



# **Caregiver Identification: Strategies for Advancing Person-Centered Dementia Care Across Settings**

*December 6th, 2021*



**Presented by:**



**In collaboration with:**



# Land acknowledgement

*The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. We acknowledge with gratitude the Land itself and the People. We take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.*



# The Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

Designed to support state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives, by...



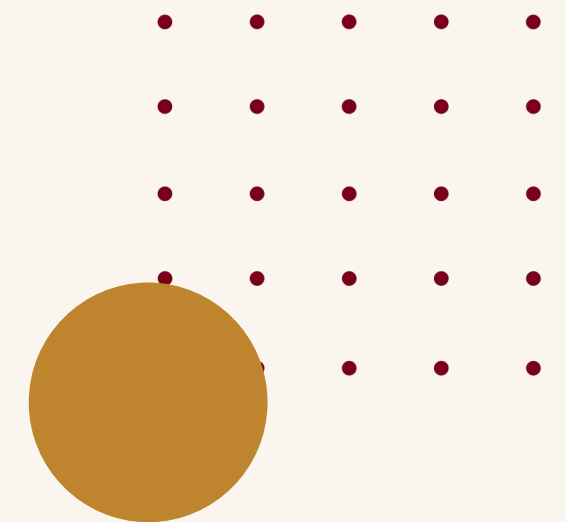
**Improving access to evidence-based programs and best practices**



**Facilitating connections and collaboration among public health agencies and a wide range of service organizations**

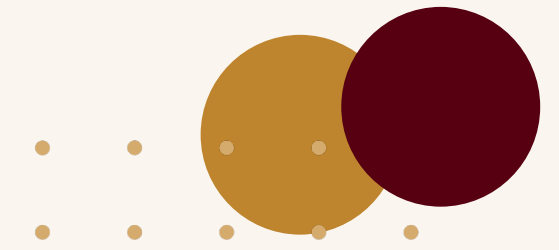


**Providing technical assistance for identifying, selecting implementing effective public health interventions and strategies**





# Welcome to our presenters...



**Alan Stevens, PhD**  
Texas A&M Health  
Science Center;  
Baylor Scott & White  
Health



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Fairfax County  
Area Agency on Aging



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Early Detection of Dementia



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Dementia



# Identification of Family Caregivers in the Electronic Health Record

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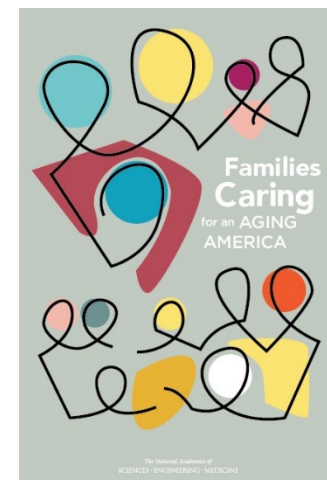


# Family Caregiving in the context of Socials Determinant of Health

- Multiple perspectives of family caregiving have emerged
  - A field of research and policy
  - A consumer group within our society
  - A key member of team based health care
- Knowledge derived from these perspectives (often from interdisciplinary research teams) along with a surge of interest in Socials Determinant of Health *position family caregivers as key contributors to health care innovations*

# Family Caregiving and Health Care

- Evidence-based caregiver interventions are being translated into family centered services
- Policy advocates and “rule makers” are looking for opportunities to leverage ongoing care innovations into family centered care
  - The CARE Act ([www.aarp.org/supportcaregivers](http://www.aarp.org/supportcaregivers))
  - Families Caring for an Aging America ([www.nationalacademies.org/caregiving](http://www.nationalacademies.org/caregiving))



# Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward

Consensus Study Report. National Academies of Sciences, Engineering, and Medicine. 2020

- The committee found two types of interventions that are supported by low-strength evidence of benefit, based on a systematic review by the Agency for Healthcare Research and Quality (AHRQ):
  - Collaborative care models, which integrate medical and psychosocial care; and
  - Resources for Enhancing Alzheimer’s Caregiver Health (REACH) II, an intervention aimed at supporting family caregivers.”



MEETING THE CHALLENGE OF  
CARING FOR PERSONS LIVING  
WITH DEMENTIA AND THEIR CARE  
PARTNERS AND CAREGIVERS

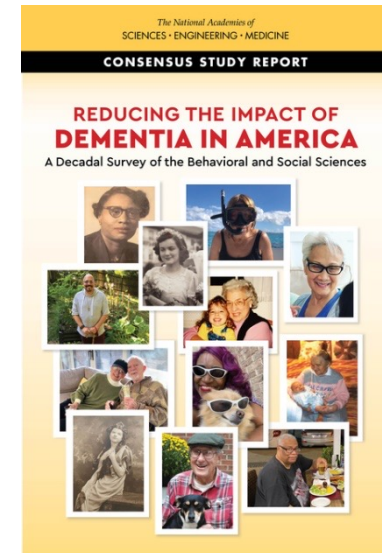
A WAY FORWARD



# Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences

Consensus Study Report of the National Academies of Sciences, Engineering, and Medicine. 2021

- “From a societal perspective, *these diseases place substantial demands on communities and on the institutions and government entities that support **people living with dementia and their families***, including the health care system, the providers of direct care, and others.”
- The economic cost of these diseases in the United States has been estimated at \$355 billion for 2021 and is projected to rise to \$1.10 trillion by 2050



# RAISE Family Caregivers Act

*Initial Report to Congress Delivered on September 22, 2021*

<https://acl.gov/RAISE/report>

- The identification of challenges faced by family caregivers, including financial, health, and other challenges, and existing approaches to address such challenges.
- An overview of federally funded efforts to address those challenges.
- A discussion of how family caregiving impacts the Medicare program, the Medicaid program, and other federal programs.
- Recommendations to improve and better coordinate federal programs and activities to recognize and support family caregivers and improve the coordination of such federal programs and activities with state programs and other programs.



# Reflects the Concerns of Caregivers Nationwide



“ I’m not a stranger to hardship. My husband was a career marine and was often gone when our children were young. Our son requires 24/7 nursing, and it was difficult to find ethical and trained nurses. Sometimes he was harmed through negligence, causing more surgeries. ”

*Debbi | Eagan, MN*



“ I felt the need to protect my wife while she wanted to maintain her independence, and we’ve achieved a balance where I trust her to ask for help when she needs it. ”

*Leslie | Vancouver, WA*



“ Caregivers run and run – they never know where the finish line is. I feel the hardest part of being a caregiver is learning how to be a caregiver. ”

*TeriLynne | Maricopa, AZ*

- 1,600 RFI responses (75% from caregivers)
- Caregiver focus groups

- Stakeholder listening sessions
- 25 caregiver narratives & videos

# FCAC Adopted Recommendations Set the Course for the Initial Report to Congress

- Five Priority (goal) Areas
  - Awareness and Outreach for Family caregivers
  - Engagement of Family Caregivers as Partners in Healthcare and Long-Term Services and Supports
  - Services and Supports for Family Caregivers
  - Financial and Workplace Security for Family Caregivers
  - Research, Data and Evidence-Informed Practices
- 26 Recommendations are the foundation for the National Family Caregiving Strategy

# Engagement of Family Caregivers as Partners in Healthcare and Long-Term Services and Supports

## **Goal 2: Family caregivers are recognized, engaged, and supported as key partners with providers of healthcare and long-term services and supports**

- Recommendation 2.1: Ensure the impact of policy and practices on family caregivers are studied and understood before changes are made in healthcare systems.
- *Recommendation 2.2: Identify and include family caregivers as essential members and partners in the care recipient's care team.*
- Recommendation 2.3: Engage family caregivers through the use of evidence supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.
- Recommendation 2.4: Increase the integration of care through the inclusion of family caregivers in all relevant care coordination and transitions across providers and settings and when desired by both caregiver and care recipient.
- Recommendation 2.5: Strengthen the training of healthcare, social service, and allied professionals to maximize family caregiver engagement and referrals to services in the community.



# Family Caregiver Representation in Electronic Health Records

## Optimal Enhancement Characteristics

- Family caregivers play a unique role and should be identified independently from emergency contact and health care agent.
- Family caregiver *contact information and relationship to the patient* are clearly visible to providers during all healthcare encounters.
- *Information reported by the family caregiver* regarding the day to day health and activities of the person with dementia can be documented by a provider and clearly visible to the patient's care team during all healthcare encounters.
- Information about the family caregiver would ideally be located in a *structured field* so that the information could be accessible via standardized reports that are used to aggregate patient data

*While persons with dementia provide a use case for the concept of family caregiver representation, these desired characteristics apply to a wide range of patient conditions in which a family caregiver is engaged in the day to day care of the patient.*

# Family Caregiver Representation from a *Population Health Perspective*

- Leading EHRs include a platform for population health management
- If appropriately collected and stored, caregiver information could be used for health care system initiatives that extend beyond the traditional clinician encounter.
  - Caregiver information could potentially improve care to high risk populations
- Using family caregiver representation in this way is distinctly unique from enhancement that targets traditional clinician encounters

# Family Caregiver Representation from a Population Health Perspective

- Fundamental to this approach is storing information in a discrete field
  - Collection of the information could be inserted into several different workflows
- Family Caregiver information would appear under the patient demographics.
- Decision support at point of care or population management reporting could be leveraged
- Information would be visible and usable for care managers of high risk patients and at times of care transitions
  - This approach is consistent with related information – emergency contact, health agent, etc.
  - Discharge planners could easily access family caregiver information during hospitalizations to improve discharge instructions. This would assist with compliance of the CARE Act

# Family Caregiver Representation from a Population Health: Specific applications

- A streamline approach is to have a new field under **Patient Demographic** titled “Family Caregiver”
  - This would need to be a change made by the EHR vendor and included in future releases. Increase the scalability of this solution.
  - This approach would allow the Medical Record Number (MRN) of the family caregiver to be included in the patient’s EMR
  - The ability to link the patient’s and family caregiver(s) MRNs opens new opportunities for supporting the family caregiver (e.g., Family Caregiver Registry).
- A more comprehensive approach is to include information about the family caregiver in the system’s approach to adopt the CMS innovation model on the social determinants of health

# The Serious Illness Conversation and Care Planning Project (SICP)

## *Mission*

*To improve treatment of seriously ill patients **and families** via more frequent, better, and earlier conversations encouraging patient centered goals of care.*

Robert L. Fine, MD, FACP, FAAHPM

Director of Clinical Ethics and Supportive & Palliative Care

Laurel Kilpatrick, MD

Division Director, Palliative Care



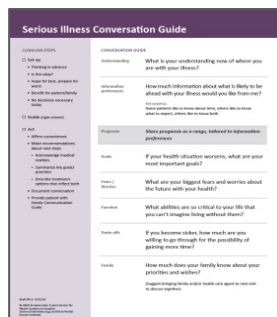


# Serious Illness Conversation Project

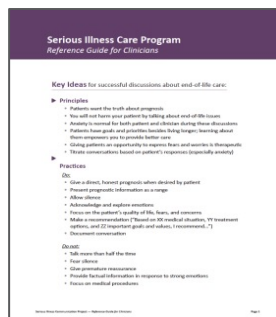
*“BETTER CONVERSATIONS, BETTER CARE”*



Tools



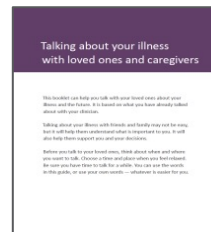
Serious Illness Conversation Guide



Clinician Reference Guide



Patient preparation materials



Family Comm. Guide

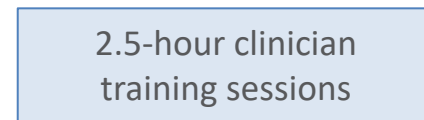


Education

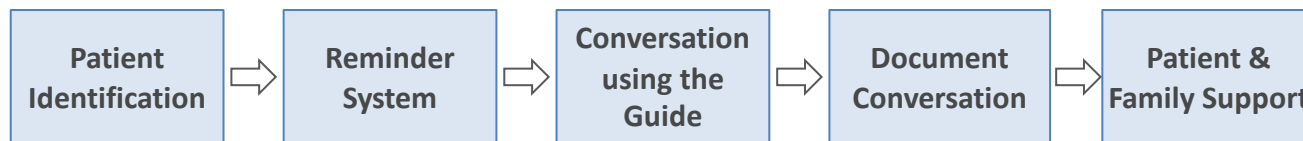
Train the Trainer



Train Clinicians



Systems Change



Measurement and Improvement (QI)

# Complete SICP Form

How much does your family or your health care decision maker/surrogate know about your priorities and wishes?

Discussion

- does not want family informed
- extensive discussion with family about goals and wishes
- no discussion, wants help in talking to family
- no discussion but plans to address these issues
- some discussion but incomplete
- wants clinician to talk with family

Insert SmartText

Given your goals and priorities, and what we know about your illness at this stage, I recommend...

Insert SmartText

Mark as reviewed.

No Changes

Now

Restore Close F9

Previous F7 Next F8

# Why, how and so what ?

- Why
  - Our mission needs to reflect the reality that family caregivers are essential to many population health management initiatives
- How
  - A single, best practice approach is unlikely
  - Use of family caregiver data cannot be separated from collection, storage and potential use of data
- So What
  - Value proposition needs to be realistic and contextually tailored

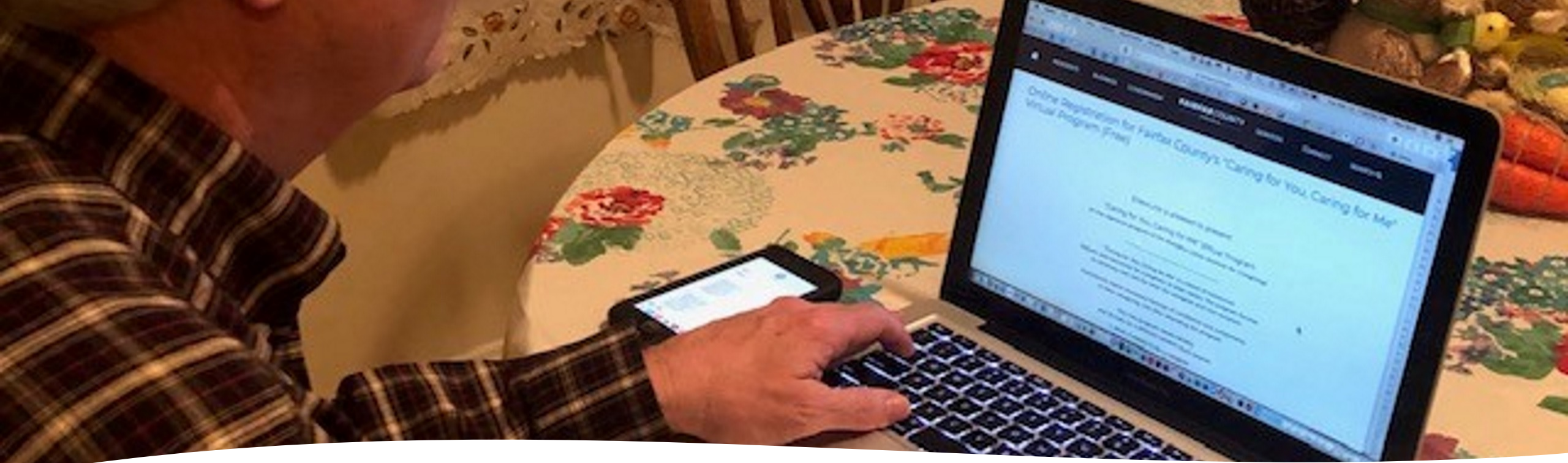


# Fairfax Caregiver Alert Notifications

# The Importance of Identifying Family Caregivers

- ❖ Critical partners in providing care and support.
- ❖ Most family caregivers are unpaid providers who often need guidance and support in their roles and need to be connected to resources and services.
- ❖ In 2018, The Virginia Department of Rehabilitative Services reported that 1 in 5 Virginians is a caregiver.
- ❖ *Fairfax 50+ Community Survey for Fairfax County and the Cities of Falls Church and Fairfax:*
  - 1 in 4 of caregivers felt a level of physical, emotional, and/or financial burden.
  - 96 percent had not attended a caregiver support group.





# Overview of Work

- ❖ Diversify Communication Methods.
- ❖ Collect and analyze Data.
  - ❖ Surveys
- ❖ Build New Partnerships.
- ❖ Implement Innovative approaches to engage family caregivers in program participation.

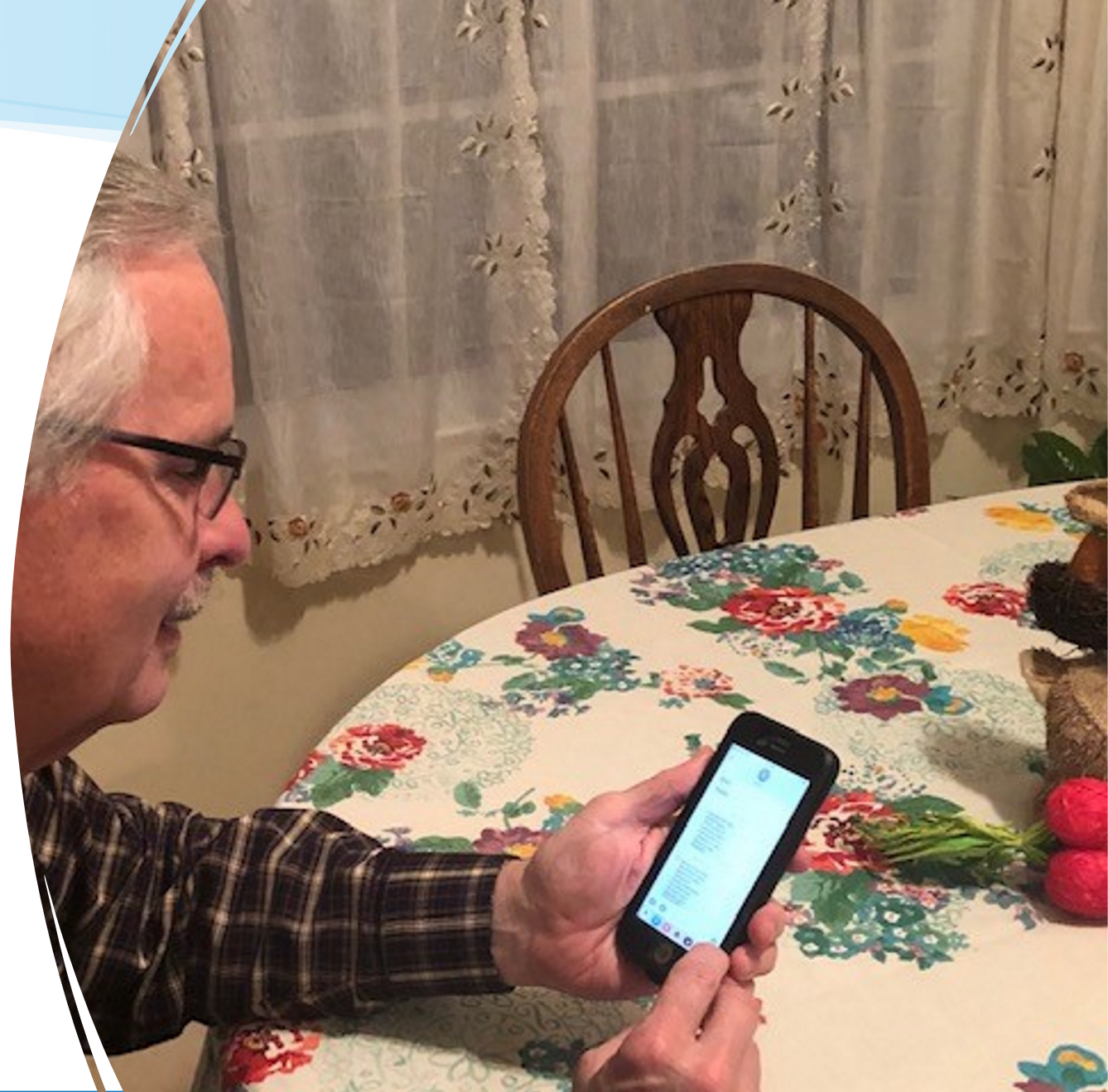


# Communications/ Outreach

- Monthly Webletter
- Caregiver Alert Notifications
- Caregiver Column in the Golden Gazette
- Facebook Page and YouTube Channel.

# Program Development

- Monthly Caregiver webinars
- Health and Wellness Workshops
- Panel Conversations







# Partnerships

- ❖ Interdepartmental Partnerships.
- ❖ Faith Communities.
- ❖ Health Care Systems: INOVA Health Care System, Capital Caring Health, Blue Ridge Hospice, and Home Health Agencies.
- ❖ Support Group Facilitators.
- ❖ Non-profits: Alzheimer's Association, Insight Memory Care Center, Northern Virginia Dementia Care Consortium.
- ❖ Initiatives: Dementia Friendly Fairfax.



It's simple. If we can't reach you,  
we can't alert you.

## Innovative Approaches

- ❖ **Fairfax Caregiver Alert Notifications:**
  - Partnership program between Fairfax Area Agency on Aging (FAAA) & Fairfax Office of Emergency Management (OEM).
  - Caregivers subscribe to the FAAA/Caregiving option offered through the Fairfax Alerts System.
  - Enables caregivers to receive weekly notifications about workshops, webinars, support groups, and other supportive services via text messages, emails, and voice communication methods.
  - The program contributes to family caregivers' quality of life and wellbeing by promoting meaningful community engagement, connection, and awareness about resources.
  - The program did not require any additional expense to either OEM or FAAA because it uses existing resources.
  - The program is handled by a caregiver support specialist, who updates and schedules the alerts weekly, as well as collects data about the program.
  - Currently, there are over 800 subscribers to the program.





# Future Opportunities

- ❖ Understating equity, diversity, and inclusion within family caregiving.
- ❖ Strategic planning to program development.
- ❖ Targeted outreach.

# Thank you!

Fairfax Area Agency on Aging  
November 2021  
Fairfax County, VA  
703-324-7948

[www.fairfaxcounty.gov/familyservices](http://www.fairfaxcounty.gov/familyservices)

# **Take Charge Program**

## **Caregiver Identification & Assessment**

**Improving Health  
Improving Healthcare  
Reducing Costs**

**Partnership between Elder Options and  
University of Florida Health**





# Unique Program Characteristics & Strengths

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- Collaborative targeting and identification
- Evidence based interventions and practices – TCARE, Care Transitions Intervention (Coleman Model), SAVVY Caregiver, PEARLS
- Patient and caregiver empowerment
- Multiple healthcare partners across settings
- Ongoing meetings to examine opportunities to improve processes
- Timely interactions at key transition points
- Communication via Emergency Medical Record - EMR





# The Importance of Including Caregiver Identification

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- Caregivers are overburdened – physical care, symptom management, emotional support, help with activities of daily living
- Potential to save costs and to minimize the long term damage to caregivers' quality of life
- Important to increase caregivers' access to effective intervention (TCARE), SAVVY Caregiver, PEARLS
- Improved compliance with patients treatment plans when caregiver is identified and empowered
- Caregivers are crucial to the overall success of the long term care system– total uncompensated care and direct care workforce shortage. We need our caregivers caring for as long as possible!



# Benefits to Identifying the Caregiver in the Healthcare Setting

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- Able to identify training needs for the caregiver
- Increased awareness of and linkages to community and social supports
- Better coordination of care
- Improving health outcomes for patient and caregiver
- Healthcare partners better understand the role of the caregiver and the challenges facing the patient
- Improved communication to hospital about issues after patient discharge



# Questions

**Kristen Griffis**

**Chief Executive Officer**

**Elder Options**

**[griffisk@aginresources.org](mailto:griffisk@aginresources.org)**



# Q&A

Please use the Q&A feature to submit your questions!



# Connect with us!

Visit us online at <https://bolddementiacaregiving.org> to....

- ✓ Find today's slides and recording
- ✓ Request Technical Assistance to support your public health work in dementia caregiving
- ✓ Access resources and materials
- ✓ Stay up to date with PHCOE-DC activities!

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@PHCOE\_DC



# Thank you for joining us today!

Please take a moment to complete our evaluation form  
at the end of this presentation.

