Module 9 Supporting Families and Caring for Ourselves



alzheimer's 95 association®

How Do Families React to a Terminal Diagnosis?



What You'll Learn

- Identify two emotions that families often feel
- Discuss a common family concern
- Describe two ways to better partner with families
- Identify two ways to prevent burnout and compassion fatigue

How Alzheimer's Disease Affects the Family

- Struggle to understand and accept
 - Stigma
 - Denial
- Grief and loss:
 - "The long goodbye"
 - Changing roles
 - Loss of control
- Guilt, shame and anger
- Physical and emotional exhaustion
- Family dynamics



Common Family Concerns



Trusting others to provide care:

- Lack of trust with outside care providers
- Prior negative experience
- Worry about voicing concerns

Build Trust with Families

- Frequent contact
- Influence
- Empathy and concern
- Reassurance
- Engagement and support



What We Can Do



- Provide updates
- Involve the family
- Offer support
- Be consistent
- Capable team

Working with Families Who are Upset or Angry

- Remain calm and professional
- Acknowledge a family's concerns and emotions
 - "I'm sorry..." always helps. It doesn't mean it was your fault.
- Don't blame the person living with dementia
- Remember:
 - If you can't answer a question, let them know & connect them to someone who can help
 - If they are still upset, notify your Supervisor

Burnout and Compassion Fatigue

Burnout

- tends to develop over time
- emotional and physical exhaustion, feelings of negativity and indifference and feeling like you're not getting the job done.

Compassion Fatigue

- typically comes on suddenly
- caused by empathy and is the result of providing continuous care to individuals who are experiencing serious illness.

What Are the Stresses?

- Stress related to Alzheimer's or dementia
 - The disease gets worse and is terminal
 - Families are grieving, upset or angry
 - It is difficult to provide care when person doesn't realize they need assistance
- Stress related to job, family life and our own health
 - So much to do and not enough time
 - Juggling work, family and health can be hard

Taking Care of Yourself

To take care of ourselves we can:

- Ask for help from your supervisor or coworker
- Help others—they'll help us
- Seek out education
- Take a deep breath, take a moment and count to ten
- Take time for the important people in your life
- Take time for yourself

Preventing Burnout and Compassion Fatigue



What Did We Talk About Today?

Let's Review...

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Let's See What You've Learned

Test 9: Understanding and Working with Families