

# HANDCUFFED



## *A Report of the* **Alzheimer's Challenging Behaviors Task Force**

December, 2010

*"Regulations handcuff nursing homes and force them to remove residents from the facility."*



*"Handcuffing an elderly person and putting them in the back of a car will not make them calm down."*



*"People come to us in handcuffs, they are out of their milieu, they are put on someone else's schedule, put on meds, and are surrounded by chaos."*

# Acknowledgements

This report was made possible with the generous support of the Helen Bader Foundation, the Greater Milwaukee Foundation, and the Faye McBeath Foundation. Support was also provided by Mark Wrobel, a family advocate. Tom Hlavacek, Executive Director of the Alzheimer's Association of Southeastern Wisconsin, initiated the Alzheimer's Challenging Behaviors Task Force and guided the process.

More than 115 Task Force members attended five large scale community meetings, shared input, and built a common understanding of issues facing people who exhibit challenging behaviors as a result of Alzheimer's disease or related dementias. A complete listing of participants is included in the report. Particular thanks go to those who made presentations, participated on panels, or shared information with Task Force members at these meetings.

In addition to the larger meetings, 25 people participated in five listening sessions. They candidly shared information and addressed what is and is not working for people who exhibit challenging behaviors as a result of dementia. Many people were extremely helpful in gathering information to advance this effort: Cindy Paulsen, Ramona Williams, John Chianelli, James Gresham, Bill Henricks, Mark Eberhage, Eva Williams, Captains Carianne Yerkes and James Shepard, Anthony Reeves, Dinh Tran, Susan Crowley, Otis Woods and Sherri Olson.

The following Planning Council staff members contributed to this effort: Kathleen Pritchard, President and CEO; Lonna Kruse, Assistant Planner; Troy Mrkvicka, UW-Oshkosh Student Intern; Danny Henken, UW-Madison Student Intern; Catherine Uggeri, Intern; Robert Williams, Intern; Erin Shawgo, Marquette University Student Intern; Ashley Tikkanen, Marquette Trinity Fellow; and Quinton D. Cotton, Associate Planner. The following staff from the Alzheimer's Association also contributed to the Task Force: Krista Scheel, Program Director; Wendy Betley, Family Services Manager; and Paul Golueke, Information and Referral Coordinator.

The quotations found throughout the report are pulled from the conversations, presentations, interviews and listening sessions of the Task Force. The perspectives and wisdom of those who contributed are appreciated. The Resource section identifies helpful materials and tools that were suggested by Task Force members and have

helped contribute to the collective knowledge of the group. More detailed notes of meetings as well as materials cited are available from the Alzheimer's Association of Southeastern Wisconsin.

Finally, appreciation is extended to all those in the community who help people who exhibit challenging behaviors as a result of Alzheimer's disease or related dementias. Particular thanks are extended to the members of the Petersen family, who bravely recounted their father's story and joined in searching for solutions. This report is dedicated to the memory of Richard "Stretch" Petersen.

## TABLE OF CONTENTS

Acknowledgements . . . . .	ii
Members of the Task Force. . . . .	iii
Task Force Meetings and Activities . . . . .	v
Executive Summary and Recommendations . . . . .	vi
Alzheimer's Challenging Behaviors Task Force Report	
I. Background and introduction . . . . .	1
II. What are "challenging behaviors?" . . . . .	2
III. Why are these important? . . . . .	2
IV. What causes these behaviors? . . . . .	3
V. How prevalent are these behaviors? . . . . .	3
VI. What do local data indicate? . . . . .	4
VII. What systemic barriers were identified? . . . . .	5
A. Nursing home regulations . . . . .	5
B. The "disappeared system" . . . . .	6
C. The scarcity of staff . . . . .	7
VIII. What is being done to deal . . . . .	7
with challenging behaviors?	
A. The use of Chapter 51 . . . . .	7
B. The use of psychotropic medications. . . . .	8
IX. What alternative strategies are available? . . . . .	8
A. Assessment and pain management . . . . .	8
B. Person-centered care . . . . .	9
C. The Star Method . . . . .	10
X. What is being done elsewhere? . . . . .	10
A. The Ontario Model . . . . .	10
B. The Dane County Model. . . . .	11
XI. What role does training play? . . . . .	11
XII. What are the next steps? . . . . .	12
Notes . . . . .	13
Resources . . . . .	14

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# Task Force Meetings and Activities

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## TASK FORCE MEETINGS

**April 14** – The initial meeting identified the purpose of the Task Force. Members provided initial suggestions for system-level improvements, and barriers and gaps in the current approach to addressing the problem.

**May 18** – The Task Force focused on assessment and intervention models including the Star Method and methods for addressing pain. Available data was discussed.

**June 22** – The Task Force heard from a panel that addressed Chapter 51 and 55, and received reports on the work of the Mental Health Complex Community Advisory Council. Additional data was reviewed.

**July 21** – Discussion focused on “person-centered care” and the presentation of a panel on nursing home regulations from different perspectives. Data needs were also discussed.

**September 23** – The Task Force discussed what had been learned and what still needed to be learned. They made recommendations for improvement.

## LISTENING SESSIONS

**April 20** – Representatives from the Wisconsin Hospital Association and Wheaton Franciscan Healthcare discussed current efforts and system issues.

**May 17** – Legal professionals discussed system challenges.

**June 23** – Community providers described system challenges.

**July 28** – Assisted living providers discussed system challenges.

**August 25** – Behavioral health representatives described their role in working with people who have challenging behaviors as a result of Alzheimer’s disease and related dementias.

## KEY INFORMANT INTERVIEWS

**May 13** – James Gresham, President of Continuing Care and Allied Services, discussed data.

**July 15** – John Chianelli, former Administrator of Milwaukee County Behavioral Health Division, discussed system issues from a behavioral health perspective.

**July 20** – Bill Henricks, Chief Operations Officer of Rogers Partners in Behavioral Health, discussed system issues from a health care perspective.

**August 2** – Mark Eberhage, President and Chief Psychologist of Behavioral Solutions, Inc., discussed system issues from a mental health perspective.

**August 3** – 2010 Eva Williams, of Milwaukee County CMO, discussed data.

**September 22** – Captain Carianne Yerkes and Captain James Shepard described the Milwaukee Police Department’s role in working with people who have challenging behaviors as a result of Alzheimer’s.

**November 4** – Richard Rau, Keri Gerlach and Ruth Hovland of Clement Manor, gave input on the Task Force findings to date.

## OTHER ACTIVITIES

**July 8** – A workgroup met to interpret Act 281 and its ramifications.

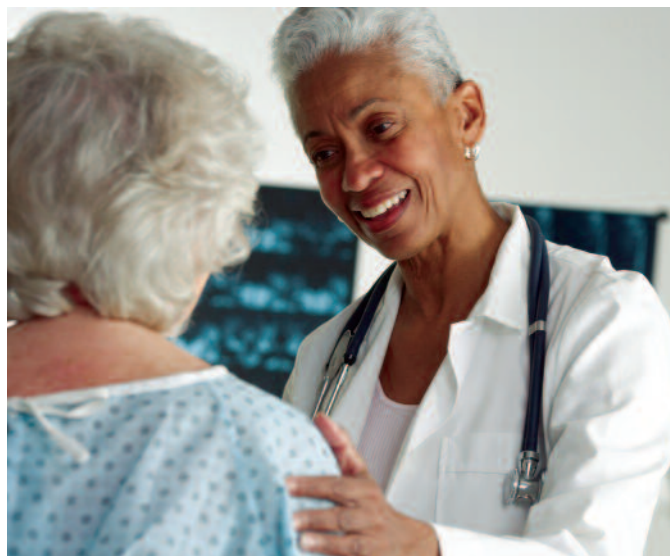
**October 4** – Task Force findings to the use of Chapter 51 for people with Alzheimer’s disease was provided to the Legislative Study Committee.

# Executive Summary and Recommendations

## EXECUTIVE SUMMARY

The Alzheimer's Challenging Behaviors Task Force was called together by the Alzheimer's Association of Southeastern Wisconsin in April of 2010 following the tragic death of Mr. Richard Petersen. Mr. Petersen, an 85 year old gentleman with late stage dementia who exhibited challenging behaviors, was placed under emergency detention after being at two hospitals, and was eventually transferred by police to the Milwaukee County Behavioral Health Division where his family found him tied in a wheel chair with no jacket or shoes. In spite of his family's efforts to intervene, he later developed pneumonia, was transferred to a hospital, and died.

The Alzheimer's Association and scores of members of the community were deeply concerned, not only about the treatment of Mr. Petersen and his family, but about others in the Milwaukee County area who are in the



same or similar circumstances. The Alzheimer's Association sought and obtained support from the Faye McBeath Foundation, the Greater Milwaukee Foundation, and the Helen Bader Foundation to partner with the Planning Council for Health and Human Services, Inc., to staff a Task Force and produce a report to the community. The Planning Council is a private, non-profit organization that works with others to advance health and human services through planning, evaluation and research. Under the Alzheimer's Challenging Behaviors Task Force, stakeholders from all sides of the issue came together to develop a set of common understandings of the associated problems, explore solutions and recommend changes.

The full Task Force came together over the course of five community meetings. More than 115 individuals representing a cross-section of the legal, medical, behavioral, service provider and caregiver communities came together to help address the problem. In addition to the plenary sessions, five listening sessions with key stakeholder groups, including legal, medical, and behavioral health experts, and providers were convened. Seven key informant interviews with a number of experts in the mental health, medical, provider, and law enforcement fields supplemented the work.

This report is intended to provide a basic understanding of "challenging behaviors" among people with Alzheimer's disease, and approaches to addressing the problem in facilities and across systems. Based on the work of the Task Force, basic recommendations for future action were generated and a series of next steps are identified.



## **RECOMMENDATIONS**

### **A. Find alternatives to using Chapter 51 and the Milwaukee County Mental Health Complex for people with Alzheimer's disease and related dementias.**

1. Convene a panel with expertise in Alzheimer's disease, mental health, geriatrics, criminal justice, health and long-term care to identify the implications of stopping the application of Chapter 51 and the use of the Milwaukee Mental Health Complex for patients with Alzheimer's and age related dementias.
2. Explore mechanisms for diverting these resources to the development of the Alzheimer's network of services.
3. Continue to provide input to the State Legislative Committee that is reviewing revisions to Chapter 51.

### **B. Establish a network of Alzheimer's care centers.**

1. Work with providers, hospital systems and nursing homes to establish a network in which adequate and defined "levels of care" are available for people with dementia in the community, skilled nursing homes and hospital emergency rooms and inpatient units.
2. Identify "lead agencies" to assure accountability at all levels.
3. Develop cost sharing and blended funding approaches to support the effort and reduce duplication by concentrating resources and developing a larger number of small sites and a smaller number of specialized sites.
4. Create a centralized resource and assessment center to serve as the hub of the network, providing:
  - a. A multi-disciplinary, mobile "triage team" to help address challenging behaviors on-site at the time an intervention is needed.
    - 1) Conduct an assessment using antecedent-behavior-consequence (ABC) model.
    - 2) Assess for and make recommendations to manage pain.
    - 3) Coach caregivers and consult with families.
    - 4) Recommend appropriate placement, services, and follow-up.
    - 5) Have authority to initiate change in placement if needed.
  - b. A combined medical, psychiatric and social service unit to integrate care for those who need to be stabilized, assessed and prepared to return to the most appropriate site and receive follow-up care.
  - c. A training resource for first-responder Emergency Medical Service (EMS) and police on topics such as identifying and responding to calls involving persons with dementia, intervention practices, and the existence, location, and services of the centers described above and their designated level of care.
  - d. Support for facilities and families.

### **C. Provide adequate and appropriate training.**

1. Acknowledge and address the need for broad-based understanding of Alzheimer's disease, associated challenging behaviors and the factors which can influence their occurrence.
2. Establish a system to provide specialized training for:
  - a. Family members.
  - b. Community providers of residential and adult day care.
  - c. Emergency responders (police, EMS and emergency room personnel).
  - d. Nursing home and other facility staff and supervisors on all shifts.



3. Provide training that:
  - a. Encourages family members to be advocates.
  - b. Uses a multi-disciplinary team approach.
  - c. Includes real time, on-site, case specific coaching.
  - d. Emphasizes the importance of a “person-centered” approach.
  - e. Stresses the significance of the interaction between the person, caregiver and environment.
  - f. Identifies procedures for seeking appropriate interventions.
  - g. Identifies resources and support available to families and facilities for follow-up care.
  - h. Is ongoing.

**D. Create an ongoing system for capturing data.**

1. Establish a pilot program to:
  - a. Collect data through the Emergency Medical System (EMS).
  - b. Identify facilities that are calling for emergency interventions.
  - c. Document the number of people coming into hospital emergency rooms with acute changes in mental state related to dementia.
  - d. Document the number of Chapter 51 petitions involving dementia-related challenging behaviors.
2. Document the trajectory and outcomes for individuals with challenging behaviors as well as the treatment of the family.
3. Use the data to:
  - a. Target interventions.
  - b. Demonstrate the economic aspects, including costs and potential savings.
  - c. Prepare for future response to challenging behaviors.

**E. Support the next steps and follow-up work of the Task Force.**

To begin to implement the recommendations above, the following action steps will be undertaken.

1. Participate in the design of the Alzheimer's State Plan, beginning with the release of this report on December 14, 2010. See the “Hand in the Plan” website at [http://www.planningcouncil.org/CMS/alt\\_login.php](http://www.planningcouncil.org/CMS/alt_login.php).
2. Provide training and information on the topic of challenging behaviors at the Alzheimer's Association's 2011 Statewide Network Conference.
3. Increase awareness and training for law enforcement personnel in more municipalities on the topic of challenging behaviors among people with dementia.
4. Convene a work group to produce recommendations on Chapter 51 and continue to provide input to the State legislature.
5. Convene a work group to recommend approaches to reducing the use of psychotropic drugs for people with Alzheimer's exhibiting challenging behaviors.
6. Convene a work group on training to refine and recommend curricula and approaches.
7. Work with health care systems and the Wisconsin Hospital Association to develop interim and long-range approaches to improve and coordinate emergency and inpatient hospital care.
8. Meet with individual nursing home administrators and state-level nursing home associations to identify interim and long-range strategies.
9. Reconvene the full Task Force regularly to report on progress and seek additional input.

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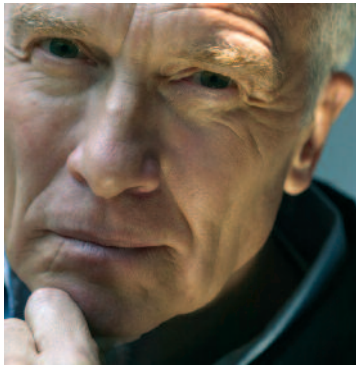
# Alzheimer's Challenging Behaviors

## Task Force Report

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### I. Background and introduction

The Alzheimer's Challenging Behaviors Task Force was called together by the Alzheimer's Association of Southeastern Wisconsin in April of 2010 following the tragic death of Mr. Richard Petersen. Mr. Petersen, an 85 year old gentleman with late stage dementia who exhibited challenging behaviors, was placed under emergency detention after being at two hospitals, and was eventually transferred to the Milwaukee County Behavioral Health Division where his family found him tied in a wheel chair with no jacket or shoes. In spite of his family's efforts to intervene, he later developed pneumonia, was transferred to a hospital, and died.



Like Mr. Petersen, too many other older adults with dementia who exhibit aggressive and agitated behaviors have found themselves caught up in the legal and involuntary commitment systems and experienced disturbing treatment

and tragic outcomes. Most often Chapter 51 emergency detention petitions originate in long-term care facilities that provide care to older adults. When Chapter 51 petitions are initiated for people with Alzheimer's and related dementias, it may be a vehicle to involuntarily medicate these individuals with psychotropic drugs despite the fact that the federal Food and Drug Administration (FDA) has issued "black box" warnings regarding such use.

The series of events that leads to the origination of a Chapter 51 petition can be very disturbing. Police are called to a facility, oftentimes a nursing home; the resident with dementia who has exhibited agitated behavior is charged with disorderly conduct or battery. The resident is taken in a squad car to one of several local hospitals for medical clearance. Commonly, the individual does not want to leave and is restrained and handcuffed in order for the law enforcement official to transport him or her.

At the hospital emergency room, the individual and police officer are required to wait in an environment that, to the individual with dementia, is chaotic and confusing. If the person with dementia is medically

cleared, the Chapter 51 petition is initiated so the person can be involuntarily committed to a psychiatric facility. On rare occasions, the psychiatric care is found at a private hospital. More often than not, residents of Milwaukee County are transferred to the Mental Health Complex, an environment that almost everyone agrees is not appropriate for older adults with dementia.

These transfers to another facility, in and of themselves, create trauma for the individual and can worsen the individual's health and behavioral issues. A person with Alzheimer's often becomes disoriented due to a move, regardless of the distance, and a change in environment is almost a guaranteed way to exacerbate difficult behavior. Reportedly, Chapter 51 is being used as a vehicle to do exactly this, to move a person out of an environment. After the person is removed, it is not unusual for a facility to "close the bed" and refuse to allow the person to return.

*"In a perfect world, nursing homes and hospitals would work together and there would be some specialists on site. . . [but] moving people around, like what happened with Mr. Petersen, happens on a weekly, if not a daily basis."*

The Alzheimer's Association and scores of members of the community were deeply concerned, not only about the treatment of Mr. Petersen and his family, but about others in Milwaukee County who are in the same or similar circumstances. A series of articles that appeared in the *Milwaukee Journal Sentinel* helped to bring the issue before the general public.

The Alzheimer's Association sought and obtained support from the Faye McBeath Foundation, the Greater Milwaukee Foundation, and the Helen Bader Foundation to partner with the Planning Council for Health and Human Services, Inc. to staff a Task Force and produce a report to the community. The Planning Council is a private, non-profit organization that works with others to advance health and human services through planning, evaluation and research. Under the Alzheimer's Challenging Behaviors Task Force, stakeholders from all sides of the issue came together to develop a set of common understandings of the associated problems, explore solutions and recommend changes.

The full Task Force came together over the course of five community meetings. More than 115 individuals representing a cross-section of the legal, medical, behavioral, service provider and caregiver communities came together to help address the problem. In addition to the plenary sessions, five listening sessions with key stakeholder groups, including legal, medical, and behavioral health experts, and providers were convened. Seven key informant interviews with a number of experts in the mental health, medical, provider, and law enforcement fields supplemented the work.

This report is intended to provide a basic understanding of “challenging behaviors” among people with Alzheimer’s disease, and approaches to addressing the problem in facilities and across systems. Based on the work of the Task Force, basic recommendations for future action were generated at a meeting on September 23rd and reviewed by this group of Task Force members. This report was released in December 2010 in conjunction with the Helen Bader Foundation’s Speaker Series and the State of Wisconsin Department of Health’s input sessions on a state plan for people with Alzheimer’s. For additional information see “Hand in the Plan” at [http://www.planningcouncil.org/CMS/alt\\_login.php](http://www.planningcouncil.org/CMS/alt_login.php).

## II. What are “challenging behaviors?”



While termed “challenging behaviors” in the work of this Task Force, the set of behaviors on which this report focuses is also referred to as “difficult behavior,” “disruptive behaviors,” “behavioral symptoms related to dementia,” “Alzheimer’s behaviors,” “behavioral issues,” “behavioral and psychological symptoms of dementia” (BPSD), and “inappropriate

behaviors in dementia” in both the academic literature and public parlance. To understand the scope of behaviors, some discussion of these terms is warranted.

The Alzheimer’s Association, in offering advice on living with Alzheimer’s disease and related dementias, lists the following range of behaviors associated with the disease: aggression, agitation, confusion, hallucinations, repetition, sleeplessness or sun-downing, suspicion, apathy, and wandering.<sup>1</sup>

Others define “difficult” behavior as “any behavior that causes distress to the resident and/ or those observing the behavior,” noting that the behavior may or may not be dangerous and that it may range from mildly irritating to severely disruptive, as well as being acute or chronic.<sup>2</sup>

A definition used by the State of Wisconsin details disruptive behaviors toward staff and other residents and includes verbally abusive behavior, physically abusive behavior, socially inappropriate or disruptive behavior and resisting care.<sup>3</sup>

Still others refer to “behavioral symptoms related to dementia or BSRD” particularly in long-term care residents. These symptoms include verbal, vocal or motor activities that are considered to be aggressive, excessive or lack adherence to social standards.<sup>4</sup>

Another variant refers to “behavioral symptoms” such as physical and verbal aggression, wandering, agitation, sexual disinhibition and screaming, and includes psychological symptoms of depression, anxiety, delusions and hallucinations which affect behavior.<sup>5</sup>

*“Keep in mind that a behavior that is challenging to a small agency may not be a challenge for a facility with more staff. It is not the behavior of the individual or the caregiver’s response, but the interaction of the two that makes a behavior challenging.”*

In a comprehensive study on the topic, yet another author refers to “inappropriate behaviors” defined as “inappropriate verbal, vocal or motor activity that is not judged by an outside observer to be an obvious outcome of the needs or confusion of the individual.” This work identifies the following references in the research and literature: problem behaviors, disruptive behaviors, disturbing behaviors, behavioral problems and agitation resulting in hitting, kicking or biting.<sup>6</sup>

## III. Why are these important?

Regardless of the technical term, these behaviors are important for several reasons. First, as the Alzheimer’s Association indicates, they are the source of misunderstanding, frustration and tension, particularly between the person with dementia and the caregiver. By whatever term or measure, they are very common and impose an enormous toll, both emotionally and economically. They reduce the quality of life and increase suffering for the person with Alzheimer’s and the burden for the caregiver. In turn, these behaviors





are often prominent factors in the decision to seek more restrictive care and earlier institutionalization.<sup>7</sup> Studies and real world experience among people with dementia have shown that these behaviors may lead to inappropriate treatment with psychotropic medications, physical restraints, or seclusion.

Caregivers, staff or fellow residents may be endangered as a result of these behaviors. They are common stressors resulting in caregiver and staff burnout and turnover. These behaviors, common among so many people suffering with Alzheimer's disease, are indeed "challenging" to all concerned.

*"It takes an average of 23 minutes to manage disruptive behaviors. Agitated behaviors are contagious, so it is advantageous to get them under control as soon as possible."*

#### IV. What causes these behaviors?

Challenging behaviors may be a result of the deterioration by Alzheimer's disease of specific parts of the brain that regulate emotions and impulse control. Behaviors may also be a response to physical pain that cannot be isolated or articulated by the person with dementia, or by an underlying medical problem such as an infection. They may also be the result or side effect of a number of medications inappropriately administered to the person with Alzheimer's.

Challenging behaviors may also be triggered by the setting – environmental conditions, noise, agitated behavior of others, or the confusion produced by the introduction of a new or different location. Whatever the source, the caregiver's

response may help ameliorate or exacerbate the behavior. In this way, behaviors are best seen as a dynamic interaction between the person with dementia, the caregiver and the specific environment.



#### V. How prevalent are these behaviors?

Just as there are different terms used to describe the behavior, there is considerable variation in reported prevalence. Due to differing definitions, lack of recognition of symptoms and the under-reporting and diagnosis of Alzheimer's disease in general, the magnitude of the problem is difficult to determine with certainty. There is inconsistency in the literature regarding prevalence and the factors associated with their incidence among people with dementia. For these reasons, data should be interpreted with caution. Nonetheless, studies provide some useful findings.

One noted study found that the prevalence of behavioral and psychological symptoms of dementia (BPSD) in nursing homes varies between 43 and 93% in the United States due to different definitions and diagnostic tools.<sup>8</sup> However, using a standardized test, others found that more than 90% of nursing home residents with dementia exhibited at least one behavioral disturbance with 60% experiencing psychosis, 42% experiencing depression and the greatest percentage (82%), exhibiting activity disturbance or aggression.<sup>9</sup> Still other studies indicate that between 60 and 90% of people with dementia will experience behavioral or psychological symptoms at some time during the course of their illness.<sup>10</sup> According to another study depending on measurement and the setting, the prevalence of behavioral symptoms related to dementia in long term care, including nursing homes, residential care and assisted living varies from 40-90%.<sup>11</sup>

While the challenging behavior may be common, most often it can be successfully managed. Studies confirm that two thirds of people displaying behavioral symptoms related to dementia can be successfully managed.<sup>12</sup> One authority that specializes in staff training reports that the industry standard for hospitalization of nursing home patients due to behavioral issues is 17%, which, after appropriate staff training, can be reduced to 2%.<sup>13</sup>



## VI. What do local data indicate?

Alzheimer's is the most common type of dementia accounting for 60-80% of total dementia cases. The number of people affected by Alzheimer's disease in the United States is reported to be 5.3 million. In Wisconsin, the number is estimated at 110,000 persons, with approximately 16,800 in Milwaukee County and approximately 8,000 in Waukesha County.<sup>14</sup>



The State of Wisconsin<sup>15</sup> provides the following information on prevalence in nursing homes, based on a single "point in time" (April 30, 2010). Numbers should be interpreted cautiously, however, due to the known under

reporting and diagnosis of dementia. Throughout the State on this single date, there were more than 15,000 people with a diagnosis of dementia living in nursing homes (See Table 1). Of these, nearly 4,900 were reported to have exhibited a recent (within the last seven days) incident of disruptive behavior. Of those, more than 1,200 were in an Alzheimer's "special unit" although it should be noted that there is no official definition or standard procedures associated with this designation in statute or regulation.

In Milwaukee, more than 2,100 people diagnosed with dementia were in nursing homes on this particular date, with more than 500 recently having exhibited disruptive behavior. Note that in Milwaukee, unlike the balance of the State, nearly all of those with dementia and recent disruptive behavior in nursing homes are living in a "special care unit." Note too, that there is no formal designation or specification of such units. The data also indicates that people in special care units in Milwaukee were significantly younger than people in special care units in other counties through the State.

**TABLE 1:**

*Nursing home residents with dementia  
April 30, 2010*

	Diagnosis of dementia	Recent disruptive behavior	In Alzheimer's special unit
Wisconsin	15,264	4,839 (32%)	1,241
Milwaukee	2,150	521 (24%)	500
Waukesha	944	223 (24%)	49

**TABLE 2:**

*People with diagnosis of dementia receiving home health services  
May 1, 2009-April 30, 2010*

	Diagnosis of dementia	Recent disruptive behavior	Receiving psychiatric nursing services at home
Wisconsin	1,927	238 (12%)	12
Milwaukee	358	37 (10%)	6
Waukesha	148	23 (16%)	0

Although the number of people receiving home health services (Table 2) represents an incomplete percentage of those being served in the community, annual figures of people with a diagnosis of dementia in Wisconsin receiving home health service suggest there are nearly 2,000 in this category. Of these, nearly 240 are reported to have exhibited a recent incident of disruptive behavior (within the last 14 days). In Milwaukee, the number of people with a dementia diagnosis is more than 350 with approximately 10% exhibiting disruptive behavior.

While these numbers may be incomplete, they do confirm the general trend that incidents of disruptive behavior are more common among people with dementia who reside in nursing homes than those who are in the community. Understandably, prevalence among patients in nursing homes has been found to be higher than in community dwelling patients<sup>16</sup> but data should be interpreted with caution since this may reflect severity of dementia or nursing home entry, the use of psychotropic medications, physical restraints or isolation.

*"Group homes and nursing homes have detailed statements about when staff must call the police to have a patient removed, and that's what they do. A family member providing care [is] less likely to have their loved one taken by the police. Families are more tolerant; that is why you're not seeing more [emergency detentions] come from families. Families may also take the person they are caring for to see a doctor right away to address their issues."*

For people with irreversible dementia or Alzheimer's disease needing special programs, Milwaukee County has 83 Adult Family Homes with a capacity of 324, and



123 Community Based Residential Facilities (CBRFs) with a capacity of 2,624.

Information gathered from the City of Milwaukee Police Department (MPD) provides one measure of law enforcement involvement in dealing with challenging behaviors. MPD indicates that the calls which they receive from private homes or community-based

Department-initiated emergency detentions is approximately four percent of the total calls made although again, in some districts the number was nearly twice as high. Not surprisingly, District 4, the area where the greatest number of nursing homes placed calls accounts for nearly half the calls leading to emergency detentions. Projecting these six month figures to the full year, Milwaukee Police may receive nearly 775 calls per year, with approximately 30 of these resulting in police-initiated emergency detention.

However, as Mr. Petersen’s story illustrates, not all Chapter 51 petitions are police-initiated. In his case, as well as in others reported by the State Public Defender’s Office, the Chapter 51 petition was initiated by a treating hospital. In addition, there are many suburban law enforcement agencies in the greater Milwaukee area that respond to similar calls from nursing homes under their jurisdiction. Because of this, the total number of persons with dementia-related challenging behaviors that have been the subject of Chapter 51 emergency detentions in the greater Milwaukee area remains unknown.

**TABLE 3:**  
*Calls from nursing homes to the City of Milwaukee Police Department*  
January-June, 2010

City of Milwaukee Police District	# of nursing homes calling	Total # of beds	Total # of calls to MPD	Call to bed ratio	# of calls resulting in emergency detention
1	5	574	147	.26	4 (.03)
2	2	110	16	.15	0
3	1	95	26	.27	2 (.08)
4	6	775	103	.13	7 (.07)
5	0	0	0	-	0
6	4	372	58	.16	1 (.02)
7	1	106	36	.34	0
Total	19	2,032	386	.19	14 (.04)

facilities are associated primarily with wandering behavior rather than aggressive or challenging behaviors. On the other hand, calls associated with challenging behaviors are reported to be more commonly coming from nursing homes.

A total of 19 nursing homes totaling over 2,000 beds placed calls for assistance to the seven districts of the City of Milwaukee Police Department. The number of nursing homes making calls per district was as great as six in District 4 while Districts 3 and 7 received calls from just one nursing home within its boundary and District 5 received no calls from nursing homes. While not all calls are resident related, overall, the total number of calls made to police in the first half of the year was 386, averaging approximately one call for every five beds in a six month period. Note however that one District had calls as high as one call for every three beds, while others had as few as one per nearly nine beds. The analysis of individual nursing homes shows at least one home where the number of calls was almost two times the number of beds.

In fourteen of the incidents when police were called to a facility, the officer initiated a Chapter 51 emergency detention proceeding. The number of Milwaukee Police

*“The reality is that nursing homes may be trying to protect their patients, but more often I think they are protecting their staff by getting rid of folks with challenging behaviors. We [get calls] on Friday afternoon or during off shifts. A lot are being discharged for one-time behaviors. When the police show up the person may be calm.”*

**VII. What systemic barriers were identified?**

**A. Nursing home regulations**

Representatives of the Wisconsin Association of Homes and Services for the Aging, Wisconsin Health Care Association, the Division of Quality Assurance (DQA), and the State Ombudsman program provided the Task Force with differing perspectives on nursing home regulations and the extent to which they contributed to the problem of appropriately addressing challenging behaviors. From the perspective of the Ombudsman office, which can serve as a resource to facilities, the “best practice” is to intervene and treat residents on site



rather than removing them from the home. From this vantage, aspects of the regulations were described as “handcuffing” nursing homes, and forcing them to remove residents from the facility when they exhibit challenging behaviors. Representatives of nursing homes expressed concern for the safety and care of other patients and staff as well as fear of fines and citations which can clearly interfere with the facility’s willingness to deal with the behavior on site. Nursing home staff, administrators, and representatives of statewide nursing home trade associations identified current federal nursing home regulations, and the enforcement of those regulations by DQA nursing home inspectors as a significant barrier. Data presented by representatives of the DQA, however, suggest that very few citations have been filed for failure to remove difficult residents.

*“Hospitals say it’s the nursing homes that are at fault and nursing homes say it’s the hospitals that refuse to take people. I think we all need to get together to address the issue. Nursing homes often don’t have the tools to stabilize a person who has challenging behaviors because they might not have a psychiatrist or medical doctor onsite. If a person is sent out of a nursing home it should be ... with the guarantee that they can come back. Nursing homes will take citations and fines ... rather than be de-certified for taking on people who are too challenging for them. The State is central to these issues. Nursing homes are between a rock and a hard place.”*

Currently, there are no state regulations defining a dementia-care facility, although several attempts have been made to pass legislation with this goal. In reporting to the Task Force, representatives of the nursing home association indicated that attempts to further regulate nursing homes would be met with stiff opposition and that because the problem is in interpretations of federal

regulations, new state regulations will not help address the problem. Short of a regulatory solution, local facility administrators and state associations have agreed to participate in a work group to explore what can be done to improve practices regarding the handling of challenging behaviors among residents with Alzheimer’s and other dementias.

*“In Wisconsin, a facility can describe itself as being a special care facility: this is not regulated and there is no legislative definition of what a special care unit is or what it must provide....there is so much variance in what they currently provide.”*

## **B. The “disappeared system”**

Despite the growth in the population likely to need services for Alzheimer’s and related dementias, systems of delivering care and services that once existed are either no longer available or are unable to meet capacity. The numbers of inpatient psychiatric facilities in general, and facilities with specific expertise in geriatrics have declined. Psychiatric beds in private hospitals have been reduced over the years. Hospital units that were once able to care for both the medical and psychiatric needs of older adults (formerly “Med/Psych” or “Gero/Psych” units) have been closed or scaled back. Without the proper facilities, hospital systems are reluctant to admit patients with challenging behaviors due to dementia. If they do accept the patient, hospitals report difficulty discharging the patients because the nursing home from which they came “closed the bed” and no new facility will accept the person.

The only crisis treatment facility in Milwaukee County is the Mental Health Complex. Given the reduction in facilities, increased use of mobile crisis teams that enabled problems to be addressed on-site might be expected. However, these resources have also been reduced and their services are now reportedly understaffed and usually unavailable due to budget cuts. Ironically, cutting resources for earlier interventions has created greater costs at the deep end of the system.

*“Addressing the challenging behaviors that stem from Alzheimer’s is difficult because of the complexity of the issues and because of the scarcity of resources.”*

### C. The scarcity of staff

Despite the growing number of people who will be affected by Alzheimer's in the future, there is an alarming lack of qualified medical and psychiatric treatment professionals who are equipped to deal with this population. According to the American Association for Geriatric Psychiatry, there are about 2,590 board certified geriatric psychiatrists in the United States right now. Current estimates are that about 54,000 are needed. The 60 geriatric psychiatry fellowship programs now produce about 80 board-certified geriatric psychiatrists nationally on an annual basis. There are currently 21 doctors in the Milwaukee area that list Geriatric Psychiatry as an area of specialty. The outcome of these scarcities is that older adults with dementia often do not receive the highly specialized assessment and intervention services they require.

*"Finding a geriatric psychiatrist who understands medications and wants to work in nursing homes is pretty rare. The ones that are doing it are about to retire and there are not many new people to replace them."*

## VIII. What is being done to deal with challenging behaviors?

Task Force members identified a number of strategies that are used to deal with challenging behaviors among people with Alzheimer's and related dementias. Two of these, the use of Chapter 51 emergency detentions and the administration of psychotropic drugs, while common, are controversial. Other approaches reflect promising practices including activities and interventions that incorporate the interaction of the person with dementia, the caregiver and the environment in which the behaviors occur. These include formal support for caregivers, training in promising methods of assessment and intervention, a culture shift toward "person-centered" care, pain management, use of the Star Method, and instituting appropriate policies and guidelines within facilities regarding the management of challenging behaviors among people with Alzheimer's disease and other dementias. This report highlights examples of systemic changes that have been put in place to better address the challenging behaviors issue.

### A. The controversial use of Chapter 51 for persons with dementia

Chapter 51 of the Wisconsin Statutes provides a means

to place persons with mental illness who are considered to be a danger to themselves or others in emergency detention and to administer involuntary treatment. For persons with Alzheimer's and related dementias, the usual treatment under a Chapter 51 petition is the involuntary administration of psychotropic drugs to reduce agitation and aggression and produce a state of sedation.

*"People come to us in handcuffs, they are out of their milieu, they are put on someone else's schedule, put on meds, and are surrounded by chaos. This will worsen their situation. If they weren't confused before, they will be now."*

Across the State, there is variation in the way different counties apply Chapter 51 to people who have Alzheimer's and related dementias. At least two counties do not believe Chapter 51 should apply to this population and will not prosecute older adults with dementia under Chapter 51.<sup>17</sup> Using Chapter 51 as a vehicle to deal with challenging behaviors in persons with dementia has been found to lead to transfer trauma, medical complications, exacerbated behaviors, and even death. Based on the work of the Task Force, the use of Chapter 51 in Milwaukee County to intervene in behavioral issues regarding older adults is seen as a symptom of larger systemic problems. It is the basis of the recommendation that the use of Chapter 51 to detain and force treatment on older adults is inappropriate, dangerous and should be stopped.

*"Chapter 51 reminds me of the telephone game; the use of it has mutated and there are 72 interpretations of it. There is an overuse of Chapter 51; police are relied on as the entry to treatment. Handcuffing an elderly person and putting them in the back of a car will not make them calm down. It's hard to believe that we are doing this to our parents."*

A Legislative Council Study Committee on Chapter 51, led by State Representative and Task Force member Sandra Pasch received testimony from the Task Force and will address implications of Chapter 51 for older adults with dementia in the Committee's final report recommending changes to the Legislature.



## B. The controversial use of psychotropic medications for persons with dementia

Whether administered voluntarily or involuntarily, there is considerable debate about the use of psychotropic medications in dementia care. The federal Food and Drug Administration (FDA) has found many of the commonly prescribed psychotropic drugs to be dangerous for persons with Alzheimer's and has added "black box" warnings to the packaging of some, calling for extreme caution in their use because of dangerous side effects. There are in fact no FDA-approved psychotropic medications to treat the behavioral symptoms of Alzheimer's disease and related dementias.

*"Two weeks ago we had a man come to us who had dementia and was on five different medications. It was when he was detained in a hospital that he was put on all of those meds. He was transferred to a facility and they continued it. I took a look at him and he was at a toxic level. He was sent to an ICU ... they took him off of all his psychotropic meds. Eleven days after that, ... he was walking and talking."*

A newly passed Wisconsin law, Act 281, appears to make the administration of these drugs easier in certain circumstances. Representatives of the State Department of Health Services and the Chief Pharmacist of the Division of Quality Assurance (DQA) have committed to making changes in the roll-out of the new law based on the input of members of the Task Force. To assure further progress on this issue, the Task Force recommends establishing a work group to reduce the inappropriate use of antipsychotic medications for residents with dementia and promote alternate approaches to behavior management. Work currently underway in the state of Massachusetts can help inform this effort.<sup>18</sup>

## IX. What alternative strategies are available?

While securing a Chapter 51 petition and administering psychotropic drugs may be common current approaches to dealing with challenging behaviors among people with Alzheimer's and related dementias, there are alternative strategies and promising practices that are both more humane and effective. Challenging behaviors are best understood as an interaction among the person with dementia, their caregivers, and elements of the



environment. There is an extensive field of research regarding appropriate treatment modalities for agitated behaviors. There are assessment tools, intervention approaches, and treatment practices that have been shown to be effective in addressing challenging behaviors, yet members of the Task Force report that they are not being used widely. The following sections highlight some of the strategies reviewed and recommended by the Task Force.

### A. Assessment and pain management

Behavioral issues related to dementia are serious and can be challenging, but there may be an underlying medical cause that has gone untreated. Too often, the person may be in pain due to conditions such as dental problems, dislocated joints, or even broken bones. From this point of view, the "challenging behavior" may be a form of communication that is going unheeded. The use of psychotropic drugs to control behaviors does nothing to address the underlying medical conditions. Thorough examinations to rule out pain should be undertaken before psychotropic drugs are considered.

Challenging behaviors can actually be caused by pain or infection. Task Force member Dr. Christine Kovach has done extensive research into pain as an underlying cause and reported that the person with dementia may be unable to describe her or his pain. That is, while the person's physical sense is not altered, he or she may

have a decreased ability to report pain or threatening experiences. Resistance to certain activities may be interpreted as a problem behavior when the person is actually attempting to avoid pain.

*"In some instances, it was taking more than 20 days to recognize that a patient had a fractured hip or abscessed tooth. Poor assessments equate to a delay in the identification of problems."*

Ruling out physical pain requires a thorough examination. According to Dr. Kovach, The examination process should begin with a physical assessment, including urine analysis to rule out urinary tract infections. Antipsychotic drugs used to sedate patients may leave symptoms untreated or the medications may actually exacerbate the behavior. In many cases, behaviors related to pain can be reduced with the use of analgesics.

If the physical assessment does not reveal a source of pain but the behavior persists, a social assessment should be undertaken. The process should include an assessment of environmental stressors such as noise, light, and over-stimulation.



If the behaviors continue after making social or environmental adjustments, other non-pharmacological interventions, like changes in diets or the use of cues can be explored. If the non-pharmacological interventions do not work, patients may receive an analgesic such as Extra Strength Tylenol or an increase in the existing dose of analgesic medication. Following the administration of analgesics, there are reports that people who were withdrawn, disengaged, or agitated were able to participate in activities.

*"Acute sedation sets people on a pathway to hospice to die. There was a man in his late 50s who was in a lot of pain and was sedated. He was non verbal. He was to be transferred to hospice, but his last medical examination revealed a decayed tooth. When his pain was addressed, he returned to a less agitated state."*

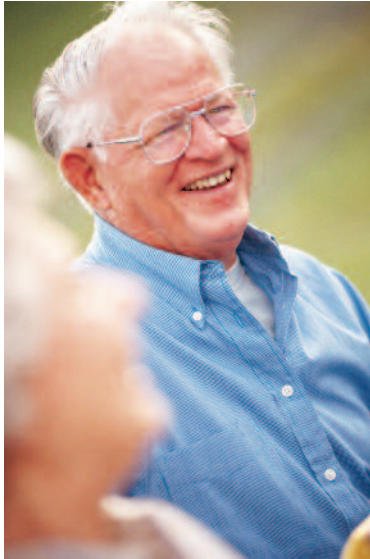
## B. Person-centered care

Another promising alternative to removing a person from their setting and administering psychotropic drugs is to seen in an approach known as "person-centered care." This approach originated in England where no facility can provide care without being licensed as a "Person-Centered Care Provider." The model has been pioneered in the United States by Tom Kitwood and advanced today through the Bradford Dementia Group.<sup>19</sup> Locally, Beth Meyer Arnold, Director of Adult Day Services at Luther Manor and a member of the Task Force, is considered an expert and advocate in this approach. It is cited as an effective, measurable and practical model that enhances the quality of life of persons living with dementia and those who care for them. It involves a continuous process of listening, trying new things, seeing how they work, and changing things in an effort to individualize care and de-institutionalize the nursing home environment. Person-centered care seeks to maximize choice and autonomy, and can thus reduce the presence of challenging behaviors.

*"You learn who the person is; there is a team of people figuring out what is familiar to them, what their needs are. Placements are adapted for each and every person."*



Person-centered care is provided according to residents' needs, desires, and preferences and staff are expected to be sufficiently flexible to accommodate these individual conditions. Staff at all levels and from all departments must be engaged in the design of the care and



committed to success. Implementation requires that person-centered care practices be viewed as part of the organization's core mission and not as a project that can be completed or set aside. Systems to support and sustain practice changes should be in place, including ongoing education, policies and procedures, and job descriptions.

Although person-centered care may require changes in the culture and the approach to care giving including care practices, workplace practices, and the physical environment, the results are more humane and effective in addressing challenging behaviors.

*"Success is really dependent on staff. You have to teach them to be passionate and understand what it is you're trying to do. People don't get culture change from theory; they need to do it for themselves."*

### C. The Star Method

The Star Method developed by Dr. Tim Howell, a geriatric psychiatrist and Task Force member, is a simple, concrete, easy to use, remember, and replicate tool for addressing the problem of complexity in geriatrics.<sup>20</sup> A 5-pointed star is drawn on a clear surface (paper or whiteboard). It enables clinical data about a person to be mapped onto a single field with five domains: medications, medical, behavioral, personal, and social. The available data for each arm of the star are written as lists. The medication arm includes an individual's medications (prescribed, over-the-counter, and "borrowed"). The medical and behavioral arms list known diagnoses, functional impairments, and/or symptoms. The personal arm highlights a person's individual traits, cultural values, and coping styles. The

social arm covers interpersonal and environmental problems and assets, such as family support, finances, housing and transportation.

Each piece of data listed thus becomes an element in a network of potentially interacting variables, with the ties between them ranging from very weak to very strong. Each arm of the star represents a different ecological level on which problems are occurring. The primary identifiable clinical challenge (e.g. client is exhibiting challenging behaviors) is written in the center of the star. In some cases the primary challenge may not be entirely clear at the onset, but gradually emerges as the situation is reviewed.

Use of the Star Method is growing in Milwaukee and is reportedly used in the Milwaukee County Department on Aging (MCDA) with Adult Protective Services (APS) and Elder Abuse cases; Aurora Health Care employees use the Star Method at patients' bedsides and in their charts; Abundant Life Manor and the State of Wisconsin Board on Aging and Long Term Care also use this Method. Its application in addressing challenging behaviors is promising.

*"We had an older man at the hospital who was having challenging behaviors and we used the Star Method to look at the various issues. Part of this work is getting clues about the patient's personal life. We had him put on his favorite clothes and his glasses and hearing aid before we talked with him; this helped switch the paradigm. We found out from his wife that he liked polka music so we made sure this was available to him. By doing these things, we were able to get on top of his problematic behaviors and he was sent home from the hospital within a handful of days."*

### X. What is being done elsewhere?

The Task Force discussed at least two examples of other communities that are undertaking systemic changes to their treatment of people with Alzheimer's who exhibit challenging behaviors.

#### A. The Ontario Model

The Ontario Model uses Psycho-geriatric Resource Consultants (PRC) to support staff in long-term care homes and community service agencies on caring for

individuals with dementia, complex mental health needs and associated behaviors.<sup>21</sup> PRCs serve three primary roles: educator, consultant and networker/developer. Rather than working directly with patients, trained psycho-geriatric experts work to train others and consult with staff and facilities. Given the shortage of trained experts and the limits of the mobile crisis team, this model could be used to assist staff in addressing challenging behaviors by providing real time coaching and consultation.

The benefits of this approach include: increased knowledge and skills among staff in Long Term Care (LTC) homes and community agencies; improved networking and collaboration among LTC homes, community agencies, and other services; increased number and coordination of educational opportunities; and more appropriate utilization of external resources.

The Canadian model utilizes a single-payer system, requires full support of the facility and requires ongoing training regarding the model and use of PRCs.

### **B. The Dane County Model**

Begun as a cross-systems model to assist persons with challenging behaviors in reintegrating to the community, the Dane County Model also uses a team approach to conduct a social-psychiatric intervention where the person is (whether that is in Mendota, a hospital, or in the community). This is a strength-based approach designed to determine who the person is, what their needs are, and to recommend an appropriate placement. In many cases entirely new placements are created for the person. Dane County funds community placements and providers receive a reasonable reimbursement rate. While some placements (and the overall model of care) involve considerable costs, they are less expensive than keeping the person in a more restrictive psychiatric facility, so they save dollars for the State-County system. This model has been in use for over a year as of May 2009 and has worked with 25 patients, all of whom were reintegrated into the community.

## **XI. What role does training play in addressing challenging behaviors?**

Based on the presentations and discussions, the Task Force concluded that any serious attempt to transform current systems of care will require extensive training. Whether in regard to understanding and dealing with dementia, pain and behaviors, or in regard to culture change in facilities, training stood out as the lynchpin between successful and failed approaches to care.

The Task Force found that for people working with individuals with dementia, training does not occur as often as necessary. Training resources were not well known, nor was there agreement regarding the kind of training needed. The lack of incentives or requirements for facilities to provide training was clear. Specialty training does not result in higher reimbursement rates and some providers went so far as to indicate that they



do not wish to provide advanced training or be seen as specializing in dementia care for fear of attracting difficult residents. The cost of training is perceived as too high, and some point to high staff turnover as a reason not to invest in training. Others pointed out that proper and sufficient training may be the antidote to turnover.

The Task Force recommends the formation of a work group to focus on training and offers the following suggestions.

To better address challenging behaviors among individuals with Alzheimer's and other dementias, training should be:

- Integrated (different levels and disciplines of staff being trained together) to strengthen greater understanding of roles, challenges, and shared expectations.
- Ongoing and continuous.
- Convenient (both online and onsite).
- Available for all who come in contact with persons with dementia including families, Emergency Medical Technicians (EMTs) and other first responders, emergency room workers, police, Certified Nursing Assistants (CNAs), primary care physicians, direct care staff, doctors, students, mental health professionals, administrators, dietary staff, security, janitorial staff and others.

To assure humane and effective treatment, content should include fundamental information regarding:

- Dementia, challenging behaviors, appropriate treatments, and basic geriatric needs.
- Methods to increase understanding of the people being cared for (focusing on the individual, personal needs and family dynamics).

*"Training is number one. When I go to places that have been cited, I often find that they don't have the right stuff programmatically to support staff. There is a lack of understanding of who they are caring for. That is one of the biggest challenges."*

- Behavioral management techniques that distinguish between "fixing" problems and managing them.
- Available resources, including appropriate placements.
- Alternatives to medication and sedation.
- How to de-escalate situations, effectively communicate with residents, and techniques to calm someone down when a situation has escalated.
- The use and importance of pre-admission forms, general assessments, and proper chart documentation.

In addition, training should be available to families to help them better understand the health and long-term care systems they will encounter and to equip them with advocacy strategies.

## XII. What are the next steps?

Based on the work of the Task Force, a number of recommendations are put forth in the Executive Summary of the report. To begin to implement these recommendations, the following action steps will be undertaken.

1. Participate in the design of the Alzheimer's State Plan, beginning with the release of this report on December 14, 2010. See the "Hand in the Plan" website at [http://www.planningcouncil.org/CMS/alt\\_login.php](http://www.planningcouncil.org/CMS/alt_login.php).
2. Provide training and information on the topic of challenging behaviors at the Alzheimer's Association's 2011 Statewide Network Conference.
3. Increase awareness and training for law enforcement personnel in more municipalities on the topic of challenging behaviors among people with dementia.
4. Convene a work group to produce recommendations on Chapter 51 for the State legislature.
5. Convene a work group to recommend approaches to reducing the use of psychotropic drugs for people with Alzheimer's exhibiting challenging behaviors.
6. Convene a work group on training to refine and recommend curricula and approaches.
7. Work with health care systems and the Wisconsin Hospital Association to develop interim and long-range approaches to improve and coordinate emergency and inpatient hospital care.
8. Meet with individual nursing home administrators and state-level nursing home associations to identify interim and long-range strategies.
9. Reconvene the full Task Force regularly to report on progress and seek additional input.

*"The biggest challenge that I run into as a nursing home administrator is the chasm between professionals. Nurses don't want to talk to occupational therapists and occupational therapists don't want to talk to physical therapists. I think we need to look at training, but specifically at how we teach, the structure of the teaching, and who we teach. This will help drive true change."*

1. Alzheimer's Association, "Behaviors: How to Respond when Dementia Causes Unpredictable Behaviors," available from [http://www.alz.org/national/documents/brochure\\_behaviors.pdf](http://www.alz.org/national/documents/brochure_behaviors.pdf).
2. Dori Ann Bischmann, PhD, and Mark G. Eberhage, PhD, Understanding Difficult Behaviors: A Visual Worksheet Approach (Behavioral Solutions, Inc.).
3. Wisconsin Department of Health Services, Division of Quality Assurance, Bureau of Technology, Licensing and Education, OASIS Data.
4. Malaz Boustani, MD et al., "Characteristics Associated with Behavioral Symptoms Related to Dementia in Long-Term Care Residents," The Gerontologist 45 (2005): 56-61.
5. SI Finkel, "Module 1: An Introduction to BPSD," BPSD Educational Pack (1998): 1-23.
6. Jiska Cohen-Mansfield, Ph.D., "Nonpharmacological Interventions for Inappropriate Behaviors in Dementia: A Review, Summary, and Critique," Focus 2 (2004): 288-308.
7. JM Swearer, "Behavioral Disturbances in Dementia," Handbook of Dementing Illnesses (1994): 499-527.
8. CK Beck and VM Shue, "Interventions for Treating Disruptive Behaviour in Demented Elderly People," Alzheimer's Disease (1994): 143-155.
9. Henry Brodaty et al., "Psychosis, Depression and Behavioral Disturbances in Sydney Nursing Home Residents: Prevalence and Predictors," International Journal of Geriatric Psychiatry 16 (2001): 504-512.
10. P.N. Tariot and L. Blazina, "The Psychopathology of Dementia," Handbook of Dementing Illness (1994): 461-475.
11. Boustani, MD et al., op. cit.
12. Ibid.
13. Cited in materials used by Dementia Care Specialists and provided in an interview with Tom Spicuzza 8/6/2010.
14. Alzheimer's Association, "2010 Alzheimer's Disease Facts and Figures," Alzheimer's & Dementia 6 (2010): 1-72. Additional information provided by Krista Scheel of the Alzheimer's Association.
15. Wisconsin Department of Health Services, op. cit.
16. Brodaty et al., op. cit., p. 505.
17. Based on information obtained in an informal survey conducted by Task Force member Dennis Purtell.
18. For more information on the Massachusetts effort to reduce the use of psychotropic medication see [http://www.boston.com/news/health/articles/2010/11/18/mass\\_aims\\_to\\_cut\\_drug\\_overuse\\_for\\_dementia/](http://www.boston.com/news/health/articles/2010/11/18/mass_aims_to_cut_drug_overuse_for_dementia/).
19. For more information see <http://personcenteredcareadvocate.org/manual-history> or <http://www.centeredcare.org/default.asp>.
20. For more information see <http://wgpi.org/starmethod.cfm>.
21. For more information see <http://www.alzheimeriniagara.ca/Psychogeriatrics.htm> or <http://alzheimerontario.org/local/files/Web%20site/Strategy/Evaluation%20Reports/Init%208/Init-8-Final-Eval-Report-Overview-of-Results.pdf>.



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## Resources

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ACE Cards Approach to an Older Adult with Delirium: Interdisciplinary Team Approach, Adapted from Michael Malone, MD

Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD)

Cohen-Mansfield Agitation Inventory – Baseline Visit, Alzheimer's Disease Cooperative Study

Geriatric Depression Scale: Short Form, <http://www.stanford.edu/~yesavage/GDS.html>

Neuropsychiatric Inventory – Nursing Home, Stephane Bastianetto, Pd.D.

- Raters' Criteria
- Neuropsychiatric Inventory Symptoms
- Scoring the Neuropsychiatric Inventory
- Grouping Neuropsychiatric Behaviors Into Categories for Medication Management

Pain Assessment in Advanced Dementia (PAINAD), Modified from: Warden, V. Hurley, AC. Volicer, L. JAMDA 4(1): 9-15, 2003

P.I.E.C.E.S. Psychotropic Template

P.I.E.C.E.S. 3-Question Template, P.I.E.C.E.S. Consult Group, Nov 2009

Behavioral Protocols, Interventions for Behavioral Challenges, Mark Eberhage, PhD and Chris Osterberg, RN, Behavioral Solutions, Inc.

- Assessing Danger to Self
- Interventions for Reducing Anger and Aggression
- Working with Residents Suffering with Depression
- Interventions for Residents Suffering from Depression
- Working with Residents who Ask for Control
- Working with Residents who Suffer from Anxiety Disorders
- Interventions for Residents who Suffer from Anxiety Disorders
- Interventions for Reducing Anger and Aggression

Understanding Difficult Behaviors: A Visual Worksheet Approach, Dori Ann Bischmann, PhD and Mark Eberhage, PhD, Behavioral Solutions, Inc.

- A Visual Worksheet Approach
- Worksheet A: ABC Behavioral Analysis
- Worksheet B: Ruling out Medical Causes of Behavior
- Worksheet C: Assessing Danger to Self or Others
- Worksheet D: Strategies for Reducing Potential Danger to the Self or Others
- Worksheet E: Initiating Emergency Detention
- Worksheet F: Referring to Inpatient Psychiatric Hospital Greater Milwaukee Area-Voluntary Patients
- Worksheet G: Referring to Your Behavioral Solutions On-Site Provider
- Worksheet H: Which practitioner should you refer to: the psychiatrist or behavioral consultant?

Serial Trial Intervention, Dr. Christine Kovach

- C-NDB Model
- Examples of Cascading Effects

NOPPAIN (Non-Communicative Patient's Pain Assessment Instrument), A U.S. Veterans Affairs METRIC™ Educational product.

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