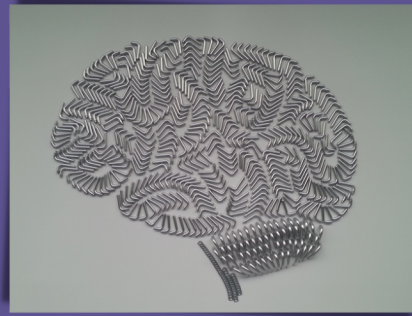


LESSONS IN DEMENTIA:

# Managing Dementia-Related Behaviors

Kaitlyn Green, Alzheimer's Services Coordinator  
Humboldt Senior Resource Center  
Adult Day Health & Alzheimer's Services



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This presentation and past workshops can be found:

- <https://www.humsenior.org/programs/cult-day-health-alzheimers-services/lessons-in-dementia-educational-series/>

# *Introduction*

Behaviors  
Triggers  
Communication  
Caring for Caregivers  
Resources  
Questions

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SOMETHING TO THINK ABOUT

Those with dementia are still people and they still have stories and they still have character and they are all individuals and they are all unique. And they just need to be interacted with on a human level.

CAREY MULLIGAN

03

"Those with dementia are still people and they still have stories and they still have character and they are all individuals and they are all unique. And they just need to be interacted with on a human level."

This quote from Carey Mulligan, is a good reminder those with dementia are still the person you've always known and shouldn't be treated any differently because of their dementia diagnoses and impairments.

# Spectrum of Behaviors



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Behaviors occur on a spectrum. At one end of the spectrum you have behaviors that are not typically considered harmful and need little to no interventions. These behaviors may just require simple redirection or distraction.

An example of a behavior that requires little to know intervention is repetition.

While, at the other end of the spectrum we have behaviors that have a negative effect on an individual's quality of life and they require more investigation too identify the trigger of the behavior and the intervention that is needed. For example, hallucinations are a behavior that may require more intervention and investigation.

# Common Behaviors

- Agitation and Aggression
- Wandering
- Hallucinations and Delusions/Paranoia
- Resistance to Care
- Sleep issues/Sun Downing
- Inappropriate Sexual Behavior



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As dementia progresses, many people may experience behavioral changes in addition to memory loss and other cognitive changes.

These behavioral changes may be due to underlying medical conditions or environmental influences.

It is often these behaviors are used by the individual with dementia as a form of communication to notify us that something is missing or wrong.

It is our job as care providers to decipher what the behavior is trying to tell us.

# Assessing the Behavior

*What can you do?*

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## WHAT IS THE BEHAVIOR

what was the individual like prior to the behavior vs how they are now.

## ANY CHANGES?

Anything new in the individual's environment, how have they been feeling, etc.

## JOURNAL/LOG IT

What is the behavior?  
Is there an obvious reason for the behavior?  
How did you manage the behavior?

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When assessing behaviors there are a few factors we want to look at to investigate what might be triggering the behavior:

-The first factor is looking at the behavior being presented and how is it different from the individual's baseline.

-The second factor is have there been any notable changes to the individual's environment, their health, routine, etc.

Lastly, you'll want to take your answers to these questions and write them down in a log book or journal and discuss what steps you took to address the behavior.

By creating this log you have something to reflect on if the behaviors were to continue and you would have a starting point on how to address it in the future.

# DICE: A Tool for Understanding & Responding to Behavior

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<https://memory.ucsf.edu/caregiving-support/behavior-personality-changes#>

Another method for assessing behaviors is DICE, a tool created by the University of California San Francisco. Which is a four step process focusing on the patient, care giver, and environmental perspectives.

Dice stands for:

- D: Describe What Happens
- I: Investigate Possible Causes
- C: Create A Plan
- E: Evaluate the Plan

The first half of the tool has you question the behavior and analyze possible triggers. Followed by your response to the behavior being presented.

<https://memory.ucsf.edu/caregiving-support/behavior-personality-changes#>

# Agitation and Aggression

Physical or verbal aggression, general emotional distress, restlessness, pacing, or yelling.



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Agitation and Aggression may be triggered by a variety of things, including environmental factors, fear, and fatigue. Most often, this behavior can stem from the loss of control and independence.

Some ways to approach this behavior are:

- Give the person space and time to calm down.
- Avoid small spaces.
- Empathize/apologize: "I'm sorry this is so frustrating."
- Offer reassurance: "I know this is difficult. It is going to be okay."
- Reduce background noise such as (tv, music, conversations.)
- Remember that anger and fear responses naturally subside within seconds (in absence of continued triggers or repeated thoughts).



# WANDERING

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Individuals with dementia may wander due to confusion, seeking out someone or to fulfill a need.

What can you do to prevent this?



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The most common triggers of wandering are: trying to fulfill a need-such as, hunger, thirst, or needing to use the restroom.

The individual can also be trying to locate someone or something. They may also become confused by their environment and feel the need to go "home" or to "work", even if they are home or no longer work.

Some things you can do to try to prevent wandering are:

- Remove any items that may trigger the individuals desire to leave, such as keys, hats, purses, and coats.
- offer opportunities for exercise during the day to minimize restlessness.
- try to create a visual barrier to mask doors with a curtain or applying a stop or a do not enter sign to the doorway.
- Offer activity or attempt to engage conversation.
- Determine if there is a pattern to the wandering- and log it. Identify the time of day the person is most likely to wander (for those experiencing "sundowning," this may be starting early in the evening.) Plan things to do during this time--activities and exercise may help reduce anxiety, agitation and restlessness.

# Hallucinations and Delusions/Paranoia

## HALLUCINATIONS

hearing, seeing, feeling or smelling things that aren't there

## DELUSIONS/PARANOIA

firmly held belief in things that are not real



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Things you can do:

- State simply and calmly your perception of the situation, but avoid arguing or trying to convince the person that their perceptions are wrong.
- Avoid using logic and reasoning if the person is insisting on a different reality.
- Respond to the fears expressed “that must seem scary” and focus on their feelings
- Keep rooms well-lit to decrease shadows, and offer reassurance and a simple explanation if the curtains move from circulating air, or if a loud noise such as a plane or siren is heard. Distractions may help. Depending on the severity of symptoms, you might consider medications.
- Remove the individual to a low-stimulation environment.
- When the person is not bothered or distressed by their hallucinations or delusions, it is generally best to acknowledge their experience with a matter of fact tone without denying or endorsing it.

Often those with dementia may become resistant to daily activities such as bathing, dressing, and eating.

What can you do?



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Things you can do:

-Break each task into steps and, in a reassuring voice, explain each step before you do it. Allow plenty of time. Find ways to have them assist to their ability in the process, or follow with an activity that they can perform.

- Make sure the person is comfortable and that the space around them is calm, quiet, and well lit.

-Encouraging and promoting independence is an integral part for self-confidence for people with dementia.

Consider personal care a therapeutic intervention for dementia and strive for the persons with dementia to remain as independent as possible.

-If the person is resistant and uncooperative, stop and try again later with a different approach.



## SLEEP ISSUES

Sundowning, increased restlessness, agitation and disorientation.

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Some approaches to avoiding issues related with sleep are:

- Keeping a regular routine
- Encourage exercise each day, limit naps, and make sure the person gets enough rest at night. Being overly tired can increase late-afternoon and nighttime restlessness.
- Be sure to set a quiet, peaceful mood in the evening to help the person relax. Keep the lights low, try to reduce the noise levels and have relaxing activities.
- Avoid alcohol and products containing caffeine.

# INAPPROPRIATE SEXUAL BEHAVIORS

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Dementia can affect a person's inhibitions, which may mean they express private thoughts, feelings and behaviors – including those related to sex – publicly

What can you do?



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Some ways you can approach this behavior are:

- Check the person for signs of a physical need such as needing to use the restroom, or feeling cold or overheated.
- Be consistent with the person about what is okay and what is not okay.
- Try changing the topic of the conversation or distracting them with an activity.

If you think the person is seeking more physical affection or intimacy, consider pet therapy, a stuffed animal and socially appropriate touching like hand holding or dancing.

# Common Triggers

- Changes in Routine
- Environmental
- Unmet Needs
- Illness/Injury
- UTIs



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In addition to individuals with dementia experiencing memory loss, their brain has altered how it processes the information it receives.

Such as changes in a person's routine, how they express discomfort, or how they respond to their environment.

This information is then translated into a trigger for behavioral changes.

# Changes in Routine

Daily routines help reduce stress and anxiety because they help everyone involved to know what to expect. Persons with dementia thrive on familiarity. Familiarity is important because dementia gradually impairs a person's ability to plan, initiate, and complete an activity.



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Things you can do to avoid behavioral changes:

Ensure that a routine is in place can help to prevent agitation, restlessness, and other behaviors from occurring.

Routines can also be beneficial to a caregivers alleviating stress by providing the individual with dementia a sense of familiarity in their confusing world.

# Environmental

People suffering from dementia have a hard time processing changes in their surroundings. If the environment is noisy the individual may have a difficult time following, conversations, become easily distracted, and may become overstimulated.



Here is an example of what could be an environmental trigger for those who experience hallucinations and how you might assess the behavior.

Try observing the environment from the individual's perspective. Are there any visual or auditory cues that may be playing a role in these hallucinations.

Are shadows being cast, triggering sounds, or objects that could be mistaken by the individual with dementia?

Other ways to respond to environmental triggers: go to a different room, minimize background noise, and limit multiple people from talking at once. And be sure to take a break from talking, if needed.





## Unmet Needs

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Behaviors are an attempt to communicate that something is missing or wrong, such as hunger, loneliness, pain or the need to rest.



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Things you can do are:

- Pay attention to the time of day or location of the action. Think about what is going on around them, such as too much noise, or bright lights that may cause scary shadows.
- Think about the person's habits, and what they like. This may give a clue about their needs, and what may be causing their actions.

## *Illness and Injury*

PAIN, OR AN UNDERLYING INFECTION OR MEDICAL ILLNESS (INJURY, URINARY TRACT INFECTION, EAR INFECTION, PNEUMONIA, ETC.).



As dementia progresses, facial expressions, body movements, or behaviors can be clues to pain. Some verbal cues may be "ouch", "hurt", "not right" or visual cues may be a grimace on their face or covering, rubbing, or protecting a part of their body.

Things you can do are:

- Ask simple yes or no questions.
- Try gently touching the area of the body where you suspect pain while watching their reaction closely.
- Look out for behaviors, such as, agitation, withdrawn and not participating in things they enjoy, or changes in eating or sleeping habits.

# UTIs and Behavior

INCREASED BEHAVIORS

INCREASED CONFUSION

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UTI (Urinary Tract Infection) are very common in older adults.

And behavioral changes can be the most common and often the only symptom of a UTI.

Any sudden change in behavior or sudden worsening confusion should be addressed.

Things you can do at home to address and avoid UTIs from happening are:

- offer at least 6 cups of fluid everyday to prevent dehydration.
- encourage them to use the bathroom frequently (about every two hours).
- look for signs like pacing or increased urgency when they need to go.

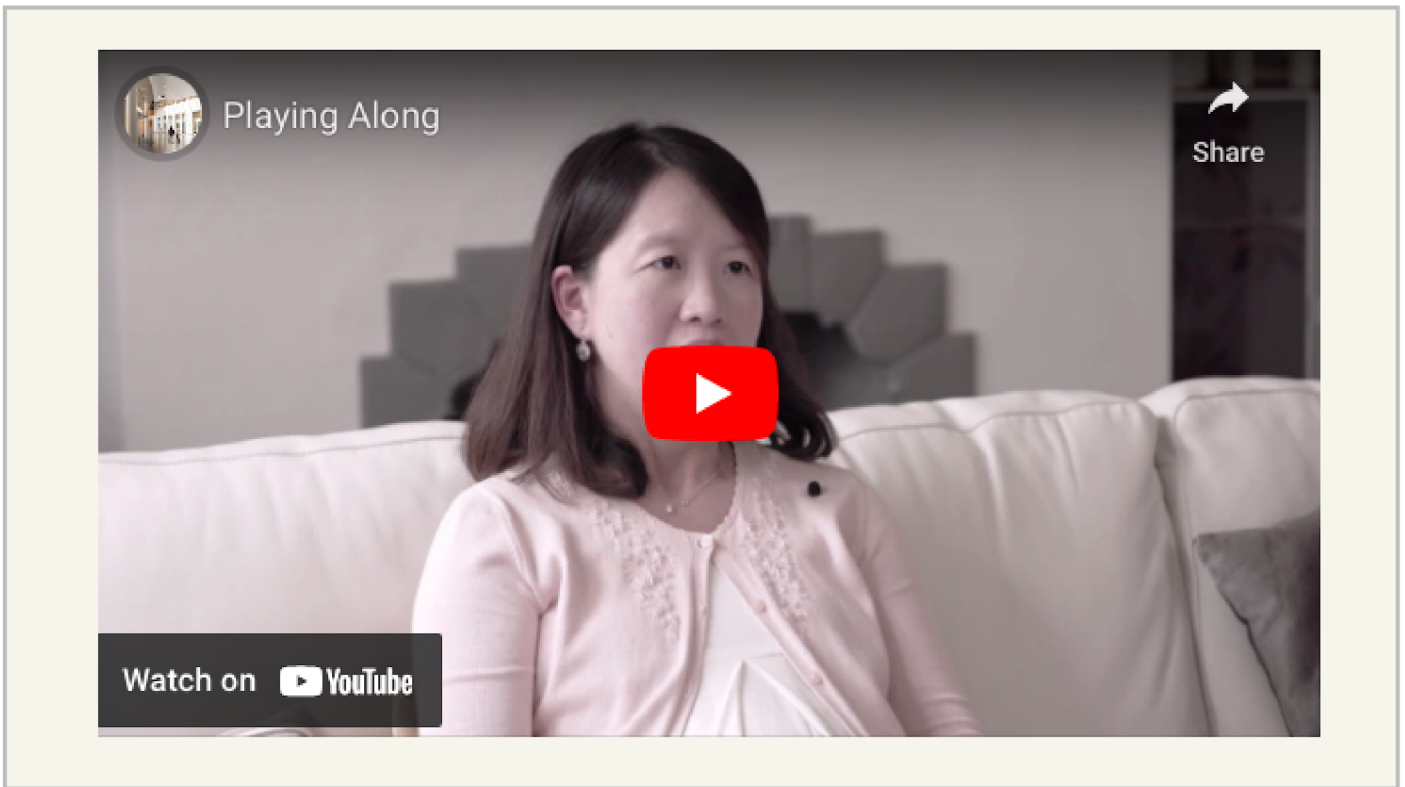


## VERBAL AND NON-VERBAL

- Conversations
- Gestures
- Simplicity

Some communication tips are:

- Apologize for your inability to understand
- Use simple and exact words
- Do not disagree or argue with made-up stories
- Respond to the person's feelings, not their words
- Use distractions
- Do not try to reason with the person
- Give yourself permission to alter the truth
- Avoid asking questions that rely on memory
- Break down all tasks into simple steps
- Respond calmly to anger; don't contradict.
- Maintain good non-verbal behavior, make eye contact, touch, smile, and move slowly.



Video can be found on Youtube.

Title: Playing Along

Creator: UCSF Memory and Aging Center

Link to the video:

<https://youtu.be/t-klPLY-LEk>



*Saying "okay"*

DIFFUSING THE SITUATION

When we use the word “okay” all we are doing is acknowledging that someone spoke and we heard them.

We are not necessarily agreeing with them.

When we say “okay” with a pleasant tone and positive look on our face we can diffuse the situation rather than argue.

Even if they are accusing us of doing something we didn’t do we can say “okay.”



## Therapeutic Fibs/Stories

- GO TO THEIR WORLD
- ACCEPT THEIR TRUTH
- FIX IT WITH A STORY, DON'T ARGUE IT.

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When okay doesn't work  
THEN we will...  
Fix it with a therapeutic fib or story.

-When using therapeutic fibs or stories, remember that you are not intending to deceive your loved one, but rather you are simply helping them feel more comfortable and they are in a more agreeable and safe place.

-The primary goal is always comfort and spare to them unnecessary upset.

\*act of kindness , rather than deception\*.

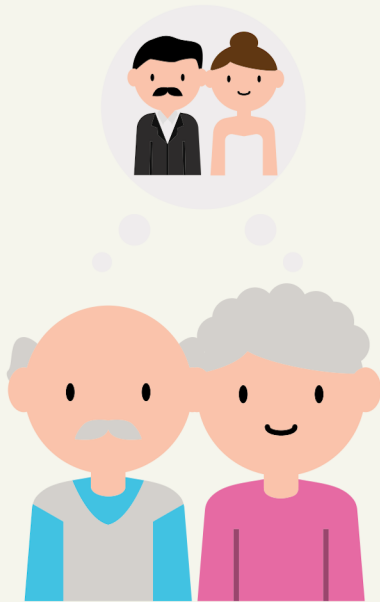
# A Story About Marie



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Marie recently moved to a new community and wanted to go to her home in Spokane, which she had sold many years before. All day she continued “is anyone going to Spokane”, “I will pay you to go to Spokane”. Distraction was not working well, and Marie was becoming agitated and not wanting to eat dinner. Finally, one staff member said, “I think I can take you tomorrow, but let’s have dinner tonight.” Marie said “Great, but I don’t have a place to stay.” The staff member replied, “don’t worry I have a room all arranged.” Marie became calm ate her dinner and then later went to bed. The next morning, she never mentioned anything about the night before.





## REMINISCENCE

A powerful tool that can promote conversation and aide in redirection.

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Reminiscence can give people with dementia a sense of competence and confidence through using a skill they still have.

Recalling past events with the help of old photographs, newspaper clippings, videos of old films or familiar items. Reminiscence doesn't always have to be a conversation it can also be listening to music or completing an activity.

Our Lessons in Dementia Workshop on May 15, 2023 presented by Dr. Samantha Day, will be going more in depth the power reminiscence has.

# Things to Remember

Family Caregiver Alliance: 5 Tips to Help You Understand Dementia Behaviors

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WE CANNOT CHANGE THE PERSON.

BEHAVIOR IS TRIGGERED.

MAINTAIN A POSITIVE ATTITUDE

BEHAVIOR HAS A PURPOSE.

WHAT WORKS TODAY, MAY NOT TOMORROW.

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It is not always easy caring for an individual with Dementia. And as a caregiver and a family member it may be hard at times to not take things personally. Here are 5 helpful tips provided by the Family Caregiver Alliance to reflect on.

# Caregiver Burnout



**"REMEMBER TO PUT ON YOUR OXYGEN MASK  
BEFORE HELPING OTHERS"**

- Take time for yourself when possible
- Don't be afraid to ask for help
- Know what community resources are available to you.

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For care providers of those with dementia it isn't uncommon for the care you're providing to begin to wear on you and to begin feeling burn out.

It is also an important reminder to "remember to put on your oxygen mask before helping others."

It is difficult to pour from an empty cup.

As the Alzheimer's Services Coordinator for our program I have spoken with many individuals and families who provide dementia care and are not always aware of the resources out there to help make their lives easier. Over the next couple slides, I will be talking about a few of the top resources in our community that I most often refer individuals and families too.



# Humboldt Senior Resource Center

## SERVICES:

- **Nutrition Program:**
  - Heritage Cafes, Home Delivered Meals, Commodities
- **Activities:**
  - Dial-A-Ride Assistance, Senior Home Repair, My Safety Call
  - Exercise classes, line dancing, Bingo, Ping Pong and more
- **Behavioral Health Services:**
  - Individual counseling, group counseling and therapeutic case management

## Phone:

707-443-9747

## Online:

[www.humsenior.org](http://www.humsenior.org)

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The first is the Humboldt Senior Resource Center.

That is committed to providing services, information, education, and recreation for seniors, families and caregivers in Humboldt County.

I often refer people from my consultations back to HSRC if they are not interested in a day center style of program, are interested in receiving meals, or those who are looking for additional therapeutic support.

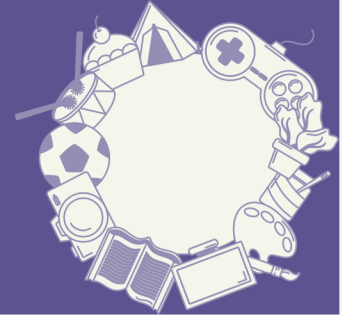
In addition to the services you see listed, HSRC also houses: Adult Day Health & Alzheimer's Services, Redwood Coast PACE, and the Multipurpose Senior Services Program, which I will be talking about more in the following slides.



## Adult Day Health

### OFFERS:

- Nursing Care & Case Management
- Individual & Group Exercise
- Recreational Activities & Socialization
- Respite for Families



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Adult Day Health is a therapeutic day program that provides activities and support to adults ages 18 and older with physical and mental disabilities. In addition to direct care provided to participants Adult Day Health provides respite and support for family caregivers.

Participants of the program benefit from individually tailored care plans, therapeutic recreational activities, seasonal celebrations, socialization, and friendship.

Costs of program services can be covered by Partnership HealthPlan (Medi-Cal), the Veteran's Administration, and Redwood Coast Regional Center. Caregiver Respite grants and Private Pay options are also available.



## Alzheimer's Services

### OFFERS:

- Free Educational Materials
- Community Referrals
- Resource Library
- Consultations



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Alzheimer's Services offers one-on-one consultations to families, caregivers and care professionals in-person and over the phone. Providing support to those who are navigating the journey of Alzheimer's disease and other cognitive impairments.

Through these consultations not only do we provide support, but also offer free educational materials, handouts, referrals to other community resources, and access to our resource library.

In addition, we offer educational opportunities such as our Lessons in Dementia series and our annual Dementia Care Conference.



Program of All-inclusive Care for the Elderly

**Services Include:**

- Primary medical care and medical specialty services
- Day Center services
- Physical, occupational, speech and recreational therapies
- And more.



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Redwood Coast PACE – a Program of All-inclusive Care for the Elderly – is a comprehensive health plan for older adults who wish to remain living in their home and community. They provide medical, social, nutritional, rehabilitation, and support services

They serve those who are 55 and older, who need a nursing home level of care, can safely live in the community with no harm to themselves or others. Cost for services provided depends on your Medicare and Medi-Cal eligibility.



## MSSP - Multipurpose Senior Services Program

### Services Include:

- Emergency response systems
- Meals on Wheels
- Non-medical home equipment
- Money management



The MSSP is a community-based care management program. Who provides an experienced Care Manager to meet with you and your family to assess your needs, and who provides long- term help with arranging the services you require.

To qualify for MSSP one must be 65 or older, a Medi-Cal recipient and at risk for skilled nursing placement.

These are just a few of the many services MSSP offers.





**Services Include:**

- Senior Information and Assistance
- Northcoast Homeshare Program
- Volunteer Driver Program
- Stay Put Services

**Address:**

333 J Street, Eureka, CA  
95501

**Phone:**

(707) 442-3763

**Online:**

[www.a1aa.org](http://www.a1aa.org)

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Area 1 Agency on Aging is a part of 33 similar agencies in California and serves Humboldt and Del Norte counties.

The agency assists older adults and people with disabilities, their families, and caregivers with finding information and resources in our local community.

One of their resources I often provide to my consultations are their Senior Information Guides. The guide is a booklet of categorized resources in our community ranging from social services, housing, medical, caregiving, and more.

In addition they have a variety of programs available to the community. Such as the ones you see listed here.



# REDWOOD

caregiver resource center

## Services Include:

- Information
- Uniform Caregiver Assessment
- Family Consultation & Care Navigation
- Respite Care
- Short-Term Counseling
- Support Groups
- Caregiver Training
- Legal & Financial Consultation
- Education

## Phone:

707-542-0282/800-834-1636

## Online:

[www.RedwoodCRC.org](http://www.RedwoodCRC.org)

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Redwood Caregiver Resource Center offers support and assistance to caregivers of adults with brain impairments through education, research, services and advocacy.

When I receive consultations calls from family members caring for a loved one with dementia, Redwood Caregiver Resource Center is one of the 1st recommendations I make due to the support they provide families through support groups, consultations, and the respite grants families can apply for that can help cover the cost of having additional respite support in the home or attending an Adult Day Health Program in addition to other services you see listed.

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SOMETHING TO THINK ABOUT

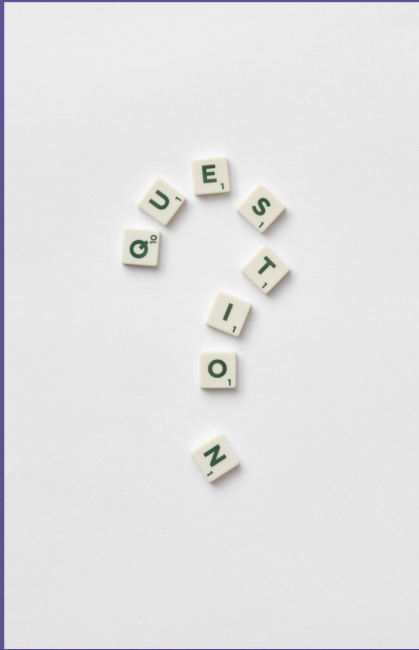
It's far more important to know what person the disease has than what disease the person has.

HIPPOCRATES

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Dementia care cannot be taught strictly through lists of “do’s and don’ts” and memorizing the best ways to respond to every situation. Empathy is needed for the care receiver to learn ways to deal naturally with situations as they arise.

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*Thank you!*

Any Questions?