UVM Project ECHO:  
*Care Giver Supports and Services*  
November 18, 2021

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Amelia Gennari, MD (UVM Geriatric Services)
• RECORDING OF SESSION TO BEGIN
Agenda

• Introductions
• Objectives
• Didactic Presentation (~20-30 min)
• Case presentation
  • Clarifying questions
  • Participants – then faculty panel
• Discussion
• Recommendations
• Summary
• Closing Announcements
  • Submission of new cases
  • Completion of evaluations
Series Objectives

Learning objectives for this ECHO series include being able to:

• Describe current standard of care for diagnosis, treatment, and care of patients with cognitive impairment, Alzheimer’s disease (AD), and dementias – evidence-based review and approaches.
• Name non-pharmacological resources for family caregivers including caregiver supports and assistance in management of caregiver stress.
• List pharmacologic approaches to sleep and behavioral issues.
• Discuss side effects of pharmacologic approaches to sleep and behavioral issues.
• Identify Vermont-specific rules regarding driving and guardianship.
CME Disclosures

University of Vermont (UVM) Office of Continuing Medical and Interprofessional Education (CMIE) is approved as a provider of Continuing Medical Education (CME) by the ACCME. UVM designates this internet live activity for a maximum of 1.5 AMA PRA Category 1 Credits. Participants should claim only the credit commensurate with the extent of their participation in the activity.

Interest Disclosures:

• As an organization accredited by the ACCME to sponsor continuing medical education activities, UVMCMIE is required to disclose any real or apparent conflicts of interest (COI) that any speakers may have related to the content of their presentations.
Care Giver Supports and Services

John Coffin – MSW, UVM Memory Program Intern (2020-21')
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Allegra Miller – M.Ed in Administration and Family Caregiver
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Care Giver Supports and Services

Session Objectives:

• Define and discuss the role and needs of Caregivers
• Offer examples of real-life Caregiver experiences
• Describe a useful model for Dementia Caregiver Supports & Services
• Provide a reference list for Dementia Caregivers and/or Providers

How can we support caregivers to be responsive to the everchanging Dementia process? How can we help them learn, adapt, and succeed?
Definition of Caregiver

A person who gives care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled. Caregivers may be health professionals, family members, friends, social workers, or members of the clergy.

"There are only four kinds of people in this world: those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers. Caregiving is universal."

- Rosalynn Carter, Former First Lady of the United States
Bob’s Story

• Timeline from PD diagnosis in 2006

• Path to being his caregiver

• What supports and training worked for me, for Bob and for our family

• How we coped with grief, acknowledged our anger, fueled our love and captured bits of joy everyday

• [Between Notes by Emily Rinkema](#)

This essay is a daughter's personal account about care giving, memories, dementia, and PD.
Special Moments.....
Caregiver to-dos:

- Creating a care team
  ("You can’t do it alone, don’t try...")

- Developing useful goals and knowledge
  ("Here’s what I can do...")

- Recognizing symptoms and responding to change
  ("I see it, now I can shift what I’m doing...")

- Making way for good moments and savoring them together
  ("By adapting to make space, we can experience...")

- Learning to grieve what is being lost and living with Dementia
  ("It’s ok to do both... It’ll be important I do both!")
How can providers intervene and help direct Caregivers so they can get to where they want to go?
- Medical & Professional team
- Friends & Family
- Peers/Mentors (Other folks who know what it’s like…)
- Community activities for engagement & recognition
- Healthy personal activities & relationships
- Individual counselling & Group therapeutic support

- Dementia (symptoms, reference materials, online communities)
- Grieving Process (what to expect, where to get help…)
- Changing roles (family/spouse/caregiver etc.)
- Shifting plans, outlook, and adapting to meet Dementia
- Concrete skills, routines, and systems > active coping
- Future planning (care, legal, financial etc.)
As provider, limited time... Try to notice:

• What is this person looking for? Why? (Care, Info, Find next step)
• Now, what is the problem that *can* be helped?
• What can I *do* to support this person in meeting that problem?
So Caregivers experience success with:

- Creating their care team
- Developing useful goals and knowledge they need
- Recognizing symptoms and responding to ongoing changes
- Making good moments and savoring together as they happen
- Grieving the losses and continuing, in-spite-of Dementia, to live

_to develop & nurture the resilience needed to find joyful moments each day..._
Getting Oriented:

What is Dementia? (alz.org)
What is MCI? (dementiacarecentral.com)

Diagnosis (Start with PCP):

Be open about symptoms...
Importance (of good diagnosis)
UVM Memory Program
Dartmouth Memory Clinic

Support agencies/services:

Vermont Area Agencies on Aging (vermont.gov)
   Ex. AgeWell “about” (Burlington Area)
Find: Area Agencies on Aging - map (vermont4a.org)
   *Consider asking about:
Adult Services Division - services list (vermont.gov)
SASH (Home medical care)

National: Eldercare locator (eldercare.acl.gov) Support services

Eldercare Connection (ex. private pay services)

Local community starting points:

What is a Memory Cafe?
Vermont Memory Cafes (memorycafedirectory.com)

Alz.org Vermont

***Please note there will be a reference sheet with helpful links included alongside this 11/18 presentation on the UVM Project ECHO webpage.***

This can be used by caregivers and/or providers.

See format to left...
Further Recommendations:

**The Last Ocean A Journey Through Memory and Forgetting**  Nicci Gerard

A personal account of living with dementia and its impact on both the person living with dementia and the caregiver.

*What I learned from my father's dementia - Nicci Gerard*

*What dementia teaches us about love - Nicci Gerard*

**Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying**  Maggie Callahan and Patricia Kelly

Stories and practical advice on responding to the requests of the dying and helping them prepare for death
**Option B Facing Adversity, Building Resilience and Finding Joy** - Sheryl Sandberg and Adam Grant

A personal account on the sudden death of a spouse, describing how loved ones realized that they could discover joy with the unexpected “Option B” in life through resilience, gratitude, perseverance, grief and love.

**Four Things That Matter Most** - Ira Byock, M.D.

Dr. Byock writes about the importance of nurturing relationships, celebrating each other, forgiving ourselves and living life more fully while experiencing family strife, end of life, or personal tragedy.

4 things that matter most - Ira Byock, M.D.
DO NOT INCLUDE:

- Names
- Address
- DOB
- Phone/Fax #
- Email address
- Social Security #
- Medical Record #

The discussion and materials included in this conference are confidential and privileged pursuant to 26VSA Section 1441-1443. This material is intended for use in improving patient care. It is privileged and strictly confidential and is to be used only for the evaluation and improvement of patient care.
Case Presentation Format

Case presentation from a participant (a real-world case, from the field)
Then
Clarifying questions about the case from group to case presenter
Then
Ideas, suggestions, recommendations from participants
Then
Ideas, suggestions, recommendations from ECHO faculty team
Then
Additional discussion, if any (All)
Then
Summary of case discussion
(course co-directors: Mary Val Palumbo, DNP, APRN, GNP-BC and John Steele Taylor MD)
• RECORDING TO BE STOPPED FOR CASE PRESENTATION
Questions and Discussion from the group....
**Prep for Next Session**

Prior to each session, if you have specific questions for our faculty expert(s), please let us know and we will pass along ahead of time.

<table>
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<tr>
<th><strong>DATES</strong></th>
<th><strong>SESSION</strong></th>
<th><strong>DIDACTIC TOPICS (in addition to case review)</strong></th>
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| Sep 16    | TeleECHO Session 1 | Importance of Early Evaluation of Cognitive Complaints  
(John Taylor, MD, UVMMC Memory Program Co-Director)                                                                                                                                |
| Oct 21    | TeleECHO Session 2 | Living Alone with Dementia – Challenges for PC teams  
(Mary Val Palumbo, DNP, APRN, GNP-BC, UVMMC Memory Program)                                                                                                                        |
| Nov 18    | TeleECHO Session 3 | Care Giver Supports & Services  
(John Coffin, MSW; Allegra Miller, Family Caregiver)                                                                                                                                  |
| Dec 16    | TeleECHO Session 4 | Dementia and Driving  
(Heather Zuk, OTR, CDRS, CDI, UVMMC Driver Rehab)                                                                                                                                 |
| Jan 20    | TeleECHO Session 5 | Community Programming for People With Dementia and Care Partners  
(Tiffany Smith, MA, CRTS, CDP, Program Administrator State Unit on Aging)                                                                                                           |
| Feb 17    | TeleECHO Session 6 | Non-pharmacological approaches to behavioral issues for caregivers  
(Lori McKenna, MSW, LICSW, UVMMC Memory Program)                                                                                                                                       |
| Mar 17    | TeleECHO Session 7 | Legal Issues of Guardianship, Competency and Power of Attorney  
(Jackie Rogers, PhD, DAIL Public Guardian Program)                                                                                                                                       |
| Apr 21    | TeleECHO Session 8 | End Of Life Planning and Palliative Care  
(Zail S. Berry, MD, MPH, UVMMC Geriatrics)                                                                                                                                               |
| May 19    | TeleECHO Session 9 | Managing Behavioral Issues and Sleep – Pharmacological Approaches  
(Doug Franzoni, PharmD, BCGP, Meds To Beds Supervisor, UVMMC Outpatient Pharmacy, Geriatric Consultant Pharmacist)                                                                  |
Dementia Clinical Consults
45 min slots available
2nd and 4th Wednesdays
2-4 PM
Sign up at: https://www.signupgenius.com/go/5080B4AACAE2FA6FC1-corner

Or Email:
Mary.Palumbo@med.uvm.edu

Diagnosis & Management of Dementia
For Primary Care and other healthcare providers.

Online Learning via Vermont Health Learn
(CMEs at your own pace)
Register at https://catalog.ytl.org/product?catalog=DementiaDiagnosis-Treatment-Management
Conclusion
• Slides are posted at www.vtahec.org
• Volunteers to present cases (this is key to the Project ECHO model)
  • Please submit cases to Mary.Palumbo@med.uvm.edu
• Please complete evaluation survey after each session
• Once your completed evaluation is submitted, CE information will be emailed to you.
• Please contact us with any questions, concerns, or suggestions
  • Mary.Palumbo@med.uvm.edu
  • Elizabeth.Cote@uvm.edu