

DCPA[®]

DEMENTIA CARE PROFESSIONALS OF AMERICA

A Division of the Alzheimer's Foundation of America

Partners in Care Supporting Individuals Living with Dementia

Presented by:
Alzheimer's Foundation of America
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Alzheimer's Foundation of America

Mission:

“to provide optimal care and services to individuals living with dementia, and to their caregivers and families—through member organizations dedicated to improving quality of life.”

Training Objectives

- Building relationships
- Understanding Alzheimer's Disease and Dementia
- Facilitating Meaningful Living
- Effective communication
- Facilitating personal care
- Promoting safety and security
- Easing care transitions
- Supporting individuals during end of life
- Importance of self care

BUILDING RELATIONSHIPS

Module 1

Exploration of Identity

What comprises identity?

- Gender
- Race/ethnicity
- Sexual orientation
- Family
- Culture
- Occupation
- Religion
- Political affiliation
- Citizenship
- Values
- Interests/hobbies

Identity and dementia care

- Knowing each person within their unique context
- Identities shift, especially as disease progresses
- Relating to individuals with dementia as whole people
- Focusing on strengths rather than dwelling on deficiencies

Building Relationships: The Cornerstone of Dementia Care

Elements of positive relationships

- Trust
- Respect
- Mutuality
- Honesty
- Open communication
- Adaptability
- Perceptiveness

Relationships in dementia care

- Why is it important to build relationships in dementia care?
- What is a therapeutic alliance and how do you begin developing one?

Therapeutic Alliance

A strong therapeutic alliance is a way in, helping an individual feel safe, trusted, and comfortable.

What can get in the way?

Empathy

A key aspect of building positive relationships in dementia care relies on care partners' ability to exhibit empathy

- Place yourself in the shoes of the individuals with dementia with whom you work
- Gain understanding to what the family is experiencing

Strengths Based Perspective

- Focusing on capabilities is essential
- Stay present, be where the client is at
- Include the individual as an integral part to the care team

Being a True Care Partner

- Acknowledging that the individual living with the illness is the expert
- Be curious
- Listen
- Work as a team
- Pay attention

UNDERSTANDING DEMENTIA

Module 2

15 minute break

FACILITATING MEANINGFUL LIVING

Module 3

Learning Objectives

- Support individuals in living meaningful lives
- Promote health and wellness throughout the disease
- Provide individuals with choice
- Integrate palliative care into daily practice

Promoting Health & Wellness

- Engage someone in a way that supports their goals
- Provide opportunity for fun and self-expression
- Build meaningful relationships
- Be mindful of needed adaptations
- Stay active

Holistic Health

To best promote holistic health, as a dementia care partner, it is important for us to acknowledge the array of human needs we all have:

- Physical
- Mental
- Social
- Emotional
- Sexual
- Spiritual

Physical Health

- “Use it or lose it”
- Stay active
- Help to maintain abilities
- Move!!
- You are what you eat
- Maintain healthy sleep habits

Mental Health

- Educate yourselves, care partners, families, and individuals living with dementia
- Comfort is important – create space to share concerns
- No need to dwell
- Individuals with dementia experience many losses

Social Health

- Know a person's comfort
- Facilitate social interactions
- Create social structure and provide assistance

Socialization increases cognitive stimulation, allows individuals to connect with one another, and highlights capabilities

Emotional Health

Living with Dementia, each day can be exhausting, and stressful

- Assist in decreasing the stress
- Provide a sense of community
- Ensure appropriate treatment is provided as needed

Sexual Health

With age, sexual desires and needs, as well as sexual identities, still exist. For individuals living with dementia, it is important to consider:

- Capacity for consent
- Stay attentive to decisions being made
- Maintain open communications with care team

Spiritual Health

- Allows opportunity for individuals to express themselves
- Influences overall health
- Important to maintain faith traditions
- Utilize pastoral care as needed or desired

Assisting with Meaningful Living

- Be flexible and creative
- Find the good
- Know what brings joy
- Maintain known pleasurable activities
- Ensure the individual can make a contribution

Don't forget to have fun!!

Alleviating Pain

- Physical, emotional, and spiritual pain
- Pain often untreated because its not communicated
- Chronic pain significantly impact quality of life
- Emotional pain can include crying, irritability, withdrawn, not eating, increased resistance, & fear

What can you do...

- Know the baseline
- Lookout for changes
- Be a detective
- Speak to medical providers
- Don't wait until pain gets out of control
- Include the individual living with dementia in pain assessment

Palliative Care

- Pain and symptom relief
- Spiritual and psychosocial support
- Provided from diagnosis through the end of life and bereavement

Palliative care is appropriate at any age and any stage during a serious illness, and it can be provided alongside curative treatment

Advanced Care Planning

Advance care planning is the process of thinking about, talking about, and planning for future health care and end of life care with family and health care professionals.

It involves making decisions about the care you want to receive and don't want to receive, as well as who will make decisions for you, if you become unable to speak or make decisions for yourself.

EFFECTIVE COMMUNICATION

Module 4

FACILITATING PERSONAL CARE

Module 5

Learning Objectives

Supporting individuals with dementia in achieving holistic health includes being responsive to personal care needs. In this module, we will explore:

- The range of emotions individuals may experience when being assisted with personal care
- How to promote dignity, choice, and maximizing a person's abilities
- Issues that may arise during personal care

Common Personal Care Tasks

- Bathing & Showering
- Eating
- Dressing
- Using the restroom
- Mobility
- Grooming
- Managing finances
- Cooking
- Grocery shopping

Put yourself in their shoes...

Imagine you wake up one morning and you walk into the bathroom...

- Disorienting, stressful, day in and day out
- Gain understanding around this experience
- Increase empathy, patience, communication, & assistance

Be Flexible

- How you do tasks
- When you do tasks
- Equipment you use
- How much help you provide
- Sequencing

Each person is unique, what works for one may not work for another. People are people first and have dementia second.

Swallowing

- Can be life threatening
- Nerve endings impaired as disease progresses
- Stay aware and seek support
- Increased risks for aspiration pneumonia

Incontinence

- Difficulty using commode properly
- Challenge in recognizing the sensation/urge

What you can do...

- Maintain dignity and respect
- Keep the individual dry and clean
- Ensure privacy, reduce exposure

Medication

- Reduced insight into why medication is needed
- Don't like side effect
- Bitter taste
- Not pill takers

As care partners:

- Important to track when meds are taken
- Organize the medication
- Understand likes and dislikes

PROMOTING SAFETY AND SECURITY

Module 6

Learning Objectives

- How to promote safety and security
- Reducing falls risk
- Minimizing use of restraints
- Understanding abuse
- Understanding substance misuse, clinical depression, and suicide

Feeling Safe and Secure

It is imperative to assist an individual living with dementia in feeling safe and secure. This can include:

- Personalize their space
- Be aware of what is available, how individuals can access things that could be dangerous
- Reduce confusion and disorientation as much as possible

Fall Risk Factors

- History of falls
- Age related changes in mobility, flexibility, reflexes, vision, and depth perception
- Problems with spatial orientation, confusion, or memory loss
- Medication interactions
- Lack of awareness

Understanding and Preventing Abuse

- Threat to individual health and well being
- Know family dynamics
- Be aware of changes
- Be aware of your burn out, frustration, and decision making
- Educate and train health care professionals and care partners

Impacts of Restraints

- Muscle loss
- Incontinence
- Increase fragility and mobility
- Bed sores
- Pressure ulcers
- Increase stress
- Withdrawn & isolated
- Depression

Substance Misuse

- Difficult to judge
- Alcohol increases risk of head injury, effects the brain
- Difficulty managing pain and other medical issues
- Increased falls
- Exacerbates dementia symptoms
- Medication management & interaction

Depression

25% of people with dementia have symptoms of depression

- Higher risk if isolated and with limited support
- Depression is a major risk factor for suicide in older adults, alcohol can accelerate this
- Keep an open conversation with care team and specialists

FACILITATING CARE TRANSITIONS

Module 7

Learning objectives

- Types of care transitions
- Impact on health and quality of life
- Strategies and barriers to facilitating care transitions
- Providing support following care transitions

Facilitating Care Transitions

- Communication
- Make sure you alert the care team about the individual, their abilities and preferences
- Establish routine and familiarity in environment
- Avoid sleep disruptions, unfamiliar foods
- Be welcoming

Let's Discuss...

- What are some things you can think of that can impact an individual during care transitions?
- What are benefits to care transitions?

SUPPORT THROUGH END OF LIFE

Module 8

Learning Objectives

As care partners, it's important for us to acknowledge that the dying process and death is an inevitable part of the dementia illness trajectory. It is important to think about the following:

- Ways individuals can perceive and experience death and dying
- What the end of life can be like for individuals with dementia
- Strategies for supporting individuals, their families, and yourself

End of Life

- Many emotions involved – confusion, anger, sadness
- Important for care givers to take a look at their own belief systems – influences decision making
- Be sure to meet goals of the individual
- Trajectory is a very gradual, continual grieving process
- Meet people where they are, goal is to maintain quality of life
- Be culturally competent
- Respect is key

Care Partner Grief

- Acknowledge relationship
- Seek support
- Strengthen self for next individual
- Very close, part of the person's life

What to Expect

At end of life, individuals living with dementia may exhibit difficulty with chewing, swallowing, walking, talking, and tending to most basic needs.

- Listen to family, this is not our decision to make as care givers, but ensure that you have a thorough and thoughtful discussion
- Let the family know the sequence of what is about to happen

Hospice

Hospice care is a type of care and a philosophy of care that focuses on alleviating the pain and symptoms of individuals who have a terminal illness, as well supporting their emotional and spiritual needs.

Grief Process

As a care giver working with a family through the grief process, it is important to remember the following:

- Stages of grief
- Family dynamics
- Listen
- Create space for person to share their feelings
- Educate around next steps

PROFESSIONAL SELF CARE

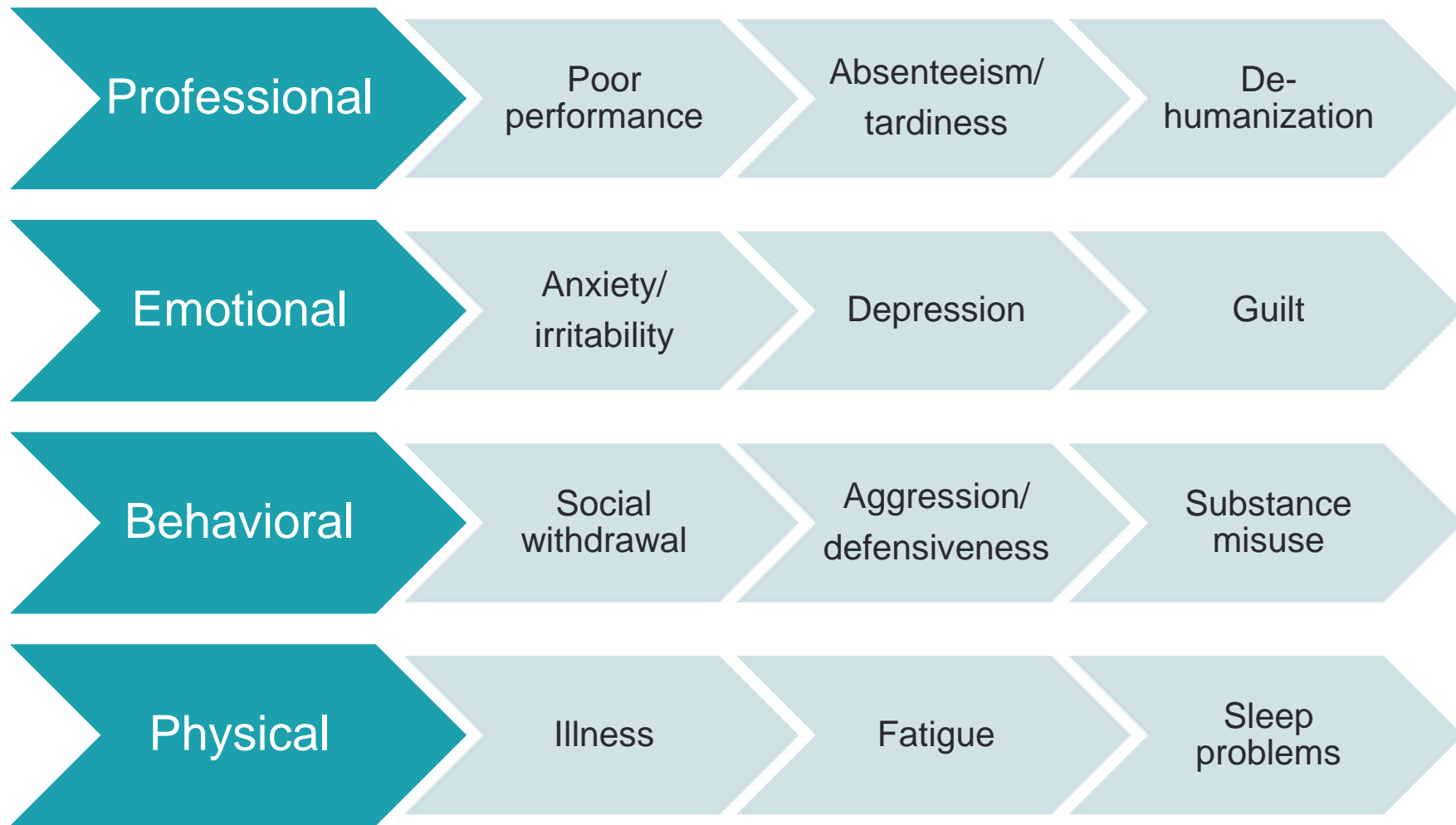
Module 9

Learning Objectives

It is important to discuss challenges that you may experience as a dementia care partner and opportunities that this work presents, both professionally and personally. We will focus on the following:

- Importance of self-care
- Common signs of burnout and compassion fatigue
- How to develop strategies to prevent and cope with these challenges

Burnout and Compassion Fatigue: Warning Signs



**What are some of the challenges
you see in this work?**

Self Care Techniques

Recharge your batteries to best help others

- Be proactive
- Get regular sleep
- Make time for yourself
- Know your limits
- Seek support
- Leave work at work

Being a Care Partner

- Educate yourself
- Be with the person
- Learn from the person
- Not just doing things for or to the individual, but with them

AFA Resources and Support

- AFA's National Toll-free Helpline (phone, email, Skype, chat)
- Dementia Care Professionals of America- training and certification
- Educating America 15th Anniversary Tour
- National Memory Screening Program
- Excellence in Care Dementia Care Program of Distinction
- Care Connection monthly webinar
- Support Groups
- AFA Care Quarterly magazine

AFA unites 2,600+ member organizations nationwide that provide direct resources and care

www.alzfdn.org

866-232-8484



Thank you!

Reach out with questions or for more information:

Alzheimer's Foundation of America

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