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A Resource Center for Today's Case Manager

## Caring for the Caregiver: Ethical Issues Managing Dementia

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**Laura Wayman**  
*Author, A Loving Approach to  
Dementia Care*



**Michelle Baker, BS, RN, CRRN, CCM**  
**Chair, Commission for Case Manager  
Certification**

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## Agenda

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- Welcome and Introductions:
  - Commission for Case Manager Certification
  
- Presentation:
  - **Laura Wayman, Author, *A loving Approach to Dementia Care***
  
- Question and Answer Session



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## Audience Notes

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There is no call-in number for today's event. Audio is by streaming only. Please use your computer speakers. There is a troubleshooting guide to the right of your screen.



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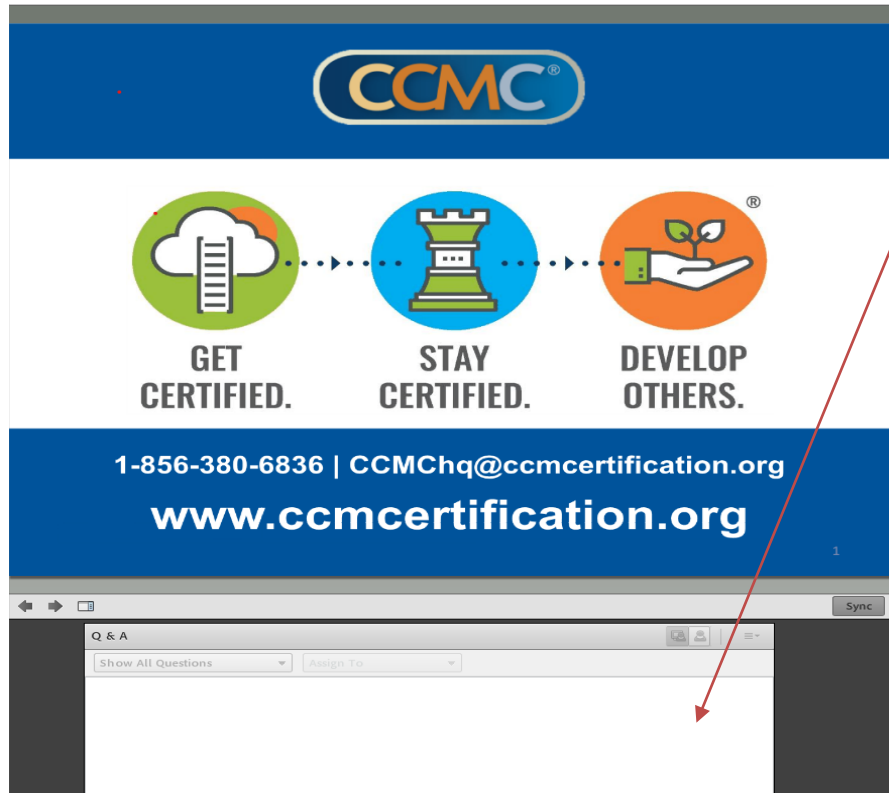
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## How to submit a question

To submit a question, Please use the "Q&A" field below the slides to ask questions throughout the presentation.

Just type in your question at any time and then click the button to submit.

- Please feel free to submit questions as they come to mind during the presentation—there is no need to wait until the end.
  - The questions will be asked by the moderator, at the conclusion of the presentation
  - We will answer as many questions as time permits



The image shows a presentation slide with the CCMC logo at the top. Below the logo are three icons in a row: a cloud with a checklist, a chess rook, and a hand holding a seedling. Under each icon is a text label: "GET CERTIFIED.", "STAY CERTIFIED.", and "DEVELOP OTHERS.". At the bottom of the slide, there is contact information: "1-856-380-6836 | CCMChq@ccmcertification.org" and "www.ccmcertification.org". Below the slide is a Q&A interface with a "Show All Questions" dropdown and an "Assign To" dropdown. A red arrow points from the text "Just type in your question at any time and then click the button to submit." to the Q&A input field.

## Audience Notes

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- A recording of today's session will be posted within one week to the Commission's website, [www.ccmcertification.org](http://www.ccmcertification.org)
- This webinar has been approved for one CCM continuing education ethics credit for board-certified case managers (CCM), one CDMS continuing education credit for board-certified disability management specialists, one nursing contact hour (ANCC), and one continuing education credit through New York State Education Department for social workers only to those who registered in advance and are participating today.



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# Learning Outcomes

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*After the webinar, participants will be able to:*

- Identify common ethical challenges that arise for caregivers of persons with dementia.
- Describe ethically-reasoned approaches for handling decisions that most commonly arise among family members who are caring for a loved one with dementia.
- Evaluate a case that can be experienced as ethically troubling by the case manager.





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## Caring for the Caregiver: Ethical Issues Managing Dementia

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**Michelle Baker, BS, RN, CRRN, CCM**  
**2019.2020 Commission Chair**  
**Commission for Case Manager Certification**

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## Caring for the Caregiver: Ethical Issues Managing Dementia

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**Laura Wayman**

**The Dementia Whisperer**

***Author of A Loving Approach to Dementia Care***

# CARING FOR THE CAREGIVER: ETHICAL ISSUES MANAGING DEMENTIA

LAURA WAYMAN, THE DEMENTIA WHISPERER



Why do we need to learn how to change our care approach in order to successfully connect, engage and communicate with any individual with dementia symptoms?

First - we must become “dementia-aware” in order to understand the changes we must make in order to help the individual have more meaningful moments and then provide the caregiver with this specialized skillset along with the tools to support them along the often long and mostly painful dementia care journey.

Becoming dementia-aware and using this care approach is counter-intuitive to how we have learned to communicate with adults who have a healthy brain and can bring up ethical questions...that is what we are going to talk about today.

# WHY SHOULD WE ALL BE “DEMENTIA-AWARE”

As our world population rapidly ages, there are a growing number of people who develop dementia. Research showed that in 2015, there was one new case of dementia somewhere in the world every three seconds. This is four times as much as new cases of HIV/AIDS. There is currently no cure for most causes of dementia symptoms.

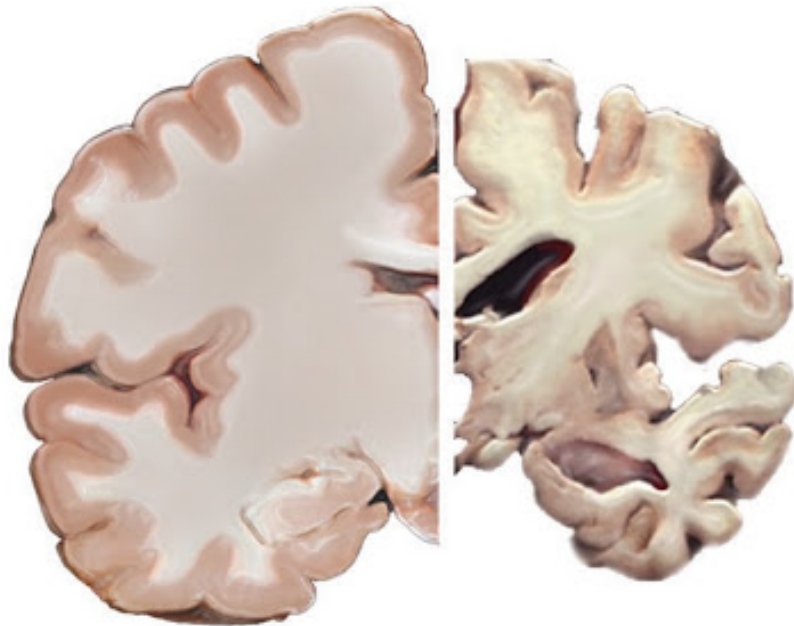
## **Where do we begin to raise dementia-awareness?**

I often get asked where to start. The number one need is improving understanding and acceptance of dementia – treating people as human beings that should not be excluded from the community or from contact with their friends and families.



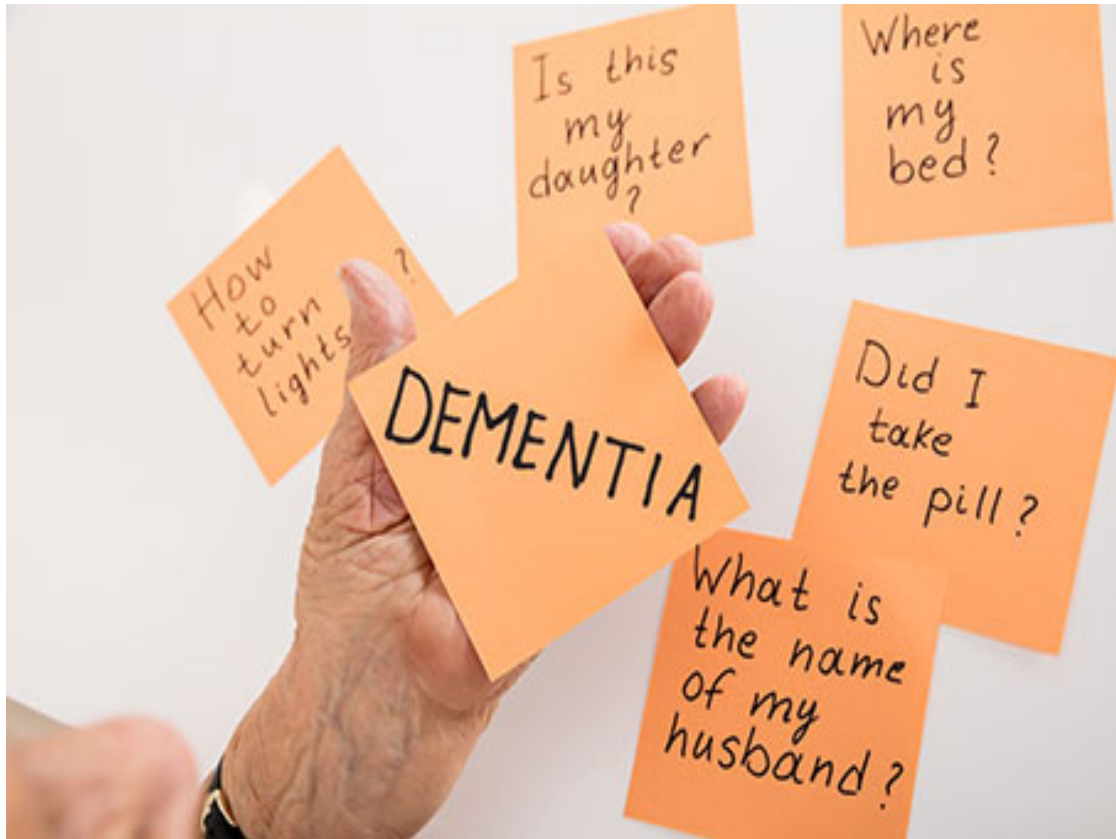
# WHAT IS DEMENTIA? WHAT IS IT NOT?

- Dementia is a List of Symptoms
- Dementia Symptoms Tell us the Individual is Losing Learned Brain Function
- Something Has to Cause this Loss
- Normal Aging Does NOT Cause Permanent and Progressive Loss
- Dementia is Not a Diagnosis
- Dementia is Not just about Memory Loss
- There are Thousands of Dementia Symptoms that Often Go Unrecognized
- There is No Cure, Recovery or Treatment for Most Causes of Dementia



THERE ARE OVER  
100 CAUSES...

THE LEADING CAUSE IS  
ALZHEIMER'S , FOLLOWED BY  
LEWY-BODY, PARKINSON'S  
AND STROKE....



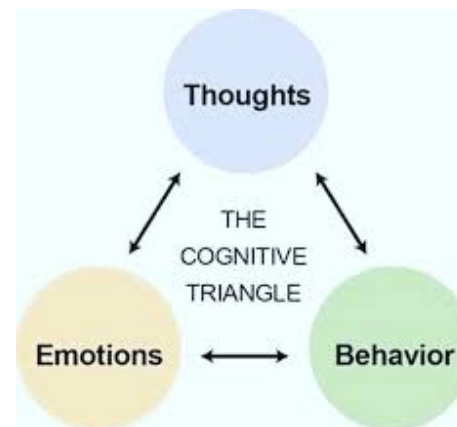
OUR BIGGEST  
CHALLENGE IS THE  
LOSS OF ABILITY TO  
PROCESS  
COMMON  
INFORMATION WE  
HAVE PROCESSED  
ALL OUR LIVES...

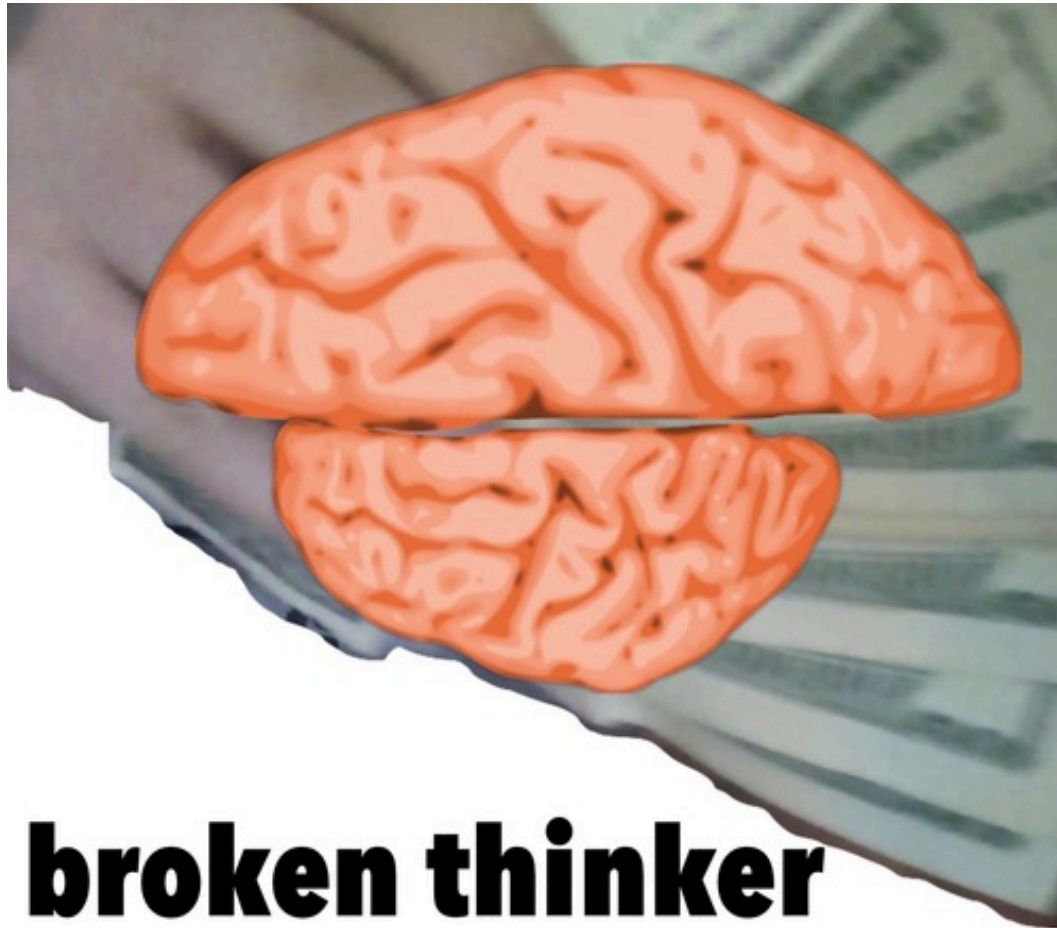
# THE EMOTIONS AND FEELINGS REMAIN!

We come to this world with a basic brain...



We learn to “think” and “process” and “regulate” how we feel...





TO PUT IT SIMPLY-  
THE INDIVIDUAL  
WITH DEMENTIA  
SYMPTOMS HAS A  
“BROKEN  
THINKER”

It is kinder to watch for ways to “think for them”, yet this is so different than successful communication with the adult who is “thinking” normally

So how do we “think for them”?

**broken thinker**



# THINKING FOR THE INDIVIDUAL WITH DEMENTIA SYMPTOMS...

DON'T ASK QUESTIONS OR GIVE OPTIONS

ONLY GIVE THEM THE INFORMATION THEY CAN PROCESS...KNOWING THEY WILL PROCESS SLOWER AND LESS AND LESS

HELP THEM TO FEEL LOVED, SECURE, SAFE AND VALUED BY JOINING THEIR FEELINGS AND USING "POSITIVE ACTION STATEMENTS"



# LET'S PRACTICE POSITIVE ACTION STATEMENTS....

When you, as a family or professional caregiver connect and attempt to communicate with the individual with dementia symptoms, our first instinct is to ask them questions. As you become more dementia-aware, it is important that we look for ways to “think for them” as much as possible by using the dementia-aware care and communication approach and strategies below.

■ Instead of greeting someone with the usual question **“How are you?”** or **“What is your name?”** Use the following positive action greetings:

- **“It is so nice to meet you.”**
- **“You have such a nice smile.”**
- **“I enjoy spending time with you.”**
- **“That color looks so good on you.”**

You may often get a negative response when you approach someone with a question such as: **“Are you hungry?”**, **“What would you like for dinner?”**, **“Would you like to come listen to the music?”**, **“Can I help you with that?”**, Take a deep breath, smile, slow down and relax, join their feelings, pause and give them time to process, then use the following positive action statements (or a combination of these examples below):

- **“It has been a while since we ate, I bet you are hungry. Come sit and have dinner with me.”**
- **“I always enjoy breakfast/lunch/dinner more when we eat together.”**
- **“I made your favorite fried chicken, let’s eat.”**
- **“I always enjoy the music when we go together.”**
- **“All of your friends are listening to the music, they are waiting for you to come, too.”**
- **“I always enjoy helping you.”**
- Keep it simple, clear and to the point. And be sure and utilize actions, hold out your hand, bring them their walker, take their arm...show and tell - not just words.
- Join their feelings-(this will help them to trust you and not feel so defensive)**“I can see that you might feel a little tired.”**, **“I am glad to see your smile.”**, **“I get frustrated sometimes, too.”**, **“I can only imagine how you might feel.”**, **“I can see how that made you feel angry.”**

# DOES THIS FEEL UNCOMFORTABLE? ARE WE “TAKING AWAY” THIS PERSONS RIGHT TO CHOOSE? ARE WE ROBBING THEM OF THEIR DIGNITY?


- Many years ago, it was thought that strict reality orientation should be used when an individual had difficulty processing and became confused. In other words, if the person thought her parents were still alive, it was recommended that she be told the truth—that her parents were dead—in order to bring her back to reality.
- Obviously, this approach doesn't work, because it only upsets the person more, any cause of brain function loss affects the brain in such a way that trying to reason or use logic with the person no longer works. They can no longer process that their loved one died and being bluntly told this affects them as if it were the very first time they were receiving this news. They may begin to cry, ask how their loved one died and then worry about attending the funeral.
- **TALK TO THE FEELINGS!**
- In most situations of confusion, reality orientation is no longer recommended. Instead, it's recommended that we *join* the person's feelings. For instance, if your father is upset and wants to see his own mother (who is no longer alive), he may miss his mother or may be thinking about something from the past that he wants to resolve. Try joining his feelings by saying, "It sounds like you're thinking about your mother. Tell me more about her." when you join him, he will begin to feel the love for his mother and forget why he was upset. By honoring and sharing in his feelings, you're neither agreeing nor disagreeing with the idea that his mother is still alive.

# HOWEVER, “CREATIVE INTERVENTIONS” MIGHT BE NECESSARY

- In addition to talking and joining the feelings, *redirection* or *distraction* is a helpful approach to these situations. Distraction involves diverting your loved one's attention to something pleasant.
- Lying could threaten the relationship between the caregiver and the individual with the disease. However, this risk only occurs when the fib is actually an outrageous lie. I like to call these “Creative Interventions” (finding a clever way to meet the immediate and specific needs of the individual with dementia symptoms, and joining them in their feelings, these work best if customized to each individual!)
- For instance, if the individual you are caring for insists that there's a stranger in the bathroom, and you tell her, "Yes, that's your favorite entertainer, Wayne Newton, and he's come to sing for you!" there is a good chance that your loved one will be skeptical of your claim and perhaps even become distrustful of you.
- This is much different from a “creative intervention” such as, "I just checked the bathroom and he must have left because there's no one there now.”


MRS.A IS 78 YEARS OLD AND IS EXHIBITING DEMENTIA SYMPTOMS WITH NO DIAGNOSIS AT THIS TIME; SHE CAME TO THE MEMORY CARE WHERE SHE WAS ADMITTED WHEN ATTEMPTS TO SUPPORT HER TO REMAIN IN HER OWN HOME WERE UNSUCCESSFUL DUE TO HER LOSS OF PROCESSING, DISORIENTATION AND LACK OF UNDERSTANDING OF RISKS. THESE PROBLEMS CAUSED HER TO NEGLECT HERSELF AND FREQUENTLY LEAVE HER OWN HOME AND GET LOST, OFTEN IN THE MIDDLE OF THE NIGHT. ONE OF THE THINGS THAT MADE HER PARTICULARLY VULNERABLE WAS HER TENDENCY TO TALK TO COMPLETE STRANGERS, TELLING THEM THAT SHE LIVED ALONE AND WHERE HER HOME WAS.

WHEN MRS.A ARRIVED SHE WAS VERY FRIGHTENED AND ANGRY AND DID NOT UNDERSTAND WHY SHE WAS NOT ABLE TO REMAIN IN THE HOME THAT SHE HAD LIVED IN FOR OVER 20 YEARS, SHE WAS SUSPICIOUS OF EVERYONE BELIEVING THAT WE WERE ALL IN SOME WAY TO BLAME FOR WHAT WAS HAPPENING TO HER. WE STARTED TO GATHER AS MUCH INFORMATION AS WE COULD ABOUT MRS.A'S LIFE HISTORY AND SIGNIFICANT EVENTS. WE WERE GIVEN USEFUL INFORMATION BY NEIGHBORS, A FRIEND OF MANY YEARS AND MRS.A'S GP WHO HAD KNOWN HER FOR OVER 20 YEARS.



The memory care team immediately adopted the dementia-aware techniques recommended for managing behaviors that are the result of the person feeling uncomfortable and fearful at this stage of the illness. These include educating the staff to not expose the person's weaknesses or loss, working with all feelings expressed including anger which can be frequent and sudden in onset, keeping our distance until invited to get closer, acknowledging and joining feelings rather than ignoring them or taking things personally. Most importantly we acknowledged Mrs. A's lifetime of experience as a senior nurse, inviting her opinions on simple issues where we knew she would be able to feel that her input was valued and helpful.

Within 4 weeks Mrs. A's behavior started to change in a way that suggested this care strategy was having a positive impact on her and helping to make her feel more safe, secure, loved, valued and comfortable; she started to confide in two staff she now trusted, she admitted that she was frightened of not being in control and of having difficulty understanding what was going on around her.



When faced with this dilemma, remember to try joining their feelings and distraction first, since these approaches often do the trick.

The bottom line is that if a creative intervention is the only way to make the individual feel better in a particular situation, and it isn't hurting anyone, then you're helping the individual by entering their world instead of forcing reality upon them.

**KEEP IN MIND THAT THIS APPROACH MAY ONLY WORK TEMPORARILY; LIKE ALL APPROACHES TO CHALLENGING DEMENTIA BEHAVIORS, IT SHOULD BE MONITORED AND ADAPTED WHEN IT CLEARLY IS NOT WORKING ANY LONGER.**

**YOU MUST STAY FLUID AND FLEXIBLE AS THE DEMENTIA LANDSCAPE WILL CONTINUE TO CHANGE.**



## Telling the hard truth could be cruel...

Most of us are taught from a young age that any kind of lying is horrible and dishonest, especially lying to family and anyone we care about and respect.

So when we hear about using a creative intervention to “lie” to someone with dementia, it seems cruel and wrong.

But always sticking to the truth, especially about an emotional subject or something trivial, is more likely to cause your individual with a “broken thinker” pain, confusion, agitation, anxiety and distress.

Dementia symptoms prevent the individual from properly processing, understanding and retaining information. Plus, if they cannot process what you say and store it for later use, it means they’ll probably not be able to retrieve the conversation, so it will come up again.

Telling the truth each time forces them to experience fresh distress over and over again-it is all about how the information makes them feel.

Is it necessary to cause them so much distress, especially when the truth you tell them is likely to be misunderstood or confusing and not really processed fully?



# QUESTIONS? THOUGHTS?

JOIN MY #IAMDEMENTIAAWARE CAMPAIGN



Laura Wayman, The Dementia Whisperer

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## Question and Answer Session

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**Laura Wayman**  
*Author, A Loving Approach to  
Dementia Care*



**Michelle Baker, BS, RN, CRRN, CCM**  
**Chair, Commission for Case Manager  
Certification**

# Thank you!

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- Please fill out the survey after today's session
- Those who signed up for continuing education will receive an evaluation from the Commission.
- A recording of today's webinar and slides will be available in one week at <http://ccmcertification.org>

## Commission for Case Manager Certification

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