

Center on
Age & Community

End Stage Dementia and Culture Change Roundtable

November 3rd, 2005

HOSTED BY THE HELEN BADER FOUNDATION, MILWAUKEE, WI

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Setting

WE GATHERED AT THE UNIVERSITY CLUB IN MILWAUKEE, Wisconsin. The previous evening many members of the roundtable attended the Milwaukee premiere screening of *Almost Home*, a feature-length documentary about a year in the life of a nursing home and the people who live, work, and visit there. References to the film peppered the conversation throughout the day. Although we called it a Roundtable discussion, we were seated in a U-shape, enabling us to see a screen. It was a glorious fall day, but the shades were pulled to enhance our ability to see the screen for various power-point presentations.

Robin Mayrl led us in introductions. Gathered at the table were people from a wide array of disciplines, including architects, social workers, nurses, a music therapist, a psychotherapist, an activity director, a nursing home administrator, foundation program officers, an accountant, a dance therapist, a hospital administrator, and an organizational change facilitator.

Dan Bader welcomed the group and spoke of how his mother, a social worker who loved dance and worked with people with dementia, would have enjoyed being in such a diverse group.

In Attendance

Andrew Alden

Architect, Engberg Anderson Design Partnership, Milwaukee, WI

Tena Alonzo

Director of Vermilion Cliffs, Phoenix, AZ

Daniel Bader

President, Helen Bader Foundation, Milwaukee, WI

Anne Basting

Director, Center on Age & Community, UWM

Uriel Cohen

Professor, School of Architecture and Urban Planning, UWM

Nita Corre

President, Jewish Home and Care Center Foundation, Milwaukee, WI

Megan Hannan

Director, Action Pact, Columbia, MO

Bonnie Jeglum

Director, Dept. of Social Services, Jewish Home and Care Center, Milwaukee, WI

Betsy Kaplan

Social Worker, Jewish Home and Care Center, Milwaukee, WI

Roseann Kasayka

Director Memory and Aging Services and Integrative Therapies, UHHS Heather Hill, Chardon, OH

Bill Komisar

President Elect, Jewish Home and Care Center Board of Directors, Milwaukee, WI

Christine Kovach

Professor, College of Nursing, UWM

Sharon Krull

Activities Director, Jewish Home and Care Center, Milwaukee, WI

Robin Maryl

Vice President, Program Development, Helen Bader Foundation, Milwaukee WI

Patricia Noonan

MSN, APNP College of Nursing, UWM

Tria O'Maille

Mutual Affective Timulation Dance/Movement Therapist, UHHS Heather Hill Hospital, Chardon, OH

Rick Rakita

President, Jewish Home and Care Center Board of Directors, Milwaukee, WI

Helen Ramon

Program Officer, Helen Bader Foundation, Milwaukee, WI

Nick Scholtz

Music Therapist, Jewish Home and Care Center, Milwaukee, WI

Mina Tepper

President, Jewish Home and Care Center, Milwaukee, WI

Jerry Weisman

Professor, School of Architecture and Urban Planning, UWM

The One's Who Can't Complain

CHRIS KOVACH

WE KNOW A GREAT DEAL ABOUT GOOD CARE, THE RIGHT KIND OF CARE to give, but it's not being put into practice. It's stopped by our fears, by lack of training, by other priorities.

The guidelines to good care are:

- Comfort
- Quality of Life
- Dignity
- Maintaining Personhood

Until now, the model for palliative care has been to focus on cure as long as possible, then to switch to palliation. This model undermines any hope that patients and family might have, and gives palliative care a bad name. The new model is to overlap these things. Cure and palliation should occur simultaneously, gradually shifting more toward palliation.

Another key to caring for older people is to maintain homeostasis. In fact all gerontology might be described as an effort to maintain homeostasis. This is a particular challenge for people with dementia, as they have a reduced ability to adjust to stimulus.

Organizational considerations: we need to create a supportive context for good care. We need interdisciplinary teams. We need various activities to tailor to advanced care (bathing, meals, dance, etc.).

We need to understand the trajectory of advanced dementia to help with the difficult decisions of care.

We need to understand individual needs and preferences.

Our bigger responsibility is to help people (caregivers) past their fears to help give good care.

We need to help families experience the value of the human journey.

We need, most of all, to think outside the box.

Homelessness

MEGAN HANNAN

Based on the work of Judith Carboni, article from the Journal of Gerontological Nursing
Homelessness Among the Institutionalized Elderly
Judith T. Carboni, RN, MSN, CS
Journal of Gerontological Nursing; 1990;Vol 16, No. 7

How can we create a context for a journey into culture change?

We live in a culture that is hostile to dementia and disability – so we need to start with ourselves and ask what “home” is to us. To do this, imagine what it is like to be homeless.

Homelessness is

- Public, without boundaries
- Powerless, dependent, without choice
- Insecure, uncertain, unsafe
- Disconnected from community
- Non-personhood

This helps us see that institutional care is very similar to homelessness. In fact, people with dementia in institutions might be choosing to disconnect from others so as not be conscious of the experience of living in an institution.

Home, on the other hand, is:

- A place to journey from (and come back to)
- Privacy
- Lived space
- Identity
- Power/autonomy
- Connectedness (things, people, activities)
- Safety/predictability

We can use technology to create privacy, or use behavior (like knocking) to create privacy when we can't use bricks and mortar.

The Three R's:

Renewing the spirit:

- Acknowledge the individual
- Find daily pleasures
- Provide choices
- Create joy and comfort
- Create opportunities for involvement
- Create a learning climate for all involved (staff, elders, management)

Reframing the organization (giving choice back to the elders):

- Non-departmental
- Versatile workers with blended roles

Resident-directed (as opposed to resident centered)

- Self-led teams
- Permanently assigned, consistent staff

Question/Discussion

Robin Mayrl suggested that Scandinavian models are excellent in this perspective – they consider each other as extended family (staff and residents) and take vacations together.

Renovation (10 rooms is their ideal household model)

Establish boundaries, places for intimacy

Question/Discussion

Nita was concerned here about regulations...that they impede this kind of work. Megan and Tena both suggested that regulators and CMS are now concerned with person-centered care. And that you must document choices you make that go against regulations in order to argue they are for person-centered care. These will almost always be given a variance.

Andrew Alden said that there are organizations that exist to help you with the regulations issues, such as the Society for Advancement of Gerontological Environments (SAGE).

It was also suggested that routines become so engrained that people THINK they are regulations, when they are not. Take a fresh look at OBRA.

There was a question about how different ethnicities perceive “privacy” issues. Megan suggested that this is where “high involvement” comes in, that the changes in an organization should come from the residents’ desires/needs, and these include cultural perceptions of privacy.

Chris Kovach suggested that there is a new level of growth for the oldest people, called “gerotranscendence,” and that there might need to be spaces for this kind of quiet reflection.

There needs to be choice - a balance of space for inner reflection and community engagement.

“Meaningful activities” emerge organically from the people and the day. There shouldn’t be “programs,” but tools for staff to use to involve elders as the day and their desires evolve.

Connectedness means both giving and receiving. It is crucial to provide elders with the opportunity to be of use.

Questions/Discussion

Chris Kovach asked how we might make such changes in conditions of high staff turnover and low pay. Megan suggested that turnover lowers among culture change facilities.

Person Centered, Advanced Dementia Care

TENA ALONZO

TENA TOLD THE STORY OF HOW THEY CHANGED FROM WHAT SHE thought of as being the worst facility to being the “jewel in the crown” of her entire organization. They started with one thing – eating. People were losing weight. They wanted to stop that one thing. They asked why. They believed that dementia did not mean weight loss. They took people off of sleeping pills. They assessed people’s sleep/wake cycles. They offered meals at different times – eventually moving to offering meals 24 hours a day. They also left the “square meal” concept, and allow people to eat what they want to.

Tena sees the following as the key components of advanced dementia care:

1. Dining:

- Flexibility in meal times
- Frequency of food offerings
- Types of food offered
- Different venues
- Ongoing attention to what best suits each person

2. Bathing/Basic Care giving:

- Anticipation of individual needs
- “Soft Approach for caregiving”
- Basic life long patterns
- Options for bathing
 - Bed baths
 - Standard tub bath or shower
 - Sink bath

3. Pain Recognition

- Grimace
- Verbal distress
- Physical restlessness
- Changes in behavior

4. Connections/Activities

- Knowing the person’s “Life Stories”
- Creating “moments” with one or two individuals
- Sensory calming and sensory stimulating events
- Letting go of “Traditional Activity Programming”
- Using caregiving events as activities

Tena sees the following as crucial to the success of a culture change program.

1. Staff involvement

- Inclusion
- Investment
- Responsibility
- Accountability

2. Core Team

- Choosing the Team members
- Creating the vision
- Developing a Strategic Plan
- Writing Policies & Procedures
- Getting approval for projects

3. Team Meetings

Questions/Discussion

Chris Kovach asked about staffing – as people in advanced dementia needed people to feed them. Tina said that when you roll eating times out to all day – you don't have 4 people to feed at once. They eat breakfast from 5:30 to 10:30 a.m., so staffing isn't a problem. They hired NO additional staff for these changes.

The Beatitudes also purchased "Bathing without a Battle" by Joanne Rader. They now do several kinds of bathing – including towel baths. Tena had the staff give her a towel bath to demonstrate it.

After this, they tackled "activities." They did extensive histories/life stories for each resident, so they could build meaningful activities around the resident's likes and interests. They also decentralized activities – "all of us had to make connections" in every activity of the day, from meals to bathing etc.

They have moved toward a universal skill and duty model. They all still have "expertise" in a certain area, but can do anything. Staff then becomes equally competent. You must ask staff for their knowledge, listen, and include them, get them invested. This breeds responsibility and accountability.

We must allow staff to return to their caring impulses.

The team leader serves the team, allowing the team to do their jobs.

Leaders give the team what the team in turn gives the residents.

The core team is then empowered to make policy, procedures, and in turn, create change.

When asked, Tena said their facility/unit is about 50% private pay.

"Stay the course," is Tena's advice.

Serial Trial Intervention (STI)

PAT NOONAN

THIS TALK ADDRESSES THE PAIN STUDY PROTOCOL DEVELOPED BY

Chris Kovach and tested by Chris and Pat Noonan. STI empowers staff. Residents need to have the ability and opportunity to give.

Pat told a story about how an older woman was having behavior problems. She was a cook in a mining camp and was up at the wee hours of the morning, prepared to make food. In the facility, the woman was also up at wee hours of the morning. Her caregivers figured out how to occupy her when she got up at 4 a.m.

The drawing of the STI is included here.

Pat described the STI, and also behaviors that were originally interpreted as “challenging.” Under STI, staff could see them as indicators of “pain” instead.

Key Points for STI

- 1.** People with dementia often use behaviors rather than specific verbal complaints to express the presence of a symptom or need.
- 2.** The Serial Trial Intervention uses systematic serial assessments and sequential trials of treatments to identify and treat unmet needs that may be underlying these behaviors.
- 3.** Because chronic pain is common and often under treated in this population, a trial of analgesics is used when other approaches including non-pharmacological treatments have not been effective.
- 4.** A systematic approach to assessment and treatment is needed to identify and treat discomfort and other unmet needs of people with dementia.

Lunch Discussion

OVER LUNCH, CHRIS KOVACH TALKED ABOUT HOW THOUGHT—provoking the morning had been. It was inspiring for sure, but there were likely many people who were thinking – “this can’t work.” To address these thoughts, Chris asked everyone to write down the hardest question they can think of to challenge this process. We went around the room and shared our questions. They included:

- How do you get staff to feel committed?
- What is the necessary payment mix to make something like this work?
- How do we make sure that everyone is engaged in the process?
- What is the ideal state you would imagine for your facility?
- Where do you cut corners if you have to?
- Is it possible to transform just one floor?
- Can we find the right leader to lead this change?
- Who will take charge and have time to lead this change?
- How can this work with a unionized facility?
- What is the writing/ record keeping that has to happen in such a place?
- How can nurses be decentralized and not burn out?
- How can we redesign to be person-centered?
- How do you achieve and verify changes to the environment to support person-centered care?
- How is family a part of the model of care?
- How is staff a part of the model?
- How can we incorporate staff into person-centered care model/design.

Questions/Discussion

Megan informed us that yes, there were unionized culture change facilities in Michigan and in Northern Minnesota.

Tena: The staffing model they used in the Beatitudes was “budget-neutral,” no additional staff members were hired.

Nita was intrigued, and wanted to see job descriptions and how they changed during culture change.

Tena said they were on a slow evolution toward universal workers – that they aren’t there yet.

Roseann said they created ladders for their “STNA” (“CNA”) by building their skills to be a dementia care specialist.

Tena suggested that one must “shift the value.” All staff are valued equally, even if the pay isn’t the same.

Megan suggested that universal workers can still have specialties – one can still honor expertise, but they don’t have to actually do the work.

MAT/DMT

ROSEANN KASAYKA AND TRIA O'MAILLE

TRIA SHOWED A VIDEO OF THE MAT/DMT PROCESS, AND EXPLAINED

the background to it. This process, originally conceived as a dance/movement therapy modality, is now thought of and taught as a process that can be used by all creative arts therapists, social workers and chaplains. MAT/DMT is rooted in the concept of the Person Centered philosophy as taught by Professor Thomas Kitwood of the University of Bradford, UK and practiced at the Corinne Dolan Center in Chardon, OH.

The MAT/DMT process consists of the following elements:

- Gathering and Welcome
- Warm Up using the Bartieniff Fundamentals
- Sharing Wisdom and the Ritual of Support
- Sending Forth

During the MAT/DMT session, members of the group as well as the person on the MAT Table are encouraged to relax the body, release tension and emotional holding and share support and wisdom as the end of life approaches. As such, the process becomes a kind of non-verbal group therapy for persons in the end stage of dementia.

A manual and DVD further describing this process can be obtained from UHHS Heather Hill and/or the Bader Foundation.

Design

ANDREW ALDEN, URIEL COHEN, AND JERRY WEISMAN

NOTE: Q and D were integrated into this session.

ANDREW STARTED WITH A DISCUSSION OF THE THREE P'S, courtesy of Martha Tyson which formed a basis for their approach to designing for culture change.

People, Place, Program

Andrew showed images of then (early 20th Century) and now (relatively) with images from the 70s, and even 2005. They don't look very different – still very medical model.

He asks if it needs to be that way.

He likes to be a place “detective,” figuring out what things will work in a given space.

He separated space issues into several categories.

Coming and Going

Megan told of a facility that put a pond in the entryway.

For “going,” we articulated ideas about the need for private space, need for public space too – for staff and family to grieve.

Tina told a story about their tradition of putting hands on the body as it leaves the facility – that it is accompanied the entire way from the room to the hearse.

Nita talked about how the Jewish Home has certain Jewish traditions they must abide by.

The use of a public to private gradient was discussed. Public spaces should greet people upon entering and progress to more private spaces (as in your own home). Discussion also covered issues of scale at the entrance (human scale), specifically addressing the appropriateness of large, covered entrances.

Room of One's Own

Technology now enables us to have wireless nurse call systems, and possibly very long med/gas tubes, so the bed can be almost anywhere. Flexibility is key, as it provides the resident with options to personalize his/her room.

The bathroom needs to allow for comfort, control, accessibility. Many direct caregivers extol the virtues of an easily accessible and operational bathroom. Ferns can soften the look of it too.

Rooms need to accommodate families so they can sleep over (especially in hospice).

Rooms should be flexible to allow for resident's furniture.

We noted that some people are resistant to wardrobes vs. closets.

Mainly, one needs flexibility.

There must be enough seating for visitors.

A wheeled lounge chair is helpful (easy to move).

Andrew talked about how he preferred ceiling mounted lifts, which can now be hidden in the ceiling and which can run all the way into the bathroom. These reduce staff injury from manual lifts, also do not clutter the room or hall with lift equipment. No need to worry about access to a lift, it's always in the room. At least one portable lift should be available to help with falls outside of the ceiling mounted lift range.

Restorative Powers of Nature

We need to acknowledge the human connection to the natural world, which can be so comforting to people in the last stages of their lives.

It's possible to bring nature inside, if you are in a tower situation, via plants etc.

Jerry told a story about a landscape designer (Martha Tyson) who had a group of people with dementia help her lay out the garden design, much to the surprise of the administrator.

Kurt mentioned environmentally sensitive materials, and that they might also help accomplish this goal (i.e. using wood, self controlled venting in people's rooms).

There were a series of cautions about having any transitions in flooring materials – wood to carpet etc. – that this can be very hazardous for people with dementia.

It was also noted that color of rooms was very important. It is important to blend the barrier between exterior and interior by providing a transition of spaces, (interior with windows, covered porch, outside in full sun).

Social spaces

All social spaces must accommodate wheelchairs. They need to be flexible, yet also marked with some kind of identity, so that their use is clear. (Andrew showed a slide of a door that was to the beauty parlor, but just looked like any other door).

Staff space can be in the social space. Residents do tend to congregate where staff is – as they are the life of the facility.

Anne talked about Transitional Keys, Andrea Sherman's approach to bringing ritual into care.

We talked of grief – of how the staff can find themselves acting as proxy for family.

Service with Ease

CNA substations can be nice, integrated into social space. The image Andrew had was of a "rolltop" desk.

Storage and service areas can be decentralized.

Decentralizing space into households is different work, not more work when it comes to, for example, stocking linens.

Wrap Up

ANNE BASTING

Out of Sight

There can be a front door and a back door to the facility.

Anne talked about how the day was framed – with Chris setting the stage with the basics of good care, and Megan asking us to break our patterns and recognize and resist what has become normalized in institutional care...homelessness. Tena and Pat pointed to practical considerations, and Tia and Roseann focused on the possibility of working in the arts with people in end stages. Andrew aimed to integrate programming, people, and place – the culmination of our day's topics. The questions we asked at lunch still haunt the edges of the conversation and we should be sure to return to them. After reading all the questions back, Anne asked if anyone's questions had evolved...but no one answered. So she read her own new question – “many people referenced the fact that culture change facilities and projects start small. They often say, ‘that’s not how they started.’ So what are your suggestions for how to start?”

What is a good first step?

- Megan suggested that the entire management structure must change or none of the smaller changes will hold.
- Others suggested that changing a single wing or unit can work.
- Passionate people are the key – the first step is finding passionate people.
- It is important to study – to track what you want and don't want – to guide the changes.
- You should assess the skills and tools you already have at your disposal.
- You need to start with a solid commitment from the top leaders.
- You need to start with an understanding of the length and challenge of the journey.
- The top management is part of the team – this is crucial to understand before you start.
- Roving leadership is crucial.
- The organization needs to commit itself to ongoing learning and an ongoing process of change.
- The important place to start is with a vision – a clear vision – so that you can keep it in mind through the challenges of the process.