Special Project for

The Centers for Health and Aging
Dartmouth Hitchcock Medical Center

Psycho/Social and Spiritual Needs:
Family Caregivers
Professional Caregivers

Submitted by
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March 31, 2009
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Mar. 20, 2009: Meeting with Dennis McCullough
Project Definition Meeting Minutes

Date: Nov. 20, 2008

Present: Suzanne Beyea, Caroline Moore, Jeanne Childs

Purpose: To determine what pastoral care clinical contribution Jeanne could make to the Centers for Health and Aging during her CPE internship concluding at the end of March 2009.

The Mission:

Help us find out:

(1) The psycho/social and spiritual needs of the aging population and their care givers.

(2) How we can touch more lives.

Ways to do that:

(1) Conduct a monthly non-denominational “Spirit Hour” for Caregivers who have just completed the Caregivers Program at DHMC.
   - This group identified their own overwhelming need for nurturing their spirits.
   - They find strength in coming together.
   - Use the same time slot as the course: 1:30 to 3 pm.
   - Four sessions: Dec ‘08, Jan, Feb, Mar ‘09.
   - Document their needs.
   - Ask them what are the needs of the people they care for.
   - Try to understand what makes them come to our events.
   - Find out what else they need.
     (e.g. grief, loss, meaning at the end of life, holiday grief, exploring religious issues, books like *The Power of Now* which help them, other spiritual concerns which might give rise to DHMC offering a series of Spiritual Concerns talks; other existential issues such as “You get to a point in your life where you figure out you are not getting anywhere.”)

(2) Interview Dennis McCullough to find out places where they have gotten spiritual care right.

(3) Research (google) spiritual care for the elderly and their caregivers.

(4) Patient visits with Lisa Firmanski and other geriatricians.
   Documenting the psycho/social and spiritual needs of the aging population and their care givers.
Project Summary

Date: March 31, 2009

Project: Chaplain Intern Project assigned to Jeanne Childs by Suzanne Beyea

Help us find out (1) the psycho/social and spiritual needs of the aging population and their caregivers; (2) how can we touch more lives?

Report: This summary is organized as follows:

a) Methodology
b) Overall Conclusions & Suggestions
c) Ideas for Future Programs
c) Bibliography

Methodology:

(1) The primary methodology was to discover needs through leading a support group for caregivers. The name created for this group was “Nurturing the Spirit for Family Caregivers.” Four sessions were planned. Three were held (one was cancelled due to snow). Questions for leading the support discussions were created. Each of these sessions has been documented and is included in this report.

(2) I also conducted two workshops last fall and they have been included in this project in order to obtain more data than the support group provided. The first was a workshop for Julie DeGalan’s “Focusing on Older Adult Series, Nov. 4, 2008: “Mind and Spirit at the End of Life” for professional caregivers. The second workshop was for family caregivers, coordinated by Caroline Moore for ServiceLink in Manchester, NH, Nov. 20, 2008.

(3) Additionally, I presented at the Geriatric Case Review on Jan. 26, 2009, to professional caregivers (MDs, Nurse Practitioner, MSW) around the topic of caring for patients who are communication-impaired. The notes from that meeting are included as they give some insight into these professional care providers’ needs and feelings around this topic.

(4) An unexpected outcome from the case review above was an invitation to visit the professional care giving staff at a nursing home and lead a discussion around the difficulties of caring for residents who are communication-impaired. That event took place on Feb. 26, 2009. The notes are included here because they too offer some insight into the needs of professional caregivers.

(5) And finally, I interviewed Dr. Dennis McCullough around the question “Where have they gotten spiritual care right?” Dennis’ answers are included in the documentation.

(6) Two other methodologies were suggested: research (google) spiritual care for the elderly and their caregivers, and patient visits with Lisa Firmanski and other geriatricians.

- There is a sea of information on the internet and weeding through it proved formidable in the time available. I have attached a bibliography of works which I believe offer quality information on this subject.

- With regard to geriatric patient visits, coordination of that project failed to get off the ground due to Lisa’s heavy commitment schedule. However, I had many clinical opportunities on 5 West (DHMC) to work with geriatric patients. Also, I had an internship at Alice Peck Day Extended Care Facility (nursing home), and two intern-
ships on 1/3 East at DHMC. Again, much information was gleaned from these experiences and many since regarding the psycho-social and spiritual needs of the geriatric population. I attempted to compress some of this into a PowerPoint presentation to the Geri Ops Committee on Sept. 22, 2009. A copy of that presentation is available, as are handouts from my presentation at DHMC Gerontology Update 2007.

Overall Conclusions & Suggestions:

Family Caregivers:

- **Psychosocial and spiritual distresses** (a partial list): loneliness, grief, overwhelm, fear of the unknown, fear of losing their health, isolation, abandonment, shock, panic, searching, disbelief, anger, hate, resentment, bitterness, guilt, ambivalence, frustration, loss of sleep, time alone, suffer at seeing care-receiver suffer, loss of love and affection, loss of social life, financial worries, trusting help, despair, hopelessness, helplessness, anxiety, exhaustion, and stress from all of the above.

- **What would help them**: allowing caregivers to release the frustration of suppressing their own needs, “being with people who expect nothing of me”, a day off, time off, suggestions for how to cope, being with other caregivers, talking, being heard.

- **Suggestions**: I discovered that the grief and loss pattern of this population is very similar to that of care-receivers and bereaved persons. There is much grieving, resistance, and attempts to control. What we know about the stages of grief can be applied to caregivers. I also discovered that their greatest wish is to talk, be heard, and to hear from others who are going through similar experiences. This too is true of the bereaved; I have witnessed it in support groups I lead. I suggest the most effective “treatment” for caregivers is in a social setting such as the one we initiated, “Nurturing the Spirit for Family Caregivers”. It affords the opportunity to meet their primary need for emotional support. As this need is met, other needs can emerge, such as the need for inspiration, practical suggestions, useful information, and ideas for wellbeing despite the challenges.

**Bottom Line:**
Continue offering “Nurturing the Spirit for Family Caregivers”, creating it into an ongoing program which is inclusive of all of the above.

Professional Caregivers:

- **Psychosocial and spiritual distress symptoms** (a partial list): overwhelm (not enough time), fear, anxiety, frustration, searching for tools to handle difficult patient/resident behaviors, emotions and conditions, e.g. dementia; exhaustion, burnout, grief, low morale, discouragement, guilt, torn among all the demands, keeping face and looking professional, and stress from all of the above.

- **What would help them**: practical problem-solving sessions; short didactic sessions.

- **Suggestions**: I discovered that professional caregivers want practical solutions, so I suggest problem solving and skill building sessions. At my case review, I believe I heard that there was guilt, frustration, and bewilderment around serving patients with dementia and brain damage. At Mertens House and in the professional caregivers’ workshop,
I heard a desire for knowledge and practical techniques. There was poor attendance at the Fall Series for Professional Caregivers offered by NNEGEC, but 15 staff members attended the Mertens House presentation, which was offered on site, straddling the shift change so both shifts could attend. This suggests time and place constraints as an inhibiting factor to attending instructional or supportive sessions off site. Perhaps some programs could be delivered at the care providers sites.

**Bottom Line:**
Consider offering well planned, problem solving sessions to professional caregivers at their sites, around questions submitted in advance.

**Ideas for Future Programs:**

**Medical Student, Resident and Nursing Education:**

1. Develop a series of “Hot Topics” for small groups. Questions are submitted in advance; an interactive problem solving/didactic would be conducted in a central location or at the site of the participants. A suggestion for reaching wider audiences is making these sessions into and videos for distribution. A less costly method would be to distribute the notes.
   - “Healing Contact”: Communicating with communication-impaired patients (stroke, dementia, brain injury, etc.)
   - “Staying in the Room When You Want to Run”: Talking with patients who have spiritual distress around their issues (e.g. poor prognosis, who won’t get well, or coping with decline). For this topic I highly recommend Elizabeth Johnson Taylor’s book with DVD (see bibliography).
   - “My Medicine Will Not Cure You”: recognizing when a patient has need for spiritual care which can address wounds of the soul.

**The Elderly:**

1. Consider care-receiver emotional support groups.
2. Consider “Spirit Hour” type groups for all elderly, not specifically targeted to caregivers, but for all in that stage in life. These groups could be supportive spiritually and emotionally. They could also be celebratory and educational.
3. Consider intergenerational activities such as Michael Verde’s Memory Bridge Project. (Dennis McCullough knows about this and Michael Verde will speak at the May 29th geriatric conference at UVM in Burlington, VT.)

**Geriatric Research:**

1. Consider a pilot program for geriatric physicians and chaplains, providing geriatric spiritual care to the elderly on an outpatient basis. This project could produce evidence that the collaboration in patient care will enhance patient health and wellbeing because it effectively treats the whole person. (This is in response to something Lisa Firmanski, MD, said about “My medicine will not cure them; they need yours”, referring to spiritual care.)
Bibliography:


http://sgec.stanford.edu/people.html  
*(JC Note: gives many exercises for developing staff ability to provide spiritual care)*


http://www.luthersem.edu


*(JC Note: recommended by Dr. Robert Santulli when I sent him a copy of my Geriatric Case Reviews)*

*(JC Note: many formal spiritual assessment tools and easy-to-read study review)*


“Spirituality is essential to healthcare. Why? Illness, life stress, and loss can trigger profound spiritual questions in people’s lives that address the very core of one’s humanity: who am I and why am I here on earth? These questions can provoke deep crisis in people and, if these questions are not addressed, people can become hopeless and full of despair. Viktor Frankl wrote that spirituality is the essence of each human being. He also found from his experiences during World War II that people can cope with suffering if that suffering has meaning. It is the meaning that people find in the midst of suffering, loss, and illness that provides opportunities for growth, love, and peace.

Physicians, nurses, and other healthcare professionals have a tremendous potential to impact the lives of patients by attending to patients’ spiritual needs and issues. By being present to patients in the midst of those “why” questions, we can help people move from despair to hope and from isolation to love. Dr. Elizabeth Johnston Taylor helps guide healthcare professionals with the skills needed to console patients as they navigate through often lonely and hopeless situations in their lives.

Spirituality can be defined as that part of people that seeks ultimate meaning in life, especially in the midst of suffering. That expression can take many forms — God, church, nature, spiritual beliefs, and values. Spirituality is that part of one’s life that gives one awe and an awareness of something greater than one’s life alone. It helps all of us touch upon the mystery of life and death. Spirituality, at its core, is relational. Thus, it underlies the very nature of who we are as people in community — communities at home, work, places of worship, and with friends. Healthcare is a community as well. And to become a compassionate system of care, it is essential that spirituality be at the foundation of that system. Healthcare was founded to serve others, to help them in the midst of their greatest needs. Yet, today’s healthcare system is lacking compassion and lacking an emphasis on service and love.

People need skilled medical and technical care that comes from a framework of patient-centered medicine, where the patients’ beliefs and values are as integral to their care as their physical and emotional symptoms. And, even if a cure is not possible, there can always be an opportunity for healing, which can best occur in the context of love and compassion for one another. Thus, as Dr. Taylor describes, in order to be a healer, every healthcare professional needs to reflect on his or her own woundedness and the need to heal. In this way, we form a bond with our patients in a community of people who seek meaning and purpose in the midst of life’s difficulties. Out of our loving presence to those whom we serve, healing can come about for the healthcare professional and the patient.”

* Associate Professor of Medicine and Healthcare Sciences, Associate Professor of Health Leadership and Management; Director, The George Washington Institute for Spirituality and Health
Event Notes

Date: Nov. 20, 2008

Event: Caring for Yourself While Caring for Others: Speaker Series for Caregivers (Manchester ServiceLink) — Session 4 “It’s Not About the Egg … and other insights for stressed out family caregivers.”

Present: Caroline Moore, Jeanne Childs, Stephanie Burt (ServiceLink) and five participants (2 caregivers for husband; one for mother; one for wife; one paid non-medical caregiver)

Notes:

(1) Feelings/issues reported by participants:
- abandonment, alone, no support, blood pressure way up (two), torn between needs of several family members, frustration with deteriorating mental ability of husband/wife, hard keeping patience, having to “suck it up” all the time, like “hitting a stone wall”, loneliness, children know nothing of what is going on, need time off/day off, could never put him/her in a nursing home; spouse cannot drive … has to provide all transportation; spouse like a child - unreliable; grief at losing spouse though he is still alive.

(2) Ages: They appeared to be 50-70 years old. One was a retired nurse; one retired social worker; one a beautician (male); one a retired administrative assistant; one who was a paid non-medical caregiver currently without a case.

(3) What is the biggest problem for you in your caregiving role?
(did not tabulate answers for this one)

(4) What do you want an answer for before you leave here tonight?
- “I did not expect any answers.”
- Support
- Ideas which can help with stress
- “being with people who did not expect anything of me”
- Information about what is happening to them (the people they care for).

(5) What are you most afraid of?
- What is coming around the corner … next stage … will I be able to handle it?
- “Losing it.”
- Losing myself.

(6) What are your sources of support?
- Three reported getting help from their religious beliefs;
  one from a support group;
  two from fitness activities;
  one from her daughter.
(7) Here are some A-ha moments I learned from that group which I am reflecting on:

“It’s not about the Egg “exercise: I realized that this list also applied to those in our group, the caregivers of these elderly! I now will add another exercise to this workshop on the losses in the caregivers life ..., and the parallel positions of family caregivers and those they care for. It is powerful in helping them recognize the burden they carry. And really prompts excellent sharing about ways to diffuse stress and grief.

I also realized how similar this group was to the Bereavement Group I lead! And another huge A-ha happened in realizing this because I saw that the most powerful ministry to this population is in a group setting! One-to-one pastoral care is not the first treatment of choice for them, although it has its place which I believe is after they have expressed the confusion and pain of their situation.
Event Notes

Date: Jan. 6, 2009 1:30-3pm

Event: Nurturing the Spirit: For Family Caregivers #1

Present: Caroline Moore, Jeanne Childs, five Powerful Tools graduates.

Notes:

(1) Reactions to having this “Nurturing” support group:
- “The book is out there .... we are here.” (referring to abstract learning, however practical, and the feelings of the heart).
- “Didn’t read the book - it’s on the coffee table as a reference. This is what I need, to talk with all of you.”
- “This is what we really wanted all along.”
- “I was not comfortable in the big group and I did not talk. I can here.”
- “The book is hard to learn.”
- “It was hard to share in the class.”
- “I need help finding services. Who can I talk to about it?”
- “This format (support group) is good to get us to articulate what is on our minds and to share.”

(2) What is on your mind now?
- “I am worried about my own health; I am emotional, my body aches, my head aches, I get no sleep.”
- “I am so lonely.”
- “I miss the closeness of dependency.” (mutual)
- “I am in the resentment phase. I cry. I am sad. I don’t want him to be sick.”
- “It is easier when it gets worse ... you expect less.” (in answer to the above)
- “My father has full control over me. His threats keep me from venturing at all.”
  (daughter who is caretaker of a blind father)
- “I felt guilty setting limits on my sister, but I had too or I would go nuts.”
  (family caregiver for disabled sister who does not live with her)
- “I had to put my mother in a nursing home and went through such guilt! She did not want to go, but I could not handle it.”
- “Dealing with the unpredictability of him and everything now.”

(3) What hurts?
- “the loss of a very bright partner.” (Parkinson’s caregiver)
- “I have no freedom. He is constantly talking.”
- “I am never really free.”
- “As a caregiver you really do lose your freedom.”
- “My life is surreal.”
- “Frustration all the time.”

General Theme: CONTROL of time, freedom, care-receiver, disease, symptoms, loss, helping services, loneliness.
Event Notes

Date: Feb. 9, 2009  1:30-3:30pm (should have been 2:00-3:30; some got it wrong)

Event: Nurturing the Spirit: For Family Caregivers #2

Present: Caroline Moore, Jeanne Childs, four Powerful Tools graduates.

Notes:

(1) Biggest challenges right now?
- “Getting my wife into a nursing home; she said no.”
- “I have an aide who comes in to bathe my wife, but the VNA says I have to pay for it now.”
- “The days are not long enough.”
- “Getting sleep. My husband naps all day and is up way early in the morning. The doctor said his daytime naps should only be for 30 min. but I cannot enforce that.”
- “My wife has a lot of pain.”
- “I need someone to come in for 4 hours in the morning and take him for exercise and do his voice training exercises with him.”
- “It’s hard for my smart husband to feel so dumb.”
- “It’s hard for my husband who was always active not to be now.”

(2) Their questions and answers from the group.
- “When do you stop having an emotional attachment to them?”
- “It comes and goes. I felt my feelings cool and that was a relief because I did not have to expect things from him any more. Then out of the blue he remembered our anniversary. I think he needs me now. He shows me appreciation. My feelings are getting warm again.”
- “My wife is always angry at me. Always has been. She takes me for granted. She is just anesthetized. So am I.”
- “How can I get respite? $224 a day at the nursing home is too difficult.”
- “How about Service Link? They have no financial rules.”
- “Do I have a right to have a relationship with someone else? My life is conflicts. My wife doesn’t know me. I have been taking care of her for 12 years. Don’t I have a right to some happiness? I want to put her in a nursing home but want someone else to make the decision because of this desire for another relationship.”

- (Group response to him was generally supportive, with members supporting his long faithfulness and the thanklessness of his situation. People did say it was a personal decision.)

General Theme: LIMITS on sleep, money, relationships and how they change, emotional attachment, stamina, the caregiver, age, commitment.
Event Notes

Date: March 30, 2009  2:00-3:30
Event: Nurturing the Spirit: For Family Caregivers #3
Present: Caroline Moore, Jeanne Childs, five Powerful Tools graduates.

Notes:

(1) New understandings (paraphrased) from observing caregiver comments:
   - My husband is good natured and cooperative. He hid his failing memory for a long time but now he clearly has dementia. He does not understand what I say to him sometimes, but he picks up on visual cues. Like I told him many times we were having friends come over for lunch. When the table was all set, he came through the room and in a surprised way asked ‘Oh, are people coming over?’ Also he does well understanding foreign movies with subtitles which he can read, but does not understand movies without these subtitles. Watching sports games, he does not know who is playing but can read the score. (Discussed idea that using visual cues to communicate could be more effective than using words.)
   - My wife came (who has dementia) came with me to a dinner party and the hosts’ daughter has Downs syndrome. People who have that are very affectionate. My wife could not have communicated with anyone at the table, but that young woman sat with her and was so attentive and affectionate the entire time we were there. (The idea that persons with Downs syndrome could be employed to provide companionship to the care-receivers was discussed.)

(2) Challenges? Successes?
   - Care-receivers need too much care for assisted living facilities and too little to be accepted by nursing homes. Caregivers wants to keep care-receiver home as long as possible, but have problems lifting, coping, “doing it all.” Hire help but problems with reliability, time constraints.
   - “I am lucky. My 99 year-old father is mentally and physically alright, except he is blind. I provide 24/7 care (daughter). He is so irritable. He has rages for no reason, and terrible mood swings. I can’t do anything. He questions everything I do. He has to come with me wherever I go. I told him this was a Wellness Group. He would be so upset and get mad at me if he thought I needed support.” (Suggestions for her were to talk to counselors at WISE in Lebanon about herself, talk to his doctor about depression or psychiatric treatment, talk to the Grafton County Senior Center in Lebanon for support for the blind and other support available.)
   - “There is progress getting my wife into a nursing home. You cannot put them in against their will, but we went to Probate Court and an attorney was appointed for my wife and evaluated her, and my son has been named guardian. She is near the top of the waiting list at Merrimack County Nursing Home.” (Described as a very nice new facility.)
- “I had my Mom moved away from a very negative roommate who was having a bad effect on her. (tears) It has been a terrible week. The new roommate is very negative also. Plus they took my Mom off her depression meds -- something about regulations- and so she had a terrible reaction. She needs those meds! So they are putting her back on. But meanwhile she is suffering. It is another whole big adjustment. I am sure God must have some plan. I have to have my faith.” (tears)

- General discussion about the fact that nursing homes have two beds to a room: really awful, no privacy, little storage space, hard to create a homey feeling, roommate problems, and the trauma of moving to another room or getting a new roommate. Accommodations in assisted living are so much nicer.

- Respite Care: “I put my husband in respite care at Valley Terrace and it was very nice except at meal time, they put him with a table of people who all had dementia. He likes to talk at dinner. The next time they moved him to another table.”

- (crying) “I would love to go away awhile --- just two days!”

- “I cannot plan. There is no definite future.”

(3) Nitty Gritty
- Incontinence and constipation
  -- Depends leak, even the new ones designed specifically for male or female.
  -- Nursing home incontinence pads are very good. (One person will try to find out how to buy them and tell the rest of the group.)
  -- Constipation can be regulated: prunes, Metamucel, and medication (name?)
  -- Getting the care-receiver to urinate every two hours can be very good.
  -- It is all a mixed bag, lots of messes, and discouraging. “I am washing all the time!”

- “Don’t give them sugar-free chocolate. She gobbled the box up and we had a major disaster. That stuff is a laxative.”

- “Don’t take all the suggestions of those friendly care-providers seriously. They told me not to use a towel for him to stand on in the bathroom after a shower. I had to get a rug. Well, he tripped on the rug! We are back to the towel.”

General Theme: BEING TRAPPED — literally by a blind father’s moods and control, being trapped between eligibility for assisted living and nursing home care, caught in the never-ending cycle of adjustments, problems, failing health, messes to clean up, discouragement and feeling like giving up.
Event Notes

Date: Nov. 4, 2008
Event: Focusing on Older Adults: Series of Educational Sessions for Professional Caregivers — Session 3 Mind and Spirit at the End of Life
Present: Julie DeGalan, Jeanne Childs, and two participants

Notes:
(1) Second career for both participants; one just started and the other had been a non-medical paid caregiver for 5-6 years.
(2) They appeared to be 40-55 years old.
(3) One had a little difficulty reading aloud, stumbled on some of the words. Literacy/Reading level?
(4) What is the biggest problem for you in your work?
   - smoking, urinating and alcohol drinking in their patients
   - helping people who do not want to be helped
   - accommodating someone else’s unhappiness
   - finding ways to move past a “pissy” state of mind: theirs and mine.
(5) What do you want an answer for before you leave here tonight?
   - Took care of lady until she died; ladies’ daughter doesn’t answer calls now. How do I handle daughter’s mental state now if it is negative/ grieving/etc.
   - Want tools for handling terminally ill.
   - Feels fearful and anxious; wants to exhibit strength and acceptance.
(6) What are you most afraid of?
   - danger of fire for those clients who smoke. (Caregiver finds lots of burnholes.)
(7) What are your sources of support?
   - local senior center which also sends me referrals.
   - monthly meeting in Hanover
(8) What advice would you give others who do your job?
   - apologize, back off, give space (when encountering others’ bad moods)
(9) Have you experienced something that you want to talk about?
   - (no responses)
Event Notes

Date: Feb. 26, 2009

Event: Site visit to Merten’s House on request of Director of Nursing to discuss “abandoning logic” in terms of coping with patients with dementia 

(an unexpected follow-up from the Case Presentation I made on this topic Jan 26 ’09)

Present: Sarah Hunt, Jeanne Childs, and about 15 people (nursing caregivers; RN; activities leader)

Notes:

(1) Nurses responses to “What is it like for you … what is hard?”
- resident has a hard time understanding me; takes double the time.
- it is frustrating; I am trying so hard to find things that work dealing with them
- it is so hard when a resident lashes out at me; I get frustrated, impatient, want to walk out.
- when they are mean … I take it personally. It drains and hurts me. I don’t want to come back to work.
- (activities leader) don’t know what to do when we play word games and a person with dementia shouts out an inappropriate word. The others know. I cannot say it is right because it isn’t. But if I say it is wrong, the person with dementia gets mad.
- I have a resident who says she needs to go to the toilet a lot and we get all set up and it is unproductive. This happens multiple times in the day, takes lots of energy and is frustrating.
- I have someone who will not get in the recliner; always wants to be in the wheelchair. We dispute this constantly.
- I can’t take the verbal abuse, the threats, the moods.
- Sometimes they get violent and hit me.
- What do I say when they say “no one likes me.”
- When there are emotional situations, like one resident went to comfort a sad woman and put his hands on her. She screamed “Don’t touch me.” He was offended when I told him to stop. It hurt his feelings. She was very mad.
- (nursing director) I want to support them. Like having this today is saying we care about you. I take time to listen to staff members problems and tell them not to take the resident’s personally. But I do not want to get too personal and I do not with the staff members.

(2) Ideas generated and shared by staff to ease the stresses above:
- think about what works for two year olds; give them your attention; sit still.
- don’t take it personally.
- take a break; come back later.
- ask someone to take over for you. I have. The RN did it one time and it was so helpful for me.
- try to explain why they need to do something ... but then they do not get it, so it isn’t always good.

(3) Ideas offered by Jeanne:
- Things in the caregiver’s behavior that make problems:
  resistance, frustrations (yours), demeaning, judging, forcing, hurrying, talking down. What is going on in you gets communicated to them.
- What is left in them when reason goes: feelings (Elizabeth McKinlay quote)
- Things to do to diffuse their feelings of resistance, aggression, difficult moods trying behaviors, etc.:
  -- seek connection (look in eyes, sit down and focus on the person)
  -- listen intently ... notice themes or evidence of distress in their imagery.
  -- abandon logic ... just get on the page their are on and produce a sense of harmony with them in your responses; mirror; soothe.
  -- Do not attempt logical responses, correcting their view of reality, or lecturing them in any way. This just confuses, irritates and disconcerts.
  -- Don’t try to talk them out of a mood or tears; just say “Tell me about how you feel” and listen.
  -- Call them by name, respectfully. (Do they like Mr./Mrs. or first name?)
  -- Announce yourself and your mission when you approach them; get buy-in by asking permission.
  -- Be very polite and non-judgmental; respectful; respect their bodies and possessions (all this is sacred to them and represents them)
  -- use warm greetings and encouraging statements.
- Other things which can help:
  -- find out their familiar routines, music, stories, poems from their families.
  Not: familiar is good! There may something in these that is embedded beyond active reasoning, and creates a feeling of wellbeing.
  -- Be sure to include them in group conversations, even if they do not participate. One woman with dementia told me, pointing to an empty cup, “That cup is my soul. It is empty.” When I asked her what would fill it up, she said “Being with everybody.”
  -- familiar music, hymns, water fountains, birds, plants.
  -- “The Pause the Refreshes” ... a meditative time of silence for you alone, with them, or in a group, in which you take deep breaths and concentrate on breathing in and out, banishing other thoughts. This resembles a smoking break and has the same soothing effect without the lung disease!
- Finally, the key to overcoming problems is to create a sense of wellbeing.
  At some level, many people with dementia can feel very uneasy; they can know things are not right; they can and do react to this with difficult behaviors and by withdrawal. Connecting with them where they are and recalling them to the world of persons with respect and listening and attention can go a long way to bridging the isolation and creating the sense of well being which they need.
Paraphrased Notes from

GERIATRIC CASE REVIEW
January 26, 2009
Jeanne Childs, Chaplain Intern

Cases and discussion centered around patients who are communication impaired (brain injury, dementia, medications, etc.) See case review handout.

Present: 6 MDs, 1 NP, 1 social worker, 1 chaplain intern

MD: There was a study about communication with nursing home residents who had dementia. Two forms of communication: adult-to-adult and patronizing “Let’s get dressed, honey” type language. The patronizing tone produced very difficult, resistant behavior/mood in the residents vs more adult conversational tone.

MD: When I am in the nursing home, I pass them in their doorways crying out for help. I feel awful but cannot take the time to sit down and give this type of communication.

MD: Too often we manage their need/anxiety with a prescription which makes them sleepy.

MD: The standard advice to nursing home staff is to redirect the conversation, not try to work with it. Maybe this is not the best way! Why correct them? Why not just follow along agreeable .... or stop when they are resistant to something like taking a shower and say “It seems this might be frightening. Why don’t we sit down a minute and talk about it.”

MD: It takes too long for staff to do that. They have so many patients to bathe.

MSW: No one has time. We have so much paper work, phoning and other things to do.

MD: But how do you teach reading imagery? Maybe we just say “don’t correct them”.

NP: The families freak out, resisting and correcting and everybody ends up anxious and tense. This is such a good way to be with them. We should coach families in this.

MD: In psychology an MD (did not catch his name) pioneered the “counter projective technique” sometimes used with paranoid patients. The MD sat along side of, not opposite the patient, and basically took the gist of what the patient said and played it back. For example, instead of telling a paranoid person “Don’t worry; you are safe here!” when the person says he cannot trust anyone, the MD joined the patient: “You’re right. It is hard to find people you can trust. You have to be careful.” The MD said this technique helped connect to the person and open up the communication in ways you can’t imagine.
ISSUE:
Communicating with patients who for one reason or another (e.g. dementia, medications, brain damage) cannot communicate coherently.

PASTORAL CONCERN:
I am riveted by the enormous challenge of communication-impaired patients. Personally, I cannot imagine greater suffering than being alive but not able to express your needs or be understood by those around you. The isolation, abandonment and marginalization of that state must be profound. In trying to join and be joined by others, I suspect such patients have felt pushed away, ignored or thwarted because of their inability to articulate and the inability of others to understand them. The impotence of their effort can create great frustration, emotional pain, loneliness and/or abject despair. Perhaps, this spiritual distress manifests in behavioral acting out, new or increased medical problems, motivational impairment, and more. It can also harm their survival system by causing stress to caregivers, over-medicating, health care complications, and more.

HYPOTHESIS:
With dedicated effort and skilled listening, we may be able to understand what is going on inside communication-impaired patients through the clues they give us. In a nursing home internship, I saw such residents communicate their realities remarkably well with their imagery. In both of the cases reviewed today, through no fault of their own, the patients were unable to perceive their situations in a fully functioning way, but I believe they made very accurate sense of their realities on some level. For those who can hear them, this is a profound tool in bridging their isolation and potentially ameliorating the negative effects of their impairment, and informing their health providers as to their needs.

QUESTIONS:
What experiences have geriatricians had in communicating with these patients?
Could geriatricians benefit from work in this area to aid in the understanding, interpretation, treatment, and coping of this population?
Is research being done on this?
Is the Center for Health and Aging interested in doing research on this?
CASE ONE:

Preliminary Data: Male, 86, retired
Diagnosis of Patient: Mental status change; operative procedure 12/08; crani for burrhole drainage; meningioma resection 10/08.
Referral source and/or presenting issue: Referred by nursing staff who were at wits end trying to handle this patient’s agitation, and unable to figure out what caused it. They said he had called the police and was trying to go home.
Observations: Patient seated in a large chair placed in the doorway to his room facing the nursing station. Bandage on his head. Bedside table in front of him. Cup of tea and Kleenex on tray. Not sure if he was restrained in chair.

Dialogue:
C1: Mr. B?
P1: Yes.
C2: Remember me? I am Jeanne, a chaplain here. We met several days ago when you first came in. I want to check in with you and see how you are doing.
P2: (Very agitated) Not good. I called the police and they did not come. I am being held illegally. Those girls are breaking the law.
C3: So you feel there has been a violation.
P3: I know there has. I went back to my office and got ready to leave the building. I want to find my boss; it should be reported. Can you take me to the parking lot and get a cab for me?
C4: Something is very wrong. I want to help. First I need to know more.
P4: I was told I was free and could go! But no one is allowing it! I’ve been working. And I have to get home. I’m expected. And I need to get the police and report this! It is against the law!!
C5: Where is your boss?
P5: Here, of course! Somewhere here.
C6: Mr. B. I think I am beginning to understand. You feel the law has been broken because you are being held here and you should not be. You want authorities to come and restore law and order.
P6: Yes! Of course! That is absolutely right!
C7: Well, I am so glad you have told me! You definitely are upset and we must get to the bottom of it.
P7: I am glad you understand! I have been trying to get someone to understand!!
C8: The part that is confusing me is that we are not at your office. We are at a big hospital. You came here because you were sick. The authorities here are your doctors. Do you think we should call them instead of the police?
P8: Well, the law has been broken!
C9: I do understand that. Something is wrong. But one thing I am very certain of is that if you are supposed to leave, no one wants to keep you here. It is a very expensive place! But a doctor who is in authority definitely has to sign the paperwork and sometimes that takes awhile. Have you seen your doctor today?
P9: No. But I was told I could go and now they will not let me.
C10: Yes, you have made that quite clear. I will be sure to communicate this to the authorities. Is this tea here for you? I am worried it is getting cold. Do you want some? Tea is quite calming, I think.
P10: Yes. That would be nice. I always like to have tea. I used to have tea with my wife. Married 60 years. Awfully happy.

(The rest of the visit involved talking about his wife and life and church. He picked a Bible verse he wanted me to read and it was absolutely perfect for being in a lost space. I ended the visit reminding him that his son would be here soon and I would inquire about his “papers”. I assured him that if they were signed he would be allowed to go with his son. He had calmed down and cried about his wife and the Bible verse, and was sipping his tea calmly when I left.)

Outcome:
I reported the conversation to the nurse who had called me. She said that another nurse had come and unhooked his IV and told him he was free, not meaning free to go home, but free of the tubes. Because his mental condition was impaired today (exactly why, I do not know), it became clear to both of us that the IV nurse’s comment had led to his misunderstanding that he was free to go home. When not allowed to do that, this misunderstanding caused him to feel violated.

CASE TWO:

Preliminary Data: Male, 79, retired
Diagnosis of Patient: Fall downstairs; complex C3-4 fracture, C3-5 interspinous ligamentous injury; operation C4 corpectomy and anterior fusion with posterior laminectomy with instrumentation.
Referral source and/or presenting issue: None.
Observations:
Patient seated in a large chair placed next to bed which was encased in a tent-like net. Bedside table in front of him. One opened get-well card and two unopened on table. Patient’s hair quite disheveled; dressed in pajamas, johnny, and robe. No one else in room.

Dialogue:
C1: Mr. D, I am Jeanne, a chaplain on this unit making the rounds. We have not met yet and I wanted to introduce myself and see how you are.
P1: Fine. Could be … (welcoming unintelligible talk).

C2: (I take a seat – it felt like he was happy to have a visitor. I realized that understanding him might be hard.) You’ve been here several weeks, I see.
P2: (More incoherent talk. He mentions a mountain, and a class.)

C3: So you and some others in your class are involved with the mountain.
P3: Yes, the Dartmouth Hitchcock mountain is the highest.

C4: Yes … it is pretty high up here. We have some higher mountains though.
P4: No. Dartmouth Hitchcock mountain is the highest. And we have to dig holes (more unintelligible words).

C5: So there has been some work going on.
P5: Yes, we have to dig and get in the holes. But there (and he gets into a lot of unconnected wording which sounds like he is thinking something through).
C6: I can see you have given this a lot of thought. There is a lot going on. You have to work a lot.
P6: Yes. The class (more references to classmates).

C7: When you are not working, what do you do?
P7: I stay drunk most of the time.

C8: So things are a bit fuzzy are they?
P8: Well, it’s all part of it I guess. (And he rambles off with a lot of unconnected phrases and unlinked thoughts.)

C9: That is really something. I can hear how much there is too it. How do you manage to keep up?
P9: Have to. Nice people. (More long rambling.)

C10: Are these from some of those nice people? (Pointing to the cards)
P10: Oh Yes. (Picks one up and starts to read it haltingly. Suspect he is creating the words not reading them. Does not make sense.)

C11: There are so many different signatures. They must like you a lot.
P11: They do. Nice people. (Again he speaks; I do not understand what he is saying but it sounds appreciative of the people. We talk some more about the cards and he laboriously opens the other two and we talk as above about each one.)

C12: It has been so nice to talk about all this. Before I go, would you like to say a prayer with me. (He had made some references to church and nice people.)
P12: Yes. (He puts down the card and folds his hands.)

Note: I pick the Our Father because it is so well known. I remembered that prayers that are said over and over readily come to mind for persons with dementia and wondered if that was also true for persons with brain injury. Amazingly, he chimed right in for almost half of the prayer, after which he followed me closely listening to the words, ending with gusto at the Amen. I was very touched by his concentration and reverence.

C13: I would like to come visit you again if that’s ok.
P13: Please ... please anytime. (Jovial. Hearty. I get the idea that he likes to talk and visit.)
LENGTH OF VISITS:
35-45 min each

INTERVENTION:
Primary effort was to build the feeling of communion. I wanted to bridge the isolating communication gap of the person’s non rational words. So I abandoned logic and jumped into their imagery, agreeing with them, reflecting back to them, joining in a comfortable conversational tone, and connecting for myself what their imagery might be conveying about their inner realities.

ANALYSIS:
The first patient used imagery of law breaking, police, authority. He was clearly relating that something had happened to make him feel violated. The way he interpreted his IV Nurse’s words that he “was free” was a legitimate interpretation! I did not know about the IV nurse’s words until after my visit with the patient, but using his own imagery helped unlock what was going on; staff could then respond appropriately to the reality he was perceiving.

The second gentleman had long involved explanations using references to the Dartmouth-Hitchcock mountain, his class and classmates, digging a hole to get into, nice people. I believe he knew at some level that he was in the top, the highest place for where he needed to be for his condition: DHMC. He knew he had to learn something here, and there were others around him, his “classmates” who were learning too. It seemed he was aware of death — digging a hole to get in — but he was not absorbed by it. He was working very hard to process and arrange/order things somehow in his mind. His reference to being “drunk” most of the time might indicate how he felt because of medications or impaired mental functioning, possibly quite accurately!
Event Notes

Date: March 20, 2009
Event: Meeting with Dennis McCullough
Topic: Discover places where they have gotten spiritual care right.

Notes:

(1) James E. Miller, minister and author, has done wonderful work:

- **Publications & DVDs**: Dennis loaned 7 of Miller’s publications to me. They are beautifully designed with photos, very accessible, informative and inspiring. Titles include The Art of Listening in a Healing Way, Autumn Wisdom, The Art of Being a Healing Presence, Finding Hope, When You Know You’re Dying, One You Love is Dying, The Time of Caregiving. He also lent me 3 DVDs: Gaining a Heart of Wisdom, When Mourning Dawns, The Art of Listening in a Healing Way. I found the materials I have previewed so far to be very suitable for caregivers, both professional and family, in didactic or support settings. I would highly recommend purchases from Millers collection for the Resource Center. ([www.willowgreen.com](http://www.willowgreen.com))

- **Blog**: Miller also has a blog, *The Thoughtful Caregiver*. For caregivers who are computer savvy, this is a wonderful outlet for frustrations and a source of coping ideas. ([www.thoughtful-caregiver.com/about-this-site](http://www.thoughtful-caregiver.com/about-this-site))

(2) American Medical Directors Association

- Dennis felt that the ongoing material of this organization ([www.amda.com](http://www.amda.com)) would be an excellent source of “places where they got the spiritual care right.” The organization is for medical providers in the long term care continuum.

(3) New England Resident Service Coordinators, Inc.

- Dennis also recommended this organization as a source of information. It is involved with community service around housing. ([www.nerscinc.org](http://www.nerscinc.org))

(4) Michael Verde and his Memory Bridge Project

- Dennis felt Verde’s work was excellent. It is a powerful way to educate the younger generation and connect them with seniors. ([www.memorybridge.org](http://www.memorybridge.org)) Verde will be speaking at the upcoming University of Vermont, Center on Aging Gerontology Symposium on May 29, 2009 (a FREE event).

(5) The Center on Aging at the University of Vermont

- This center is quite new and except for the conference mentioned above, the only information about it was UVM press releases. There is no website yet.