

Finding the Way in Dementia Care

Use of Care Navigators for People Living with Dementia and their Caregivers

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Part of the National Alzheimer's and Dementia Resource Center webinar series sponsored by the Administration for Community Living.



CAIz Connect

Michelle Johnston, MPH
Program Director, Dementia Initiatives

Objectives

- Create and sustain a dementia-capable home and community-based services system for people living with Alzheimer's disease and related conditions and their caregivers, using a no wrong door (NWD) approach.
- **Ensure access to a comprehensive, sustainable set of quality services that are dementia-capable and provide innovative services to people living with dementia and their caregivers.**

Funding Acknowledgement

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Offer University of California San Francisco's (UCSF) evidence-based Care Ecosystem program in a community setting

Also incorporate HomeMedsSM (medication reconciliation) developed by Partners in Care Foundation

Care Ecosystem Core Components

Protocol Topics

- Immediate needs
- COVID-19, disasters & related events
- Medication reconciliation & review
- Safety screen & recommendations
- Resources, referrals & education
- Caregiver well-being
- Behavior management
- Advance care planning



California Department of Aging (CDA)

Pilot Counties

- Imperial (Area Agency on Aging)
- Marin (Center for Independent Living)
- Ventura (Area Agency on Aging)

Clinical Support

- Partners in Care Foundation (HomeMedsSM & Nurse)
- Alzheimer's Los Angeles (Social Worker)

Evaluator – The Gigas Group



Why Community Health Workers (CHWs)

Community Health Worker

- Frontline public health worker
- Trusted member and/or has close understanding of community
- Serves as link to facilitate access to services
- Improve quality and cultural competence of service delivery
- Builds capacity of individuals and community

Source: [American Public Health Association](#) ↗

Competencies and role fits with Care Ecosystem model
More commonly used term than care team navigator

Use of CHWs Offers Potential for Sustainability

Medi-Cal CHW benefit

- Launched in July 2022
- Covers CHW services as preventive services and on the written recommendations of a physician or other licensed practitioner
- May address issues that include, but are not limited to, the control and prevention of chronic conditions...aging.
- CHW may assist in developing plan of care with licensed provider.
- CHWs may be supervised by a community-based organization (CBO) or local health jurisdiction (LHJ) that does not have a licensed provider on staff.

Medicare CHW benefit – potential for sustainability

- CMS is finalizing coding and payment changes to pay separately for services when clinicians involve certain health care support staff (including CHWs) in furnishing medically necessary care
- Designed to describe services involving community health workers, care navigators, and peer support specialists
- Person-centered assessment, care coordination, education, health system navigation, support, service access, etc.
- Address unmet social determinants of health needs
- Navigation for those with high-risk conditions (e.g., dementia)
- CHW can work for CBO, supervised by billing practitioner

Planning Process

- Securing grant, contracting with partners, updating plans, etc.
- Set up systems and document processes to be used throughout project (e.g., referrals, enrollment, data collection)
- Pilot counties each recruit and hire 1.0 FTE bilingual (English & Spanish) CHW to serve as care team navigators
- Train CHWs and agency staff who will be handling referrals
- Resource materials available through UCSF Care Ecosystem and local Aging and Disability Resource Connection (ADRC) partners
- Develop materials and plans for outreach (English and Spanish)

Hiring Community Health Workers

- Developed sample job description
- Each organization modified it to fit their internal requirements
- Key attributes of successful CHWs:
 - ✓ Communication and learning skills
 - ✓ Problem solving skills
 - ✓ Organizational skills
 - ✓ Ability to communicate with dyads in their preferred language

Training Community Health Workers

- Training required by employer
- Project background; training on data collection system
- Care Ecosystem online training
- Review role of CHW
- Additional background on Alzheimer's and related conditions, tools for caregivers
- Review Care Ecosystem materials (protocols, dyad resources)
- Learning about local resources
- Observing care consultations and support groups
- Role plays and responding to sample cases
- HomeMedsSM training
- Scope of role, escalations, Adult Protective Services (APS) reporting, boundaries

Implementation - Started October 2023

- Sites are conducting outreach to promote program
- Trained staff will process referrals
- Community health workers:
 - ✓ Enroll dyads (person living with dementia and care partner); goal is 240 dyads per county over 2 years
 - ✓ Conduct regular calls to assess needs, provide education, make referrals and follow up on whether needs have been met, using Care Ecosystem protocols and resource materials
 - ✓ Collect information for HomeMedsSM medication reconciliation (with pharmacist consult) and for project evaluation
 - ✓ Create and update care plans as needed

Ongoing Monitoring and Development

- Clinical support team conduct weekly huddles with the community health workers for case reviews, ongoing professional development and to raise and address issues
- Training will be conducted with the referral staff annually
- Project team meet 1-2 times per month to assess progress, discuss best practices, identify issues and plan for sustainability
- Steering Committee meets quarterly
- Implement evaluation plan and provide reports every 6 months

Care Navigation Examples

- Connecting dyads with additional community resources
- Providing tips for caregivers to improve quality of life
- Support in communicating with health care providers



Some Early Lessons

- Difficult to try and launch simultaneously in 3 counties
- It can be challenging to figure out the best solution related to data collection if everyone isn't already using the same system
- It takes time and patience to ramp up enrollment
- Remote clinical support can work



- **Care Ecosystem toolkit, care protocols, and CTN training program are available at: [Care Ecosystem | Memory and Aging Center \(ucsf.edu\)](https://www.ucsf.edu/memory-and-aging-center/care-ecosystem)**

Care Ecosystem

The Care Ecosystem model was designed to help address the unmet needs of persons with dementia and their caregivers.



Research & Clinical
Trials

[Research FAQ](#)

[Clinical Trials](#)

What is the Care Ecosystem?

The Care Ecosystem is a model of dementia care designed to provide personalized, cost-efficient care for persons with [dementia](#) (PWD) and their caregivers. This telephone and web-based intervention was developed and studied across California, Nebraska and Iowa via an award from the Center for Medicare and Medicaid Innovation (CMMI grant number 1C1CMS331346) from 2014–2018 and continues to be studied with funding from the National Institute for Health (NIH grant number RO1 AG056715) from 2018–2022.



Contact Information

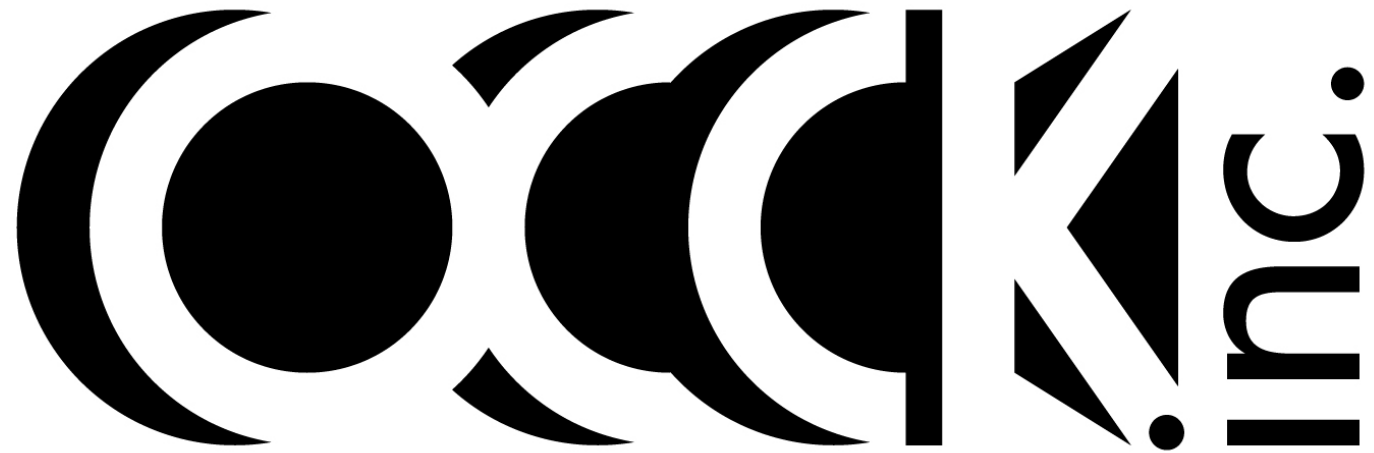
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ALZHEIMER'S PROGRAM

Brooke Bryson
Cognitive Care Navigator

OCCK: MORE THAN YOU THINK

Private Not For Profit 501 C 3

- Services for any person of any age with any short or long-term disability.
- 325 Employees serve 4,500 people per year
- Cover 43 of the 105 Kansas counties
- 16 Departments offering over 100 unique services
 - * Infant Toddler
 - * Autism
 - * Brain Injury
 - * Case Management
 - * Alzheimer's Disease
 - * Adaptive Technology
 - * Transportation
 - * Occupational Therapy (OT)
 - * Residential Homes
 - * Home Health
 - * Chore Services
 - * Day Program
 - * Retirement
 - * Work Force
 - * Financial Management
 - * Physical Therapy (PT)
 - * Speech Therapy
 - * Independent Living



GRANT HISTORY

REDUCING DISABILITY IN ALZHEIMER'S DISEASE (RDAD)

- 2016 collaboration between 2 Universities and 4 non-profits awarded a US Department of Health and Human Services Administration for Community Living Alzheimer's Disease grant
- Support the families of and people living with dementia or with intellectual or developmental disabilities (IDD) who were at risk for dementia.
- The four-year program supported over 150 families and trained over 200 care workers in the region.

MY ALLIANCE FOR COGNITIVE HEALTH (R24)

- National Institute on Aging to Increase participation in research by underrepresented populations (Black, Latino, Rural)
- Created social support and education networks
- Preliminary results of the project indicate meaningful improvement in the number of individuals from these medically marginalized communities participating in clinical research.



GRANT HISTORY

ACL

2021 Awarded grant to strengthen dementia capacity by adapting the Care Ecosystem model to rural extension sites.
August 2022 Began Implementation

Objective 1: Establish dementia extension offices capable of providing in person and telehealth support service to individuals with ADRD and their caregivers.

Objective 2: Advance referral pathways from primary care providers, health care professionals to Care EcoSystem Staff includes Community Support Facilitators (CSF) and Cognitive Care Navigators (CCN)

Objective 3: Develop and implement use of early recognition support tools among formal and informal caregivers including how to access the Care Ecosystem

Objective 4: Build awareness among primary care practices and community front line professionals to advance understanding of tools and resources related to early detection and behavioral symptom management

This program is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,298,599 with 75% funded by ACL/HHS and \$324,999 and 25% funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.



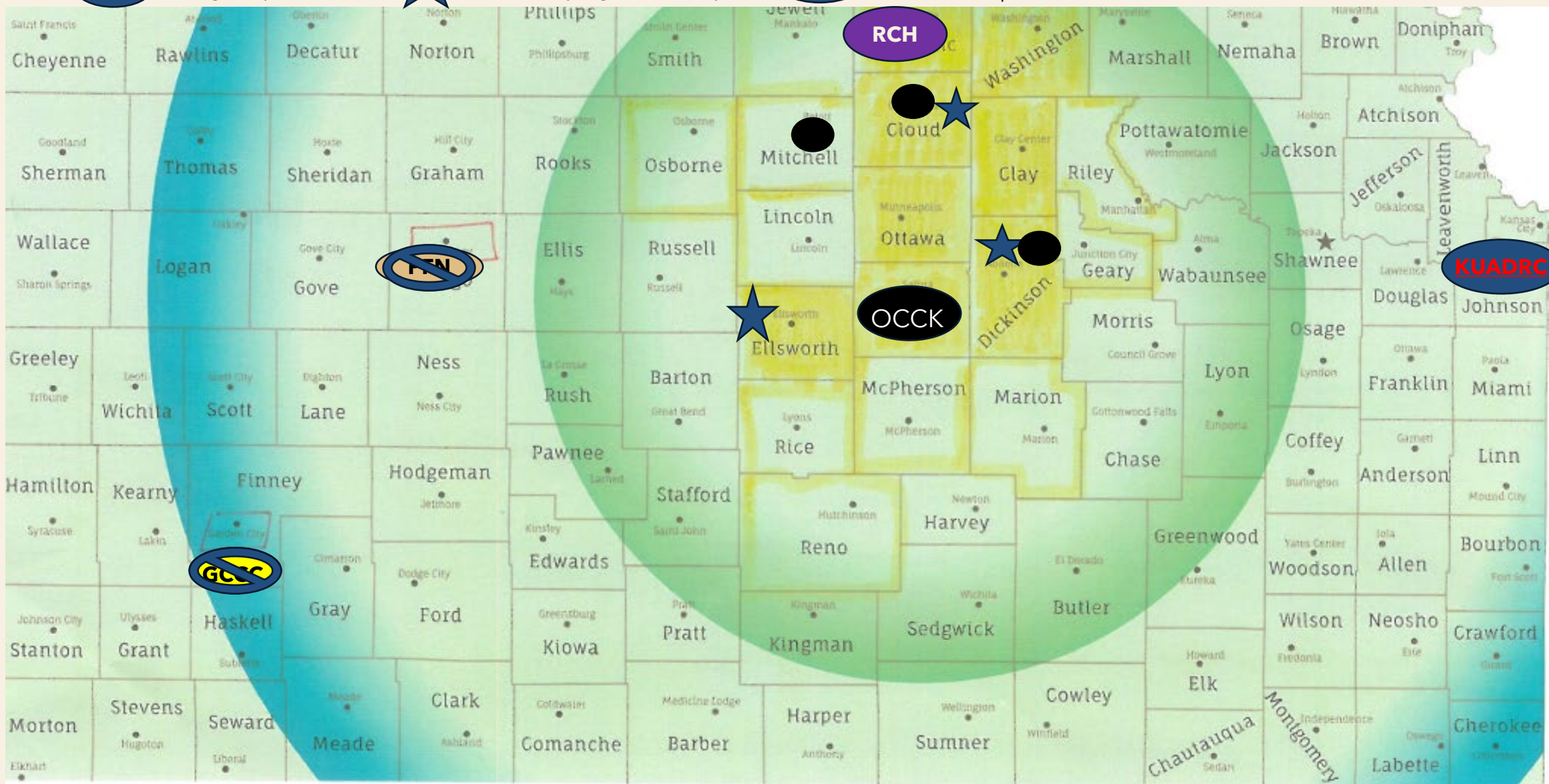
Original partners



Developing Partnerships



Partnership ended



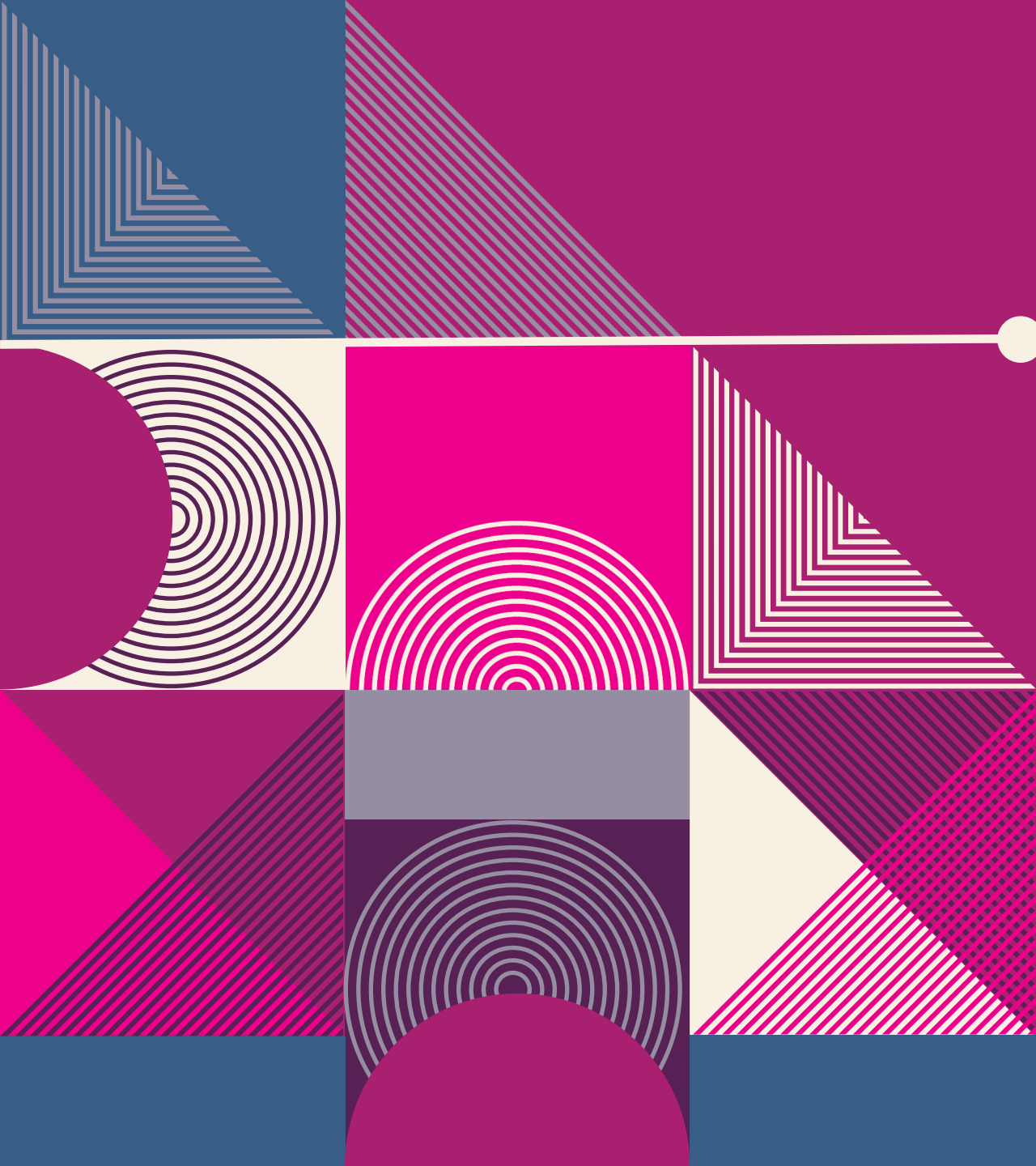
KANSAS



100 Miles



200 Miles



CARE ECOSYSTEM

The Care Ecosystem model includes:

- Care team navigators (CTNs)
- Clinicians with dementia expertise (nurse, pharmacist, social worker)
- Care protocols
- Curated information and resources

OUR ADAPTATION

COMMUNITY BASED NOT MEDICAL

- NO CLINICAL TEAM
- CONNECTIONS FOR MEDICAL NEEDS

COMMUNITY SUPPORT FACILITATOR

- LOCAL PERSON
- KNOWN TO COMMUNITY
- WARM HANDOFF TO NAVIGATOR

COGNITIVE CARE NAVIGATOR (CCN)

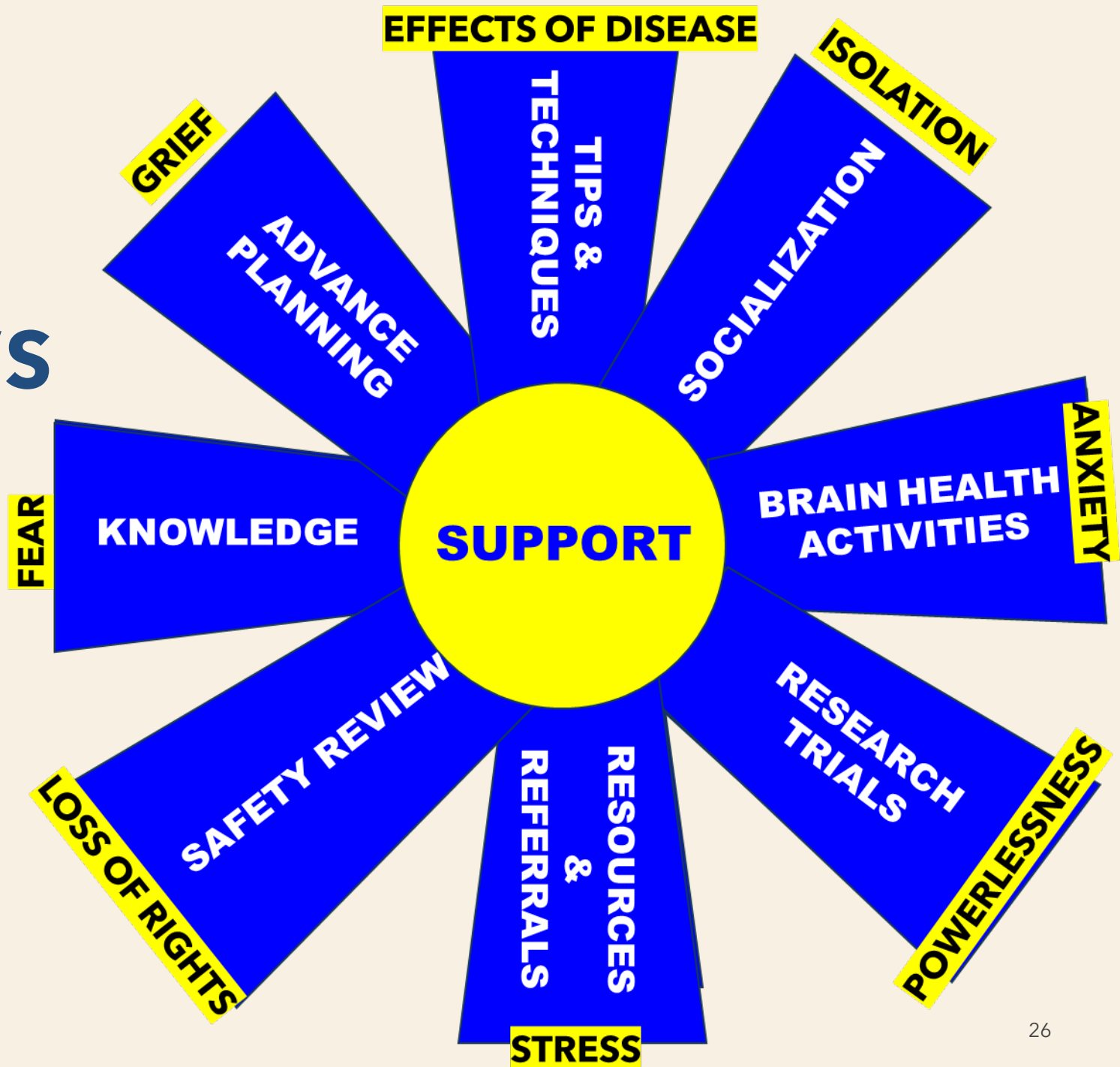
- RURAL OUTREACH
- IDD POPULATION
- PEOPLE LIVING WITH DEMENTIA (PLWD) WHO LIVE ALONE
- ZOOM ROOMS

COGNITIVE CARE NAVIGATOR'S ROLE

SUPPORT ROLE

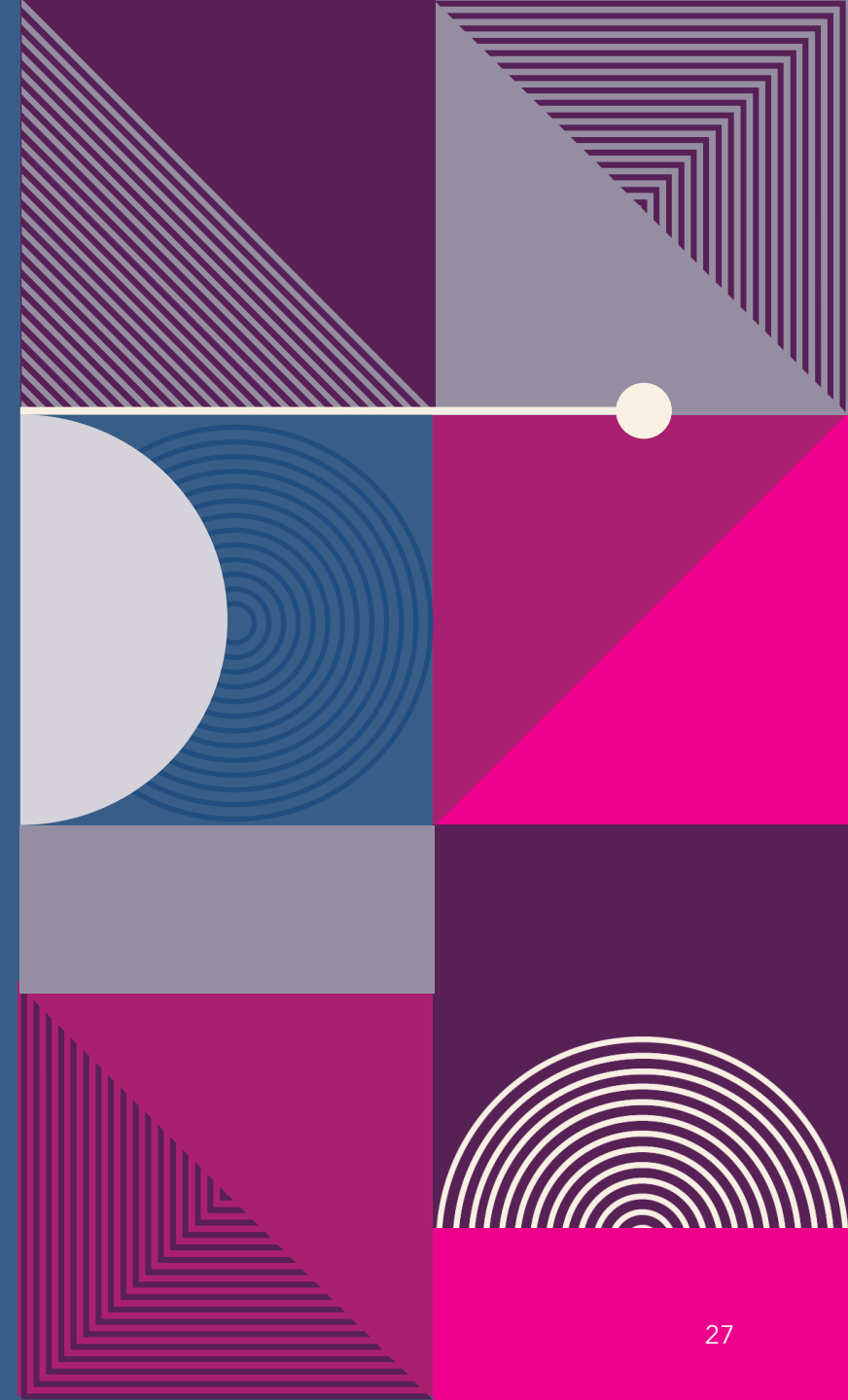
BOOTS ON THE GROUND

DIRECT SUPPORT



BENEFITS TO PERSON LIVING WITH DEMENTIA (PLWD)

- ✓ Empowers
- ✓ Fosters an environment of hope
- ✓ Meaningful and purposeful contact
- ✓ Affirms their value
- ✓ Provides targeted interaction
- ✓ Expands their voice
- ✓ Addresses fear and worries
- ✓ Adapts and individualizes to needs
- ✓ Restores socialization





BENEFITS TO CAREGIVER

- Emergency Respite
- Provides Presence
- Models interaction
- Possible Answers
- Leg-work/research
- Validation
- Reassurance
- Finding a way to YES
- Offers services and ideas
- Reminding You are enough!



OCCK'S CARE ECOSYSTEM INFORMATION FOLDER

TARGETED TO AUDIENCE

Family/ Live Alone
Community
Medical

BASIC INFO SHEETS

Normal Aging
Telling Others
You are not Alone

Screening Tools & Flyers
Communication Chart
CCN Contact Sheet
Stages of Disease

CHALLENGE SPECIFIC INFO

Driving
Sundowning
Aggression

Wandering
Seeing the Doctor
Bathing

RESOURCE INFO

Hello!



My Name is:

BROOKE

I am your Cognitive Care Navigator

My role is to:

- Meet with you and your caregiver on a regular basis
- Talk with you about your safety and support needs
- Share information with you about dementia diseases
- Present tools that can be used to screen for yearly changes
- Discuss planning options available for your future
- Research resources, assistive devices or trials as requested
- Review tips for coping with stressors and managing behaviors
- Offer activities that promote brain health

You can reach me by:

- Office Phone: 785-827-9383
- Toll Free Phone: 800-526-9731
- Work Cell Phone: 785-829-6179
- E-mail: BBRYSON@OCCK.COM



Kansas Community Care Ecosystem
1710 W. Schilling Rd Salina KS 67402

Phone: 785-827-9383
Toll Free: 1-800-526-9731

WHEN is it NOT a normal part of aging?

YOUR DIAGNOSIS DOES NOT DEFINE YOU

TELLING OTHERS ABOUT YOUR DEMENTIA CAN MAKE THE JOURNEY EASIER

COGNITIVE CARE ECOSYSTEM

1-800-526-9731

YOU ARE NOT ALONE

OUR KANSAS COMMUNITY CARE ECOSYSTEM PARTNERS help Rural Kansans and their caregivers who are living with Alzheimer's or a related dementia.

EARLY DETECTION OF COGNITIVE CHANGES is KEY

START YEARLY SCREENINGS BY AGE 55

- At age 55 almost 1 in 8 people have Alzheimer's disease (increasing to 1 in 5 people by age 85).
- Almost 20% of individuals with Down's Syndrome experience Alzheimer's disease. Screening should begin at age 35 due to early onset of aging issues.

TREATMENT OPTIONS
Screening may catch treatable causes of symptoms. You may also be able eligible for clinical trials or new treatments that if taken early may improve the benefits to you.

PLANNING AHEAD
You will be able to make your wishes known and be a part of the process. How do you want matters handled, who will be in charge, and what type of care plan fits you?

PEACE OF MIND
Knowing your diagnosis can ease anxiety about symptoms for you and your family. It can give you the opportunity to maximize your time together.

CALL US FOR SCREENING TOOLS
Cognitive Care Navigator with the Kansas Community Care Ecosystem
1-800-526-9731 (toll free)

KANSAS COMMUNITY CARE ECOSYSTEM
Alzheimer's Information and Support

YEARLY SCREENING FOR DEMENTIA STARTING AT AGE 35
for individuals with Intellectual Disability

INCREASED RISK
Persons with intellectual disabilities (ID) are at increased risk to develop dementia. Individuals with Down Syndrome are at significant risk of developing Alzheimer's disease due to the duplication of chromosome 21.

EARLIER ONSET
Individuals with ID are on average experiencing signs of dementia at least 10 years earlier than the general population.

WE CAN HELP - REACH OUT FOR MORE INFORMATION
A Cognitive Care Navigator will assist you in developing a baseline and yearly screening.

OCCK, INC.
1710 W. Schilling Road Salina KS 67402
785-827-9383 phone
785-825-3055 FAX

1-800-526-9731

BUILDING THE CARE TEAM AROUND THE INDIVIDUAL



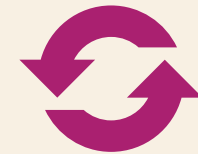
REFERRALS

Primary Care
or Agency

Community
Support
Facilitator (CSF)

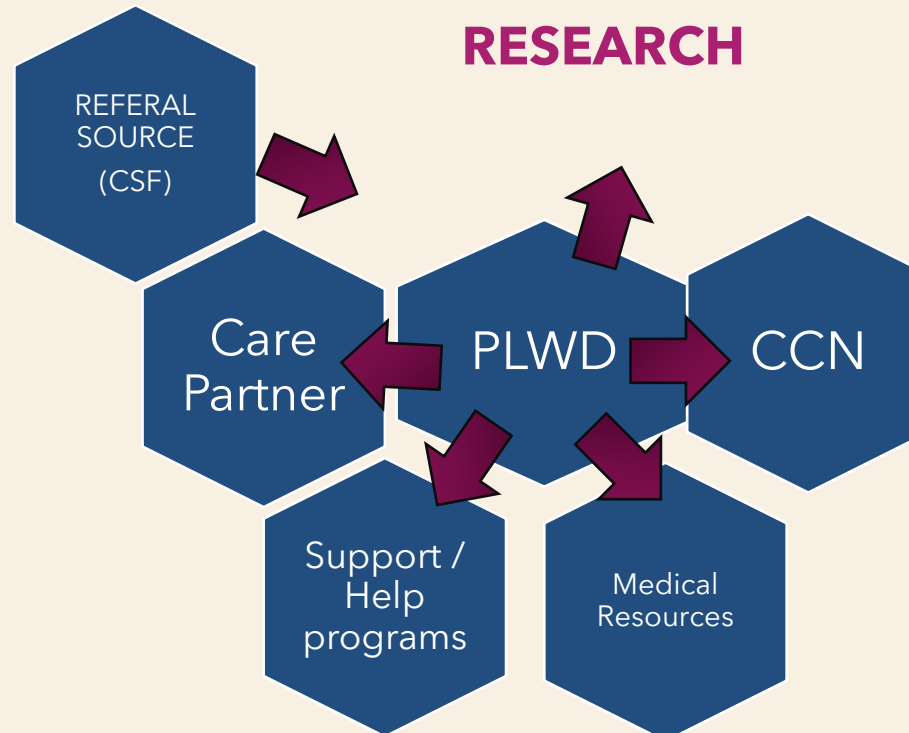


RESEARCH



BUILD CONNECTIONS

Pharmacist
Speech Therapy
PT/OT
Chore Service
Home Health
Church
Volunteers
Adaptive Needs
Funding Sources



OUTREACH

QUARTERLY NEWSLETTER



Covers 8 "SLICES" of Support Wheel

1. Effects of Disease
2. Resources and Referrals
3. Tips and Techniques
4. Knowledge
5. Brain Health
6. Research
7. Safety
8. Advanced Planning

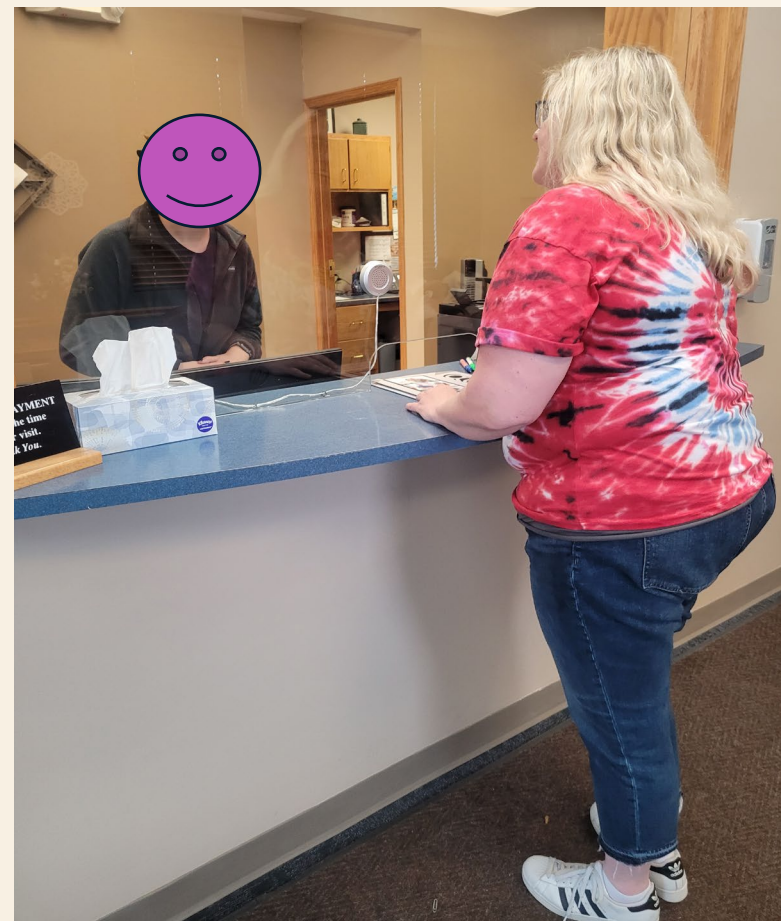


COGNITIVE CARE NAVIGATOR: MORE THAN YOU THINK

- Bridge the gap between medical services and community resources with the individual
- Reduce the stigma associated with dementia through community education, trainings and screenings
- Support for health and well being of both the PLWD and the caregiver

NETWORKING

"I love her! {CCN} helps us deal with issues in the kindest way. She is a positive and helpful person, helping us to bridge the gaps."



MEMORY CAFE



“Can we just clone the {CCN}? I have been so lucky to have access to them. They have been life changing and live saving.”

“I felt like I was drowning. I couldn’t keep my head above water. I don’t know where I would be without {CCN}.”

SPECIALIZED ACTIVITY AND SUPPORT GROUPS



Very much appreciate her {CCN}, she gets stuff done. She makes him feel like he is her only client."



Having this service has "been a game-changer!" {CCN} is always a step ahead of her and has "utterly changed her emotional state for the better."



TARGETED TRAININGS



"{CCN's} insights have helped me to better understand the progression of the disease and guide us in planning and identifying other resources we will need to provide care going forward."

COMMUNITY GATHERINGS



"Absolute lifesaver! We'd never be where we are on this journey without {CCN}, they are always available. There is no number high enough to rate them, they explain things in a way that someone with no education and not well-versed can understand."

SCREENING DAYS

“I think what you all provide is a much-needed service; you need to triplicate {CCN}! There’s such a need for the support that {CCN} provide. We have really appreciated ALL of her input... she even helps doctors with questions and suggestions. Thanks to her input and knowledge on things we even adjusted our medical care approach for the better. This disease is coming so fast... the need is only going to increase--there's just not enough hands-on deck to help the way {CCN} does, but I hope that changes!”





DATA SUMMARY

8/2022 - CURRENT

- **1451 Contacts**
- **496 Screenings (AD8, NTG-EDSD, SLUMS)**
- **85 Individuals sought services**
- **29 had IDD Diagnosis**

LESSONS LEARNED

TARGETS NOT A BULLSEYE

PLWD's and Care Partner

1. Offer supports rather than ask for needs, easier to see needs in person
2. Keep things simple and short
3. Become the bridge between services
4. Model and Repeat
5. You are creating an impact just by being present.

Community and Medical Partnerships

1. Plan for a 3-minute introduction with multiple follow ups before connection is made
2. Respectfully hold tight to those that share your passion. Find a way to collaborate that doesn't overwhelm
3. Support staff, clinic directors and discharge planners are already familiar with referral systems. Reach out to support team.
4. Think outside the doctor's office. Pharmacists, Adult Protection, Senior Centers all have repeated contact with individuals at risk.
5. Word will spread as you make an impact.



THANK YOU

Brooke Bryson

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Thank you for your attendance today.

- To be alerted when the next round of Alzheimer's Disease Programs Initiative funding is announced, sign up for Grants.gov notifications (<https://www.grants.gov/>)
- Search term: Alzheimer's Disease Programs Initiative (ADPI)

