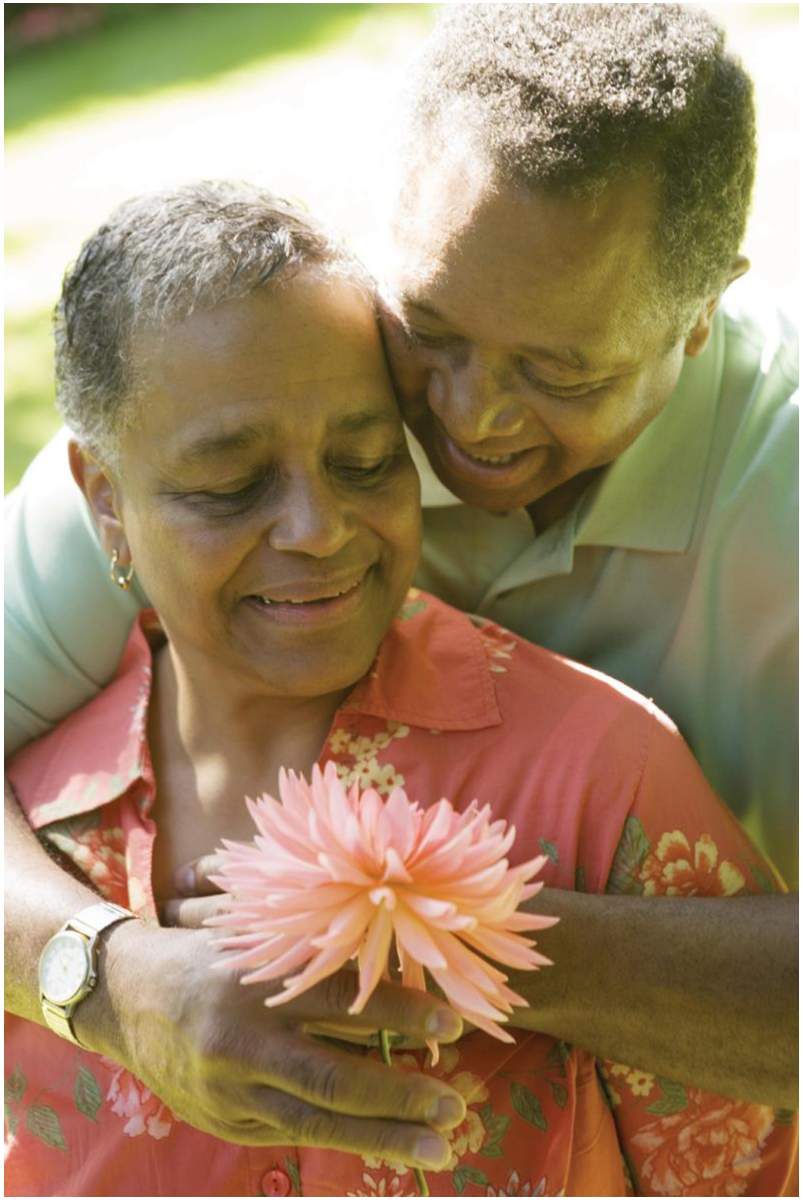
Care Consultation for People With Early Stage Dementia:

An Innovative Model



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Learning Objectives

- Identify special issues & challenges of PWESD
- Look at the care consultation process
- Explore building a relationship with PWESD
- Identify the role of the family in this model
- Screening, Intake, and Evaluation
- Other logistics

Increased Focus on the Needs of People with Early Dementia

- –Early diagnosis
- –Research
- –Medications
- –Early Stage Programs

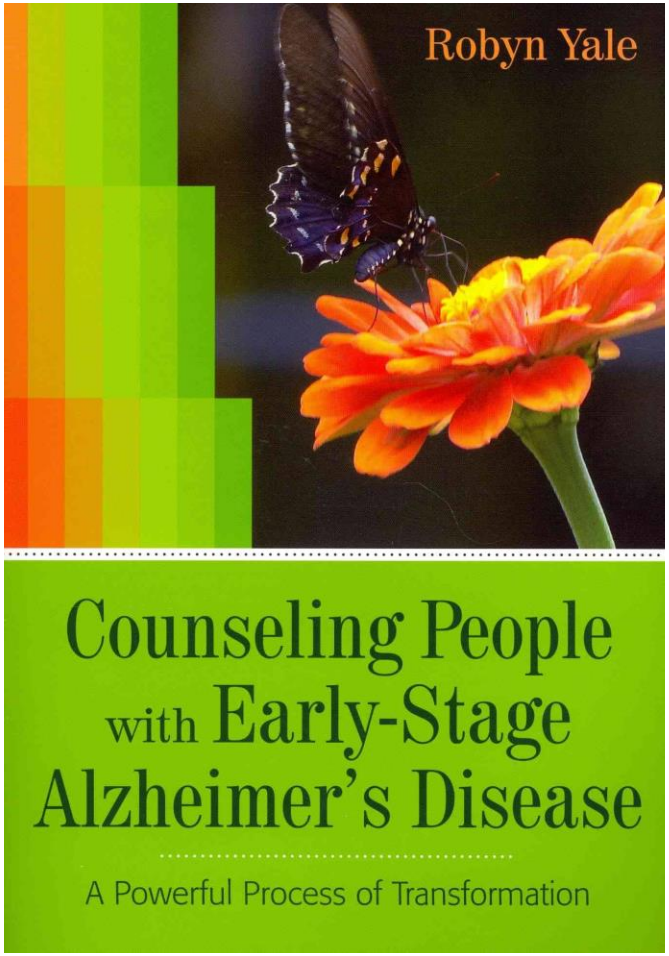
Town Hall Meetings

- PWESD expressed their concerns and interests:
  - Assistance with coping
  - A sense of purpose and meaning
  - Empowerment, rather than feeling marginalized
  - Driving
  - Stigma
  - Practical Issues: loss of employment, benefits; social security disability

Administration on Aging Grant

- Our partners in developing the model
  - AoA (now the ACL, Administration for Community Living)
  - Robyn Yale, source of this material
  - AAA's
  - DAS

Book by Robyn Yale



Robyn Yale

Counseling People with Early-Stage Alzheimer's Disease

A Powerful Process of Transformation

Paving New Ground

- Care Consultation for persons with Early Stage Dementia
  - Requires a “paradigm shift” in our thinking as professionals who work with people with dementia

A Refresher: Early Stage vs. Middle/Late Stage Dementia

- Terminology
  - Early Stage—a person of any age who has only mild impairment
  - Early Onset (Younger Onset)—a person whose symptoms of dementia began before age 65, regardless of current age
  - Newly diagnosed—refers only to recency of diagnosis, not level of impairment

Why Are We Doing This? The Need

"After I got the diagnosis of Alzheimer's from my doctor, I felt lost. I didn't feel like I could really talk to my family and friends about it. Some of them were too upset, some I think just didn't want to face it. It was a very lonely time for me."

Why Are We Doing This?

- Traditional services have been focused more on the care partner than the PWESD
- Physicians often do not refer patients to services after diagnosis
- Although progress has been made, the prevailing belief has been that people with dementia are not able to benefit from one-on-one care consultation

Differences and Similarities

- How working with PWESD is different from "traditional" care consultation
  - No cure, which changes expectations of improvement
  - Needs of the person are different
  - Often have challenges in communication
  - Memory loss is involved
  - Structure becomes more important, for PWESD and the professional
  - There are also similarities

Emphasizing the Positive

- While we address issues of grief, anger, sadness, and uncertainty, our focus is on positivity:
  - Abilities vs. Impairments
  - Finding new—or renewed—purpose and meaning
  - Building new relationships
  - Helping people go on with life

Special Issues and Challenges of People with Early Stage Dementia

- Alzheimer's affects each person differently, but there are issues and challenges common to those in early stages.
- Issues we'll discuss have many dimensions, are presented in random order, and are not meant to represent all the issues that may arise.
- As we discuss issues, we'll see where each fits into the three domains of the framework.

Special Issues and Challenges: Family Issues and Relationships

- The PWESD’s role in the family may be affected by their symptoms or by the diagnosis itself. For example, he/she may have been the “breadwinner,” but this may be changing.
- Person may be feeling disempowered or unsure of new roles and changes in identity .
- Families deal with these issues very differently – may or may not be open in discussing changes.

Special Issues & Challenges:

Memory Loss & Other Cognitive Impairments

- The PWESD may need education around practical strategies and assistive techniques (memory aids, calendars, etc.)
- The disease may also affect people’s judgment, decision-making, and ability to complete tasks. People can learn to manage their symptoms and their stress, which may improve functioning; or they can adjust/adapt to the difficulties.
- Functioning is optimized when people practice good self-care and pay attention to their physical, brain, and mental health.

Special Issues & Challenges: Planning

- While the person is still in Early Stage, it is important to deal with legal, financial, and healthcare issues
- If the person has lost a job, there are matters of both loss of income and of insurance; and possibly applying for Social Security Disability.
- If the person has not executed advance directives, powers of attorney, or a will, they will need to do so.
- These practical matters, especially in the face of dealing with the emotional impact of the diagnosis, can seem overwhelming.

Special Issues & Challenges: Psychological Impact

- Emotional Adjustment
  - In past, focus has been on practical issues like advance planning and using memory aids, *with little attention to the emotional needs of coping.*
  - People often experience a myriad of emotions, and don’t know how to cope with them. This model helps the person identify feelings and work through them.

Special Issues & Challenges: Psychological Impact

- Acceptance of Condition
  - The PWESD may have questions about how to recognize symptoms of dementia, whether it might get better, or how fast it will get worse.
  - People with AD have varying degrees of awareness about the severity of their cognitive impairment.
- The PWESD may also have feelings of fear or frustration around their memory loss
- May be struggling to balance autonomy with the need to sometimes ask for help

Special Issues & Challenges: Psychological Impact

- May feel adrift because no strategies for coping have been offered
- Often dealing with monumental issues of loss of independence, identity, and self; and, eventually, of mortality
- May be experiencing feelings around the loss of what the person thought his/her life would be like, over their loss of abilities, and many other issues

Special Issues & Challenges: Denial

- Denial is complicated and sensitive.
- Individuals do not always accept the diagnosis or admit difficulties.
- May be part of a natural defense protecting person emotionally from the full impact of the reality of the diagnosis
- Or, the person’s level of impairment may make them unable to understand this reality.
  - Anosognosia

Special Issues & Challenges: Denial

- Denial is often rooted in one's sense of self:
  - Who am I ?
  - Who am I going to be?

Each person works through the difficult process of acceptance differently.

Special Issues & Challenges: Stereotyping & Stigma

- In the general public, there is a lack of understanding about dementia
  - Some see dementia as a form of mental illness, something to be ashamed of and concealed
  - Many see the person as incapable of former activities, once the diagnosis is made.
- People with early dementia often say they feel they are treated differently because of their diagnosis—marginalized, condescended to, or avoided

Special Issues & Challenges: Interruption of Work or Career

- If the person has lost a job due to his or her symptoms, there may be a profound loss of identity, particularly for those who felt the job strongly defined them.
- Changes in daily routine, lifestyle, perceived status, and financial resources can be extremely difficult.
- If still working, the person may have a dilemma around whether to tell the employer about the diagnosis.

Special Issues & Challenges: Other Financial Issues

- The loss of a job due to symptoms of AD can be devastating.
- For those no longer working, there may be the issue of whether he/she can continue to handle household finances.
- And, there may be serious concerns about the cost of care, if and when that becomes necessary.

Special Issues & Challenges: Identity & Self Esteem

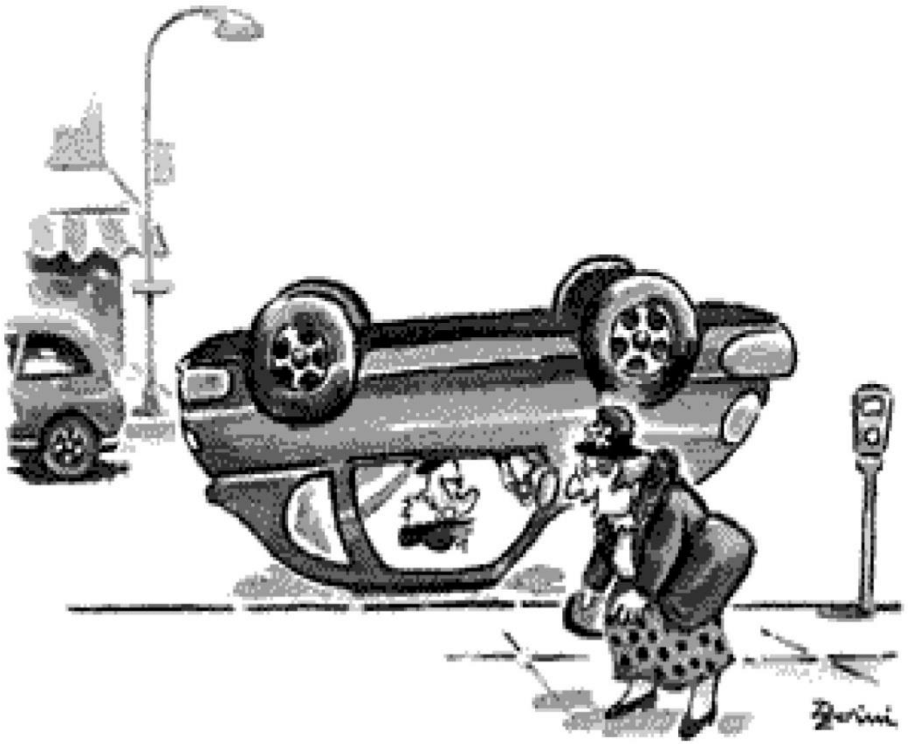
- The person may feel his/her sense of self has been overshadowed by becoming “someone with Alzheimer’s.”
- Person may also have concerns about how the progression of memory loss will affect a sense of who he/she is.
- Self-esteem may be affected by loss of abilities, the need to ask others for assistance, loss of independence and control; being stigmatized or marginalized

Special Issues & Challenges: Changes in Other Activities

- Memory loss often necessitates change in daily life. The PWESD may now need assistance with managing finances, remembering appointments or medications, or with transportation
- Longstanding activities may be affected—for example, a person who's been an avid reader may now have trouble focusing on what they're reading, or remembering the storyline of a novel
- Finding ways to enjoy old activities in new ways can be of great help—for example, getting someone to read to the person

Special Issues and Challenges: Safety Issues Including Driving

- Even in early stage, safety issues may need to be addressed. For example, the person may forget a pot on the stove or that they've already taken medications
- One of the most common safety-related issues, and one which is often the most difficult and emotionally charged, is driving.
  - Some PWESD may be safe to drive, but there is the possibility of getting lost, even in familiar places
  - Decision about when to stop driving more difficult when denial is present
  - Driving assessments can help determine when to stop



"Marie, are you still driving?"

Special Issues and Challenges: Communication

- The PWESD may have difficulty with speech, language, and communication, particularly in the area of expressive communication
- Also affected may be word-finding, attention span, focus, keeping a train of thought, and the ability to accurately convey what the person means to say
- People with vascular dementia (and others who have had CVAs) may also have physical difficulties with speech
- Loss of ability to communicate can be extremely frustrating. Some people withdraw from conversation for this reason.

Special Issues and Challenges: Existential Issues

- AD is a terminal diagnosis, although some people are more aware of this fact than others.
- There is usually some understanding that the person will continue to lose his/her memory, forget loved ones, and perhaps their own identities
- PWESD may have questions around:
  - “who am I now, and who will I become”?
  - “What will come after ?”
  - “How do I talk to others about these issues?”

Special Issues and Challenges: Summary

- Each person experiences the journey differently
- This wide range of issues, and the accompanying feelings, do not usually present all at once

Areas of Focus in Care Consultation

- Emotional Adjustment
- Practical Coping Strategies
- Lifestyle Issues

A FRAMEWORK FOR COPING WITH EARLY DEMENTIA

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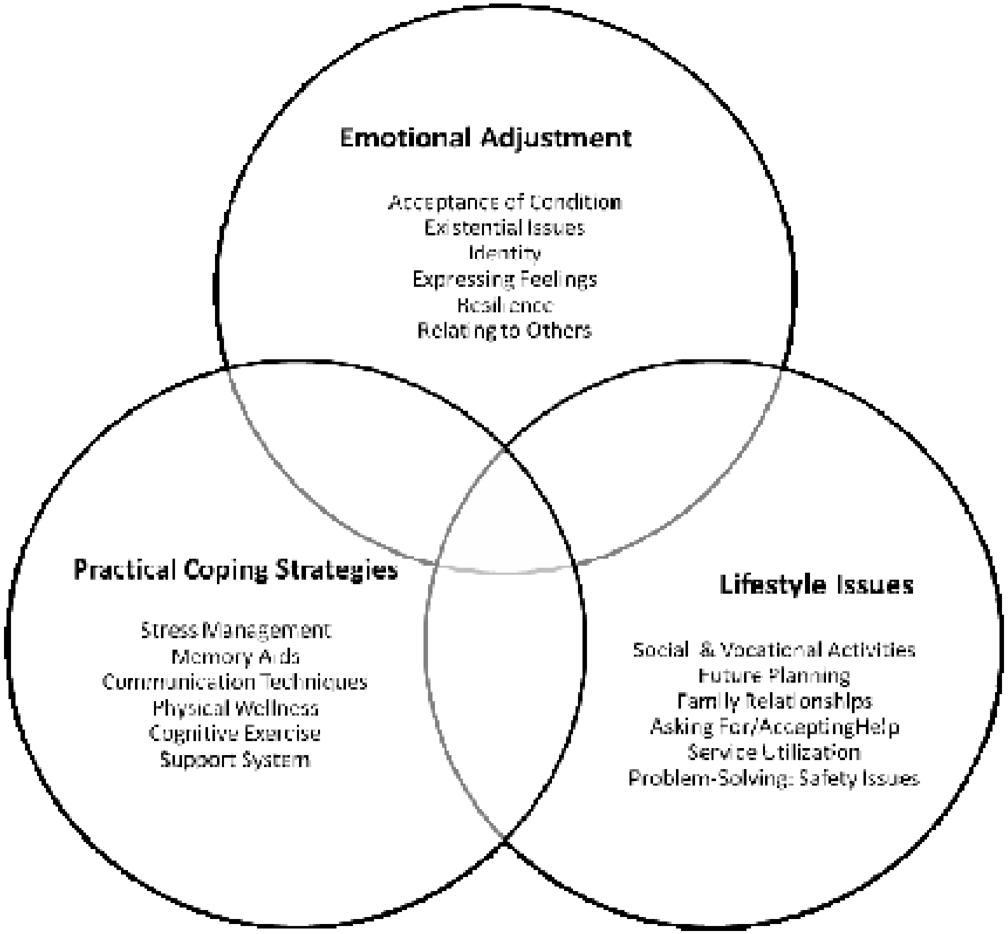


Emotional Adjustment

Acceptance of Condition
Existential Issues
Identity
Expressing Feelings
Resilience
Relating to Others

Practical Coping Strategies

Stress Management
Memory Aids
Communication Techniques
Physical Wellness
Cognitive Exercise
Support System

Lifestyle Issues

Social & Vocational Activities
Future Planning
Family Relationships
Asking For/Accepting Help
Service Utilization
Problem-Solving: Safety Issues

Areas of Focus in Care Consultation

- The person with early dementia may be experiencing a myriad of **emotions.**
- The professional helps the person identify and express their feelings about all the issues and challenges they are facing.
- It is helpful for the professional to know where the person is in his or her understanding and acceptance of the illness, because this will color their emotional responses.

Interventions

- Acceptance of Condition—understanding the disease; acknowledgement of condition; “coming to terms”
- Existential Issues—meaning/purpose in life; spirituality
- Identity—sense of self in past/present/futures; life review; self-esteem
- Expressing feelings—expressing grief and loss; fear, worry; relief?
- Resilience—Strengths, successes; attitude change; wellness; letting go
- Relating to others—reactions; stigma; respect; autonomy; expectations; educating others

Areas of Focus

- With memory loss/other cognitive changes, many **practical matters** of daily life are affected.
- Person may not have had any guidance on how to use tools like memory aids, to cope. May need help in finding ways to *simplify* things.
- Counselor helps the person find the best tools for his/her situation. Also addresses *feelings* challenges are causing.

Interventions

- Stress Management—simplifying (slowing down, having a routine); relaxation (rest, breathing); humor; balance
- Memory Aids—notes; reminders; tips for where to put things; taking a break
- Communication techniques—e.g. word substitution; taking more time
- Physical Exercise—movement; self-care
- Cognitive Exercise
- Support System

Areas of Focus

- **Lifestyle changes** may include
  - Changes in family roles
  - no longer being able to drive, work, manage finances, or pursue old activities
- Counselor assists person in identifying these and finding ways to adjust, both practically and emotionally.
- Finding new ways to accomplish tasks and activities successfully may help empower the person, improve their self-esteem, or boost their morale.

Interventions

- – Social, vocational, and recreational activities
- – Future planning—powers of attorney, etc.
- – Family relationships—communication; role changes
- – Asking for/accepting help
- – Problem solving—driving; managing finances

The Process

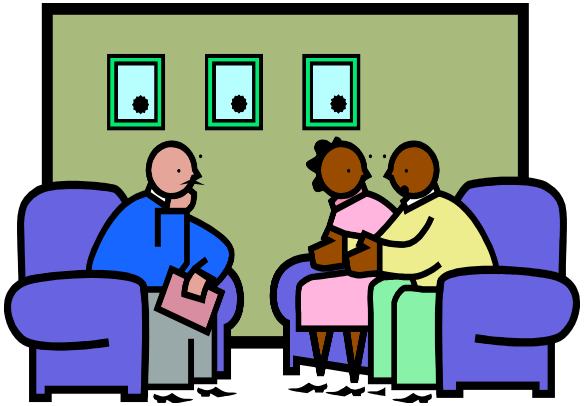
- Building trust
- Determining the PWESD’s understanding, acknowledgement, and acceptance of his/her diagnosis
- Determining concerns
- Forming goals
- Working on coping
- Evaluating Progress

Building a Relationship

- Relationship matters more than theory or technique
- Relationship is the key to a successful working alliance
- Relationship comes from trust, warmth, encouragement
- Dealing appropriately with denial

Professional's Qualities and Credentials

- Listening
- Acceptance
- Empathic understanding



- Care consultation experience
- Knowledge of dementia

Process Issues/Challenges

- Memory Loss
- Communication impairments
- Emotional reactions
- Fluctuating capacity
- Transference

Professional Responsibilities

- Be aware of issues of:
  - Countertransference
  - Depression and suicidal ideation/backup for serious psychiatric issues
  - Cultural sensitivity
  - Knowledge of the disease and resources

Setting and Evaluating Goals

- Using Pre and Post forms
- Measured by “Early Dementia Counseling Goals” tool—Robyn Yale, LCSW

Role of the Family

- Diagnosis affects not just the PWESD, but his/her loved ones as well.
- Although this model focuses primarily on the PWESD, families/care partners will be involved. THE WAY WE PRESENT THIS TO THE PERSON AND FAMILY IS VERY IMPORTANT.
- Counselors are encouraged to give the PWESD the choice of bringing the care partner into the last few minutes of the session (especially important when the person is being sent home with memory aids or techniques).
- Information about families of people with dementia is readily available elsewhere, but things ARE different for families of PWESD; at this point it’s not really a matter of providing care; other issues are at the forefront

Role of the Family: Potential Family Issues

- Denial/level of acceptance
- Marginalization
- Stigma—wanting to keep the diagnosis secret
- Driving, “taking the keys”
- Not knowing when to step in with assistance or supervision, or intervene with matters like finances
- Providing too much assistance—”smothering”
- Adjusting to new roles within the family

Role of the Family: Potential Family Issues cont.

- Changes in family dynamics
- Issues of sexuality
- Issues around POAs, advance directives
- Some family not wanting to accept/assist, causing dissention
- Changes in communication—not wanting to talk about the situation, fearful of upsetting the person or the family member
- Unresolved interpersonal issues and dynamics

Role of the Family: Confidentiality

- Standards of confidentiality apply as much to this population as any other
- Exceptions: Matters of safety, emergencies, other issues which the person gives permission to share with others
  - Explain that everything you discuss in counseling will be confidential with these exceptions, and be explicit about what the exceptions might be
- Make clear the purpose of contact with the family/care partner

Screening

- Is the person appropriate for the counseling program?
    - Has a diagnosis of dementia been made, and has the person been told the diagnosis?
    - Does the person at least occasionally acknowledge that they have memory loss or other cognitive impairment?
    - Is the person's dementia early enough to clearly understand and participate in the process?
    - Is the person willing to discuss feelings and concerns—does he/she want to be in counseling?
    - Is there a family member willing and able to be involved?

Screening and Intake cont.

- When is a person not appropriate?
  - No diagnosis made; person hasn’t been told
  - Person does not at any time acknowledge diagnosis
  - Dementia is too advanced for the person to clearly understand and participate in the process
  - Person unwilling/uninterested in being in counseling
  - Family unavailable or resistant
  - Other issues need to be addressed first:
    - Safety Issues
    - Untreated or insufficiently treated mental illness
    - Logistical issues
- Contingency plan

Logistics

- 45 minutes to one hour per session
- Best time for sessions is late morning or early afternoon
- Keep records as you ordinarily would, including information about:
  - Highlights of each session
  - Themes discussed
  - Anything pertinent about the relationship between you and the PWESD
  - Progress toward goals

Case Study #1

- A man with early dementia has had to quit his job due to his cognitive impairments, and has just been told by his doctor that he should not drive anymore. His wife is still working.

Case Study #2

- A woman has been diagnosed with Alzheimer’s. Her family has rallied together to do things for her, and she is feeling smothered. The family feels that she does not appreciate the help they are trying to give.

Questions?

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