Presented by The COPSA Institute for Alzheimer's Disease of Rutgers University
and The New Jersey Department of Human Services

FOUNDATIONS

of Dementia Enabled Care in Adult Day Programming

INTRODUCTION

The COPSA Institute for Alzheimer's Disease of Rutgers University, along with the New Jersey Department of Human Services, Division on Aging, is pleased to provide you with "Foundations of Dementia Enabled Care", the third part in the trilogy of training for Adult Dementia Day Programs.

"Foundations of Dementia Enabled Care" provides an overview of the basic skills and knowledge needed to create and maintain dementia capable adult day centers. It includes a basic conceptual model of how dementia impacts those who have the illness, and provides strategies and approaches for dealing with these changes. It also offers you the opportunity to put your knowledge into practice with thought provoking exercises.

We know how busy you are and how little time there is for training. This program is designed to easily fit into your busy schedule. You can do one or more sections at a time, as your schedule permits.

You can work through this manual on your own, or in a group. You'll find that many of the exercises will generate conversation with your colleagues and your supervisors. It is our hope that you will add what you learn here to your repertoire of approaches to working with individuals with dementia and that this strengthens the team collaboration in your center.

The companion works in this trilogy, "Circle of Harmony" and "Bridges", offer further opportunities to learn about effective dementia care. "Circle of Harmony" teaches innovative ways to prevent and deal with challenging behaviors. "Bridges" is a toolkit for caregivers and day program professionals that fosters collaboration in caring for the person with dementia. For more information on these training programs, please call our hot-line at **800-424-2494**.

The information shared in Foundations is based on the work and practice of the staff at the COPSA Day Program, COPSA Institute for Alzheimer's Disease and Related Disorders at Rutgers University Behavioral Health

Care. Opened in 1982, the COPSA Day Program was the first specialized, dementia day care program in the state. Over the years, it has been a model training program on providing dementia-specific care. All of the successful practices and techniques of the COPSA Day Program have been summarized for you in Foundations.

We offer special thanks to Terri Wilson, RN, BSN, Caregiver Initiatives Specialist, New Jersey Department of Human Services, for her expert leadership in overseeing dementia care in Adult Day Centers. Without her vision and support, this training would not be possible.

We wish you success as you continue to provide vibrant programs where individuals with dementia can flourish and be appreciated for who they are. We also wish that, as professionals, you may be enriched by this training and continue to find deep satisfaction and pride in your work.

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OVERVIEW OF DEMENTIA

"Senility" ... "Hardening of the Arteries" ... "Second Childhood" ... "Old Timer's Disease"

You may have heard all these names used to describe the confusion and memory problems that we associate with Alzheimer's disease. The correct term is ***dementia.***

Dementia is a syndrome, which means it is a group of symptoms. It is characterized by impairment in various brain (cognitive) functions. The most common of these include memory, language, visual-spatial skills, executive function, calculation, and recognition. People are never born with a dementia. It is acquired.

In a way, dementia is a very broad term similar to the way cancer is a very broad term. When someone has cancer we want to know, "Is it lung cancer? Bone cancer? Breast cancer?" When someone has a dementia we want to know, "Is it Alzheimer's Disease? Parkinson's Disease? Vascular Disease? Lewy Body Disease?" Just as there are many different kinds of cancer, there are many different kinds of dementia.

OVERVIEW OF DEMENTIA

There are many conditions and diseases that cause dementia. Some of these are treatable. The only way to determine what kind of dementia someone has is to have a ***comprehensive evaluation.***

A comprehensive evaluation includes the following:

- ✔ Complete Physical
- ✔ Blood work
- ✔ Brain scan
- ✔ Psychiatric Evaluation
- ✔ Neuro psych Assessment

This kind of testing will rule out conditions that are treatable and will usually determine what kind of dementia someone has. Unfortunately, even with these extensive workups, doctors cannot always provide a definitive diagnosis.

TYPES OF DEMENTIA

Dementia can be categorized in different ways. When we think about a dementia diagnosis, we find the following information helpful to keep in mind.

Onset – Does the illness come on slowly or was there a sudden change? Does it progress gradually or quickly? Alzheimer's Disease, for example, has a gradual onset. When someone has Alzheimer's Disease, families will often make statements such as " I don't know when it started." or " It was little things at first but then it got worse."

Cause of the Illness or condition – Vascular dementia is caused by problems in the blood supply to the brain. Some dementias can be caused by cancer cells that have metastasized to the brain. Pick's Disease is caused by a protein buildup that causes the brain to shrink.

Pattern of deficits/symptoms – In the next section, we are going to discuss cognitive deficits and symptoms in more detail because they play such an important role in our work with dementia clients. Briefly, when someone has Alzheimer's Disease, we see a decline in many areas of cognitive functioning.

Progression – Dementias progress at different rates. Some may last a few years while others go on for over twenty. Unfortunately, the end stages are very similar. The person becomes bedridden and is unable to care for themselves.

On the following page is a table that lists different kinds of dementia, their causes and symptoms. Note that may people suffer from a mixed dementia such as Alzheimer's Disease and Vascular Dementia. Study the table carefully and then use it to answer the questions that follow.

TYPES OF DEMENTIA

Chart continues on next page.

Disease	Onset	Progression	Symptoms	Cause	Deficits	Strengths
Alzheimer's	Slow/gradual, most common dementia in middle age	Slow, insidious	Short term memory loss, language, progressing to global impairment	Brain cell death due to plaques and tangles	Attention, language, memory	Can learn routine social interactions and social skills
Vascular	Can be gradual or sudden	Step-like – the person stays at one level for a while and then drops again, can also be gradual	Depression, attention problems, mood swings, poor short-term memory, symptoms manifested depend on area of brain damaged	Impaired blood flow and diminished oxygen to brain	Personality changes, depression and memory	Language, some insight
Lewy Body	Gradual, often onset begins before 65	Fluctuating course – can be dramatic, changes from day to day or within the day	Visual hallucinations, paranoia, delusions, mood distrubances, often misdiagnosed as a psychiatric disorder	Lewy Bodies plaques similar to those found in Parkinson's but diffusely located in brain including cerebral cortex	Fluctuations in alertness and attention, visual, motor skills, and Parkinsonian symptoms, increased risk of falls	Prominent memory loss not as evident in early stages

TYPES OF DEMENTIA

Chart continued from previous page.

Disease	Onset	Progression	Symptoms	Cause	Deficits	Strengths
Parkinson's	Many people with PD may develop dementia 10-15 years after onset of PD	Gradual	Tremors, depression, memory loss, muscle stiffness, short shuffling steps, festinating gait, speech	Brain cell abnormalities leading to a loss of dopamine in the brain	Loss of motor abilities, depression, slow thought process, muffled speech, risk of falls	May have more preserved memory and insight
Frontal Temporal Lobe (Pick's is one form)	Second most common form of dementia in middle age after Alzheimer's, gradual	Quick progression, three subtypes	Disinhibition, personality changes, bizarre behaviors, severely impaired judgment	Shrinkage in frontal and temporal lobes of the brain	Social skills, changes in personality, severe language problems – echolalia, mutism depending on subtype	May have more preserved memories, more fluent speech, able to initiate activity, artistic ability
Wernicke-Korsakoff Syndrome	Often associated with alcohol abuse, gastric bypass, other conditions that impact nutrient absorbtion	Varies	Certain memory functions	Sever thiamine deficiency, alcohol misuse, liver disease	Confusion, apathy, inability to concentrate, confabulation, ataxia	Thinking and social skills may be intact along with access to memories and language
Delirium Medical Emergency Treatable (Acute Confusional State)	Very sudden	Develops over hours to days with fluctuations over the course of the day	Sudden, disorganized thinking, incoherent speech, fluctuates between hyperactivity & lethargy, unable to focus, fluctuates over minutes to hours	Medical conditions, infections such as UTI, injury, stress, electrolyte imbalance, dehydration, drug interactions	Attention, speech, disoriented, disorganized thinking, fluctuation level of consciousness	Treatable and reversible if addressed promptly

TEST YOUR KNOWLEDGE

Match the number of the Dementia with the symptom, cause or progression:

1. Pick's Disease or Frontal Temporal Lobe Dementia
2. Delirium
3. Alzheimer's disease
4. Vascular Dementia
5. Lewy Body Disease
6. Parkinson's disease

_____ This dementia is characterized by onset in middle age, as well as disinhibited and often bizarre behavior.

_____ This dementia is characterized by a fluctuating course and paranoid hallucinations.

_____ This dementia has a sudden onset, is often caused by an infection, and is a medical emergency.

_____ Over 30% of people with this illness will develop a dementia.

_____ People who have the risk factors for coronary heart disease such as high blood pressure, diabetes, history of stroke or high cholesterol.

_____ This is the most common form of dementia and has a slow gradual onset.

_____ This dementia is often associated with alcohol abuse, but it also occurs in people who have liver disease and no history of alcohol abuse.

Think about the participants at your center:

For how many participants do you know the cause of their dementia?

_____

Do you routinely have access to this information?

_____

Can you tell there is a difference in the types of dementia for some of your participants? Explain.

_____

_____

_____

Can you identify a current participant in your center, or maybe someone from the past, who may have one of the following types of dementia? If so, what symptoms did you see that support this? Refer to the chart for assistance.

Vascular Dementia _____

Alzheimer's Disease _____

Lewy Body Disease _____

Parkinson's Disease _____

Frontal Temporal Lobe or Pick's Disease _____

How might knowing what type of dementia a person has help you provide better care for them? Give an example.

_____

_____

_____

_____

_____

5 IMPORTANT POINTS TO REMEMBER

Dementia is a syndrome. That means it is a group of symptoms. There is always memory loss but there are also problems with other areas of cognitive functioning such as language, orientation, visual spatial skills, judgment, and recognition.

The onset and progressions of dementias varies. Alzheimer's has a slow, gradual decline. The onset of Vascular Dementia is often sudden. Pick's Disease often lasts around 10 years, while 20 years is not uncommon when someone has Alzheimer's.

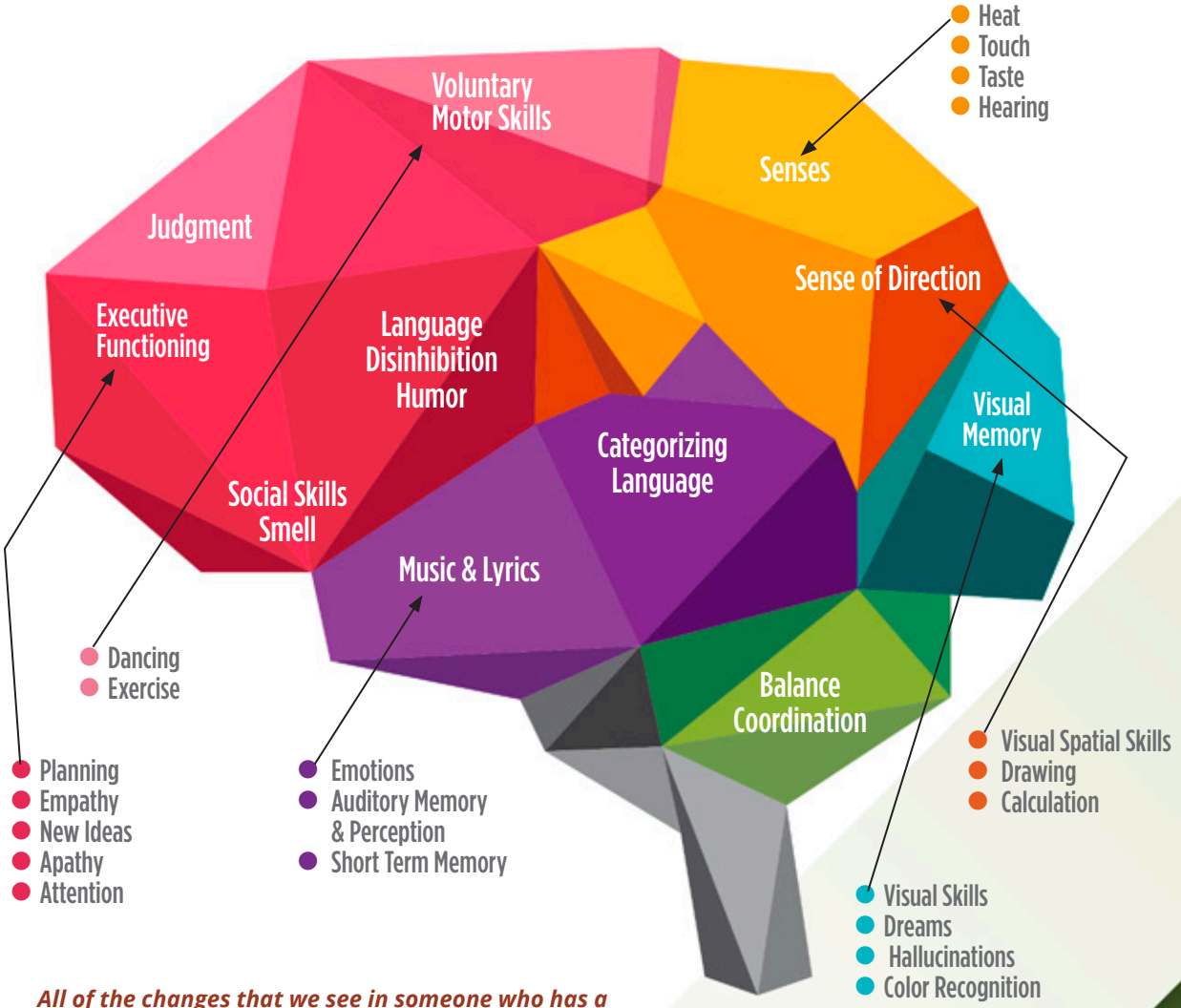
There are many different kinds of dementia. They are caused by different illnesses or conditions. They all cause damage to the brain but the areas they impact varies. Some common dementias are Alzheimer's Disease, Vascular Dementia, Lewy Body Disease, Pick's Disease, and Delirium.

Cognitive deficits and strengths change with the type of dementia because of the pattern of brain damage. People with Pick's Disease may be very disinhibited or be totally mute. Someone with Lewy Body Disease may have paranoid hallucinations. Alzheimer's patients may have a great deal of trouble finishing a sentence or finding the right word.

People often have a mixed dementia. This means they may have a combination of both Alzheimer's and Vascular dementia, or Lewy Body and Alzheimer's Disease, and may demonstrate symptoms of both.

AREAS of **BRAIN/ COGNITIVE** FUNCTION

A solid understanding of cognitive deficits is the foundation of successful day programming. Once we can identify and understand the deficits, we can structure the environment, our interaction, and activities to support the highest functioning of the person.



All of the changes that we see in someone who has a dementia, including their personality and behaviors, can be attributed to changes in their brain.

As you know, individuals with dementia often experience difficulties with normal everyday activities due to damage to their brain.

Depending on the area that is damaged, someone with dementia may have trouble with long and short-term memory, language, judgment, attention, orientation, recognition, executive function and visual-spatial abilities. These are called areas of cognitive function.

Look at where these areas of cognitive functioning are located in the previous picture of the brain. When a person has a problem with one of these skills, it is because that area of the brain has been damaged.

Areas of cognitive function are called cognitive deficits if they have been changed or damaged. They are called cognitive strengths if they are intact.

MEMORY

There are many different kinds of memory.

Working Memory is what is remembered immediately and is dependent on attention. For example, if someone gave you the phone number to the service department of a store, you would most likely remember the number while you made the call and then forget it later. That is because the phone number was never really stored in your brain.

Short-term Memory is what happened recently, such as what you ate for breakfast this morning. ***Long-term Memory*** is what happened many years ago, such as being scolded by a teacher in the 1st grade. These are the most common definitions of long and short-term memory and the ones we will be using in this

manual. Researchers, however, would consider both remembering what you ate yesterday, and remembering what happened years ago, as examples of long-term memory.

Procedural Memory consists of things that we have learned by repetition, such as getting in line, saluting the flag, or bowing our heads when we say prayers.

Often, people whose memory impairment is severe may still be able to remember all the lyrics to familiar songs. If you look at the image of the brain above, you may be able to figure out why. The part of the brain associated with lyrics and music is different from the one that handles memory.

If dementia were just a matter of memory problems, it would be much easier to manage. But there are many other areas of cognitive impairment that combine to make it hard for people with dementia to carry on their lives.

ATTENTION/ CONCENTRATION

A person with dementia may have difficulty paying attention.

- This means they may have a hard time initially focusing.
- They may be easily distracted.
- They may have difficulty refocusing.

We see this in craft sessions when a person cannot stay on task, or when they are doing a crossword puzzle and stop after filling in one answer. If someone walks into the room, or if they hear a noise outside, they become easily distracted.

Using multi-sensory cueing such as calling their name, maintaining eye contact, and giving them something visual to look at, can help a person maintain attention.

PERSEVERATION

Perseveration seems like the opposite of an attention problem. In this case, the person is paying too much attention to one thing and cannot be distracted from it. It is the continued repetition of a word, phrase or behavior. Like a needle stuck in a record, the person asks the same question over and over again. You may have heard "What time is it?" or "When are we leaving?" You may have watched one of the ladies in your program continually rummage through her pocketbook, or fold and refold paper napkins or tissues.

Tip to stop perseverating: Introduce other stimuli – hand them an object, ask them to help you with a task, sing a song.

COMPREHENSION

Comprehension is our ability to understand what is being said or what is happening around us.

If a person hears what you say but has no idea what it means, he or she will have trouble following directions and, during even simple activities, may not be able to provide an answer, participate in craft sessions, or follow along during a board game.

When comprehension is impaired and people don't understand what is happening around them, it is easy for them to misinterpret simple situations. They may become frightened, angry, or confused.

LANGUAGE

Dementia can impact ***language*** in many ways.

Most common are word finding problems. You may notice some participants struggle to find the right words or finish a sentence.

Sometimes the words flow but the content makes no sense.

Dementia can take away the ability to use words completely and the person becomes mute.

It's important to remember that clients who have problems with speech may still be able to fluently read aloud or sing the lyrics to songs. We will discuss more about language in the next section.

ORIENTATION

Those who suffer from an ***orientation*** deficiency may not know the month, day or year, may not even know they are in daycare, or may believe your center is a place from their past.

A client who is disoriented may insist that it is time to go home even though it is 10:00 in the morning.

JUDGMENT

Judgment is a person's ability to make a decision about the best course of action. Impaired judgment can ruin lives and even be life-threatening. It is not unusual to hear stories about dementia patients giving away thousands of dollars, wearing heavy winter coats on a hot summer day, or deciding to walk ten miles on a busy highway to visit a friend.

INSIGHT

Insight is our ability to understand our situation. When a person has dementia, the area of the brain that handles insight is often damaged. In such cases, that person often thinks they have no memory problems and there is nothing wrong with them. They are not in denial. Their insight is impaired.

VISUAL SPATIAL SKILLS

Visual Spatial refers to how we operate in space. Impairment of visual-spatial skills is not due to a vision problem but a problem with the way the brain interprets what is seen.

A person with this impairment may have difficulty finding food on their plate, or they may get lost in their own home. They may bump into walls, may not be able to find the door handle, or almost miss the chair when they try to sit down.

APATHY

Apathy is a lack of initiative. The individual doesn't do anything unless they are really encouraged.

People affected by apathy can't plan their day. When a daughter tells you that her mother used to be a go-getter, but now just sits around in a chair all day, she is describing apathy. Apathy is often confused with depression. When someone is depressed, there is usually an underlying sadness. That is not the case with apathy.

A person who may be experiencing apathy at home can be highly-engaged and active for many hours when at a day program, if given adequate prompting from staff.

APRAXIA

Apraxia is when a person has the physical ability to do something but no longer knows how. We see this when people have trouble putting on a coat, washing their hands, or using utensils when they eat.

RECOGNITION

When this ability is affected, the person may not recognize their home or the day care center as familiar. They may not even recognize family or staff members.

EXECUTIVE FUNCTIONING

Dementia may impair a person's ***executive functioning***. This is the cognitive skill you use when you plan and carry out strategies. It includes activities that involve multiple steps, such as balancing a checkbook or baking a cake. It involves generating new ideas.

ABSTRACT REASONING

A person with dementia may interpret things in a very concrete or literal way and miss the deeper meanings of phrases and situations.

During an exercise session, Joe was told "Reach up to the ceiling." He stood up and started to reach for the ceiling, taking the command literally. He did not understand that it was just a stretching exercise.

PSYCHIATRIC SYMPTOMS

Psychiatric symptoms are not cognitive deficits, but they often occur in people with dementia. Sometimes, in the early stages of the disease, they are the most pronounced symptoms.

PSYCHOTIC SYMPTOMS

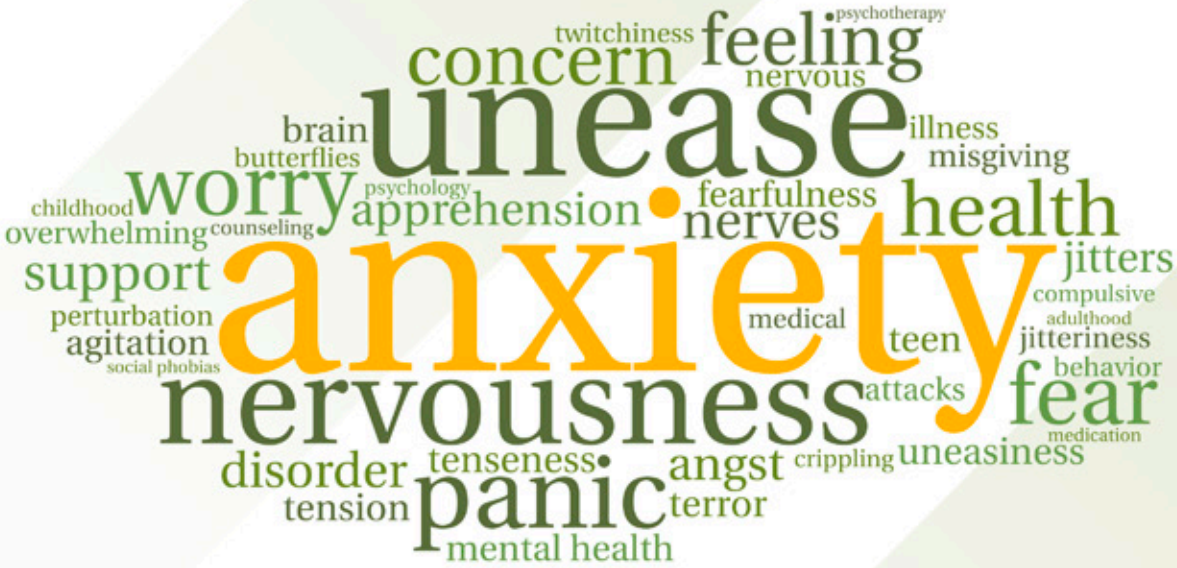
Many people with dementia may ***hallucinate***, or have ***delusions***. Hallucinations are sensory experiences where people see, hear, feel or smell things that are not really there. Two common hallucinations are of small children running through the house, or of animals playing on the lawn. Two common delusions are the beliefs that someone is stealing their things or that their spouse is being unfaithful.

DEPRESSION

People with dementia often become depressed. It's important to remember that ***depression is a whole body disease*** and is not something that just occurs in one's mind. Older adults with depression will often feel tired and have trouble concentrating. They may have poor appetites and problems with sleep. Irritability, overwhelming feelings of guilt and hopelessness are other symptoms. Depression is easily treated with medication or a combination of medication and therapy. People with dementia who are depressed will function better if the depression is treated.

ANXIETY

Anxiety is the most common of psychiatric disorders in older adults. It can take many forms: from pacing, to racing thoughts, pressured speech and Obsessive Compulsive (OCD) behaviors. When a person with dementia suffers from anxiety, it should be treated to help maximize the person's ability to function.



REFLECTION

Use the image of the brain and the descriptions of the various cognitive deficits to do the exercise below. Think about the clients that you work with and what we have reviewed. How many of these deficits have you seen in action? Can you think of examples? You may do these reflection exercises on your own, or discuss them with your colleagues. See how many circles you can fill in.

I know

_____

has attention deficits when

I know

_____

has apathy when

I know

_____

has executive functioning difficulties when

I know

_____

has short term memory problems when

I know

_____

has comprehension deficits when

I know

_____

is experiencing apraxia when

I know

_____

has long term memory problems when

I know

_____

has impaired judgment when

I know

_____

has orientation deficits when

STRENGTHS – The Cornerstone of Successful Dementia Programming

Uncovering Strengths

It may seem that we have been focused only on the limitations of people with dementia, their "impairments" and "deficits". This is just the stepping stone to what is really important in day programming – ***a person's strengths.*** Only when we understand what the disease has forced someone to struggle with, can we fully see the person behind the illness and engage them on the highest level possible.

Remember that someone with Alzheimer's Disease can have the illness for 20 or more years. We may be fortunate enough to have them in our program for years and their strengths will change with time. They may come to us early on, or when they are further along and have more significant problems with functioning.

Either way, it is up to us to find the person's strengths, and to continue looking for them as the disease progresses. We must be flexible and tailor our interventions to meet the person where he or she is on any given day.

A person's strengths are the building blocks on which we base our programming.

IMPROVING **SELF ESTEEM**

We all know that people come to our centers because of the things they cannot do. We turn this around. We make the person feel good about themselves despite their illness and limitations. When we focus on what a person can do, it gives them the experience of feeling valued and increases their self esteem.

Day program staff members have the advantage of not knowing who the person was before they became sick. We do not have the same expectations a spouse or children have of them, based on who they used to be. It can be hard for family members to let go of who the person was. At home, a person with dementia may constantly feel that they are letting someone down.

> ***In day program, their experience is very different. We see the person from a fresh point-of-view, appreciate them for who they are in the moment, and engage them in meaningful programs.***

Sometimes it can be a challenge to identify an individual's strengths and figure out how to engage them. We have two tools that will assist you with this process. The first is the ***Client Profile*** from the ***Circle of Harmony***, which is at the end of this chapter.

You can use this helpful tool at admission and throughout the participant's stay in your program. It provides a way to record important information about a person's history including work, leisure, talents, spirituality, family life and proudest moments.

The second is the ***Strengths Assessment Tool*** which follows. These two tools will help you focus on all the preserved strengths of your participants and engage them as much as possible.

After you review the Strengths Assessment Tool, you will find a sample assessment filled out. At the end of this chapter, you will have the opportunity to fill out the Strengths Assessment Tool for one of your participants.

Day Program participants can enjoy activities using their cognitive and social strengths.

STRENGTHS ASSESSMENT

Participant Name _____

Date _____

Check the strengths you have observed

Activity

- ❑ Responds to music
- ❑ Good eye contact
- ❑ Tells stories
- ❑ Writes
- ❑ Reads aloud
- ❑ Can make choices
- ❑ Asks questions
- ❑ Eager to participate
- ❑ Good range of motion
- ❑ Good fine motor skills
- ❑ Follows simple directions
- ❑ Uses scissors properly
- ❑ Demonstrates effort
- ❑ Singing
- ❑ Responds to visual cues
- ❑ Can share memories
- ❑ Likes parties

Other_____
Other_____
Other_____
Other_____

Social

- ❑ Cheers for peers during games
- ❑ Good listener
- ❑ Supports peers
- ❑ Wants to help others
- ❑ Offers pleasant greetings
- ❑ Uses automatic speech
- ❑ Saves seat for friends
- ❑ Holds door for others
- ❑ Makes friends easily
- ❑ Initiates conversation
- ❑ Maintains conversation
- ❑ Enjoys group conversations
- ❑ Offers handshakes/hugs
- ❑ Remembers names
- ❑ Positive rapport with peers
- ❑ Maintains social graces
- ❑ Converses well 1:1

Other _____
Other _____
Other _____
Other _____

Personality

- ❑ Cooperative
- ❑ Shows empathy
- ❑ Openness
- ❑ Asks for help
- ❑ Responds to touch
- ❑ Likes to entertain
- ❑ Sensitive to environment
- ❑ Patient
- ❑ Cheerful mood
- ❑ Follows routines
- ❑ Bright smile
- ❑ Laughs
- ❑ Curious
- ❑ Sense of humor
- ❑ Good sport
- ❑ Shares feelings
- ❑ Shows leadership

Other _____
Other _____
Other _____
Other _____

Making a plan: Based on what you have identified as this person's current strengths, how will you invite them to use these strengths? Doing what? When? How often?

Activity Strength: _____ Plan: _____

Social Strength: _____ Plan: _____

Personality Strength: _____ Plan: _____

STRENGTHS ASSESSMENT

Participant Name Ron G.

Date May 14

Check the strengths you have observed

Activity

- ☐ Responds to music
- ☑ Good eye contact
- ☑ Tells stories
- ☐ Writes
- ☐ Reads aloud
- ☐ Can make choices
- ☑ Asks questions
- ☑ Eager to participate
- ☐ Good range of motion
- ☑ Good fine motor skills
- ☐ Follows simple directions
- ☐ Uses scissors properly
- ☐ Demonstrates effort
- ☐ Singing
- ☐ Responds to visual cues
- ☑ Can share memories
- ☐ Likes parties

Other knows a lot about Pres Lincoln
Other recalls World War II years
Other loves country music & opera
Other _____

Social

- ☐ Cheers for peers during games
- ☐ Good listener
- ☐ Supports peers
- ☑ Wants to help others
- ☐ Offers pleasant greetings
- ☐ Uses automatic speech
- ☑ Saves seat for friends
- ☑ Holds door for others
- ☐ Makes friends easily
- ☑ Initiates conversation
- ☑ Maintains conversation
- ☐ Enjoys group conversations
- ☑ Offers handshakes/hugs
- ☑ Remembers names
- ☑ Positive rapport with peers
- ☐ Maintains social graces
- ☑ Converses well 1:1

Other always thanks staff
Other remembers facts about peers
Other _____
Other _____

Personality

- ☑ Cooperative
- ☑ Shows empathy
- ☐ Openness
- ☐ Asks for help
- ☐ Responds to touch
- ☐ Likes to entertain
- ☐ Sensitive to environment
- ☐ Patient
- ☐ Cheerful mood
- ☑ Follows routines
- ☐ Bright smile
- ☐ Laughs
- ☑ Curious
- ☐ Sense of humor
- ☑ Good sport
- ☑ Shares feelings
- ☐ Shows leadership

Other very dry humor
Other _____
Other _____
Other _____

Making a plan: Based on what you have identified as this person's current strengths, how will you invite them to use these strengths? Doing what? When? How often?

Activity Strength: Telling stories
Plan: During daily reminisce sessions, Ron will be asked to share stories based on his personal experience as they relate to the topics of discussion.

Social Strength: Saves seat for friend
Plan: Before everyone else goes into the lunch room, Ron will be invited to go first so he can choose a seat for him and his friend.

Personality Strength: Curious
Plan: During cognitive activities, especially those using visual aids such as books with pictures, the leader will offewr the materials to Ron so he can explore on his own and look at the pages.

TIPS on FINDING a Person's STRENGTHS

- Be attentive.
- Watch how they react during activities and social encounters.
- Pay attention to their non verbal communication – smiling, frowning, crossing arms, eyes brightening and maintaining eye-contact.
- Find what makes them come alive and do more of that. If a person is good with singing, add more music to all of their activities. Engage in a short song with them when you are walking them to the bus.
- Note what comes easy for a person and build on it. If they are good with fine motor skills, offer them more opportunities to do craft or baking activities.
- Offer a variety of tasks for them to engage in.
- Know their history including their hobbies and talents.
- Periodically ask them to do something out of their skill level. Make sure you provide adequate support. They may surprise you and do something you didn't think they could do.

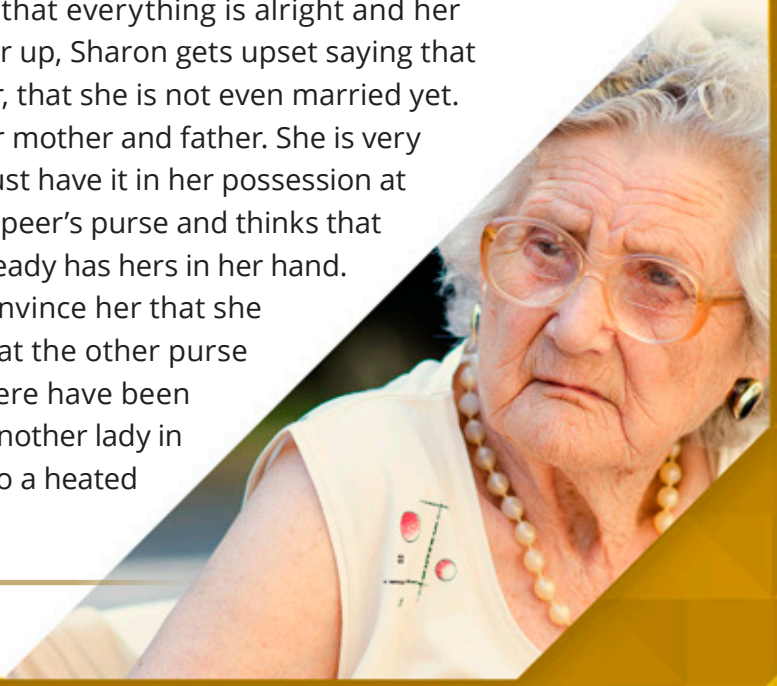
As the disease progresses, a person's interests may change. One year ago, Sarah had no interest in painting and would refuse to participate. Now she asks to paint, remains engaged and is very proud of her work.

CASE EXAMPLE: SHARON

Sharon is a 77 year old female. She has a Master's in Education. During her 40 year career, she taught every grade from kindergarten to college. ***She has Alzheimer's Disease.***

She experiences many symptoms, including severe aphasia, confusion, delusions, catastrophic reactions, lack of insight, poor judgment, and impaired recognition. Sharon has great difficulty with word finding. At times she does not understand what people are saying to her. She can form words and string them together, but her thoughts do not make sense. She often tries to convey important thoughts but is hindered by her language impairment. Sharon has a hard time participating in cognitive verbal activities. She will often fall asleep and, when sleeping, she sometimes mumbles or reaches out in front of her and makes motions with her arms. If staff wake her up, she will be confused and have a hard time responding.

She has periods of intense confusion with anxiety and restlessness. Especially after lunch, she will rummage through her purse mumbling about her ride or bus ticket. At times she is difficult to redirect and reassure. When staff tell her that everything is alright and her daughter is coming to pick her up, Sharon gets upset saying that she does not have a daughter, that she is not even married yet. She says she is waiting for her mother and father. She is very attached to her purse and must have it in her possession at all times. At times, she sees a peer's purse and thinks that it is hers, even though she already has hers in her hand. It takes a while for staff to convince her that she already has her purse and that the other purse belongs to someone else. There have been occasions when Sharon and another lady in the program have erupted into a heated



CASE EXAMPLE: SHARON

argument over whose purse is whose. At the end of the day, Sharon does not recognize her family members, and it takes several minutes and many attempts to reassure her before she will leave with them.

Family reports that, on many days, Sharon will not get out of the car because she does not recognize her home. Sharon has catastrophic reactions. She will suddenly become highly-agitated with yelling, gesturing and trying to leave the program. These are related to the delusional thoughts that she has.

Sharon takes medication to help reduce the delusions, agitation, and anxiety. These medicines, along with her disease progression, have affected her walking. At times, she is unsteady and stiff. She gets confused in the bathroom and needs help from staff. Sharon lives with her daughter, son-in-law, and two teenage grandsons because she is no longer able to live alone. When she is home, she often walks up and down the steps. She sits on the couch and anxiously rummages through her purse. She is afraid if she is left alone and, when someone goes into the other room, she will follow them, calling out "Is anybody home?"

From this synopsis, we get a sense of just how much Sharon struggles to get through the day. It may seem that in light of all this, she may be miserable and constantly suffering. On the contrary, Sharon is a great SUCCESS story that highlights how dementia day programming can dramatically improve a person's life. Even though Sharon is handicapped by all the symptoms of dementia, she attends a day program five days a week and typically has a very productive day.

CASE EXAMPLE: SHARON

Because she is in a dementia capable program, she is able to enjoy a calm, peaceful, and appropriately stimulating day. She frequently smiles. She offers gratitude to staff for all their help when she is in the bathroom and when walking to and from the bus. She still has periods of confusion and anxiety but she is reassured by the routine of the program. She is able to benefit from a well-designed activity schedule that rotates periods of verbal and motor sessions to keep her engaged. Staff know her deficits and they continually draw on her strengths. She has difficulty participating in the cognitive verbal sessions and will often nod off to sleep. If staff call her name, she is able to awaken and focus. If she is shown pictures or given things to look at and hold, she is able to maintain stronger attention. She will nod her head, smile, and laugh when appropriate.

Although, at times, it is difficult to understand what she is saying, staff is very supportive in listening, and offers statements that let her know they care about what she is saying. They will repeat back to her what they think she is saying until Sharon is reassured that she is understood. Staff consistently responds to the feelings underneath Sharon's speech.

Sharon is highly engaged whenever there is music and movement. If the group starts to sing a song, Sharon perks up and can fluently sing along. At times, she will clap her hands to the beat. She is highly engaged during all exercise and stretching sessions. She will very attentively watch the leader and follow all the movements. At times, she may need extra cues before she understands what to do, but she has excellent strength, flexibility and endurance.

If the group is playing a motor game such as bowling or horse-shoes, Sharon is very excited. She is careful in her participation and

CASE EXAMPLE: SHARON

expresses great pride when she scores. She walks around the room and gives everyone a high five. She makes pleasant comments about her peer's performance and often cheers for them.

During games like bingo she stays awake and engaged. She has difficulty finding the words or numbers on her board and, at times, gets confused, but with staff and peer assistance she is able to put the chips on her board. She is thrilled when she wins a prize. During craft activities, Sharon has a lot of difficulty following directions but wants to participate. She will ask for frequent reassurance from staff. With consistent intervention from staff, Sharon is able to complete the projects and expresses pride in her work.

Although Sharon has a hard time communicating, she is very kind and friendly in her exchanges with others. On walks to and from the bathroom she will strike up a conversation with staff, using clichéd statements such as "How many children do you have, or are you in school?" She has developed strong friendships with select peers. They will walk from one activity to the other next to each other and save each other a seat. During an informal social period, Sharon can be overheard having a lengthy conversation with a peer where it is evident that they are really connecting despite the language impairment.

Sharon responds very well to routine. Doing the same thing every day at the same time is very reassuring. Although she has severe memory impairment, she has been able to adjust to the routine of the program. If there is a change in the routine she becomes anxious. If the same thing happens the same day, she is more likely to be calm and peaceful.

CASE EXAMPLE: SHARON

The point is that despite Sharon's impairments, she is engaged in meaningful activity all day that makes her feel good about herself. She participates in a variety of activities. She has friendships and positive relationships. She makes others feel good. She is able to try things, succeed and feel pride about herself. She expresses positive energy in the group. She is productive. This is all because she is cared for in an environment and by staff that is aware of her limitations, compensates for them and gives her opportunities for success throughout the day. The routine, the quality of the activities, the expertise of the staff all contribute to an environment where the person is seen as a person, fully engaged in their community and where the disease does not define the person. Difficult symptoms are managed and, over time, can diminish or not be an impediment to an individual's participation.

Despite her impairments, including severe expressive and receptive aphasia, her delusions, her catastrophic reactions, and her periods of more profound confusion and disorientation, she is able to fully participate in day program because the environment has been structured to help her be successful.

CASE EXAMPLE: SHARON

Exercise: Reread the story about Sharon. Make 2 lists – one with some of her deficits and one with some of her strengths.

Deficits

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Strengths

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Now, make a list of what the Day Program staff did to make a supportive environment where Sharon could be successful.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

EXAMPLES of ENGAGING A PERSON'S STRENGTHS

Matthew *was a school custodian for 40 years. He likes to help keep the environment clean. If he notices something on the floor, he wants to throw it away. After craft and baking activities, Matthew is invited by staff to stay and help them clean up. He smiles as he helps staff and is remarkably able to stay focused and on task.*

Neil *was a New York City police officer. He wanders throughout the day. At first, this was disturbing to staff because he could not sit and attend during cognitive and recreational sessions. When he walks in the hallways, he will often stop and talk to people he encounters along the way. Although his speech is severely aphasic, he is trying to connect and engage in motor and social patterns that he used during his professional life. Staff offer supervision while he wanders, they check the security system daily and periodically offer him chances to re-engage with the group. They thank him for walking the beat and his efforts to keep everyone safe.*

Susan *was a high school English teacher. She is still able to read aloud fluently. At times she may jump around in the text but she reads with great feeling. Several times a day she is asked by staff to read aloud for the group. It may be from the paper for morning current events or during a presentation on a famous person, when she is asked to read a paragraph from the person's biography. When the nursery school comes to visit for story time, she is in her element.*

Jeannie *is having a harder time understanding conversation and calling out answers during question and answer periods. To keep her involved, staff gave her a bell and asked her to ring the bell every time someone gives an answer. This has worked very well. Jeannie stays focused and is able to respond. If she forgets, staff calls out "Jeannie, ring the bell." Often times this spurs clapping from her peers and adds to the positive mood in the room.*

STRENGTHS ASSESSMENT

Participant Name _____

Date _____

Check the strengths you have observed

Activity

- ❑ Responds to music
- ❑ Good eye contact
- ❑ Tells stories
- ❑ Writes
- ❑ Reads aloud
- ❑ Can make choices
- ❑ Asks questions
- ❑ Eager to participate
- ❑ Good range of motion
- ❑ Good fine motor skills
- ❑ Follows simple directions
- ❑ Uses scissors properly
- ❑ Demonstrates effort
- ❑ Singing
- ❑ Responds to visual cues
- ❑ Can share memories
- ❑ Likes parties

Other _____
Other _____
Other _____
Other _____

Social

- ❑ Cheers for peers during games
- ❑ Good listener
- ❑ Supports peers
- ❑ Wants to help others
- ❑ Offers pleasant greetings
- ❑ Uses automatic speech
- ❑ Saves seat for friends
- ❑ Holds door for others
- ❑ Makes friends easily
- ❑ Initiates conversation
- ❑ Maintains conversation
- ❑ Enjoys group conversations
- ❑ Offers handshakes/hugs
- ❑ Remembers names
- ❑ Positive rapport with peers
- ❑ Maintains social graces
- ❑ Converses well 1:1

Other _____
Other _____
Other _____
Other _____

Personality

- ❑ Cooperative
- ❑ Shows empathy
- ❑ Openness
- ❑ Asks for help
- ❑ Responds to touch
- ❑ Likes to entertain
- ❑ Sensitive to environment
- ❑ Patient
- ❑ Cheerful mood
- ❑ Follows routines
- ❑ Bright smile
- ❑ Laughs
- ❑ Curious
- ❑ Sense of humor
- ❑ Good sport
- ❑ Shares feelings
- ❑ Shows leadership

Other _____
Other _____
Other _____
Other _____

Making a plan: Based on what you have identified as this person's current strengths, how will you invite them to use these strengths? Doing what? When? How often?

Activity Strength: _____ Plan: _____

Social Strength: _____ Plan: _____

Personality Strength: _____ Plan: _____

COMMUNICATION

The language problems caused by dementia can be thought of as barriers or obstacles to us connecting with the real person.

Surely you have noticed that many of your clients have trouble finding the right word. Word finding is just one of the many forms of language disturbances that people with dementia experience.

Consider the scenario below. Do any aspects of the conversation seem familiar to you? Have you heard interchanges like this at your center?

Martha, Barbara, Tom and Fred are all sitting down to lunch.

Martha points at the salt shaker on the table and says

"Can you pass the hmm, hmm. "
(She is having trouble finding the word)

Her tablemate Barbara fills in for her. "Salt" she says and Martha nods and smiles.

Tom replies, "What is salt? " Tom can pronounce words but is forgetting their meaning.

Fred says – "The white stuff you shake". He is speaking around the word.

John at the next table over hears what's being said and says, "I love swimming in the ocean."

COMMUNICATION

Language, an ability we take so much for granted, becomes a tremendous challenge for people with dementia. As a dementing illness makes its way through the brain, it damages the many areas associated with language. That is why language disturbances can be so complex and confusing. It can cause people to forget the meaning of words (***semantic anomie***) or to just repeat what they hear (***echolalia***). They may have trouble expressing themselves (***expressive aphasia***) or have trouble understanding what is being said (***receptive aphasia***). Researchers have spent entire careers studying the language problems that occur when the brain is damaged.

LANGUAGE DISTURBANCES
that accompany Dementia:

Anomie – inability to remember the names of things even though the person knows what it is. For example the word "phone". The person knows what it is, and can use the phone, but the name of the object, the word "phone", is lost.

Automatic Speech – expressions said without much thinking on the part of the speaker, including songs and statements such as "Hello, how are you".

Circumlocution – describing the word or idea when the word cannot be remembered i.e. talking around the word.

Comprehension Deficit – difficulty in understanding oral instructions or directions.

Dysarthria – disorder of articulation due to impairment in part of the central nervous system which directly controls the muscles of articulation.

Echolalia – tendency to repeat a word, phrase, or sentence just spoken by another.

Expressive Aphasia – loss of ability to express one's thoughts in words.

Paraphasia – Person produces unintended syllables, words or phrases when they try to speak.

Phonemic Paraphasia – the substitution of a word with a non-word that preserves at least half of the segments or syllables of the intended word, such as papple for apple, ragon for wagon.

Receptive Aphasia – loss of ability to comprehend spoken language.

Remote Paraphasia – the substitution of a word that is only distantly related to the target word.

Semantic Anomie – when a person does not know the name of an object and also doesn't know what it is. For example, if you were to say to someone with semantic aphasia "Hand me the phone." They would respond "What is a phone?"

Semantic Paraphasia – the substitution of a word closely related to the target word such as cat/dog.

Verbal Apraxia – unable to produce the correct sounds or sequence of words even though there is no paralysis of speech muscles.

COMMUNICATION

How do we express ourselves without words? Imagine not being able to say "I'm tired", "I'm hungry", "I didn't sleep at all last night", or "I'm in a bad mood"?

How do we connect to people without words? Imagine not being able to share a joke, talk about the TV show you watched last night, or kid around with a friend?

Can you imagine trying to say something and having it all come out wrong? How much courage would it take to keep trying?

Words and language are such an intrinsic part of how we express ourselves and how we understand the world that their loss has profound consequences. Some people may turn totally inward and stop engaging with their surroundings. Others become so frustrated and angry that they lash out, while others make up stories or confabulate.

The language problems caused by dementia can be thought of as barriers or obstacles to us connecting with the real person who exists behind the wall created by this impairment.

So, no matter how nonsensical it seems to us, any attempt that a person makes with speech should be respected.

COMMUNICATION

Sally *has trouble finding words but that doesn't stop her from talking. She loves animals. When she wants to talk about her dog "Oreo", she says, "You know, the black and white one that needs to go for a walk."*

Every day ***Amy*** *says to those around her, "I wish you and your family a Merry Christmas and a Happy New Year." or she says, "Oh Honey, I love you" or "How many children do you have?" This is automatic speech.*

Tom *suffers from echolalia. He can only repeat what he hears. When staff says "Good morning", he smiles and says, "Good morning." When they say, "How are you?", he says, "How are you?" So it goes throughout the day. Tom's only way to verbalize is to repeat what he hears and, while that seems a poor substitute to us, his repetitions keep him connected to those around him.*

Sometimes, ***people with dementia*** *revert to their native language or mix it with English. For instance,* ***we once had a woman who reverted to only speaking Yiddish.*** *No one on our staff spoke Yiddish, so we had the family provide us with important words that we wrote on cards to help us communicate with her.*

COMMUNICATION

*Do you have an example of someone like **Sally** who uses circumlocution in their speech?*

*Do you know someone like **Tom,** who suffers from echolalia?*

*Can you name someone like **Amy** who uses the same set phrases every day?*

*Do you have **participants who have reverted to their native languages?***

*What are some **other language problems** do you observe?*

How Do We ENHANCE COMMUNICATION?

Fortunately, it's not necessary to know every single kind of language impairment to help our clients.

Most of us think about communicating in terms of language and, as we can see from the language table, many of our clients will have trouble with verbal communications.

How do we maximize whatever verbal skills they may have?

The following suggestions may help.

- Speak slowly
- Use simple words
- Be calm and reassuring
- Address the person by name
- Ask one question at a time
- Give the person time to respond
- Restate using different words, if necessary
- Approach the person from the front
- Use humor when possible
- Use more than one sensory area – visual plus auditory
- Be aware of your non-verbal cues
- ***Remember – the feelings expressed in your voice are more important than the words you say***

CUEING –
The Key To Successful Communication

We can think of words as the first step in communicating, but sometimes the person needs more. There are different types of cues and different levels of cueing.

Non-verbal cues play a key role in communicating with dementia clients.

TYPES OF CUES:

1. ***Visual*** – eye contact, pointing, showing an object, written note or picture
2. ***Verbal*** – spoken word, song, command
3. ***Tactile*** – touch

LEVELS OF CUES:

Successful interactions rely on cues. Sometimes we just need one level. Other times, the exchange is enhanced by two or three levels of cues. The level of cueing may need to be increased as the level of difficulty of the task increases. Start with the lowest level of cueing and advance to a higher level in order to foster a meaningful exchange.

EXAMPLES of **CUEING:**

Here are some examples of cueing during tasks in the day program:

EATING:

1. ***Visual Cue*** – Putting the plate of food in front of someone
2. ***Verbal Cue*** – Reminding them to take a bite or sip.
3. ***Tactile Cue*** – Putting the fork in their hand or lightly touching their elbow when they are holding a sandwich.

DURING A COGNITIVE ACTIVITY:

1. ***Visual Cue*** – Showing a person an illustration during a discussion.
2. ***Verbal Cue*** – Asking a question to an individual or the group.
3. ***Tactile Cue*** – Giving a person an object to hold that's related to what you are discussing.

DURING A MOTOR TASK:

1. ***Visual Cue*** – Demonstrating standing and throwing the ball yourself.
2. ***Verbal Cue*** – Telling the person to stand and toss the ball.
3. ***Tactile Cue*** – Gently helping the person move their arms.

DURING TOILETING:

1. ***Visual Cue*** – Walking them into the bathroom and pointing to the toilet.
2. ***Verbal Cue*** – Telling the person it is time to use the bathroom.
3. ***Tactile Cue*** – Helping them pull down their pants to sit on the toilet.

Tips For
SUCCESSFUL COMMUNICATION:

1. ***Always treat the client like an adult.*** An adult experiencing aphasia should be treated as an adult and not as if he or she were a child.

2. ***Speak loudly, slowly and clearly.*** In addition to comprehension, processing and language deficits, many of our clients also have age-related hearing deficits. Talk loud enough so the person farthest away from you can hear. Seat those who are hard of hearing or who need extra cueing in the front near staff.

3. ***Use economy of words.*** People with dementia may have difficulty both receiving and processing verbal information, as well as formulating verbal responses. You increase a person's chance of being able to participate in an activity if you speak succinctly. Don't rush it if they don't respond right away. Give them some time to process what you are saying. Brief moments of silence can be helpful. It may give a person the time to formulate a response. This technique may be helpful during activities involving direct questioning. If a person is not able to give a response on the first try, then try repeating the same question. If they still can't answer, try rephrasing the question. If still no answer, offer the person a multiple choice between two responses. If no answer still, give the participant some type of positive affirmation and move on to the next person.

Tips For
SUCCESSFUL COMMUNICATION:

4. ***Listen.*** Even if you can't understand what a person is saying, encourage them to continue talking until you can pick up on the feeling or general gist of what they are trying to communicate. Someone is in there and they want to connect to you, but they need your help. Help them find the word. Give them words to choose from, or try saying what you think they are trying to say and then ask them if that is what they mean. Give each person time and space to answer. It may take someone quite a few minutes of your undivided attention to convey a feeling to you.

5. ***To get a person's attention, say their name and look them in the eye.*** Once they are looking back at you, you probably have their attention. A person with dementia typically has a short attention span so you may need to use this technique several times during a conversation or an activity. If a person does not respond to you calling their name, a light touch on the arm or hand may get their attention.

6. ***Allow extra time.*** While normal adult conversations tend to flow naturally from one word and thought to the next, speaking with someone who suffers from aphasia may seem anything but natural. After speaking, allow extra time for the person to process the thought, and then attempt to articulate or gesture a response, before moving to the next thought.

Tips For
SUCCESSFUL COMMUNICATION:

7. *Avoid the temptation to speak for someone* who has aphasia. Find a way to help them express themselves.

8. *Use non verbal communication.*

a. The actual words we use only account for a small percentage of our communication.

b. If the person can gesture or use other non-verbal forms of communication, recognize those efforts and encourage continued interaction with others. People who have aphasia may be tempted to withdraw from others and may be at high risk for depression.

c. Head nodding, smiling, gesturing, facial expressions, body posture, and arm and hand positions, are all a part of the way we all communicate with each other.

9. *Incorporate music.* For some people, singing may help make words come easier. Also, many people who have lost fluent speech can still sing fluently, articulate, and remember all the words to familiar songs.

10. *Verify the message.* If the person is trying to say something and you think you understand what he or she is trying to say, repeat the words back to give that person the opportunity to verify that what you understood is correct.

Tips For
SUCCESSFUL COMMUNICATION:

11. *Listen to the subtext.* We must listen with our hearts as well as our minds. We must be sensitive to the emotions expressed, not just the words. "I want to go home" is a phrase we hear often. Sometimes this is an expression of anxiety, but it can also be an expression of loneliness. When we recognize the emotion, we can choose a response that matches that emotion. If someone is anxious, we can reassure them. If they are lonely, we can talk to the person about their family or, if they are confused, we can lead them in the right direction.

Barbara is a mute participant. During a recent Mother's Day celebration she cried as the staff spoke about her many years raising her children and how she created a loving, kind and devoted family.

12. *Decipher and acknowledge feelings.* People with dementia have a full range of complex and powerful feelings. Just because they can't express those emotions in words does not mean they are not there. As day program professionals, we have to learn how to decipher what people are feeling, even though they cannot verbally articulate it.

During a Veteran's Day celebration, a World War II veteran who had seen active combat in the South Pacific cried when a picture of the Marines holding the flag at Iwo Jima was passed around the group. It's not unusual to see World War II veterans react strongly to reminders of the war.

ACTIVITIES

Activities are at the heart of what we do in adult day care. Creating dementia-enabled programming every day is not easy. We face many challenges.

- We will have participants in our groups who have different types of dementias.
- We will have participants who are at different stages of dementia.
- Some will be very verbal.
- Some may be disruptive.
- Some will be passive and not speak much.
- Some will have difficulty following simple directions.
- We will have limited time to prepare for activity sessions.
- We will have limited financial resources to spend on activities.

"My mom loves coming to the day center. When she is at home, she sits in her chair all day and sleeps. When she is at the center, I know she is busy and active. When I pick her up, she is always smiling and happy. That is priceless."

ACTIVITIES

Despite all this, it is still possible to design and implement a vibrant activity program for your participants. In this section, we will review the elements essential to successful dementia-enabled programming. We will talk about the Structure of the Day, Exercise, Transitions, Mixed Abilities in Groups, Multi-Modalities of Engagement, Sleep Issues, Activity Preparation, Staff Collaboration, and Tips for Assisting with Activities of Daily Living.

THE STRUCTURE OF THE DAY

As a person loses their internal abilities to organize their world, it is essential that the environment provide reliable organization. Participants benefit from a consistent schedule that offers a variety of age and culturally-appropriate activities.

- ***Routine is essential.*** The same thing should happen each day at the same time.
- ***Activity sessions should be short,*** 45 minutes or less.
- ***Leaders should change when an activity changes.*** If there are multiple staff, it is helpful to switch with groups so participants can benefit from the interactive styles of each staff member.
- ***Alternate*** sessions that focus more on verbal or cognitive skills with sessions that offer ***music and /or movement.***

EXERCISE

Exercise and stretching should happen frequently.

- There should be a few scheduled periods of structured exercise.
- During structured activities, allow for many brief periods of movement, such as a two-minute chair stretching break.
- Right before lunch is an excellent time for a longer period of exercise.
- Avoid more intense exercise right after lunch.
- Include a good workout at the end of the day. Exercising right before the buses arrive can be a good way to channel any anxiety that clients may be experiencing in anticipation of the bus ride home.

- ***How often*** does exercise happen at your center?
- ***How long*** does each exercise session last?
- ***What provisions are made*** to include everyone regardless of ability?
- ***What challenges*** do you find during exercise/movement sessions?
- ***What works well*** at our center with exercise sessions?

TRANSITIONS

- Allow ample quiet times for transitions, such as at the beginning and end of the day.
- For many people, getting ready in the morning, taking the bus, and coming into the center can be a taxing process. Once they are at the center, offer participants some down time with relaxing music to help them unwind from this phase of their day.
- The same is true for the afternoon transition to going home. Having departure rituals, such as always singing the same song, or hanging up your name tag, stopping in the bathroom, or reviewing what happened during the day, can be reassuring for a participant and help them successfully transition to the ride home.

- What are ***transitions*** like at your center?
- Is there ***one time of day*** that is particularly ***more challenging?***
  - — ***The morning arrivals?***
  - — ***The afternoon departures?***
  - — ***Going to lunch?***
- ***What routines*** do you already have that foster smooth transitions?

MIXED ABILITIES in Groups

Chances are, each group we lead will have many individuals who are at different stages in the disease process. Rarely will we have a group where all clients have exactly the same deficits and strengths. It will always be a mix. This can be a good thing. If people have varied strengths, then more is offered to the group process. For instance, some participants may be able to recall more memories that they can share with the group, which can be beneficial to all. The challenge for us as professionals is to engage each person during the activity in a way that is tailored to their unique strengths.

*Do you see **a range of abilities** in your group?* _____

What do you notice? _____

_____

_____

_____

_____

***How does this impact you** when you are leading an activity?* _____

_____

_____

_____

_____

*How do you **make the best** of this?* _____

_____

_____

_____

_____

MULTI MODALITIES of ENGAGEMENT

Next, we have to think about how many ways we are presenting the material to the client, or how many opportunities we are giving them to engage.

- Are we asking ***verbal questions?***
- Are we showing them ***illustrations?***
- Do we have ***objects for them to touch?***
- Do we have related ***music or songs for them to sing?***
- Are there ***movement-related activities*** in which they can engage?

For instance, if the discussion is on a current or historical event in US history, why not sing a patriotic song and give everyone a flag to wave? It takes one minute, but it may get the person who is otherwise unable to engage, very awake, alive and participating

Recount a successful activity *that used multi modalities. What did you do?*_____

Think about an upcoming activity. *What illustrations, objects, music and/or movement can you add to enhance the session? What did you do?*

A CLOSER LOOK at MULTI MODALITIES of ENGAGEMENT

Use as many modalities as possible. For example, the topic of discussion may be famous places. Stop and think for a minute what kind of skills a person needs to participate in a discussion. A person needs access to memories, comprehension abilities, attention skills, expressive and receptive language capacities.

Some of our participants may have some of these skills intact and be able to talk about having visited famous landmarks. Those who don't have access to these memories, or to the speech to share their thoughts, can be further engaged in the session if they are shown pictures of landmarks.

Staff can point to various parts of the illustration and see if it evokes a response from the participant. Look for clues that a person is connecting. Do you see their eyes light up? Do they smile or make a statement, even one that is not coherent? Do they point to something in the picture? Do they reach out to hold the picture and want to take a closer look? Do they pass it to the person next to them? Do they nod their head? What happens when staff point to parts of the picture and ask questions?

We can even take this a step further and offer objects, to hold or see, that relate to the topic of conversation. This requires advance preparation on the part of the staff, to think about the activity, to reflect on the abilities of the participants, and to offer ways for all people to engage, despite their level of impairment. A person may not be able to speak but they may be able to actively participate non-verbally. It is our responsibility to give them a chance.

A CLOSER LOOK at MULTI MODALITIES of ENGAGEMENT

The opportunities are limitless. For instance, if you write down a few words related to the discussion, can a participant read it aloud for the group? Maybe they can fluently read a whole paragraph. Many times, a person who cannot speak fluently can read aloud fluently. What about a song related to the topic? You can have the words already printed or just wing it. You may be surprised who sings along. A rousing round of "I Left My Heart in San Francisco" can be beneficial for everyone in the room.

If the activity is heavy on the verbal, are there ample breaks where non-verbal exchanges are introduced? Is music played? Every 10 to 15 minutes, are participants encouraged to show motor response such as raising their hand, clapping, stretching?

VISUAL AIDS

Visual aids can be very helpful in engaging all participants, especially non-verbal participants, in activities. They may include illustrations or objects. For instance, an activity about the beach may include pictures of the shore as well as some actual sea shells or a small bowl of sand that people can touch. The more modalities we use in our activities, the greater chance we have of engaging each member of our group. For each activity you lead, think about how many modalities you are engaging. Ask yourself, "Am I engaging participants . . ."

- Verbally
- Visually
- Tactile/touch
- Sensory/Scent
- Musically
- Motor

EXAMPLE:
Leading a Successful Activity about the Beach

The group is arranged in a circle so the leader can walk in front of each person. Extra staff are in the room to handle disruptions, and the leader is free to focus on group process. The leader has visual aids to set the tone; objects such as sand in a bowl, sea shells, or pictures of the beach.

Clients may have been invited to bring in pictures of themselves at the beach on previous vacations. Staff may share pictures of themselves at the beach, or have pictures from magazines. If technology is available, the group may watch a short video clip of the beach. Staff may use an audio tape of beach sounds.

Cognitive stimulation would consist of question and answer periods which draw on their personal experience, their fund of knowledge, and their cognitive abilities. Have you ever been to the beach? Where did you go? What did you like about it? This will draw on their personal experience and invite reminiscence. Can you name states in the US that have coastlines, or how many beach towns can you name in New Jersey?

Some people may be able to easily call out names of beach towns in New Jersey . They may have some recall of geography and preserved list-generation abilities. Some people may be able to give you a name if you give them a few clues. Others who cannot do this may be able to read aloud the name of a beach town that you have written on a piece of paper. Still others may be able to look at map of New Jersey that you have placed in front of them and nod when you point to a town on the map. Everyone in the group could sing “By the Sea” or if the ages in the group are younger, “California Girls” by the Beach Boys. There could be a beach ball toss to get some motor involvement as well.

TIPS for SUCCESSFUL ACTIVITIES

- The room is quiet with limited distractions.
- The chairs are arranged facing each other and the leader. (This helps participants to focus on the leader and the interaction with the group.)
- There are extra staff in the room available to redirect and care for those clients who have an immediate need and must be removed from the group so as not to cause a disruption. (i.e. go to the bathroom, etc.)
- There may be a table in front of the participants for them to lean on, write on, or hold objects in front of them. Or there may be a table in the middle of the group with objects, and visual aids that the leader will use.
- There will be space for the leader to roam and stand in front of each person throughout the activity to get their attention, show them a picture, hand them an object, etc.
- The topic will be relevant, age and culturally appropriate.
- The leader will engage clients verbally and visually.

TIPS for SUCCESSFUL ACTIVITIES

- Clients will be asked to assist with the activity as they are able, such as someone writing information on the board as it's collected from the group, or a member passing out materials, or a higher-functioning person sitting next to a lower-functioning person and assisting them with a task, or someone reading a paragraph aloud.
- The leader will use music and movement to support the session.
- The leader will have adequate time to prepare for the activity.
- There will be material available at the center to assist staff with activity.
- The staff will have an opportunity to reflect on how the activity went, and to note what was successful, what challenges they faced, and what they might try differently the next time.
- Staff will have regular time to share their reflections on activities with team members.
- The activity will engage the strengths of the clients.
- Each activity will use multi-modalities such verbal, visual, music and movement.

About SLEEP in the PROGRAM

Although sleep disturbances are a common problem with dementia, day programming is one of the best remedies to foster good sleep habits. If a person is awake and active during the day, they are more likely to sleep well at night. Still, we frequently see people falling asleep during the day.

Here are some reasons why a person may be sleepy:

- a poor night's sleep at home
- medication side effects
- medical conditions
- disease progression
- advancing age

It is important that we do our best to keep our clients awake and engaged as much as possible.

Some individuals may also tune out and fall asleep when it is too difficult to engage in their environment. As the dementia progresses, a person may be more prone to withdraw, which leads to an increase in sleepiness. No matter what we do, some people will doze off during the day.

Participants who have fluctuating levels of energy and attention, and who demonstrate only an intermittent ability to stay awake and focused, should be encouraged to have brief periods of rest.

About SLEEP in the PROGRAM

We need to remember that participants come to the center for stimulation and engagement. Families report that when their loved one is home they just sit in the chair or lie in bed and sleep all day. When they are at the day program, they are consistently awake and actively engaged in all the activities. This is our goal for each person, to keep them as engaged as they are able.

When a person is sleepy, we need to run through the check list:

- ❑ Are there contributing medical reasons?
- ❑ What kind of sleep did the person have the previous night?
- ❑ Did the person have breakfast, do they need a snack?
- ❑ Are they able to engage in the activities or is it beyond their ability level?
- ❑ Are they offered frequent periods of music and movement?
- ❑ If the activity session involves sitting and they are sleeping, what happens when staff takes them for a walk?
- ❑ Am I doing everything I can to keep them alert and engaged?

About SLEEP in the PROGRAM

When a participant is sleeping, it is preferable that we gently try to wake them and engage them in the session. You may want to try these approaches.

- Call their name. If they do not respond, you may try lightly touching them on the hand, arm, shoulder, or knee.
- Sit next to them and maintain eye contact.
- Give them a few moments to awaken and focus.
- Offer them a warm greeting.
- Solicit a verbal and /or non-verbal response.
- Keep trying until you get a smile, a head nod, or some kind of response.

STAFF TASKS

ACTIVITY PREPARATION

Ideally, staff should have adequate time to prepare for an activity. The activity coordinator should make sure they have the material they need for each session. Knowing what the activities are, in advance, and having adequate time to prepare, can help make the activities more engaging for participants. Some centers report success when they discuss upcoming activities as a group on a regular basis, and then help each other prepare. One center was planning an activity on cooking tools. On that day, many staff brought in a variety of cooking tools so the leader of the group had more visual aids.

> ***We cannot make anything happen for our clients. We cannot force them to have a good time. We can create the conditions that make it conducive for them to fully engage to the best of their ability on that given day. We cannot control how they respond, but we can offer the best possible environment for them to unfold, to express themselves, to engage with each other, and to grow.***

STAFF TASKS

ACTIVITY REFLECTION

After each activity, it is helpful to take a few minutes to evaluate how it went. Think about the last group you led. How did it go? How did you feel at the end of the group? Did you feel that it was successful? Why, or why not? How many people in the group were participating? How could you tell? How many people were sleeping? Did you have success in trying to keep those who were passive engaged? What worked? What might you try differently next time? What might you suggest to a colleague who was doing this activity next month? Did it give you any ideas on other activities you may want to try with this group? Write down your thoughts. Keep them in the folder with the activity so the next person doing this activity can benefit from your experience.

BACK UP PLAN

Have a contingency plan just in case what you are doing flops. One time, we had a great activity planned on camping. We had thought of everything. It was going to be great! We had a small tent that we set up in the room, camping gear to pass around and talk about, songs to sing, ingredients for s'mores, and even a fake camp fire made out of twigs and tissue paper. It was a recipe for success, except that one gentleman was in a very bad mood and very vocal, which quickly spread to the rest of the group despite our efforts. No matter what we tried, nothing worked. We finally had to switch activities and move on to exercise.

STAFF TASKS

STAFF COLLABORATION

It is crucial that staff work together to make activities interesting and therapeutic. Think for a moment about the different gifts that each staff person brings to your center. You may do hangman with the group one week, but when your colleague does it with the same group, they may have a different way of leading the session. What can we learn from each other? How can we assist each other? How can we share what we have learned about participants to make the people we serve happier, and our jobs easier?

STAFF TASKS

REFLECTION / EXERCISE

What do you think? You walk into the room and observe a colleague leading an activity. There are about 15 clients in the room. Three clients are wandering around, two of the clients are engaged in conversation with each other, and at least 5 clients are sleeping. The leader is talking about the beach. Only one or two of the clients seem to be calling out responses. What do you think is going wrong here? What suggestions do you have for her? What questions should she be asking herself?

FOSTERING SUCCESS with Activities of Daily Living

MEAL TIME

No matter how hard we try to make meal time pleasant and relaxing, it doesn't always happen. Harold is served a large portion at lunch, yet he demands more and will try to steal it from others. Marsha seems to get more food on the floor than ever makes it into her mouth.

The difficulties we see a person having with eating, walking, or toileting, are directly related to the brain changes they are experiencing. Our job is to help compensate for the brain damage so the person can be successful in completing the task with dignity.

As professionals, it is important to remember that these behaviors are related to damage in the client's brain. Marsha wasn't always a messy eater. Most likely, she has a visual-spatial deficit that makes it impossible for her to see part of her plate or get the food directly to her mouth. Harold may not remember that he just ate and his brain may not be able to interpret feelings of fullness in his stomach.

Strategies, such as leaving the empty plate on the table while peers are still eating, may be a visual cue to the client that they did just have a meal.

Some clients do better with finger food and, if given a fork or spoon, they will not eat. Try giving them whatever the entrée is between two pieces of bread that they can hold. They may need encouragement from the staff to stay on task. Know your clients. One client might only eat one half of the sandwich if you cut it in half. Leave it whole so they have more chances of getting the most nutrition. Another client may be overwhelmed by a large sandwich and do better if they are handed two or four small pieces. Also, you can offer them soup that is appropriately strained in a cup so they can drink it without having to maneuver a spoon.

VISUAL SPATIAL IMPAIRMENT and MEAL TIME

A person with visual spatial impairment may have many difficulties with self feeding. He or she may have difficulty finding the food on the plate and then getting the food successfully into the mouth. They may only see food on one half of the plate. They may not be able to successfully get the food onto the fork or spoon. They may think they are done eating when, actually, they have only eaten half of the meal.

Here are some ways for staff to help:

- Serve the food on a white plate so the food can be clearly seen.
- Use a bowl or plate with a lip to enhance the person's ability to get food onto a utensil.
- Monitor the client and shift the plate during meal time so they can see the rest of the food.
- Mix the food with applesauce or another binder to aid in keeping the food together as the person lifts food to mouth.
- Try finger foods.
- Place the food in the person's hand if necessary.

GENERAL TIPS for Successful MEAL TIME

- Have a good exercise session right before lunch.
- Small café tables are optimal.
- Limit noise – if using music, it should quiet and calm.
- Present one course at a time – too many plates or bowls may be overwhelming or confusing.
- Use a larger vessel than needed for the amount of food. This can help a person spear the food with less spilling.
- Use sturdy tableware and avoid flimsy plates and cups which may tip. Styrofoam can be eaten by mistake, so it is best to avoid it. Use stainless steel utensils if possible.
- Table decorations can be useful in creating verbal and non-verbal communication, but make sure they are not a distraction or a safety hazard. Change them frequently to correspond with the season.
- Adequate staff should be available to assist as needed to monitor food intake and facilitate conversation.

TOILETING STRATEGIES

Toileting can become problematic as dementia progresses, due to changes with orientation, confusion, mood, judgment, executive-functioning skills, and decreased body awareness. People with dementia have difficulty properly following through with the steps of self care. Personal hygiene can become an issue. This may increase a person's risk for developing an infection, such as a urinary tract infection, which can lead to episodes of incontinency.

Furthermore, a person with dementia usually has limited insight into their situation. They may not realize that they are not properly cleaning themselves or that their underpants are soiled. Their pants or the chair may be wet and they will adamantly deny that they have had an accident. They may be irritable if someone offers to help them, or if family or staff even alludes to them needing help. This is a delicate situation for everyone involved. Toileting issues are extremely private for all of us. Imagine how you would feel if you started to have difficulties in this area. As professionals assisting individuals with this very private matter, we must strive to offer sensitive and dignified assistance.

- Encourage the regular use of the bathroom. Having regularly scheduled times when everyone uses the bathroom may make a person feel less like they are being singled out.
- Use the walk to and from the bathroom as a time to socially connect with the person. Talk with them about things that are important to them. Ask them how they are doing. Listen to what they have to say.

TOILETING STRATEGIES

- Sometimes pretending that you are going to use the bathroom, and asking them if they want to go with you to keep you company, helps get a resistant person at least in the door.
- Once in the bathroom, first try using non-verbal cues, such as motioning toward the bathroom stall. Take your cue from the person. Some people will do well with verbal cues, while others may get confused if someone keeps telling them what to do. Sometimes just motioning is enough. Or just handing them what they need, such as toilet paper, is enough to get them started on the task.
- Be kind and sensitive, even if it is a messy situation. Do not call attention to the accident. Just focus on the clean up, and getting the person through the task in a way that still leaves them feeling good about themselves. Thank the person for cooperating. Ask them to help as they are able. While you are finishing up and in the hand-washing phase, talk about something else. Move on to one of the person's strengths.
- Do not talk about any toileting issues with other staff anywhere a participant can overhear you. Even the most impaired client may be processing what you are saying and be hurt by your broadcasting the incident. Do not assume that just because the person can't talk, they don't understand or won't be hurt or humiliated by what you say.

ACTIVITIES

RATE YOUR CENTER'S ABILITY TO PROVIDE EFFECTIVE ACTIVITY INTERVENTIONS:					
	Excellent	Good	Fair	Poor	Needs Improvement
Our activities are age appropriate					
Our participants have adequate time to transition between sessions					
Our activities are varied, seasonal and interesting					
We have adequate time to prepare for activities					
We have adequate supplies for activities					
There are adequate staff available to assist during activity sessions					
Daily I have opportunity to reflect on how my activities are going					
I can engage the higher-functioning and lower-functioning participants					
I know how to engage more impaired participants					
We follow a regular schedule in our center					
I feel comfortable drawing out the more impaired client					
Our center tries to keep participants awake and engaged					
I use verbal, visual, tactile, music, and motor cues during each session					

ACTIVITIES

Now, from the list, ***choose three items*** that you are most interested in working on. What can you do to help your center improve?

1. _____

Ideas to Improve:

a. _____

b. _____

c. _____

2. _____

Ideas to Improve:

a. _____

b. _____

c. _____

3. _____

Ideas to Improve:

a. _____

b. _____

c. _____

KEEPING THEM SAFE

Damage to the brain makes people with dementia very vulnerable. No doubt family members have told you horror stories of loved ones taking too many pills, leaving the pilot light on, or taking the car and getting lost or in accidents. Most of the people in our programs are there because they cannot safely be left at home alone.

Our centers provide a safe haven for people with dementia but, even here, there are serious hazards. We must always be vigilant if we are to keep our participants safe.

In the day program setting, the most common safety issues include:

- Ambulating/Falls
- Wandering
- Activities
- Food Safety Delirium
- Assault due to combativeness

KEEPING THEM SAFE

AMBULATING / FALLS

A person with dementia may have difficulty when walking and, therefore, be at increased risk of a fall, especially as the disease progresses. Those with certain dementias, such as Lewy Body Disease, Frontal Temporal Lobe Dementia and Parkinson's Disease, typically experience more motor and gait disturbance. They have an even higher risk of injury related to falls. When a person is walking we may observe:

- Short, tiny steps
- Shuffling of the feet
- Poor balance
- Unsteadiness
- Fatigue
- Slow rate of paces
- Festination (involuntary, quick, short, accelerating steps when trunk gets ahead of feet often seen with Parkinson's Disease)
- Inability to walk a straight line and may bump into the wall or doorways
- Stooped posture
- Decreased arm swing
- Impulsivity of movement
- Sudden change of pace or gait pattern

Damage to the area of the brain that handles walking, causes some participants to walk abnormally. They have no control over it.

KEEPING THEM SAFE

In addition to ***brain changes,*** there are other factors that contribute to a person having difficulty walking. They include:

Side effects of medications – Most medications that our participants take have side effects which may make them sleepy, more confused, and/or off- balance. They can cause dizziness or a drop in standing blood pressure. Multiple medications can increase these symptoms and the risk of falls.

Age-related physical decline – Many of our participants will have arthritis or osteoporosis in the back, knees, or hips. They may have joint replacements or suffer from chronic pain related to previous injuries.

Medical conditions – Many clients may have fluctuations in blood pressure when changing position called orthostatic hypotension. This makes them feel faint, or have poor balance when first standing, because they experience a drop in blood pressure. Our participants may also suffer from fatigue, Parkinson's Disease, a history of a stroke, osteoporosis, arthritis, vision changes or hearing loss.

Visual Spatial Impairment – A participant may miss when they try to sit in a chair, or trip when walking up a step onto the bus. They may hit their back on the tank of the toilet when they sit down or bump into walls or doorways. When walking they may have difficulty recognizing borders or changes in patterns from rugs to smooth surface, curbs or other boundaries.

KEEPING THEM SAFE

Use of Assistive Devices – Oftentimes, our participants who use a cane or walker may exercise ***poor judgment*** and not hold or position the device properly when they are walking. This is a great safety hazard and increases their risk of falls.

Behavioral Disturbances – Some of our participants may periodically have episodes of sudden and increased ***confusion, fear, anxiety,*** or ***irritability*** which may cause ***motor restlessness,*** and result in them quickly exiting the room. ***Active psychotic symptoms,*** such as ***delusions, hallucinations,*** and ***paranoia,*** may also contribute to changes in a person's ability to safely ambulate.

Wandering Behaviors can be accompanied by poor judgment, poor choices, and fatigue from excessive pacing. Nursing staff should regularly exam the feet of those who wander.

How to REDUCE FALLS at Your Center

1. ***Assess for Fall-Risk upon Admission, and Daily.***
   Each person should be assessed upon admission for fall-risk and mobility. Can a person stand and sit independently? Do they require verbal prompts or mild contact guard? Does a person use a cane or walker appropriately?

   Staff should be observing participants daily and report to the nurse/administrator any changes they see in gait as soon as possible. (At the end of this section there is a sample form you may use for fall-risk.)

Participants should be encouraged to wear safe, non-slip, and comfortable footware.

How to REDUCE FALLS at Your Center

CHANGE = ASSESSMENT

Any sudden change in a person with dementia, whether it be a decline in their functioning or a change in gait, is cause for concern. A change in gait may mean the person may have experienced an injury that went unnoticed by family. They may be overmedicated, or be having an adverse reaction to new medication. They may be dehydrated, experiencing delirium, or have had a vascular episode such as a TIA. A change calls for evaluation from your staff, immediately, with appropriate referrals for follow up, as needed.

2. Monitor Participants when Ambulating, and during Motor Tasks.

Our supervision is the key to our participants' safety. Some of our participants may be fine when walking, but may experience balance problems when in motion. These problems may occur when they are involved in the steps of toileting, or while participating in a motor skills game such as shuffle board. Each client is unique, and their ability can change from day to day. Monitoring and reporting any difficulties we see is essential.

- Do you know what procedures your center has in place to assess a person's risk of fall and mobility upon admission?
- Does your center have a way of daily assessing a person's gait and motor abilities when a change occurs?
- How does your staff share information with each other when they notice a person's gait and motor skills have declined? Who do you tell if you see a participant having difficulty walking?

How to **REDUCE FALLS** at Your Center

3. ***Provide the appropriate level of assistance when walking and during motor tasks.***

   - Some participants may do fine with us just walking with them and being nearby. Others may need verbal cues such as "Jeannie, try to put the walker down on the ground when you are walking," or "Let's hold onto the hand rail."
   - You may need to provide a gentle touch on the shoulder or arm to steer them in the right direction and help them avoid running into the wall.
   - Some may need full-contact assistance whenever they are up and moving. Others may only need to hold on to your arm.
   - You may need to stand by someone to make sure they are positioned correctly before they sit on a chair or the toilet seat.
   - A consultation with a physical therapist may be needed in order to evaluate for possible use of a gait belt.
   - Participants with more severe unsteadiness when first rising from a seated position, due to ***orthostatic hypotension***, may need to be reminded to wait until staff is next to them before rising. If staff is nearby, they can encourage the person to wait a few seconds to give their blood pressure a chance to regulate before they start walking. This can greatly decrease a person's risk of fall.

How to REDUCE FALLS at Your Center

4. *Environment should be free of safety hazards.*

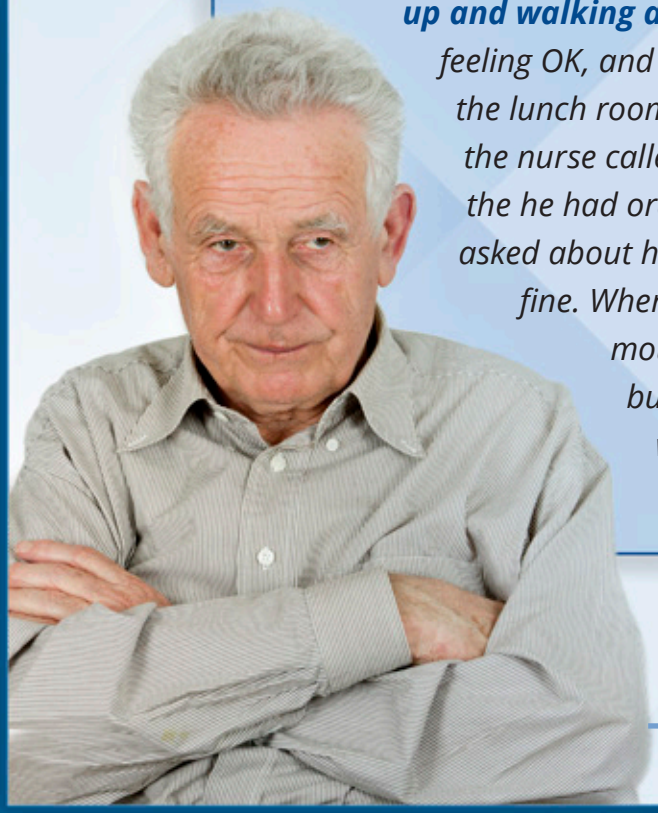
- Arrangement of tables and chairs - Is the seating arrangement so cramped that it is difficult to get in and out of an area?
- Is there ample room for participants to exit the room without having to shift people from in front of the door?
- Are participants encouraged to exit and enter the room in single file to avoid tripping on each other?
- Are canes, walkers, and wheelchairs stored safely when not in use, so as to not pose a tripping hazard to walkers?
- Is the floor clear of potentially hazard items such as balls or activity aids?
- Are doorways and walkways clear of clutter? Can people fit through the door with canes, walkers and wheelchairs?
- Are necessary items, such as garbage cans, stored safely in the room?
- Are there handrails for participants to use in the hallways?

The risk of falls is such an important safety issue that a fall-risk assessment should be included in every person's plan of care.

WANDERING

Wandering is very common in people with memory disorders.

- Wandering can be a sign of pain. Many people with dementia cannot identify the discomfort that they feel as a specific pain.
- Wandering can be caused by boredom or excess energy.
- Wandering can be an expression of anxiety or agitation, a reaction to a new environment, or a signal that a person needs more physical activity.
- Wanderers often forget where they are going, and why.



One day, Mr. Williams, who was usually very relaxed, was very restless during activities. He kept getting up and walking around. *Staff asked if he was feeling OK, and he replied he was fine. He went to the lunch room, but then refused to eat. When the nurse called his home, his wife explained the he had oral surgery the day before. When asked about his teeth, Mr. Williams said he was fine. When the nurse asked him to open his mouth, he winced. He was in pain, but could not identify, or explain, where it was coming from.*

TIPS on WANDERING

- Try to understand the underlying reason or emotion for the wandering. Is the person anxious, bored, or restless? Are they in pain? Are they reacting to a new environment or stimulus in the room?
- Be sure each participant has some form of identification that includes name and contact information.
- Inspect the security system daily, including doors and any transmitters that participants may wear while at the program.
- Be sure that all doors that are supposed to be locked stay shut and are not propped open.
- Disguise doors.
- Provide a safe place to wander.
- Provide adequate supervision for the person as needed.
- Frequently engage the participant and try to redirect them into other meaningful activities.
- Think back to what was going on in the room just prior to the wandering. How was the person responding? Were they engaged, or where they bored, distant or frustrated? Does this give you any clues as to what they may have been feeling? Does it give you any ideas about what you may do the next time this happens?

SAFETY During ACTIVITIES

Always think about what could happen, then structure the activity to prevent it from happening.

Here are some of the dangers and preventative measures to consider during activities.

Ingesting NON-FOOD Objects

During arts and crafts sessions, a client may accidently ingest an item not meant for human consumption. For instance, when doing watercolors, they may think that the cup of water in front of them, which is used to rinse the brushes, is a cup of juice, and they may try to drink it. Or when dyeing Easter eggs, they may see the brightly-colored liquid in the cup and drink it.

- Clients have been known to eat seeds or soil during a planting project.
- A client, who is put on the bus with a craft object in their pocket, or in a small bag, might mistake it for food and eat it on the way home.
- Not every client is at risk for eating inappropriate objects, but this is a real safety issue for many day program clients.
- Also, a client who you are sure will not ingest an inappropriate item on one day, may try to eat something harmful the next day.

Ingesting **NON-FOOD** Objects

So how can we prevent clients from eating things they shouldn't? Here are some suggestions:

1. Always provide ***close supervision*** during all craft sessions where there are any items that could potentially be ingested. It takes one second for a client to pick up a cup of paintbrush water and drink it. ***Clients may also mistake small craft objects such as magnets, bingo chips, or pom-poms as candy.***
2. ***Seat*** participants, who may be at risk for this behavior, ***close to staff*** so they can quickly intervene.
3. ***Keep supplies out of the reach*** of the person who may be at risk of ingesting non-food items. Sit next to them and, when needed, hold their paintbrush rinse cup for them. Then take the cup away from the table. Give them an object to glue and then sit there while they glue it on. Then move the item away from them while you assist other clients.

EXERCISE

Think about common objects you use in your activities. What might a person with dementia mistake for food?

_____

_____

_____

_____

Have you ever had a participant try to eat an inedible object? What was it? What did you do? What would you do differently in the future to prevent this?

_____

_____

_____

_____

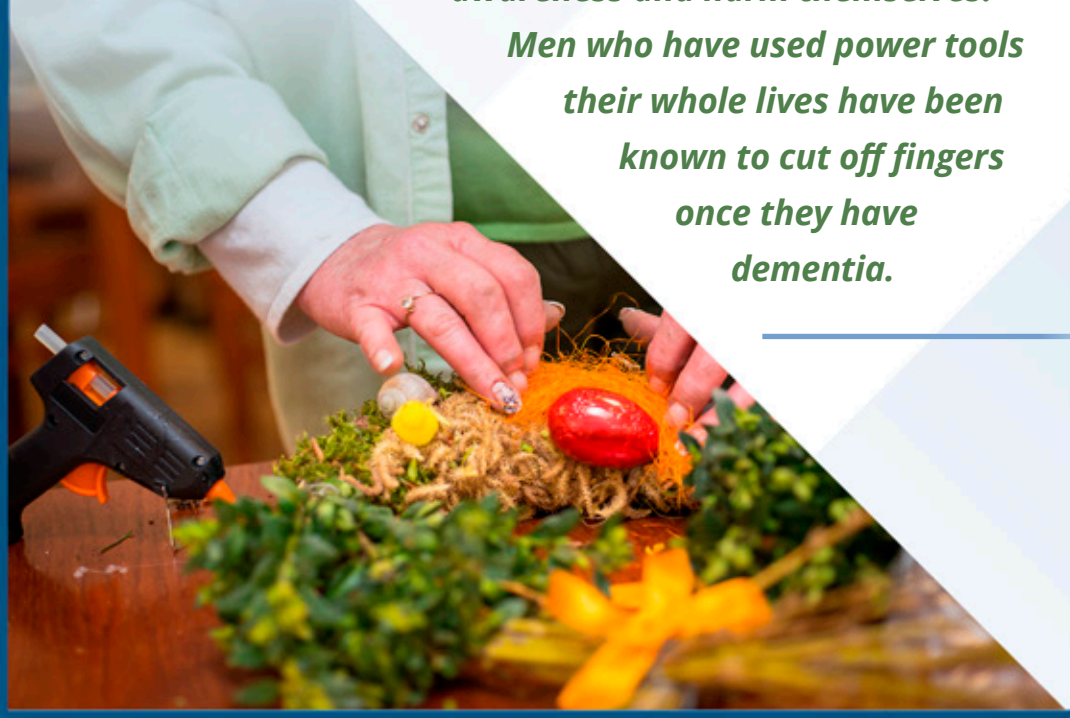
SHARP OBJECTS (They're not always scissors!)

Think ahead before you send anything home on the bus. Is it an object with sharp edges that poses a safety risk?

Routinely access client's ability to manipulate and properly use tools such as scissors.

Keep dangerous items, such as hot- glue guns, at a separate table, and only have staff use them.

Even people who have a life history of crafting and using hot-glue guns may potentially have diminished awareness and harm themselves. Men who have used power tools their whole lives have been known to cut off fingers once they have dementia.



FOOD SAFETY

CHOKING

- Cut food as needed for clients who may have difficulty using a knife and fork.
- Provide soft foods in the optimal consistency for client needs.
- Staff should be familiar with the Heimlich maneuver.
- Be aware of friends sharing food with each other, such as candy or cough drops. What might be OK for one person could be a choking hazard for someone else.

Clients EATING food OFF OTHER'S PLATES

- Monitor clients who may take food from others' plates.
- Seat them strategically so they cannot reach.
- Seat them next to vocal clients who will talk if something is amiss at the table. Do not seat them next to a non-verbal client who cannot speak up.
- Peers are no substitute for staff supervision but they can be an added level of protection.

FOOD SAFETY

RESTRICTED Diets

- Plan for all activities involving food and have substitutes available for those on restricted diets, such as sugar, low salt, food allergies, etc.
- Be careful of other clients sharing candy or other food that may cause an allergic reaction in a peer.

Eating Food from HOME

- Most of the time food from home is fine. Some clients may have particular tastes and will prefer to eat food made at home. Sometimes the food may be questionable.
- If it is prepared food that you feel may not have been properly refrigerated, tactfully offer a better option from approved food at the center. Speak with family members who are preparing the food at home.

BURNS from Spilling or Ingesting Hot Liquids & Foods

- A person with dementia may forget to wait to drink a liquid if it is given to them when it is hot. Judgment and insight are impaired. All liquids including, tea, coffee, soup, etc. should only be served when they are at a safe temperature and there is no risk of a burn. Older adults have thinner skin so hot liquids can cause a burn even if they are briefly exposed.

DELIRIUM

A Change Always Needs to Assessed

A sudden change in the functioning of someone with dementia can be a sign of delirium. Delirium can be caused by dehydration, a urinary tract infection or other illness such as the flu or a problem with medication. Older adults with cognitive impairment are at greater risk of experiencing a delirium.

Delirium is a medical emergency. Staff must be aware of the symptoms of delirium and be prepared to refer client for a higher level of medical care. Inform your supervisor or nurse immediately if you feel a participant may be experiencing any of these sudden changes. Your nursing staff may use the Confusion Assessment Tool (CAM) to diagnosis dementia. Here is a brief review of the four features:

Feature #1: *Acute Onset and Fluctuating Course*

Is there acute change in mental status from the person's baseline? Does the abnormal behavior fluctuate?

Feature #2: *Inattention*

Is there difficulty focusing?

Feature #3: *Disorganized Thinking*

Is the person's thinking disorganized or incoherent?

Feature #4: *Level of Consciousness*

Are they alert (normal), vigilant (hyper alert), lethargic (drowsy), stupor (difficult to arouse) or coma (unable to be aroused)?

DEHYDRATION

DANGER!

Older adults are at risk for dehydration because they often develop an impaired thirst mechanism. A person may not realize that they are thirsty and therefore may not be adequately hydrating.

When most people are thirsty, they get something to drink. But when we are older, we may not feel thirsty even though our bodies need water. Add to this fact that a person with dementia may be unable to identify their needs or ask for water. Some people may cut back on their liquids because they are afraid of being incontinent.

Dehydration can be a common occurrence with our participants. It may make a person more confused, affect their level of alertness, cause them to feel unsteady or dizzy and negatively affect their blood pressure.

What can we do to prevent dehydration in our participants?

- We can offer water throughout the day.
- Avoid caffeine and sugary drinks. ***Caffeine is a diuretic that can dehydrate people.***
- Offer broth based soups for lunch.
- Increase fluid intake during warm weather.

ASSAULT Due to COMBATIVENESS or CATASTROPHIC REACTIONS

Joan walks into the room and sees that someone is sitting in "her chair". She starts yelling, "What are you doing in my chair! Get out of here right now! And you have my purse!! Give me my purse! What kind of place is this! Someone help me! I am calling the police!" There is a lot of screaming and yelling. Joan is agitated, waving her arms and gesturing angrily in front the peer and staff. Staff is unable to reassure or redirect her. Joan runs from the room swearing and yelling, "I am not going to take this anymore".

The terms ***combativeness*** and ***catastrophic reactions*** are often confused. The two are not interchangeable.

COMBATIVENESS

- Combativeness is when a person lashes out at others verbally or physically. The person is in "fight" mode. They may push, strike or harm anyone in their way.

CATASTROPHIC REACTION

- A Catastrophic Reaction is a behavior that is severe, intense and extended in duration. It may involve yelling, screaming, crying, aggression, violent outbursts or fleeing with the level of emotion expressed not in keeping with the situation. Someone experiencing a catastrophic reaction may act combatively with peers or staff.

ASSAULT Due to COMBATIVENESS or CATASTROPHIC REACTIONS

Tips for preventing and managing combativeness and catastrophic reactions are reviewed in detail in ***The Circle of Harmony,*** the companion training program to this manual. The ***Circle of Harmony*** teaches day program professionals how to effectively manage behavioral disturbances. Following the techniques described in ***The Circle of Harmony*** can greatly reduce or prevent combativeness and catastrophic reactions.

*Included at the end of this chapter is the **Staff Log on Behavioral Interventions** from **The Circle of Harmony.** You may find it helpful regarding these more serious and troubling incidents that often occur in the adult day program setting.*

- Combative behavior poses risks for both staff and clients.
- Combative behavior must be managed in a way that ensures safety.
- Incidents of combativeness need to be identified and shared with the entire staff.
- Incidents can serve as learning scenarios helping staff to grow in their professional capacity to serve participants in all aspects of the disease process.
- Having a separate room, away from all activity can be a useful aid in deescalating an upset participant who may be lashing out at others.

CATASTROPHIC REACTIONS

POINTS to REMEMBER

- ***Remain Calm*** – Don't let emotions dominate your approach to an aggressive participant.
- ***Respond to Feelings*** – Sometimes the content of what the person is saying is not as important as the feelings that are expressed. Are they angry, frightened or sad? Be compassionate and warm.
- ***Reassure*** – Help to decrease the level of confusion. Use simple language, repeated in a comforting tone. Gently touch and redirect the person.
- ***Remove Yourself*** – It is important to assess the level of agitation. You may need to step away to help dissipate the situation. Have another staff member step in.
- ***Return Later*** – Observe how the person is feeling. Staff are often surprised at how quickly such intense displays of emotions can be forgotten by the person. Offer a distraction that is normally soothing, such as listening to music, looking at pictures or having a drink of water or a snack.
- ***Protect Yourself*** – Make sure that you signal to other staff the nature of the situation. Do not go to a separate location with the combative person unless other staff is nearby watching and ready to intervene. Think about your position in the room and the logistics of you being able to make a quick exit out the door if the situation escalates.

RATING SAFETY

WHAT DO YOU THINK IS YOUR CENTER'S SAFETY RATING FOR THE FOLLOWING?

	Excellent	Good	Fair	Poor	Needs Improvement
Preventing Falls					
Assisting with Ambulation					
Assessing Mobility					
Managing Wandering					
Preventing Ingestion of Non-Food Items					
Keeping Participants Safe During Crafts					
I can engage the higher-functioning and lower-functioning participants					
Providing Safety at Meal Time					
Preventing Dehydration					
Identifying a Potential Delirium					

REFLECTION

We have reviewed the safety issues associated with ambulation, falls, wandering, injury during activities, accidental ingestion of non food items, safety when eating, delirium, dehydration, combativeness and catastrophic reactions.

Which of these safety issues are you most concerned about at your center?

1. _____
2. _____
3. _____

Do you have any ideas for reducing the safety risk for the items you listed above?

1. _____
2. _____
3. _____

Do you have other safety issues at your center that we have not reviewed? Please list them here and then discuss them with your supervisor.

1. _____
2. _____
3. _____

DAILY FALLS RISK ASSESSMENT

Date:_____

LOW: Alert, no history of falls, no assistive devices, adequate vision, normal gait, normal balance, stable blood pressure, no medications, no predisposing factors (hypertension, vertigo CVA, PD, seizures, arthritis, osteoporosis, fractures) **STAFF PROVIDES VISUAL SUPERVISION WHEN PATIENTS ARE AMBULATING & USING B/R.**

MODERATE: Disoriented, history of 1–2 falls, correctly uses assistive device, poor vision, change in gait pattern with walking, moderate balance problems, slight drop in blood pressure, takes 1 or 2 medications, 1 or 2 predisposing factors (hypertension, vertigo CVA, PD, seizures, arthritis, osteoporosis, fractures) **STAFF PROVIDES 1:1 SUPERVISION WITH CONTACT ASSISTANCE AS NEEDED WHEN AMBULATING AND IN USE OF B/R.**

HIGH: Intermittent confusion and/or disorientation, history of 3 or more falls, uses assistive device, poor vision, visuospatial impairment, poor balance, disturbed gait, decreased muscular coordination, change in gait pattern while ambulating, difficulty with transfers from sit to stand and from stand to sit, unstable when turning, takes 3 to 4 medications, medications were changed recently, 3 or more predisposing factors (hypertension, vertigo CVA, PD, seizures, arthritis, osteoporosis, fractures) **STAFF PROVIDES 1:1 SUPERVISION WITH CONTACT ASSISTANCE WHEN AMBULATING AND IN USE OF B/R.**

CHANGE: If patient exhibits higher level of symptoms within their assessed category, nurse is contacted for evaluation of patient's status as well as family contacted with recommendations for medical and/or psychiatric follow up.

When Indicated Exam by Nurse	Low	Moderate	High	Change	Not Present
Charles B.					
Joan C.					
Sarah C.					
Natalie D.					
Julie G.					
Jean H.					
Norma L.					
Michelle L.					
Mateo N.					
Genevieve P.					
Maria R.					

DESIGNING for DEMENTIA

Seeing the World Through Their Eyes

The environment of your day care center** can enhance your work or make it more difficult. When we think about environment we are not just considering the structural aspects, such as room layout, chairs and decorations but also **the emotional tone of a space.

In an ideal world the setting of every dementia program would be homelike. There would be several rooms. One for activities and another that offers a relaxing quiet place. There would be a separate dining area and a large interior courtyard where clients can walk around or do some gardening. Staff would have their own bathrooms, luncheon area and offices.

In reality, we know centers are located in a variety of places such as office parks, church basements, hospitals and nursing homes. No matter where your center is you can provide a dementia enabled environment.

Even on a limited budget, you can make simple changes that will make your clients feel safe, secure and engaged.

DESIGNING for DEMENTIA

Multiple Visual Cues – Signs should be written in easy to read print with strong contrast between the back ground and type. Signs should include images. The word "LADIES" is not enough on the bathroom door. You will also want to include the image of a toilet. The same goes for the dining room or any other areas that are designated for a specific purpose.

Client maybe able to read but not comprehend what they are reading.

Space Size – Large spaces can be overwhelming, especially if they are used by different groups. Turn them into smaller spaces. Arrange chairs in circles. Use screens, modules or decorations to define smaller spaces.

Clients will get distracted by other activities, especially if those are noisy or busy.

DESIGNING for DEMENTIA

Calendars – can help clients orient themselves. Posters and decorations that refer to season or holidays are also helpful.

You may orient your clients first thing in the morning, but problems with short term memory may cause them to forget current holidays or the season as they move from one room to the next.

Calendars can help clients orient themselves.

Cultural Issues – Your decorations should be multicultural and sensitive to your clients' religious beliefs, ethnicity and race.

Respect for cultural background is an essential ingredient in providing person centered care.

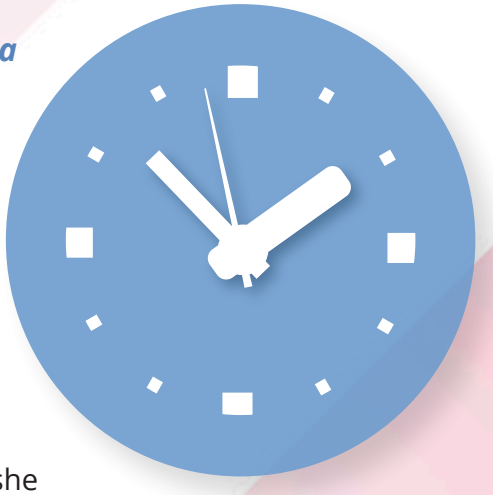
DESIGNING for DEMENTIA

Sound – Use music to create a specific mood and block out distracting noises. Sounds from the street such as police sirens can cause group members to become anxious and confused.

> ***Sometimes staff are the ones guilty of making too much noise. Staff should not be chatting during activities.***

Limit Visual Cues that can distract. Keep doors closed in activity rooms. Use curtains or blinds to prevent clients from getting involved in what's going on outside.

> ***Clocks are an example of a visual cue that can cause a great deal of distraction, even disruption, so use them judiciously in your program.***



You must know your client. One person may get anxious if they can't see the clock. Another may get anxious and restless if she can. You would want to make sure she sits with her back to the clock.

DESIGNING for DEMENTIA

Wandering – Wanderers must always be supervised but you can subtly influence where your wanderers go by creating a "wandering" path. Place interesting objects on walls or tables. Keep other doors shut and make sure there are places to sit. This allows the participant who wanders an outlet for their restlessness and a sense of independence.

Wandering is a good example of how environmental changes can transform problem behavior.

Quiet Room or Area for people who are upset or agitated. This prevents the agitation from spreading and can help calm an upset person. ***A quiet area should include a relaxing chair, calming scents and music.*** If you have a Snoezelen room, great! If not, you can still arrange a room with objects, lighting and furniture that is soothing and appropriately stimulating.

Homelike – Decorate with décor from the era when your clients grew up. This will not only make them feel comfortable but can be used to start conversation.

EMOTIONAL TONE & ENERGY

People with dementia are exquisitely sensitive to the emotional environment of their surroundings.

Clients are not only sensitive to other clients they are also sensitive to how staff is feeling. Be aware of how your mood may be affecting your participants.

Colors – Walls the same colors as doors may be fashionable but it is very likely to confuse people with dementia. Paint doors a contrasting color from the walls. The same goes for floors and rugs.

Color walls and doors the same if you are trying to hide them, such as the doors to storage rooms or offices.

Lighting – As we get older it takes longer for our eyes to adjust to changes in light. Make sure lighting works with you and not against you. Some clients will be hesitant to go from a well lit room to one that is less so.

Some clients may need to be in more subdued areas with less lighting for portions of the day. Think about how the environment affects the person and then adapt the environment as necessary.

EMOTIONAL TONE & ENERGY – Putting It Together

1. When someone with dementia gets lost at your center what cognitive deficit(s) may be causing the problems?
   - **A.** Visual spatial skills
   - **B.** Long term memory
   - **C.** Executive function
   - **D.** Calculation
   - **E.** All of the above

2. If you want to conceal the area where you keep things stored which strategy would be your best bet?
   - **A.** Paint the cabinets the same color as the wall so they blend in
   - **B.** Don't put handles on the cabinet doors
   - **C.** Put a screen in front of the cabinet
   - **D.** Don't put labels on the cabinet doors
   - **E.** All of the above

Comment on these statements. What do you think?

3. Clocks prominently displayed in all areas of your center are very helpful because they help keep your clients oriented.

4. Most dementia clients can still read well so it's important that signs are in large print with a lot of contrast.

5. Dementia clients who hear the siren of a police car going down the street may become anxious and upset.

6. What change could you make in your center that might be of most benefit to your clients?

7. How could you created a wandering path for your program?

EMOTIONAL TONE & ENERGY – Exercise

You are the director of a medical day care center. You have clients at various levels of dementia. You also have other clients who are not diagnosed with dementia. Some speak different languages.

Your center consists of 4 small offices for staff and two large rooms. One of those rooms has tables and chairs and is used as a lunch room and craft room. How can you make the layout of this environment dementia friendly?

You notice that dementia clients often stop and study a lovely oil painting of an apple tree that hangs in the entrance of your center. You are glad they enjoy the painting but sometimes they are blocking the way. Some participants try to pick apples off the tree. You decide to remove it. How could this painting be used to benefit dementia participants?

EMOTIONAL TONE & ENERGY

Are you having behavioral problems with any of your clients? Have you considered the way the environment is influencing them? Is there anything you can change?

Think about your center and your usual routine. What is the emotional environment? Does it change throughout the day? When is it the least calm? What are some ideas you have for improving environment during this time of day?

EMOTIONAL TONE & ENERGY

Have you ever seen anxiety spread through the clients in your group? What happens when one person gets upset? How do other members respond?

Here's an example of a behavior problem that was solved with a simple environmental change. When Betty is seated facing the door she sees the people passing in the hallway and gets up to see what is going on. She is so distracted that she cannot focus during activities. If she is seated with her back to the door, she is calm, remains seated and stays engaged in the session. Can you think of any examples in your own center?

CREATING a CULTURE of RESPECT

All people, regardless of the level of their illness, want to be treated with dignity and respect.

Even a person who has great difficulty with ADL's such as feeding, toileting and bathing, still wants and needs to be treated in a dignified manner.

How would you feel if you were dependent on someone else to feed you or to clean and assist you in the bathroom? Most of us are horrified at the thought. We reassure ourselves with, "That would never happen to me." The truth is it really could happen to any one of us.

Make It a Non-Issue

Be sensitive. Be Discreet. The best way to do this is to make it a non-issue. It is not always easy to do. Never negatively comment, joke or tease about a problem with basic skills. Carefully screen what you say. It's easy for an innocent remark to be interpreted in the wrong way, especially if this is a sensitive issue for the client. Be as discreet as possible. Make them feel that they are still in control.

EXAMPLE 1:
When assisting someone at lunch who is not eating, gently put the piece of sandwich in their hand. Sometimes this is the only cue a person may need to continue feeding themselves.

EXAMPLE 2:
It's time to use the bathroom", say "Why don't we take a walk down the hall?" or "Will you keep me company while we take a walk?"

Praise a Person Frequently

A participant may feel badly if they cannot answer a question during a question and answer session.

We need to reward them for whatever way they can participate. If a person only offers eye contact, a smile or a nod, remember to acknowledge their input.

You can make a positive comment. Compliment them on their smile, mention how wonderful their grandchildren are or that you have heard they have a great coin collection.

Regardless of the level of response a person is able to give during an activity, always affirm their effort, contribution and presence.

CREATING a CULTURE of RESPECT

When they cannot speak you can still draw them into the circle of conversation. Ask them to nod their head or make a statement about something you know about them that is relevant to the conversation. The interaction we have with each client, in each activity should always be positive and affirming.

During a group activity the facilitator says "What is known as the Keystone state?" Betty calls out, "Florida". The facilitator acknowledges her remark, "Florida is a great state. Lots of people retire to Florida." She then turns to Fred who does not speak and says, "Fred you retired to Florida for 20 years down in the Keys, right? You like fishing?" Fred smiles. Both Betty and Fred were affirmed and acknowledged.

Promote Autonomy by Offering Choices

Promoting autonomy allows us to show respect. It gives us an opportunity to respond to each person's individuality. This is essential in providing person centered care.

One simple way for a person to exercise decision making skills is to offer them choices when possible. During meals, participants can decide on entrees, drinks and condiments. They can also decide on activities, i.e. "Would you like to play number bingo or travel bingo?"

CREATING a CULTURE of RESPECT

Be Genuine

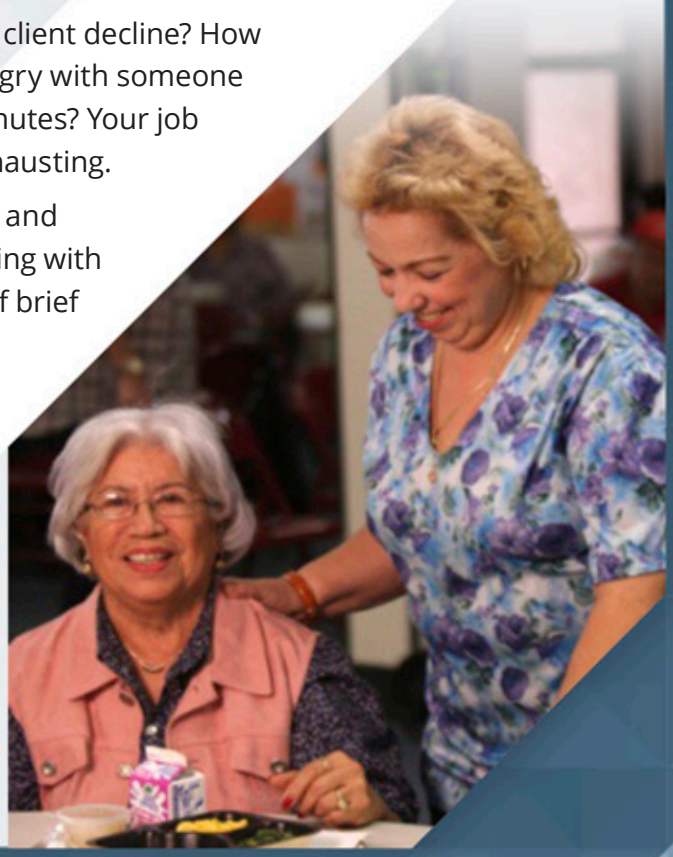
Our clients are usually very sensitive to the moods and attitudes of people around them. It's important to be genuine. You cannot patronize clients and expect them not to notice.

Acknowledge Your Own Feelings

No matter how dedicated you are, this kind of work can be stressful. You have a unique relationship with the people who come to your program. You spend a great deal of time with them and come to know them in a special way.

How could you not feel sad watching a client decline? How could you not be frustrated or even angry with someone asks to go to the bathroom every 5 minutes? Your job is very rewarding but it can also be exhausting.

It is important that day program staff and supervisors support each other in dealing with their feelings. This may take the form of brief conversations throughout the day or discussions during weekly meetings. Particular sources of frustration should be identified and strategies developed to reduce them. It can help if staff alternate activities and tasks.



CREATING a CULTURE of RESPECT

Cultural Competence

Cultural competence is an essential element in providing person centered care to our clients. New Jersey is the most diversified state in the country. This is reflected in the ethnic and racial diversity of both staff and clients in our many day care centers.

Culture touches every aspect of our lives. It influences how we think, what we value, what we eat, and what we wear. Like the air we breathe, we take it for granted. It is invisible until we encounter people from another culture who may be thinking or doing things very differently from ourselves. In order to appreciate people from other cultures we really need to be aware of our own.

Marsha Biltmore is a Jehovah's Witness. Her daughter explained that her religion prohibited her from attending parties. Staff notifies her daughter of the days when a party is planned and instead they have Marsha participate in other activities in rooms separate from party festivities.

CREATING a CULTURE of RESPECT

Here is an exercise for two or more of your staff. Answer the following questions:

When you were growing up was there a holiday or tradition that you celebrated that you would associate with your ethnic background? Describe what it was and what you did.

When you were growing up what was the role of the older adults in your family? Did they take care of grandchildren? Did they cook for the family? Did they live by themselves or with other family members?

Who were the caregivers in your family? Was it a daughter or daughter-in-law? Was there someone else who may not have been providing care but was responsible in other ways? For example, did one sibling provide care while another handled finances?

Finally, ***what did your family have to say about Alzheimer's disease or what you know now as dementia?*** When an older adult became forgetful what was their attitude? Did they feel it was normal? What did they call it? Was any one in your family placed in long term care?

Now share your responses with your colleagues. What are the similarities and differences?

Other areas where we frequently see cultural differences:

Gestures

Mr. Hussein was struggling with a modeling project during a craft session. When he finally completed it, the staff person Sarah gave him a "thumbs up" gesture and said "great job". He stood up and angrily headed for the door. Poor Sarah was confused and it took two other staff to calm him down. Later on his family explained that in the Middle East that particular gesture is very offensive.

Family Systems

Family systems vary with cultures. The nuclear family of mom, dad and two kids is not the norm throughout most of the world. Who is in the family and what their roles are varies. In some cultures great aunts or great uncles may be considered grandparents, or cousins have a sibling role. A daughter may be caring for her mother but her oldest brother may be making the medical and financial decisions about her care.

Eye Contact

Have you ever heard the expression "Look me in the eye when I talk to you" or "He was lying so much he couldn't even look me in the eye"? If you have, then you know that direct eye contact is often considered a sign of honesty and attention. Often, but not always, in many cultures direct eye contact is considered rude and disrespectful.

Touch

For some people a hug and kiss on the cheek is a typical greeting, for others it's a firm hand shake. Touch is an important tool in our work. We often use a hug or pat on the arm to convey warmth or provide reassurance. However we need be aware that there may be cultural norms that would make these well meaning gestures uncomfortable or offensive to some program participants.

Topics of Conversation

Many people feel uncomfortable speaking about bodily functions or illness. Sometimes there are taboos about what members of the opposite sex may discuss.

Mr. Sanson suffered a bout of urinary incontinence during a day program session. Although his pants and chair were wet he insisted there was nothing wrong when one of the female staff attempted to help him. When she mentioned the problem, he kept saying, "No! No! No!" He became cooperative when a male staff member came to assist him.

CREATING a CULTURE of RESPECT

Tips on Cultural Competence

- None of us can be an expert on every culture. Even when we are familiar with a culture we cannot make assumptions about a client because of their cultural background.

- That does not mean we shouldn't learn about different cultures. There is a gold mine of information on the internet. Our best teachers will be our clients and their families. But we must be open to what they can tell us. We must be the ones to ask the questions and not expect them to be aware of what we need to know.

- It is important not to limit your concept of culture to race or ethnicity. There are many different kinds of culture. People who are in recovery such as AA share a common culture, so do members of the gay and lesbian community. Sometimes religion can be the primary cultural influence such as in the case of the Pennsylvania Dutch.

- Cultural competence is an ongoing process. We all need to be sensitive and open to our participants' many cultures. This creates a much richer environment for all of us.

For REFLECTION

What are some cultural issues that exist at your center?

1. _____
2. _____
3. _____

Have you been successful in adequately addressing these issues?

1. _____
2. _____
3. _____

What ideas do you have about increasing cultural competency at your center?

1. _____
2. _____
3. _____

GLOSSARY

Agitation – motor manifestations of over activation including roaming, talkativeness, restlessness, kicking, arm flailing

Agraphia – ability to express ideas in writing

Akathisia – a movement disorder involving a feeling of inner restlessness and an uncontrollable need to move, fidget, walk or pace, can be related to use of certain medications

Alexia – inability to understand written language, may read aloud but not comprehend

Anomia – inability to recall appropriate word, talk around it

Anosognosia – implied unawareness of deficits or condition

Apraxia – inability to perform precise movements, carry out voluntary acts, loss of motor power, brain forgets how to use muscles to perform common activities

Astereognosis – inability to recognize objects by touch

Ataxia – disturbance in balance and a wide based stance and gait (lack of voluntary coordination of muscles and movement)

Attention – ability to stay focused and concentrate on specific task

Automatic Speech – items said without much thinking on part of the speaker, including songs and statements such as “hello, how are you”

Balance – ability to keep a steady position and not fall over

Blunted Affect – reduced emotional tone, reduction in normal intensity of feelings

GLOSSARY

Bradykinesia – slowness in movement when doing tasks, often seen in Parkinson's Disease

Capgras Syndrome – delusion that people are imposters

Catastrophic Reaction – behavioral reaction that is severe, intense and extended in duration, may involve yelling, screaming, aggression, fleeing, violent outbursts with the level of emotion expressed not in keeping with the situation

Circumlocution – use of word to describe word or idea which cannot be remembered

Combativeness – when a person lashes out at others verbally or physically, they may push, strike or try to harm others in their way

Comprehension Deficit – difficulty in understanding oral instructions or single or multistage commands, also understanding the environment or situation

Confabulation – making up facts or events

Disinhibition – socially inappropriate comments/actions, including sexual content, or inappropriate to the situation and/or outbursts of temper or feelings

Distractibility – when the attention cannot remain focused

Dysarthria – disorder of articulation due to impairment in part of central nervous system which directly controls muscles of articulation

Echolalia – tendency to repeat word, phrase or sentence just spoken by another

Expressive Aphasia – loss of ability to express one's thoughts in words

GLOSSARY

Fatigability – rapidly fatigues, lethargic

Festination – term used to describe abnormality in a person's walking usually seen in people who have Parkinson's Disease, the trunk gets ahead of the feet when walking

Field Cut – defect in visual field

Fine Motor – use of small muscles to perform intricate tasks

Gait Belt – belt worn by participant around the waist that allows staff to safely guide person who may be unsteady when walking

Gross Motor – activities in which groups of large muscles are used

Immediate Recall – recollection of events immediately following their occurrence

Impaired Thirst Mechanism – often happens in the elderly, when a person has decreased awareness of the need for liquids which can result in dehydration

Judgment – ability to make appropriate decisions

Lability – notable shifts in emotional response

Orthostatic Hypotension – a significant drop in blood pressure when a person has a postural change such as going from seated to standing or lying down to seated position

Paraphasia – interchange of words, nurse for purse

Perseveration – inability to stop once a pattern or behavior is started

Phoenemic Paraphasia – the substitution of a word with a non-word that preserves at least half of the segments and/or number of syllables of the intended word such as papple for apple, ragon for wagon

GLOSSARY

Pyschosis – psychiatric disturbances that may include hallucinations, delusions, paranoia

Recent Memory – recollection of events occurring within a matter of minutes

Receptive Aphasia – loss of ability to comprehend spoken language

Remote Memory – recollection of events in the distant past, months to years

Remote Paraphasia – the substitution of a word that is only distantly related to the target word such as horse/dog

Selective Attention – ability to focus

Semantic Paraphasia – the substitution of a word closely related to the target word such as cat/dog

Sequencing – placing things in proper order such as making a bed, telling a story

Stereognosis – ability to recognize objects by touch

Tactile Agnosia – unable to interpret touch

Verbal Apraxia – unable to produce the correct sounds or sequence of words even though there is no paralysis of speech muscles

Visuospatial Difficulties – inability to perceive direction, distance and spatial relationship

Visual Agnosia – unable to recognize and identify familiar objects and/or people by sight. This occurs without loss of the ability to actually see the object or person.