

2019

# Caring for an Aging Loved One

meredith ann lackie  
*University of Vermont*

Follow this and additional works at: <https://scholarworks.uvm.edu/fmclerk>



Part of the [Medical Education Commons](#), and the [Primary Care Commons](#)

---

## Recommended Citation

lackie, meredith ann, "Caring for an Aging Loved One" (2019). *Family Medicine Clerkship Student Projects*. 504.  
<https://scholarworks.uvm.edu/fmclerk/504>

This Book is brought to you for free and open access by the Larner College of Medicine at ScholarWorks @ UVM. It has been accepted for inclusion in Family Medicine Clerkship Student Projects by an authorized administrator of ScholarWorks @ UVM. For more information, please contact [donna.omalley@uvm.edu](mailto:donna.omalley@uvm.edu).



# Caring For Aging Loved Ones

Community Health Center of the Rutland Region July – August 2019

Meredith Lackie, MS3

Mentor: Dr. Baker

# Problem Identification & Description of Need

## I noticed...

Many patients are caregivers for aging family members. Many of them work in addition to taking care of their family member. The caregivers frequently worry about their loved one when they are not there. This added responsibility has a dramatic impact on their health.

## I researched:

"81 % of caregivers feel inadequately trained for the skills they perform"  
(skills include wound care, proper positioning when lifted, etc. ) [1]

Caregivers who report the highest burden are more likely to be less educated, to live with the care recipient, and to perceive they had no choice in assuming the caregiver role [2].

# Public Health Cost

- 80% of adults requiring long-term care currently live at home in the community, and unpaid family caregivers provide 90% of their care [3]
- These caregivers serve as a critical extension of US health care system, and provide big savings estimated \$470 billion nationwide in 2013 [4]
- The National Family Caregiver Support Program is the first federally funded program to formally recognize caregivers.
  - In 2016, they only got \$150 million in federal funding (~1/20th of one percent of the estimated value of caregiver contributions to the health system) [1]
- In the next few decades the demand for family caregivers is expected to increase. By 2030, one in five adults will be 65 years or older, and a large number of them will need assistance with either instrumental or basic activities of daily living [5]

# Community Perspective on Issue

## Community Connections:

1. Aron Brush, Caregiver Coordinator of Southwestern Vermont Council on Aging
2. Nicole Morgan, Director of Palliative Care & Hospice Services VNA & Hospice of the Southwest Region

## What types of questions do caregivers usually ask?

- *"Frequent questions include 'Do you know of any support groups in the area', or 'are there any respite grants available' or 'Do you know of any training and/or educational workshops in the area'. Those are the most common questions that I get and I can always direct them in the right direction." – AB*
- *"What is available for respite? How do I manage medications?" – NM*

## Are there ways that health care providers, in family medicine or otherwise, could engage and support caregivers?

- *" Yes. They can take initiative and hold additional support groups, trainings and education for family caregivers whom want to learn more or whom don't know where else to turn. Additionally, they could refer family caregivers whom they have contact with to their local AAA such as SVCOA (which many Health Care Providers such as the VNA currently do). We could take it from there. " - AB*
- *"Advanced directives are key." -NM*

## Have you identified any caregiver needs that are not currently being addressed by local services?

- *" Not many. Rutland is very rich in community resources including caregiver resources; the caregiver or family simply need to reach out for help. The only thing I will say is that there is a growing number of caregivers who are caring for family members and loved ones who are affected by Alzheimer's Disease and Dementia and I feel that communities need to start learning more about the disease(s) and slowly become more 'dementia capable' or 'dementia friendly'. There is a lot of stigma that is associated with Alzheimer's Disease and dementia, and the stigma not only makes family caregivers and those affected by the disease feel left out, but it also creates a sense of isolation for caregivers and their families whom are caring for individuals with ADRD. Thankfully, our community (Rutland and Bennington County) as well as many others in Vermont are adapting by offering many different Alzheimer's Disease educational workshops, ADRD support groups, and other trainings focused specifically on ADRD. The Alzheimer's Association is also an excellent resource for ADRD caregivers and their families." -AB*
- *"There are many resources available, but for someone just starting out it can be really overwhelming online. There should almost be a single list of resources available organized by the service." – NM*

## Moving forward, what services could be implemented locally or nationally to better support caregivers?

*" Speaking locally AND nationally, I just think that the more caregiver support groups and educational opportunities the better. Evidence-based programs such as Powerful Tools for Caregivers (PTC) and workshops alike are essential in my opinion for caregivers to live healthy, balanced and sustainable lifestyles and to provide the highest quality of care without stretching themselves too thin. Too often I see caregivers reaching out when they have reached a point of complete exhaustion or burnout. We want to (and can) help them before they get to that point. If communities work together to offer a wide variety of different caregiver supports and different dates, locations and times, then I think you will see a lot of engagement from caregivers and they will be much better off. Lastly, I just want to say that a big problem that caregivers face when interested in taking education is who will take care of their loved one while they are gone...? This is a very valid concern and I see it all the time. And often times, it deters them from going out and attending the support group or taking the education. This is all the more reason why local adult days should be utilized (when appropriate) and also why caregivers should seek respite help from their local AAA and other organizations as soon as possible so that they have the opportunity to engage in education and support."*

Discussions with the local AAA and VNA Hospice and Palliative Care team and observations made in the family medicine practice elucidated (1) The need to increase awareness about the local resources available to caregivers who are patients at CHCRR, and (2) The frequently asked questions and sources of confusion for new caregivers of elderly persons.



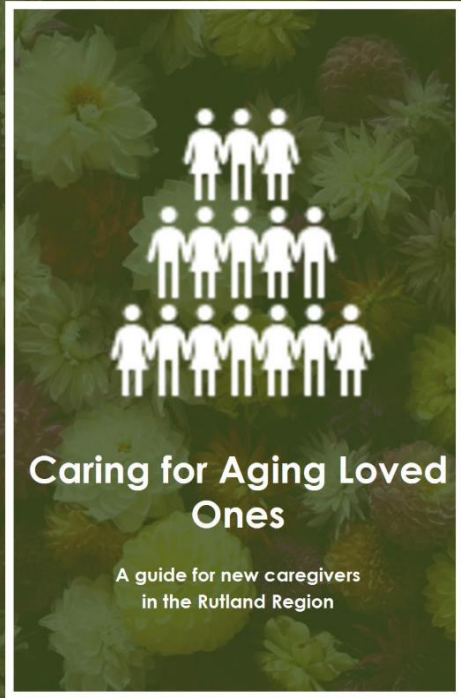
# Intervention and Methodology

This project hypothesizes that the prevalence and severity of caregiver burden would be reduced by increasing awareness of the many community resources available for caregivers in the Rutland Region.

A booklet was created containing (1) important contacts for caregivers in the area, (2) a summary of some of the available resources, (3) an overview of new terms related to caregiving and (4) a collection of frequently asked Q&A.

The handbook was emailed to the Community Health Team and is to be distributed in the public waiting areas at Community Health Centers of the Rutland Region.





# Caring for Aging Loved Ones

A guide for new caregivers  
in the Rutland Region

## Table of Contents

- Community Resources.....1
- Getting Started .....2
- Important Contacts.....2
- Important Documents .....2
- Frequently Asked Q&A.....3
- Choosing Care .....4
- New Definitions .....5

## New Definitions

1

**Advanced Directive (aka "living will")**  
Written legal document that outlines your wishes for medical treatment in the future. Any adult can make one at any time, regardless of how young, old, healthy or sick they are, and should update it on an annual basis

You do not need a lawyer to complete an advance directive. Find the form at: [www.vtelhicsnetwork.org](http://www.vtelhicsnetwork.org), then register it with the Vermont Advance Directive Registry, a secure online database that gives your health care providers immediate access to your wishes about health care decisions : [www.healthvermont.gov/vadr](http://www.healthvermont.gov/vadr)

2

**Activities of Daily Living**  
Basic Activities of Daily Living (BADLs) include: eating, bathing, dressing, toileting, and functional mobility (being able to get out of bed, or into chair)

Instrumental Activities of Daily Living (IADL's) include: housekeeping, money management, shopping, meal preparation, money management

3

**Hospice vs Palliative Care**  
Hospice is for anyone with a terminal illness. A doctor must verify a prognosis of six months or less of life. Covered by Medicare, Medicaid, and most private health insurers. Unlike hospice, palliative care can be used at any stage of an illness (not just the advanced stage). A doctor's order is required for admission. Often covered by Medicare and other health insurance plans.

## Choosing Care

### Skilled home services

- Skilled services are those provided by licensed providers such as nurses, physical therapists, speech therapists, etc.
- Medicare and most private insurances will cover a limited amount of skilled services at home.

### Other home services

- Home care agencies provide home health aides, who assist with ADLs (bathing and dressing); homemakers, who assist with IADLs (laundry, housework, errands); and companions, who provide sitting and respite services
- Not covered by most insurance plans, and generally cost between 15 and 30 dollars an hour. Some patients who own their own houses enter into a reverse mortgage, in which the home care is paid for gradually from the value of the house, all the while allowing them to stay at home.

### Long-term care such as nursing home or adult day program

- If there is a need for skilled services, Medicare will cover 100% of the cost for the first 20 days of a nursing home stay after a hospitalization.
- Long-term care is not covered at all. Adult day programs cost anywhere from 50 to 100 dollars a day, while nursing homes cost between 150 and 250 dollars a day. Most states have payment assistance programs to help families that cannot afford these rates. Many families purchase separate long-term care insurance policies that cover these types of services.



4

## Community Resources



### Caregiver Resource Guide, by the SVCOA

Document listing local in-home nursing and private duty agencies, educational workshops and seminars, support groups (ie. The Memory Café), national disease-specific organizations such as the Alzheimer's Association and Parkinson's Association and contact information for elder law resources.



### Powerful Tools for Caregivers

6-week caregiver workshop that teaches caregivers how to better support and take care of themselves which in turn makes them a more efficient and effective caregiver

2-4 workshops held a year by organizations including SVCOA and Rutland County Caregiver Coalition



### Memory Café

Social gathering for caregivers, folks affected by Alzheimer's Disease and Related Dementia (ADRD), and for any other aging individual who feels isolated and who could benefit from social contact and engaging in activities. Activities include crafts, music and games that help to stimulate brain activity. Memory Café gathering times and information can be found at SVCOA.

1

## Getting Started

### IMPORTANT CONTACTS

Southwestern Vermont Council on Aging (SVCOA)

Rutland Office: 802-786-5990;

Bennington Office: 802-442-5436

Rutland County Caregiver Coalition

Phone: 802-786-5990

---

*"From caring comes courage." – Lao Tzu*

---

### IMPORTANT DOCUMENTS

#### Medical Records:

- Advanced Directive
- Personal medical information (list names and numbers of doctors, a summary of care recipient's medical history, and information about the health of immediate family members)

- List of current medications

#### Identity records:

- Social security card
- Driver's license
- Birth certificate

#### Insurance

- Health insurance
- Long-Term Care insurance
- Life insurance

2

## Frequently Asked Q&A

### How do I find Respite Care?

SVCOA offers respite grants for qualified *unpaid family caregivers*, FREE In-home caregiver counseling program (by their Eldercare Clinician) and Adult Day Health Service Programs. For more information, ask your family physician, or see "Important Contacts" on page 2.

### How do I manage their medications?

Work together with the primary care physician to create a list of medications, what they are for, timing and frequency of dosing, and how to monitor for common side effects!

### When should we go to the ER?

Signs that indicate distress include, but are NOT limited to:

- Usual medications are not helping
  - Hard to finish a sentence
  - Heart beating very fast or irregularly
  - Lips or fingernails are gray or blue
  - Breathing is fast and hard, despite medications
- Call 911 or go to the ER if you are uncertain. Ask the primary care doctor for advice specific to your loved one's unique state of health.

### When should I worry about their memory?

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, work, or leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgement
9. Withdrawal from work or social activities
10. Changes in mood or personality

For more information: [www.alz.org](http://www.alz.org)

3

# Results

- Specifically in the Rutland Region, there is a wide availability of resources for caregivers. A major barrier to access of these resources was lack of awareness. Improving communication between primary care offices and organizations such as the local AAA and VNA will be essential to increase awareness of the resources they provide moving forward.
- Many patients are caregivers. Caring for a caregiver includes helping them connect to the community supports that are available.
- The booklet is meant to serve as a straightforward tool for new caregivers, directing them to the services in the area that can help them, as well as to familiarize them with some of the important topics in caring for elderly persons.

# Evaluation of Effectiveness and Limitations

- Limitations include that the booklet is available in the office, and therefore inaccessible to caregivers who do not take time for themselves to go to the doctor. Although it directs caregivers to resources that would benefit mental health, it does not directly include any tips for selfcare. Furthermore information in the booklet will need to be updated as time goes by and the availability of resources changes.
- Due to time constraints, I was not able to evaluate the response from patients on the booklets. A survey could be created and administered to caregivers to evaluate the effectiveness of this tool.
- Additionally assessments could be implemented by the family medicine practice to evaluate if there are statistically or clinically significant health benefits in those who use community resources.
- Collecting quality evidence that supports the clinical recommendation for psychoeducational, skills training, and therapeutic counseling interventions for caregivers is critical, as evidence that asserts the clinical relevance of such programs are needed to drive the restructuring of reimbursements that allow for sustainability.

# Recommendations for Future Interventions/ Projects

- Create smart phrase in EMR to implements caregiver assessments, then offer repeat assessments as the care recipient or caregiver's condition changes:
  - Practical in-office questions: <https://www.caregiver.org/caregivers-count-too-section-3-caregiver-assessment-table>
  - Modified caregiver strain index: <https://consultgeri.org/try-this/general-assessment/issue-14>
  - Zarit Burden Interview <https://bit.ly/2Hso3qt>.
- Create tools to facilitate the conversation about advanced directives. Improving advanced directive completion rate in the community will ease caregiver burden.
- For now, Family physicians can focus on practical individualized interventions aimed at assisting caregivers, and to help connect them to the local AAA and VNA Care team.

# References

1. Swartz, K., & Collins LG. (2019). Caregiver Care. *American Family Physician* 99(11), 699-706.
2. AARP Public Policy Institute; National Alliance for Caregiving. Executive summary: caregiving in the U.S. June 2105. <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-executive-summary-revised.pdf>. Accessed July 21, 2019.
3. Institute of Medicine (US) Committee on the Future Health Care Workforce for Older Americans. Retooling for an Aging America: Building the Health Care Workforce. Washington (DC): National Academies Press (US); 2008. 4, The Professional Health Care Workforce. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK215402/>. Accessed July 21, 2019.
4. Reinhard SC, Feinberg LF, Choula R, Houser A. Valuing the invaluable: 2015 update. AARP Public Policy Institute. July 2015. <https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>. Accessed July 21, 2019.
5. National Association of Chronic Disease Directors; Centers for Disease Control and Prevention; Health Benefits ABCs. CDC seeks to protect health of family caregivers. January 15, 2009. [https://c.ymcdn.com/sites/www.chronicdisease.org/resource/resmgr/healthy\\_aging\\_critical\\_issues\\_brief/ha\\_cib\\_healthoffamilycaregiv.pdf](https://c.ymcdn.com/sites/www.chronicdisease.org/resource/resmgr/healthy_aging_critical_issues_brief/ha_cib_healthoffamilycaregiv.pdf). Accessed July 21, 2019.

# Interview Consent Form

Thank you for agreeing to be interviewed. This project is a requirement for the Family Medicine clerkship. It will be stored on the Dana Library Scholarworks website. Your name will be attached to your interview and you may be cited directly or indirectly in subsequent unpublished or published work. The interviewer affirms that he / she has explained the nature and purpose of this project. The interviewee affirms that he/she consented to this interview.

Consented:

1. Name: Aron Brush, Caregiver Coordinator of Southwestern Vermont Council on Aging
2. Name: Nicole Morgan, Director of Palliative Care & Hospice Services VNA & Hospice of the Southwest Region