- Cognitive impairment, disorientation, or both
- Dehydration, constipation, or both
- Hypoxia
- Immobility or limited mobility
- Infection
- Multiple medications
- Pain
- Poor nutrition
- Sensory impairment
- Sleep disturbance

When the use of a psychotropic medication is warranted, NICE recommendations call for short-term use, defined as one week or less, starting at the lowest dose possible and titrating cautiously.

Pharmacologic approaches to treating BPSD:
psychotropic medications in general

An alert issued in 2008 by the Food and Drug Administration warned that, “Antipsychotics are not indicated for the treatment of dementia-related psychosis…both conventional and atypical antipsychotics are associated with an increased risk of mortality in elderly patients treated for dementia-related psychosis.”

20 Ibid


Current efforts by CMS address the inappropriate use of antipsychotics in nursing homes. Antipsychotics are the top-selling class of drugs in the US, generating revenues of $14.6 billion. Reducing the use of these medications in nursing homes will result in significant savings for the Medicare program. Our work group, however, believes that inappropriate medication use should be addressed across a broader spectrum of psychotropic medications that includes benzodiazepine, antidepressant and anti-anxiety medications in addition to antipsychotics; these classes of medications have their own set of potential problems and side effects. One of our concerns is that as the use of antipsychotics decreases, the use of other psychotropic medications may increase. This explains the need to address the inappropriate use of all psychotropic medications and the importance of non-pharmacologic approaches as the first step in addressing challenging behaviors. The Work Group cautions that while this summary frequently cites information related to the use of antipsychotics, it is primarily due to an abundance of data about this class of medications, and should not be construed as the primary focus of our recommendations.

Pharmacologic approaches to treating BPSD: antipsychotic medications in particular

In addition to the treatment of harmful behavioral and psychological symptoms associated with dementia, antipsychotics are typically used to treat such conditions as schizophrenia, bipolar disorder, and the treatment of psychotic symptoms such as delusions and hallucinations. According to the American Geriatrics Society, possible side effects of antipsychotics in treating older people with dementia include increased mortality, cerebrovascular events or metabolic syndrome. “Typical” antipsychotics, e.g., haloperidol (Haldol), traditionally were used to control behavioral disturbances in older people; however side effects such as increased morbidity and increased likelihood of falls led more physicians to the use of second generation or “atypical” antipsychotics. Atypical antipsychotics are associated with an increased risk of stroke and death in older adults with dementia, in addition to other side effects such as tardive dyskinesia, weight gain, diabetes, insomnia, sedation, Parkinsonism, and cognitive difficulties.

After the FDA approves a medication to be marketed for a specific use, physicians are permitted to prescribe that medication for other uses. This is commonly referred to as off-label use, which is how psychotropic medications are used to treat BPSD. The FDA has issued a “black box” warning that requires physicians who prescribe antipsychotics to older patients with dementia-related psychosis to discuss the risk of increased mortality with their patients, patients’ families or their legal representatives. In addition to the known side effects of antipsychotics, the work group has also noted that the use of other psychotropic medications in older people with dementia can result in sedation and a diminished quality of life.

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25 American Geriatrics Society “A guide to the Management of Psychotic Disorders and Neuropsychiatric Symptoms of Dementia in Older Adults,” April 2011.
WORK GROUP REPORT: 
psychotropic medications

Original Charge to the Work Group and Short Chronicle of Activities
One of the recommendations from Phase 1 of the Alzheimer’s Challenging Behaviors Task Force was to, “establish a work group to reduce the inappropriate use of antipsychotic medications for residents with dementia and promote alternate approaches to behavior management.” The Psychotropic Medications Work Group met on two occasions at the end of 2011 (November 9th and December 8th), and on four more dates in 2012 (January 12, March 8, June 4, and August 21st).

The Work Group members included Waukesha and Milwaukee County geriatricians, geriatric psychiatrists, nurse practitioners, and other medical providers with representation from each of the major health systems in southeastern Wisconsin. Other members included social work staff from skilled nursing and assisted living facilities, staff from the Alzheimer’s Association of Southeastern Wisconsin, the State of Wisconsin’s Consultant Pharmacist, and other representatives from the Wisconsin Department of Health Services/Division of Quality Assurance (DQA).

Work Group members reviewed literature on the topic, shared experiences from their practices, analyzed data from the State’s Division of Quality Assurance, and arrived at a set of recommendations by consensus.

Key Findings
The first action taken by the Work Group was to expand the scope of charge from the inappropriate use of antipsychotic medications to the inappropriate use of all psychotropic medications. Since the prescribing practices and beliefs about the efficacy of medications varied among the work group members, there was no agreement on specific medications that should/should not be used.

The Work Group agreed to the following key findings.
• Psychotropic medications are often prescribed as a default for challenging behaviors, and are thereby used inappropriately.
• Non-pharmacologic approaches to challenging behaviors should always be attempted before psychotropic medications are prescribed.
• The medical community needs to do a better job in monitoring use and gradual dose reduction strategies of psychotropic medications in individuals with dementia.
Psychotropic medication use: Local and National Data

National Data

Despite black box warnings regarding the dangers in prescribing antipsychotic medications for older adults, it is estimated that up to one-third of nursing home residents receive these medications, mostly for the treatment of behavioral disturbances.26 Data from the Center for Medicare and Medicaid Services (CMS) indicates that over 17% of nursing home patients had daily doses exceeding recommended levels in 2010.27 In May 2011, the Office of the Inspector General of the US Department of Health And Human Services issued a report with the following key findings.28

- Fourteen percent of elderly nursing home residents had Medicare claims for atypical antipsychotic drugs.
- Eighty-three percent (83%) of Medicare claims for atypical antipsychotic medications for elderly nursing home residents were associated with off-label indications; 88 percent were associated with the condition specified in the Food and Drug Administration (FDA) boxed warnings.
- Forty-one percent (41%) of Medicare atypical antipsychotic medication claims for elderly nursing home residents were erroneous, amounting to $116 million.
- Twenty-two percent (22%) of the atypical antipsychotic medications claimed were not administered in accordance with CMS standards regarding unnecessary medication use in nursing homes.

It is important to note that this analysis was limited to the utilization of only the newer generation (i.e., atypical) antipsychotics and did not include the use of first generation or “conventional” antipsychotics, antidepressants, benzodiazepines (or anti-anxiety agents). We believe that the inappropriate use of all groups of psychotropic medications to treat behavioral disturbances in dementia is higher.

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26 Huybrechts, Krista F et al “Comparative Safety of Antipsychotic Medications in Nursing Home Residents” JAGS, 60:420, 2012. The authors cite four separate studies regarding prescribing rates and concluded “up to one-third of all NH [nursing home] residents receive APMs [antipsychotic medications].”


Local data

Local observations on the use of psychotropic medications in adults with dementia mirror the national data. The picture in Wisconsin and specifically in Waukesha and Milwaukee Counties is consistent with what is being observed nationally as depicted in the State of Wisconsin Department of Health Services/Division of Quality Assurance data presented in Table 1.29 The work group noted differences in the prescribing rates between Waukesha and Milwaukee counties. For example, while the Waukesha County facilities were noted to have lower rates of administering anti-anxiety medications, there were higher rates of administering antidepressants. The Work Group did not draw any conclusions about these differences, rather emphasized the need for the reduction of the use of all psychotropic medications across the board.

Possible reasons for the problem

The Work Group agreed that the differences in prescribing rates among facilities may be due to several factors including but not limited to the staff: resident ratio; mix of residents in terms of health status and age; level of physical, recreational and social activities; access to a geriatric psychiatrist; caregiver education and attitudes about dementia; and non-prescribing or prescribing culture of providers. The work group noted that skilled nursing facilities have significantly decreased their use of physical restraints to control behaviors. However, members expressed the concern that physical restraints have to some extent been replaced by chemical restraints. In addition, lawsuits filed across the country suggest that the pharmaceutical companies have engaged in illegal off-label marketing of these medications.30

According to a handbook published by the Dementia Education and Training Program for the State of Alabama, common reasons that nursing homes have problems with psychotropic medications include:

• No consideration of behavioral management.
• No diagnosis for medication.
• Wrong diagnosis for medication.
• No assessment of medication’s side effects.
• No documentation of medication’s benefit for resident.
• Unnecessary dose reduction for schizophrenia or bipolar disorder.
• No explanation for continued medication.31

Table 1.

<table>
<thead>
<tr>
<th>Drug Type</th>
<th>Wisconsin Average</th>
<th>Milwaukee County</th>
<th>Waukesha County</th>
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<tr>
<td>Antipsychotics</td>
<td>19.0%</td>
<td>18.7%</td>
<td>20.2%</td>
</tr>
<tr>
<td>Anti-Anxiety</td>
<td>19.1%</td>
<td>16.1%</td>
<td>12.7%</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>52.5%</td>
<td>51.5%</td>
<td>55.5%</td>
</tr>
</tbody>
</table>


Importance of non-pharmacologic approaches

Experts agree that the first step in treating someone with dementia who is exhibiting challenging behaviors should be non-pharmacologic in nature. According to the American Geriatrics Society, “Non-pharmacologic interventions have been shown to be more effective than pharmacologic treatment for dementia-related behavioral problems and therefore should be attempted first.” Furthermore, the Alzheimer’s Society (UK) notes that many people with BPSD will experience significant improvement or resolution of symptoms over a 4-6 week period. The organization states, “watchful waiting is the safest and most effective therapeutic approach unless there is severe risk of or extreme distress.” It defines watchful waiting as “an active process over four weeks involving ongoing assessment of contributing factors and simple non-drug treatments. It does not mean ‘doing nothing’.”

Examples of non-pharmacologic interventions include:

- Music during meals and/or bathing
- Walking or light exercise
- Reducing noise
- Examining environmental stimuli including light and sound not only to prevent challenging behaviors but to help promote overall well-being
- Engaging in meaningful activities, e.g., the TimeSlips program (a research-based creative engagement program for people with dementia)
- Pet therapy
- Person-centered care.

The willingness of residential facilities to approach challenging behaviors using a spectrum of non-pharmacologic approaches varies. The extent to which staff is trained in these approaches is one critical factor. The Training Work Group of the Alzheimer’s Challenging Behaviors Task Force is recommending that in choosing a care facility, family members ask questions about the extent of staff training, including what topics are covered under dementia-specific training. To help understand what constitutes “good training”, the Work Group has developed a list of “Key Concepts in Dementia Training”, building on the work of over 30 national organizations.

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34 ibid

35 Information about the TimeSlips program can be found at http://www.timeslips.org. TimeSlips is licensed by the University of Wisconsin-Milwaukee.

36 “Summary Report of the Training Work Group of the Alzheimer’s Challenging Behaviors Task Force” September 2012. (not yet published) – when this document is published, do not say not yet published, write the page numbers
Training family caregivers in preventing challenging behaviors is also critical. The Alzheimer’s Association recommends training and education for both professional and family caregivers on psychosocial interventions that might include:

- Routine activity
- Separate the person from what seems to be upsetting him or her
- Assess for the presence of pain, constipation or other physical problem.
- Review medications, especially new medications
- Travel with them to where they are in time
- Don’t disagree; respect the person’s thoughts even if incorrect
- Physical interaction: maintain eye contact, get to their height level, and allow space
- Speak slowly and calmly in a normal tone of voice. The person may not understand the words spoken, but he or she may pick up the tone of the voice behind the words and respond to that
- Avoid point finger-pointing, scolding or threatening.
- Redirect the person to participate in an enjoyable activity or offer comfort food he or she may recognize and like
- If you appear to be the cause of the problem, leave the room for a while
- Validate that the person seems to be upset over something. Reassure the person that you want to help and that you love him or her
- Avoid asking the person to do what appears to trigger an agitated or aggressive response

When are psychotropic medications necessary?

According to the Alzheimer’s Association, “If non-drug approaches fail after they have been applied consistently, introducing medications may be appropriate when individuals have severe symptoms or have the potential to harm themselves or others. Medications can be effective in some situations, but they must be used carefully and are most effective when combined with non-drug approaches.”

In its guidelines governing the use of medications issued to nursing home surveyors, the CMS provides indications for the use of antipsychotics in the elderly. In F329 42CFR 483.25(l) it states: “Based upon a comprehensive assessment of a resident, the facility must ensure that:

(i) Residents who have not used antipsychotic drugs are not given these drugs unless antipsychotic drug therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record; and

(ii) Residents who use antipsychotic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs.”

While the Work Group agreed that reducing the use of psychotropic medications in general is a positive step, they also acknowledged that in some situations, these medications might be indicated. It is not the Group’s intention to make it impossible for physicians to prescribe psychotropic medications, rather it is merely to change the practice default.

When are psychotropic medications unnecessary?

According to CMS Regulation F329, 42CFR 483.25(l):

“The each resident’s medication regimen must be free from unnecessary medications. An unnecessary medication is any medication used

- In excessive doses (including duplicate therapy); or
- for excessive duration; or
- without adequate monitoring; or
- without adequate indication for use; or
- In the presence of adverse consequences which indicate the dose should be reduced or discontinued.”

The Pharmacy Practice Consultant for the Wisconsin Department of Health Services’ Division of Quality Assurance, who is a member of the Work Group, suggests that it is important to ask three questions before considering whether or not to administer a psychotropic medication for a challenging behavior. He asks, “Is the behavior

1. Persistent?
2. Harmful?
3. Caused by other treatable reasons?”

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Barriers in achieving work group outcomes

1. **Insufficient data on use of psychotropics outside skilled nursing facilities.**
   While there was interest in addressing the use of psychotropic medications in community and other residential settings aside from skilled nursing facilities, the work group found there was insufficient data to indicate the extent of the problem outside of skilled nursing facilities. It was also noted that people treated in community settings may often see multiple physicians, which makes monitoring and evaluating their medications even more difficult. Given the complexity of the problem and the need for the work group to limit its scope given the amount of time and resources available, the group agreed that recommendations would be general so that they could apply to anyone involved in managing medications, regardless of the setting.

2. **Insufficient data on psychotropic use other than antipsychotics.**
   The current CMS focus on reducing the use of antipsychotics has resulted in numerous studies and data-tracking programs specific to this class of medications; however, comparable information is lacking on the use of other psychotropic medications.

3. **Insufficient data on prescribing rates and practices**
   While representatives from the State Division of Quality Assurance worked hard to provide data on the use of psychotropic medications in skilled nursing facilities, use of the Minimum Data Set (MDS 3.0) pointed to data inaccuracies and an incomplete picture as to variables that may be affecting the data, e.g., the work group was unable to draw any conclusions about prescribing rates because of possible variations in resident selectivity or access to a geriatrician/psychiatrist.
Work Group recommendations

1. Psychotropic medications should not be used as a default for treating challenging behaviors associated with dementia.

2. Psychotropic medication should only be used after ruling out all possible causes for the behavior and exhausting non-pharmacologic interventions.

3. Before prescribing psychotropic medications, current medications should be carefully reviewed. Many medications can worsen the symptoms of dementia and can actually exacerbate challenging behaviors (Refer to 2012 AGS Beers Criteria for a listing, found in the “Resource” section)

4. When psychotropic medications are used, they should be prescribed at the lowest effective dosage possible.

5. A written care plan should be developed to monitor and document the challenging behavior. Documentation should include indication(s) for the medication, side effects, effect on the quality of life of the person with dementia, anticipated duration, and plan for gradual dose reduction over time. (This is often not done and leads to an inability to ascertain whether the treatment is working or is worsening the condition).

6. If a person with dementia moves to a different care setting, written or electronic medication lists should be reconciled to assure accuracy.

7. Written or electronic care plans should be reviewed on at least a quarterly basis with more frequent review for medications prescribed for the onset of new behavioral symptoms.

8. When antipsychotic medications are used to treat delirium related behavioral disturbances, the medications should be tapered and subsequently discontinued after a short period of time (days to weeks) rather than waiting for the quarterly review.
Resources identified by the Work Group to share with others

The Work Group reviewed the literature surrounding practice guidelines and algorithms for the management of BPSD. The Group concluded that the field of psychopharmacy is rapidly changing, and now that the issue of reducing the use of inappropriate psychotropic medication has the attention and resources of CMS, there will likely be new developments. Two of the more useful resources identified by the Work Group are described here.

   

   This 2011 practice guide developed in the United Kingdom was developed by an advisory group of leading clinicians specializing in dementia for use in all care settings with the exception of acute care hospital stays. The guideline is straightforward and easy-to-follow, utilizing a color-coded traffic light toolkit system. The guide, “aims to provide evidence-based support, advice and resources to a wide range of health and social care professionals caring for people with dementia.” The Work Group noted its applicability in treating BPSD in everyday settings and its emphasis on alternatives to medication treatment.

2. 2012 AGS Beers Criteria (Medications to Avoid - Delirium, Dementia, Cognitive Impairment)

   The Beers Criteria, a list of potentially inappropriate medications for older adults, was originally published in 1991 by Mark Beers, MD and colleagues for nursing home residents and subsequently expanded and revised in 1997 and 2003 to include all settings of geriatric care. The criteria were again updated by the American Geriatrics Society and an interdisciplinary panel of experts in 2012. An abridged list can be found in the Resource section of this document.

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Success Story

A Residential Facility’s Success Story:
Reducing Medications While Increasing Nonpharmacologic Interventions

Alice, a retired beautician, and her husband, Lenny, enjoy fishing and trips to the cottage. She was 74 years old when she moved into a nursing home. She maintained a very active lifestyle and was still walking independently when she arrived. On the day she moved in, however, Alice’s husband was unable to awaken her until 3 p.m. due to her being overly sedated from the clonazepam he had been giving her at home. His physician instructed him to increase the dose when Alice became upset, agitated or had difficulty sleeping. Lenny was only trying to keep her safe and living at home for as long as he could. Alice’s family knew that it was time for her to move to a dementia care facility.

Alice has been living at the nursing home for almost 2½ years. She seemed to enjoy her new environment. The number of other residents living with her was both overwhelming and exciting. Being a beautician, she loved all the wonderful heads of hair that she could “work” on. Unfortunately, the recipients were not as accepting of this. Some of her peers communicated their dislike by hitting, pushing and yelling at her. Alice, unable to understand, would reciprocate those actions. In response, the staff turned her room into a makeshift beauty shop, with wigs, hair accessories, brushes, clips etc. But this would only hold Alice’s attention for a short time. The interactions with her peers continued and become somewhat dangerous as she would often times pull their hair in an attempt to “style” it.

Meanwhile, Alice was also dealing with insomnia. She had sleepless nights and restless days. She started to eat less. Mirtazapine was started in an attempt to increase her appetite (at one time she did need an IV placed for severe dehydration). Several other medications were initiated over the course of this time. Alice’s medication regime included the use of clonazepam, divalproex sodium, mirtazapine, and quetiapine, plus Tramadol for pain management.

Staff moved Alice to the other side of the facility where her peers were less mobile and there was less chance for confrontation. Family remained very attentive and would come in to assist her with meals and take Alice for walks. As Alice’s dementia progressed, her ability to walk independently also declined. She participated in physical therapy and was able to maintain her ability to walk with assistance. Dose reductions in her clonazepam and divalproex sodium were attempted and successful. Gradual reductions in quetiapine were also attempted and successful.

During this time, Lenny and Alice’s daughter noticed that she was becoming more responsive during their visits, talking more, and overall her mood seemed to be improving. Her appetite also increased greatly (she really liked the donut Lenny would bring her every day) and the mirtazapine was slowly decreased with no adverse effects. Alice is now receiving only trazodone for insomnia, which Lenny agrees should slowly be decreased.

Initially, the use of medications helped Alice through a difficult stage of her dementia; however the gradual reductions, along with meaningful, engaging, social situations, have improved her quality of life as she continues her journey with dementia.
Opportunities to move this issue forward

- Following the May 2011 release of the Inspector General report described on page 8, the United State Senate Special Committee on Aging, chaired by Sen. Herb Kohl, held a hearing in November of 2011 to review the report, receive testimony, and consider possible regulatory or legislative changes that may be needed. Tom Hlavacek, Executive Director of the Alzheimer’s Association/Southeastern Wisconsin, provided testimony on our Task Force findings from year one. While no federal legislation or regulatory reform has been advanced so far, it is possible there will be activity in the future, and the hearing provided an opportunity to educate members of Congress on our issues.

- In February, 2012 the American Health Care Association, a non-profit federation of affiliated state health organizations representing more than 10,000 non-profit and for-profit assisted living, nursing facility, developmentally-disabled, and subacute care providers nationally, announced a new, three year quality initiative to help nursing homes and assisted living facilities improve their delivery of person-centered care. As part of this initiative, the Association set a goal of reducing the off-label use of antipsychotics by 15% by December 2012. (Note: The Wisconsin Health Care Association / Wisconsin Center for Assisted Living Division is a member organization).

- In March of 2012, the federal Centers for Medicaid and Medicare Services (CMS) announced it was launching the Partnership to Improve Dementia Care, a “national initiative to improve behavioral health and reduce antipsychotic use in Nursing Homes”. CMS’s goal is to reduce antipsychotic medication use by 15% by December 2012. The Executive Director of the Alzheimer’s Association of Southeastern Wisconsin is currently serving as an Advisory Committee member on the CMS initiative. Four steps already identified to achieve the goal of improved care include:
  1. Enhanced training – CMS had developed “Hand in Hand”, a training series for nursing homes that emphasizes person-centered care, prevention of abuse, and high-quality care for residents. CMS is also providing training focused on behavioral health to state and federal surveyors;
  2. Increased transparency – CMS is making data on each nursing home’s antipsychotic medication use available on its Nursing Home Compare website;
  3. Alternatives to antipsychotic medication – CMS is emphasizing non-pharmacologic alternatives for nursing home residents, including potential approaches such as consistent staff assignments, increased exercise or time outdoors, monitoring and managing acute and chronic pain, and planning individualized activities.
  4. The establishment of state-level Partnership Coalitions to coordinate and advance these goals. In Wisconsin the first teleconferences related to this coalition took place in the summer of 2012 and more activity is planned.

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40 ASCP 1.

41 CMS Media Relations Group 1.
• The Wisconsin Clinical Resource Center (WCRC) project is jointly sponsored by the Wisconsin Department of Health Services (DHS), Wisconsin Health Care Association (WHCA/WICal) and LeadingAge Wisconsin (formerly known as Wisconsin Association of Homes and Services for the Aging – WAHSA), through funding from the Wisconsin Department of Health Services (DHS). This project involves the development of the WCRC website, along with access to companion training materials.

• The WCRC website is designed as a user-friendly resource to provide key information about thirteen care areas along with access to companion training materials. The care area modules include challenging behaviors, dementia and distressed behaviors, pain management, and transitions in care, among others. In addition, companion training programs for staff have been developed including Getting to the Root of the Matter: Review of the Care Process; Identifying Change in Resident Condition: Medical Provider Notification; Resident-Directed Care Planning; and Use of Antipsychotic Drugs.

• The State of Wisconsin Office on Aging is developing a state plan to address Alzheimer’s disease. The Committee for a Wisconsin Response to Dementia is charged with developing a set of implementable recommendations to expand current resources, make effective service and support programs widely available, enact legislative changes for systems improvements, and identify sources of funding to embed the changes in the system permanently.

• The State of Wisconsin Division of Quality Assurance is actively seeking greater access to Medicare Part D data and data from the Medicare/Medicaid Care Coordination Office, to enhance our understanding of variables affecting prescribing rates on a facility-by-facility basis. The State is also launching Virtual PACE, a managed care program for dual-eligible (Medicare and Medicaid) individuals residing in nursing home settings. Among many other quality indicators, Virtual PACE will focus on medication utilization, including psychotropic medications within this population, many of whom have dementia diagnoses.
Our challenge to the community

As a result of the recent Helen E.F. ruling in Wisconsin that Chapter 51 is not an appropriate vehicle for people with dementia (without a co-occurring mental illness), work group members are concerned that the use of psychotropic medications will increase as a form of chemical restraint for people with challenging behaviors. One community challenge would be to establish a system to monitor the use of all classes of psychotropic medications to ensure that a decrease in one does not lead to an increase in another. Who will take the lead in this effort?

Summit Response to the Report of the Work Group on the Use of Psychotropic Medications

Participants in the Summit praised the report presented by the work group and many expressed their surprise and relief that there are non-pharmacological alternatives and options that can be effective in addressing the challenging behaviors that may be exhibited by those with Alzheimer's disease. Many of the practitioners indicated that they were not aware there was so much overuse of psychotropic medications or that there were contraindications for their prescription. Recommendations from participants at the Summit included the following:

• Recognize that reducing the use of psychotropic medications must be done in conjunction with an associated increase in behavioral interventions and that these interventions require training, time and funding;

• Train staff and families on the use of non-pharmacological approaches including exercise, music, art therapy and environmental adaptations;

• Engage the resident, doctor and caregiver in reviewing social history and establishing an individualized plan of care which gives preference to behavioral approaches; and

• Establish protocols and parameters that promote an institutional culture so that antipsychotic drugs are used as a last resort, in the smallest effective dose and for the shortest feasible time.
There is widespread agreement across the Task Force Work Groups that more emphasis should be placed on non-pharmacologic interventions to manage challenging behaviors. This implies education and training efforts for everyone who comes into contact with an individual with dementia including first responders, physicians and other medical personnel, staff of residential facilities and other programs, and family members. Training should aim to increase their knowledge about the disease while increasing their knowledge and skills in approaches to prevent and/or manage challenging behaviors.

“Dementia care” is not uniformly defined, nor are the terms “dementia specialist” or “dementia capable” in reference to staffing. Legislative attempts to define these terms have been unsuccessful. Training standards and requirements in this arena are virtually non-existent, with the exception of a recent requirement under the Affordable Health Care Act that certified nursing assistants receive ten hours in dementia-related training.

Instituting training on a wider basis is complicated by the fact that it is often not included in an organization’s budget. Organizations such as residential care facilities may have high rates of staff turnover and employers may be reluctant to invest in training employees who will not be staying on the job. While care providers are resistant to adding new government-sponsored mandates and requirements, overall, they do have an interest in improving the level of care they provide.

Family members of individuals with dementia often find themselves in a new role as a primary caregiver. Navigating the health care and social service systems is no easy task, especially for someone who is reluctant to ask for help. Amidst all of the stress involved in caregiving, family members find themselves in a position of needing to become advocates for their loved ones. Education and training efforts for caregivers in “how to advocate” are a missing piece of the puzzle, despite the importance of this function.
**WORK GROUP REPORT:**

**training**

**Original charge to work group:**
To identify or develop training models and curricula that promote a broad-based understanding of Alzheimer’s disease and related disorders and associated behaviors, and the factors which can influence their occurrence. The group will identify training resources, models, and curricula that have the potential to meet the needs of a) family members, b) community providers of residential and adult day care services, c) emergency responders, d) caregivers and administrators in nursing homes and other skilled care facilities, e) in-home care and hospice staff.

(Note: a separate work group was subsequently established specifically to address training issues related to law enforcement)

**Short chronicle of work group activities:**
The Training Work Group met on two occasions at the end of 2011 (November 9th and November 29th), and on seven more dates in 2012 (January 10th, February 14th, April 16th, June 28th, July 26th, August 3rd, and September 13th). Work Group members included those from social service agencies, universities, family caregivers, residential care facilities, the Bureau on Aging and Long-Term Care’s Ombudsman Program, training professionals, and education and advocacy organizations such as the Wisconsin Alzheimer’s Institute and the Alzheimer’s Association of Southeastern Wisconsin.

The Work Group reviewed literature regarding best practices in training diverse groups of individuals with the aim of increasing knowledge in dementia, associated behaviors, and factors that may influence the behaviors. The group analyzed the training materials available and developed specific recommendations regarding the ideal training curricula. The group also surveyed training organizations on the content of their training, developed a new online training inventory, and created an outline of a caregiver-as-advocate resource for family members, for further development at a later date.

**Key findings:**
- Many training programs are available, some for free or at no cost, but may not be utilized
- Anecdotally we know that staff turnover is one factor that contributes to the reluctance of organizations to invest in training. Other contributing factors include an unwillingness to designate staff time, cost of training, and lack of administrative commitment.
- The content of dementia training programs varies, along with delivery methods; there are no minimal standards or state requirements in terms of what constitutes dementia training
- Keeping people who have behavioral challenges in residential facilities, and therefore training to “treat in place” may not be in the financial best interest of the facility (inadequate reimbursement for residents who may require more staff time). The Work Group noted that residential care facilities are often willing to take the fine or citation that goes along with not readmitting someone who has left the facility for care related to behavioral issues.
Barriers in achieving work group outcomes

Per its charge, the Work Group limited its scope to the content of training programs rather than delivery of training. The Group feels that it is important, however, to develop strategies to increase the number of organizations willing to provide training, and to develop incentives and delivery mechanisms that encourage greater use of training programs.

Work Group Recommendations:

1. Encourage organizations to use the Institute on Medicine’s “Six Domains of Health Care Quality” to formulate specific outcomes for the care they provide to people with dementia.

2. As organizations develop their outcomes, the Work Group recommends that the “Key Concepts for Dementia Care Training”, developed by national organizations and amended by the work group, be incorporated into their training plans.

3. Encourage the use of the Dementia Training Content Inventory (soon to be posted on the Alzheimer’s Association website) by organizations seeking to meet training needs following their adoption of the Six Domains.

4. Set state and national standards for dementia care training, using the Work Group’s Key Concepts for Dementia Care Training document.

5. Work with the State to develop requirements for competency-based dementia care training for nurses and certified nursing assistants, based upon the Work Group’s Key Concepts for Dementia Care Training document.

6. Create “Caregiver as Advocate” training material, using the outline created by the Work Group.

Resources to share with others:

- The Institute on Medicine’s “Six Domains of Healthcare Quality” (a summary can be found in the Resource section of this document)

- The “Key Concepts for Dementia Care Training” list developed by over thirty national groups and amended by our Work Group. These concepts are derived from the evidence based, consensus built Alzheimer practice dementia care practice recommendations published by the Alzheimer's Association in collaboration with significant national organizations, including all major care industry groups. (see the Resource section of this document)

- Coming in 2013 – the “Dementia Training Program Content Inventory” on the Alzheimer’s Association of Southeastern Wisconsin website http://www.alz.org/sewi/ The inventory includes basic information about local and national dementia training programs and their content in relation to the Work Group’s recommended “Key Concepts in Dementia Training”.

- “Caregiver as Advocate” training material outline created by the Work Group for future development

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Success story from a residential care facility:

Two years ago, our dementia care team took on the task of creating dementia training for our staff. After many months of planning, we developed an eight-hour training that, with time, all our staff would complete. In addition we would also train hospice personnel, law enforcement officers, EMS staff, crisis center workers, families, and others.

The process of developing training specifically on dementia has been ever changing. We knew it needed to be interdisciplinary and include all departments. Social services, nursing, dietary, and activities were all included, after all dementia doesn’t just affect someone medically; it affects their social lives, their family relationships, what they engage in throughout the day, and many more dimensions.

Secondly, we relied on our staff to tell us what they needed to learn. These were the people who were taking care of our residents; therefore, each time we did the training, we took each evaluation and changed our training based on their feedback.

The content of our training is also ever changing. It is impossible to talk about all aspects of dementia in just eight hours, so we used our time to hone in on changing the perception of dementia. The title of our training is “Stop, Starting It.” As caregivers, many times we unintentionally start a “behavior” by our approach. We often are just trying to do what we think is best, which often ends up with the person with dementia getting unnecessary psychotropic medications. We as caregivers need to “Stop” and change our approach and listen (often not with our ears) to what the person is trying to tell us. Is the person misbehaving or are they experiencing symptoms of a disease they don’t know how to deal with? Are we engaging people throughout the day or are we just keeping them busy? Is the person doing this on purpose or are they trying to tell us something we are not getting?

Take Robert for example. Robert was always an independent man even after developing dementia. He lived at home with his second wife. Before he moved to our nursing home, he was extremely paranoid, once taking a gun out on his wife, and had a failed placement at another nursing home. When Robert moved in, the staff were aware of his history, but not once did someone say, “He’s terrible,” or “I heard he did this.” He was just a new resident who needed our help. Robert lived many happy years with us.

Recently Robert’s dementia progressed rather rapidly. He started to get more agitated at night. He also seemed to be more sexual with some of the younger CNAs. Because of the combination of staff training and the culture of our program, we were able to look at these “behaviors” with an open mind. His evening agitation was due in part because he grew up in California in the area where riots happened every night and he had to sleep with a gun for his own protection. Agitation and frustration throughout the day were also caused because his permanent CNA, whom he had become good friends with, was on vacation for a week and someone new was taking care of him. His sexual “behavior” was not seen as gross or disgusting, but instead was noted as a natural male reaction to a younger female assisting him with a task he had never needed help with before. Robert was never given a psychotropic medication during this time. Training helped the staff understand the medical changes; culture helped them see Robert.

In the last two years we have trained a lot of people. This is not why we are successful though. Every day is an opportunity to train, to help change a perception, to help change the culture, to help show the person still inside. Implementing a training program and being available each and every day to mentor, coach, and guide our staff has been the real success, it has changed the culture of care we provide.

Training and culture change need to go hand in hand. They must complement each other. One without
the other doesn’t work or only works for a short time. You can teach caregivers about a topic, but until they abandon their old ways, old perceptions, and the medical model, they won’t ever truly understand the person.

Some closing quotes from our training:

“It’s not about the floor you walk on, but about the people who walk on the floor.”

“Try to stop thinking ‘he’s confused, he has dementia’ and start thinking ‘I’m confused; I don’t know what he’s trying to tell me’.”

“Know that people caring for those with dementia are doing the best they can and they can only do better when they know better.”

And finally a quote from a family member of one of our residents; “They say that people with dementia regress in the same way that a child grows. It’s too bad that they don’t also get smaller like a baby, because when a baby is crying and upset we hold them and comfort them, why are we so scared to do that for people with dementia when they are so in need of us?”

Opportunities to move this issue forward:

• With additional funding, the development of the “Caregiver as Advocate” training materials will be useful if disseminated by a variety of sources who come into contact with caregivers

• Trade groups and associations may offer the best opportunity to incorporate the key concepts and establish training standards

• Commitment of individual organizations within the Task Force to follow the Work Group’s recommendations re: Key Concepts in Dementia Training will elevate training standards and expectations.

Challenges to the community:

• Will Task Force members sign on in terms of committing their organizations to dementia training following the standards developed by the Work Group?

• Find the resources to develop and make available the “Caregiver as Advocate” training outline

• Keep the Dementia Training Concepts inventory up-to-date and relevant

• Ensure there are enough adequately trained professionals and adequately reimbursed care facilities to provide quality care as defined by the IOM’s Six Domains of Healthcare Quality

• Begin educating people about Alzheimer’s disease at an early age, e.g., ages 6-12, before they begin to form stereotypes/prejudices
Summit Response to the Report of the Training Work Group

In each work group, there are recommendations that relate to the need for a comprehensive and interdisciplinary approach to training. The Training Work Group provided a set of recommendations that were based on adaptations of currently available materials and participants at the Summit were grateful for their systematic and focused approach. Suggestions and reactions from the attendees included:

• Integrate training materials into approaches for reinforcing knowledge in practice including coaching, guiding and reinforcing following training. Reinforce and incentivize positive interventions;

• Establish basic training on non-pharmacological approaches to addressing challenging behaviors and modify for different audiences with different needs. Include primary care physicians, staff, family, caregivers, first responders, maintenance staff, adult day care staff nurses, allied health workers, social workers, CHA’s and the general public;

• Develop best practice guidelines for all types of providers based on research and effective approaches. Include evidence based practices, gray literature, and local examples such as the “Stop Starting It” program in Kenosha;

• Provide guidance on analyzing family and staff behaviors that may aggravate or alleviate the behavior; Emphasize the importance of documentation in learning to control the challenging behaviors. Simplify methods of recording when the behaviors started, the environmental conditions, and how people responded, etc.;

• Model team decision-making by training multi-disciplinary teams to utilize non-pharmacological approaches.
Alzheimer’s Challenging Behaviors Task Force
APPENDIX A:
Resources
Psychotropic Medications Work Group

Table 2:
2012 AGS Beers Criteria for Potentially Inappropriate Medication Use in Older Adults Due to Drug-Disease or Drug-Syndrome Interactions That May Exacerbate the Disease or Syndrome

<table>
<thead>
<tr>
<th>Medications</th>
<th>Recommendation</th>
<th>Rationale</th>
<th>Quality of Evidence (QE) &amp; Strength of Recommendation (SR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All TCAs</td>
<td>Avoid</td>
<td>Highly anticholinergic; clearance reduced with advanced age, and tolerance develops when used as hypnotic; increased risk of confusion, dry mouth, constipation, and other anticholinergic effects/toxicity.</td>
<td></td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>Avoid</td>
<td>Use of diphenhydramine in special situations such as acute treatment of severe allergic reaction may be appropriate.</td>
<td></td>
</tr>
<tr>
<td>a. First-generation antihistamines (as single agent or as part of combination products)</td>
<td></td>
<td></td>
<td>QE: High (Hydroxyzine &amp; Promethazine), Moderate (all others); SR: Strong</td>
</tr>
<tr>
<td>• Brompheniramine</td>
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<td>• Carboxamine</td>
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<td>• Chlorpheniramine</td>
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<td>• Clemastine</td>
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<td>• Cyproheptadine</td>
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<tr>
<td>• Dextromethorphan</td>
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<tr>
<td>• Dextramethorphan</td>
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<tr>
<td>• Diphenhydramine (oral)</td>
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<tr>
<td>• Doxylamine</td>
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<td></td>
<td></td>
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<tr>
<td>• Hydroxyzine</td>
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<td></td>
<td></td>
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<tr>
<td>• Promethazine</td>
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<td></td>
<td></td>
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<tr>
<td>• Tripolidine</td>
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<td></td>
<td></td>
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<tr>
<td>b. Antiparkinson agents</td>
<td>Avoid</td>
<td>Not recommended for prevention of extrapyramidal symptoms with antipsychotics; more effective agents available for treatment of Parkinson disease.</td>
<td></td>
</tr>
<tr>
<td>• Benztropine (oral)</td>
<td></td>
<td></td>
<td>QE: Moderate; SR: Strong</td>
</tr>
<tr>
<td>• Trihexyphenidyl</td>
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<td></td>
</tr>
</tbody>
</table>
c. Antispasmodics
• Belladonna alkaloids
• Clidinium-chlordiazepoxide
• Dicyclomine
• Hyoscyamine
• Propantheline
• Scopolamine

Avoid except in short-term palliative care to decrease oral secretions.
Highly anticholinergic, uncertain effectiveness.

QE: Moderate; SR: Strong

d. Skeletal muscle relaxants
• Carisoprodol
• Chlorzoxazone
• Cyclobenzaprine
• Metaxalone
• Methocarbamol
• Orphenadrine

Avoid
Most muscle relaxants poorly tolerated by older adults because of anticholinergic adverse effects, sedation, increased risk of fractures; effectiveness at dosages tolerated by older adults is questionable.

QE: Moderate; SR: Strong

Benzodiazepines

Chlorpromazine

Corticosteroids

H2-receptor antagonist

Meperidine

Sedative hypnotics

Thioridazine

Medications to Avoid: Dementia & Cognitive Impairment

Avoid antipsychotics for behavioral problems of dementia unless non-pharmacologic options have failed and patient is a threat to themselves or others. Antipsychotics are associated with an increased risk of cerebrovascular accident (stroke) and mortality in persons with dementia.

QE: High; SR: Strong
Resources:
Training Work Group

The Training Workgroup of the Alzheimer's Challenging Behaviors Task Force recommends that organizations use the Institute on Medicine’s “Six Domains of Health Care Quality” to formulate specific outcomes for the care they provide to people with dementia. As organizations develop their outcomes, the Workgroup recommends that the “Key Concepts for Dementia Care Training” be incorporated into their training plans.

The Six Domains of Health Care Quality
The Institute of Medicine (IOM) has led the way in providing a framework for defining quality in health care services, which has implications for long-term care services as well.¹ The IOM has developed six domains of health care quality, ensuring that services are:

Safe: Both emotionally and physically, avoiding harm to patients from the care that is intended to help them. Providing care that protects people from medical errors.

Effective: Providing evidence-based services to all who could benefit and refraining from providing services to those not likely to benefit (preventing underuse and misuse, respectively). Providing care that gets results.

Person-centered: Providing care that is respectful of and responsive to individual patient preferences, needs, strengths, culture, and values and ensuring that patient values guide all clinical decisions.

Timely: Reducing waits and sometimes harmful delays for both those who receive and those who give care. Ensuring that care is goal-directed.

Efficient: Avoiding waste, including waste of ideas, caregiver input, and energy.

Equitable: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

These quality domains provide a starting point for provider organizations to consider areas for improvement and to develop and implement interventions to improve performance. This may require an organization to shift its focus in order to emphasize service quality rather than strictly the number of people served.

Once organizations have assessed their service quality in relation to the domains, they can begin to identify desired outcomes in terms of areas of improvement and related training needs.

In thinking about training for staff who work with people with dementia, there is agreement among the Alzheimer’s Association and over thirty national associations that a number of key concepts should be covered. These organizations have issued a joint document that includes “Key Concepts for Dementia Care Training”.²

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Key Concepts for Dementia Care Training

Note: these concepts are derived from the evidence-based, consensus-built Alzheimer practice dementia care practice recommendations published by the Alzheimer's Association in collaboration with more than 30 other significant national organizations, including all major care industry groups.

Organizations supporting these practice recommendations:

- AARP
- American Academy of Hospice and Palliative Medicine
- American Assisted Living Nurses Association
- American Association for Geriatric Psychiatry
- American Association of Homes and Services for the Aging
- American Association of Nurse Assessment Coordinators
- American College of Health Care Administrators
- American Dietetic Association
- American Health Care Association
- American Health Quality Association
- American Medical Directors Association
- American Occupational Therapy Association
- American Pain Foundation
- American Physical Therapy Association
- American Society of Consultant Pharmacists
- American Seniors Housing Association
- American Therapeutic Recreation Association
- Assisted Living Federation of America
- Catholic Health Association
- Consumer Consortium on Assisted Living
- Hospice and Palliative Nurses Association
- John A. Hartford Foundation Institute for Geriatric Nursing, New York University College of Nursing
- National Association of Activity Professionals
- National Association of Directors of Nursing in Long Term Care
- National Association of Social Workers
- National Center for Assisted Living
- National Citizens’ Coalition for Nursing Home Reform
- National Conference of Gerontological Nurse Practitioners
- National Gerontological Nursing Association
- National Hospice and Palliative Care Organization
- Paralyzed Veterans of America
- Service Employees International Union
- Supportive Care Coalition
About dementia
Workers need a basic overview and understanding of dementia and Alzheimer’s disease, including general information about symptoms and cognitive losses.

Improving communication
There is a knowable skill to be built to effectively communicate with persons with Alzheimer’s, as well as valuable conceptual knowledge about non-verbal communication and dealing with word search and/or repetitive word problems.

Understanding behaviors
This critical learning area rounds out the previous two topics with a practical approach to understanding that all behavior has meaning, that behavior is often a resident’s way of communicating when other modes of communication are unavailable or impaired by disease. Understanding these concepts can translate into better patient care and more competence when dealing with agitated or difficult behaviors.

Food and hydration
Many persons with Alzheimer’s in residential care lack adequate food and/or hydration which are essential to health, behavior, and overall well-being. Residents with dementia benefit from cueing, reminding, and assistance with eating, all of which are issues to be addressed in training.

Understanding pain
Direct care workers have a unique role in identifying early signs of pain in individuals in their care. Pain can be reported, monitored and cared for in a timely manner. Direct care workers need to understand that untreated pain may lead to increased resident distress or difficult behaviors.

Social connections
Providing opportunities for meaningful social interaction is at the heart of quality dementia care. Many facilities provide robust activity programs that may be hard for persons with memory loss and confusion to follow. All staff can be trained to create true opportunities for social engagement anytime with anyone, contributing to the emotional well-being of the person with Alzheimer’s.

Understanding wandering
Training on wandering brings a new perspective on an issue that is a top concern for many caregivers. Teaching the difference between safe and unsafe wandering and understanding exit-seeking and how to protect the resident in a caring and person-centered way is critical.

Reducing risk of falls
The first step in reducing falls is really understanding what a fall is and what puts a resident at risk. Training must clearly define falling, including any contact with a hard surface – a wall, a door, a table, a doorway. It also emphasizes that while we do want to protect residents from injurious falls, it is important to promote mobility as a way to sustain strength and balance over time.
Promoting restraint-free care
In most cases, facilities are officially restraint-free. The importance of this training topic module is that it helps caregivers think about ways that items that are not considered restraints – such as wheelchairs (when wheels are locked) – can in fact be considered restraints because of the effect on the resident.

End of life care
Training in this area of care enables workers to recognize the signs of the end of life of a person with dementing illness, to feel confident in delivering supportive care, and to know where to direct family members to extra support they made need.

The Training Workgroup of the Alzheimer’s Challenging Behaviors Task Force recommends that the following concepts be incorporated into training as well.

Assessment, prevention, and early intervention re: challenging behaviors
Assessment is key in identifying red flags that may lead to challenging behaviors and trying to prevent them, particularly for family caregivers. Prevention/early intervention strategies to reduced agitation should be tailored to the individual.

Person-centered care/creating an organizational culture promoting quality care
Understanding the framework of this approach to quality care is essential in creating a culture committed to caring for people with Alzheimer’s disease as individuals.

The use of life stories
Having the knowledge of the individual’s language, culture, and life stories and training in how to use this knowledge is important for anyone communicating with individuals with dementia.

Cultural competence
An understanding of culture can shape the relationship between the person with dementia and his/her caregiver, whether it’s consideration of race, gender, sexual orientation, religious beliefs, age, etc. As the disease progresses, past experience with discrimination may become a factor in the relationship.

Asking for help/caring for the caregiver
Training to ensure that caregivers, particularly family caregivers, have the knowledge and resources needed to take care of themselves in order to reduce stress and prevent the onset of depression and/or burnout.

Legal interventions
Training on the “basics” in terms of what caregivers need to know re: Power of Attorney for Health Care and when/how this is activated.

Environmental factors
Looking at environmental stimuli including light and sound not only to prevent challenging behaviors but to help promote overall well-being.
APPENDIX B:
Glossary and Acronyms

ADRC – Aging and Disability Resource Centers
A national program designed to streamline access to long term care.

ADL – Activities of Daily Living
Daily self-care activities used to measure a person’s ability to function.

AGS – American Geriatrics Society
A large national professional organization of health care providers.

APS – Adult Protective Services
Social services provided to abused, neglected, or exploited older and/or disabled adults

BPSD – Behavioral and Psychological Symptoms of Dementia
A group of behaviors and symptoms that occur in people who suffer from dementia.

BUN – Blood Urea Nitrogen
Measurement of nitrogen in urine, used as an indicator of renal health.

CAM – Confusion Assessment Method
A method used to detect delirium.

CIT – Crisis Intervention Team
Teams that respond to possible mental health crisis.

CMS – Centers for Medicare & Medicaid Services
Federal agency that administers Medicare, and works with states to administer Medicaid.

DHS – Wisconsin Department of Health Services
State agency that is concerned with public health.

DQA – Wisconsin Department of Health Services/Division of Quality Assurance
Division within DHS that is concerned with assuring quality in health care facilities.

EMT – Emergency Medical Technicians
Providers of emergency medical care.

FDA – Food and Drug Administration
National agency which monitors drugs and medical devices.

IOM – Institute of Medicine
Non-profit which provides information and advice concerning health and science policy.
MDS – Minimum Data Set
Part of the U.S. federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes.

MUTT – Mobile Urgent Treatment Team
The Milwaukee County Crisis Intervention Team.

NICE – National Institute for Health and Clinical Excellence
English health authority.

TCA - Tri-Cyclic Antidepressant
A group of antidepressants that have been used to treat many anxiety disorders.

VA—Veteran’s Administration
Department of the US government that provides care and benefits to veterans and their dependants.
APPENDIX C: Promising Practices

This section briefly highlights selected efforts that may be of interest to those searching for promising practices in addressing the issue of challenging behaviors among those with Alzheimer’s or other dementias. Research was conducted by Ed jj Olson Associates and included examples noted in an internet search of grey literature as well as telephone interviews with key informants. Grey literature is “that which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers.” Examples of grey literature publications include reports, theses, non-commercially published conference papers, government reports, translations, committee reports, working papers, technical specifications and standards, and bibliographies.¹

In pursuing research and searching for best practice programs, the consultant team found a number of examples of efforts to manage care transitions for older adults but few which focused specifically on issues associated with Alzheimer’s disease. While there may be promising practices or successful efforts in the non-pharmacological treatment of Alzheimer’s behaviors, the field has not advanced to the level of rigorous testing of approaches. The scientific documentation of the outcomes of programs dealing with people with Alzheimer’s or dementia is sparse, with little application of codified criteria. Thus, this search includes information provided by key informants or found in the grey literature which can identify interesting approaches to follow. The full report may be found at http://planningcouncil.org

What follows is a sample of efforts that relate to some of the key themes and recommendations contained in this report. Specifically, the recommendations to minimize and monitor the use of psychotropic medications, to treat people in place whenever possible and to manage care transitions, are themes consistent with these programs. Still, it should be noted that lessons that can be drawn from research which focuses on older adults, or even studies which focus on those with dementia, may not conclusively transfer to the topic of those who have Alzheimer’s and exhibit challenging behaviors. Nonetheless, there are some interesting examples which may offer some suggestions to follow.

The Aging and Disability Resource Centers (ADRC) model is one effort to promote the use of more evidence-based strategies in all stages of care transitions. The approach includes five different models: 1) Better Outcomes for Older Adults through Safe Transitions (BOOST); 2) Bridge Program; 3) Guided Care; 4) Transitional Care Model; and 5) Care Transitions Intervention. These models emphasize person-centered care and the importance of assisting clients at home, between home and hospital and between hospital and home, or skilled care.² The model was developed by the Administration on Aging (AoA) and Centers for Medicare and Medicaid Services (CMS)³ in 2003 to build upon and improve transitional care options by implementing a program to “assist individuals in ‘critical pathways,’” defined

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² http://wwwAoA_programs/HCLTC/ADRC_CareTransitions/index.aspx

³ http://wwwAoA_programs/HCLTC/ADRC_CareTransitions/index.aspx
as the times or places when people make important decisions about moving to and from long-term care.

Applications of some of these models may be found in the following programs: the Illinois Transitional Care Consortium (ITCC); Colorado Care Transitions Program (CCTP); the Awakenings Project; Dane County Human Services Dementia Support Team; and the North Carolina Black Mountain Neuro Medical Treatment Center. Brief summaries are highlighted below.

**The Illinois Transitional Care Consortium (ITCC)** is an example of the ADRC’s Bridge Program which is evidence based and has shown to have had an impact on understanding of discharge plan; readmissions; physician follow-up; understanding of prescribed medications; access and timeliness of community services; and mortality. The Illinois program includes a consortium of community organizations, hospitals, a research university, and a health care policy organization. The ITCC is a social-work based model of transitional care which serves older adults transitioning from the hospital to the community by linking hospital-based services with the aging network through intensive care coordination.

“The Bridge Model is not specifically focused on clients with dementia or Alzheimer’s. However, insofar as it is a psychosocial model focused on accurate comprehensive assessment, connection of appropriate post-discharge providers and the social determinants of health that prevent an efficient utilization of those providers, the model is appropriate for any diagnosis facing an older adult. Our social workers thoroughly assess an older adult and make sure they connect to appropriate help. We are part of Rush Geriatrics, but since our model is focused on the post-discharge period, we operate autonomously with older patients from the entire hospital.”

The Bridge Model consists of three intervention phases. Prior to discharge, Bridge Care Coordinators (BBC’s) identify older patients who may be at risk for post-discharge complications. Referrals often are identified by hospital discharge planners or by analysis of an integrated risk screen of the electronic medical record. The older adult’s hospital room or the internal ARC in the hospital serve as the point of interaction with the BCCs who meet with the older adult and caregiver to identify unmet needs and to set up services prior to discharge. In addition, Bridge Care Coordinators prepare for patient discharge by reviewing medical records and meeting with an interdisciplinary team established within the hospital. BCCs call consumers two days after discharge to conduct a secondary assessment and assist the client on itemized needs such as understanding discharge directions, access to transportation resources, physician follow-up, overwhelmed caregivers, confusion regarding home health care, and accessing medications, etc. Further follow-up is provided when the Bridge Care Coordinator contacts clients at 30 days post-discharge.

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4  [www.transitionalcare.org](http://www.transitionalcare.org)

5  [www.transitionalcare.org](http://www.transitionalcare.org)

The Colorado Care Transitions Program (CCTP) is an example of the evidence-based ADRC Transition Program concept. It is based in the Division of Health Care Policy and Research, University of Colorado Denver, School of Medicine and utilizes a specific measure to assess the quality of care transitions. This effort has been lauded as a highly successful continuum of care model that facilitates quality programming for individuals with Alzheimer’s, their family members, and community institutional settings such as acute, skilled and community-based settings. In addition, it supports patients and families; increases skills among healthcare providers; enhances the ability of health information technology to promote health information exchange across care settings. The CCTP implements system level interventions to improve quality and safety and develops performance measures to gauge the effectiveness of the interventions. The CCTC trains Coaches who in turn train staff of collaborating agencies and organizations. Tools being used to measure success include; the Care Transitions Measure, a 15-item uni-dimensional measure which focuses on patient-centeredness; and The Medication Discrepancy Tool, a new tool for identifying and characterizing medication discrepancies that arise when patients are making the transition between sites of care.6

Awakenings Program of Minnesota
The Awakenings Program, operated by Ecumen of Minnesota is a pilot project that attempts to reduce and replace dangerous anti-psychotic medications prescribed for Alzheimer’s and other skilled care patients. Ecumen is a non-profit organization made up of a diversity of skilled and assisted living facilities throughout the state of Minnesota and is the sponsor of the Awakenings Program. The Awakening project is being implemented in 15 skilled nursing facilities and is funded by a $3.7 million dollar grant from the state of Minnesota. The program educates administrators and health care professionals on the dangers of over prescribing these medications and actively engages the nursing home patients and their families by using specific strategies that help to reduce anti-social behaviors. They use a range of professional approaches to reduce anti-psychotic medications prescribed for Alzheimer’s residents. Measures being used to track success include: the Evidence Based Guideline System, purchased from the University of Iowa; the Patient Safety Advisory from Pennsylvania; and the Alternative Care Plan Interventions Plan, also developed by the University of Iowa.7

The Awakenings program also uses Jolene Brackey’s Book “Creating Moments of Joy” and her DVDs to help relationship-building and improve communication among staff and residents, and the Screening Tool of Older People’s Potentially Inappropriate Prescriptions (STOPP) as well as a free on-line training site called the CARES Approach.8 The program links facilities with key experts and consultants who help educate and advocate for reduced prescription medications for patients. Experts in the areas of pharmaceutical use and psychiatry are included in the implementation of individual care plans and affect the general philosophy of care. Early indications suggest the program is effective in helping to reduce the over-prescribing of anti-psychotic medications for “difficult” patients.

6  www.caretransitions.org
7  www.ecumen.org
Stephanie Johnson, a registered nurse involved in Awakenings said “We try to look at the behaviors as more of a way for patients to tell us what they need.” This philosophy has resulted in a change of culture in these facilities that now see the patient and their family members as active participants in their care.

**Dane County Human Services Dementia Support Team**

The Dane County Dementia Support Team (DST) was established in 2009. The team works with older adults who have dementia and have been placed at Mendota Mental Health Geriatric Treatment Unit. The team’s goal is to develop strategies for ultimate reintegration into the community upon their discharge from Mendota. When older adults with behavioral issues are admitted to Mendota by law enforcement for Emergency Detention (ED), Mendota staff contact Dane County Human Services which in turn contacts the Dementia Service Team. The team includes social workers and nurses employed by South Madison Coalition of the Elderly. The case manager who works with a DST team is responsible for gathering pertinent information, and working with the older adult and the family or guardian, Mendota staff and related community resources. A physician conducts an assessment and diagnosis and the case manager and staff from the Alzheimer’s and Dementia Alliance then develop a person-centered behavior plan. The goal is to minimize the risks and behaviors that often become barriers to reintegration back into the community. The case manager and the Training Specialist use the plan to work with DST and the client, to teach management and integrative skills to family and caregivers, and help assure that all individuals and resources understand the particular needs of the client. This comprehensive approach fosters successful community placements.

Upon discharge, the case manager may follow the client for up to 30 days. If the client meets income standards, cost of the program is covered by The Community Options Program Waiver (COPW).

**North Carolina Black Mountain Neuro Medical Treatment Center** treats dementia patients needing extra care and supervision and is considered the last transition for difficult Alzheimer patients. In 1988, funding was established through the state legislature to create a specific program for the care and treatment of patients with mid to late stages of Alzheimer’s disease in order to help care for the most difficult Alzheimer’s patients who may be violent or otherwise too difficult to be placed with others. The Alzheimer’s Program is certified as a nursing facility and serves individuals from throughout the State who have a diagnosis of Alzheimer’s disease and whose assaultive or combative behaviors preclude care in traditional nursing home settings. The Center focuses on state-of-the-art treatment of Alzheimer’s disease and the management of associated behaviors. The care program is person-centered and involves family members in all facets of the programming. In addition to direct services, the Center provides family and community education in support of effective partnerships regarding dementia and Alzheimer’s.
Characteristics of the models include that they are patient-centered, identify critical pathways, have trained staff, develop a plan of action and activities to assist the client and caregivers to manage home, hospital, skilled and community resources, involve “in-place” assessments, engage a cross-disciplinary Assessment Team, designate staff nurses or social workers who collaborate with hospital staff, address the immediate needs of the client, and establish transition plans that are shared with the individual and care giver and formalized with community agencies. These are consistent with the recommendations of this report.
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