

National Task Group on Intellectual Disabilities and Dementia Practices

#### Communication Challenges and Difficult Behaviors

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- Dementia is a loss of intellectual functions (such as thinking, remembering, and reasoning) that is severe enough to interfere with daily activities and quality of life.
- "Dementia" describes symptoms but is not a disease.
- Alzheimer's disease is the leading cause of dementia.
- Individuals progress through the stages of dementia at different rates.
- Generally, there is a progressive downhill decline over a period of years.

\*\*Remember, with every symptom, there must be a cause! Alzheimer's disease causes dementia. Let's make sure there isn't something reversible going on before we jump to that conclusion!! NTG Education & Training Curriculum on Dementia and ID. Copyright 2014. 2 All rights reserved.

#### REGARDLESS OF THE STAGE, THE GOALS OF CARING FOR A PERSON WITH DEMENTIA ARE:



Protect the person from physical injury.



Maintain independence as long as possible.



Focus on what the person can still do.



Provide physical and mental activities that the person can do.



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CARING FOR A PERSON WITH DEMENTIA MEANS WE MUST UNDERSTAND THAT...

- S/he does not see the world the same way we do.
- What we see as normal can be very confusing and threatening.
- We must enter their reality as they cannot conform to ours.
- Need us to be patient, supportive and understanding.
- WE HAVE TO CHANGE BECAUSE THEY CANNOT.



## CONCEPT IN DEMENTIA CARE #1 MAINTENANCE SUPPORT

- Generally accepted as the **best practice** in dementia care.
- **Proactive** approach
  - A few minutes of pro-action can eliminate hours of reaction.
- Focus is on **support of remaining abilities**.
  - Respect changing needs of the person
  - Provide meaningful, failure-free activity.
  - Allow the person to do as much as they can for themselves but...be aware that as the disease progresses the need for assistance will increase.
- Can reduce or eliminate difficult behaviors at all stages by reducing frustration, boredom, anxiety, fear, etc.
- Can be done in all settings.

# KEY CONCEPT IN DEMENTIA CARE #2

Everyone has a life story that needs to be honored and respected.

- The story is the essence of each person and should be documented over the lifespan.
- When a person can no longer tell their own story, activities related to storytelling can still be used to inform caregiving and plan activities.



# KEY CONCEPT IN DEMENTIA CARE #3 VALIDATION APPROACH

- Focuses on empathy and understanding.
- Based on the general principle of *validation*...the acceptance of the reality and personal truth of a person's experience... no matter how confused.
- Can reduce stress, agitation, and need for medication to manage behavioral challenges.
- Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
- Emotions have more validity than the logic that leads to them.(I question this... How do we understand feelings if we are not listening to the person... Listen and understand that no matter how illogical it may seem, these emotions are very valid!)

#### Key Concept in Dementia Care #4 To Reorient or Not Reorient

- Best practice in dementia care: Do not correct or try to "reorient" the person.
- Requires staff to shift their care philosophy...

#### Example:

"What time is my mother coming?" (You know Ken's mother died 20 years ago.)

#### Which response is better:

- a. "Your mother is dead, Ken. Your sister will pick you up at 4:00."
- b. "She'll be here in a little while. Let's get a dish of ice cream while we wait."

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#### Key Concept in Dementia Care #5 REDIRECTION

#### **Distract AND Divert**

- Distract and redirect to minimize or avoid outbursts and challenging behaviors.
  - Redirected with gentle distraction or by suggesting a desired activity.
    - Providing food, drink, or rest can be a redirection.
- Smile, use a reassuring tone.

Redirection & Training Curriculum on Dementia and ID. Copyright 2014. All rights reserved. End Redirection should not be a first line of defense. We must FIX the problem! If we need to understand what the problem is, and/or time to come up with a creative solution, we redirect for the purpose of buying time! Redirection is a temporary fix. The same problem will occur less and less if we <u>solve it</u>!

#### Be flexible... What works today may not tomorrow.

- Solutions that are effective today may need to be modified tomorrow—or may no longer work at all.
- The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.



## TEN HUMAN DESIRES

What makes us tick??

#### WE DIDN'T COVER THE NEXT SET OF SLIDES...

 Think about these desires... consider what happens to you... How do you feel when these desires are unfulfilled?

Can you remember a time when you had something so important to say but you weren't being taken seriously?

~How about when you felt you didn't belong?

~ or weren't making connections... with other people, or a new home or town you moved to...

These ten desires are connected to our sense of wellbeing. Our loved ones with dementia NEED these desires to be met. Just like we do... They just communicate their discontent differently than we might..

#### THE DESIRE TO BE TAKEN SERIOUSLY

Isn't it a wonderful experience when someone gives you the gift of their undivided attention?

It's not just that they're listening, it's the unspoken message that they're taking you seriously enough to listen.

 Possibly the most compelling of all of the desires, for the person with dementia.

#### THE DESIRE TO CONNECT

communication is Our lifeblood

Connecting overrides the task

 Connect your loved one to the 'place' they happen to be occupying at the moment.

#### THE DESIRE FOR MY 'PLACE'

- We all need places that say things about us that we're pleased to have said.
- We all need places that symbolize us, places that make some tangible contribution to our sense of who we are.
- For the person with dementia, identifying that 'place' is key
- How do we connect the person with the 'place' we need them to be??

### THE DESIRE TO BE USEFUL

- It's one of the deepest of all the drivers of our behavior.
- It's easy to be cynical about humans but let's remember that it's in our nature to be useful.
- It's the ultimate putdown, isn't it, to be told that we're useless.
- The biggest fear among our senor population is 'not being useful'

#### THE DESIRE TO BELONG

 Our sense of identity, our sense of emotional security, depends on satisfying our desire to belong

#### THE DESIRE FOR SOMETHING TO BELIEVE IN

- Neuroscientists are now telling us it's easier for people in terms of brain function to believe than to remain skeptical.
- "Man is a credulous animal and must believe something. In the absence of good grounds for belief he will be satisfied with bad ones." Bertrand Russell

#### THE DESIRE FOR CONTROL

#### THE EVOLUTION OF CONTROL

- From birth to adulthood...
- The desire for control has deep origins within us
- Our loved ones with dementia are hanging on to their sense of control for dear life
- Utilize creativity to allow them to feel that they are in control

#### THE DESIRE FOR SOMETHING TO HAPPEN

- All of us need things to look forward to. We all need stimulation.
- We insist that we need stability, routine, etc...
- The truth about us as a species is that we thrive on change.
- We all need something to look forward to.

The person with dementia is different...

- Routine is critical
- That exciting 'something' needs to be carefully thought out
- Presented just before the event, not weeks or even days prior

#### THE DESIRE FOR MORE

All of us want more life, don't we?
When we're young we say quantity of life is unimportant. It's all about quality -

#### THE DESIRE FOR LOVE

- We all know that it's love in our lives that enlarges our own capacity for compassion, for empathy.
- It brings out the best in us.
- It contributes more than anything else to our sense of emotional security and personal serenity.
- We show our loved ones with dementia love, by fulfilling their basic human desires

### THANK YOU FOR THE GIFT OF YOUR TIME AND ATTENTION!

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