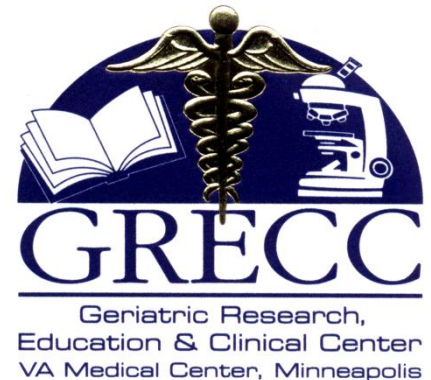


Dementia Friendly Healthcare and Community
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Training Providers for Caregiver Education

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Disclosure Information

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A. I have no financial relationships to disclose.

B. I will not discuss off label use and/or investigational use in my presentation.

Objectives for Providers

When educating patients and caregivers about dementia/major neurocognitive disorder:

- Understand the importance of sharing a diagnosis.
- Empower the patient and family to manage the disease.
- Utilize the care team.

GRECCs

- Geriatric Research, Education and Clinical Centers
 - VHA centers of excellence focused on aging
 - Established by Congress in 1975
 - Minneapolis GRECC founded in 1976
 - Three main missions:
 - Build new knowledge in geriatric care through research
 - Improve health care for older Veterans by developing innovative models of clinical care
 - Provide training and education on best practices for students and staff
- The Minneapolis GRECC historically has focused on aging brain.

Sharing the diagnosis of dementia/major NCD

- The Family Meeting (FM)
 - With chronic, progressive, terminal disease that impacts the whole family, have the FM early.
 - Interventions for dementia are or will be essential.
 - Finances, health care, transportation, appointments, supervision/abode/LTC
 - QOL – Finding meaningful and enjoyable activities while alleviating stress that comes with responsibilities
 - The FM is often your most important intervention.

Sharing the diagnosis of dementia/major NCD

- If you won't know diagnosis until tests are complete, tell patient/caregiver you will review results with them AND family.
- If you know the diagnosis, e.g., Alzheimer's disease, tell patient/caregiver to share with family before the family meeting.
- In either case, recommend a family meeting:
 - Do not make the patient/caregiver responsible for sharing.
 - You/patient/caregiver cannot anticipate all questions.
 - It is not their job to answer questions. Let family ask you.
 - Patient/caregiver decides whom to invite to the family meeting.
 - Encourage being inclusive.

Sharing the diagnosis of dementia/major NCD

- Just because it's in the medical record, don't assume the diagnosis of dementia has been shared or discussed.
- If you recognize/diagnose dementia, add to Problem List.
- Estimate severity of dementia – for family and providers.
 - Mild – needs assist with instrumental ADLs
 - E.g., finances, meds, transportation, shopping, meals
 - Impairment at work is also significant, may warrant major NCD label.
 - Moderate – needs assist with basic ADLs (includes reminders)
 - Severe – dependent in all ADLs

Sharing the diagnosis

- Your goal in the family meeting:
 - Get the family on the same page. Be aware:
 - You can't anticipate the questions.
 - You may not know the family dynamics.
 - There may be hidden agendas, e.g., money, new obligations, old scores.
 - It's still important that everyone hears the same message.
 - It's hard to move forward if family doesn't agree on needs.
- Your goal is **NOT** to convince the patient they are impaired.
 - Family should not try to do this either.

Sharing the diagnosis

- Always have the patient present
 - Time is spent counseling.
 - The patient deserves to be there.
 - If they are intact enough to understand, they should be there.
 - If they are too impaired, being there will not hurt.
 - You may sabotage your relationship with the patient if they feel you are going behind their back.
 - Even forgetful patients may recognize and remember who they dislike.
 - Always ask the patient's permission, treat them with respect.
 - Model behavior for family.

Utilize the Care Team

- Introductions.
 - Establish your credentials.
 - Learn who the family members are.
- Use a team if possible, e.g., Physician/APP, Nurse, SW, Psychologist/Family Therapist, OT, Pharmacist; Students:
 - Force in numbers—It's not just you. "We" think you have Alzheimer's; BUT...
 - Only the physician/APP can give the diagnosis.
 - Physician/APP can't be expected to know all resources.
 - Physician/APP presence reinforces what team members say.
 - Team members may be better at recognizing family dynamics.
 - Team can address most future questions.

Sharing the diagnosis

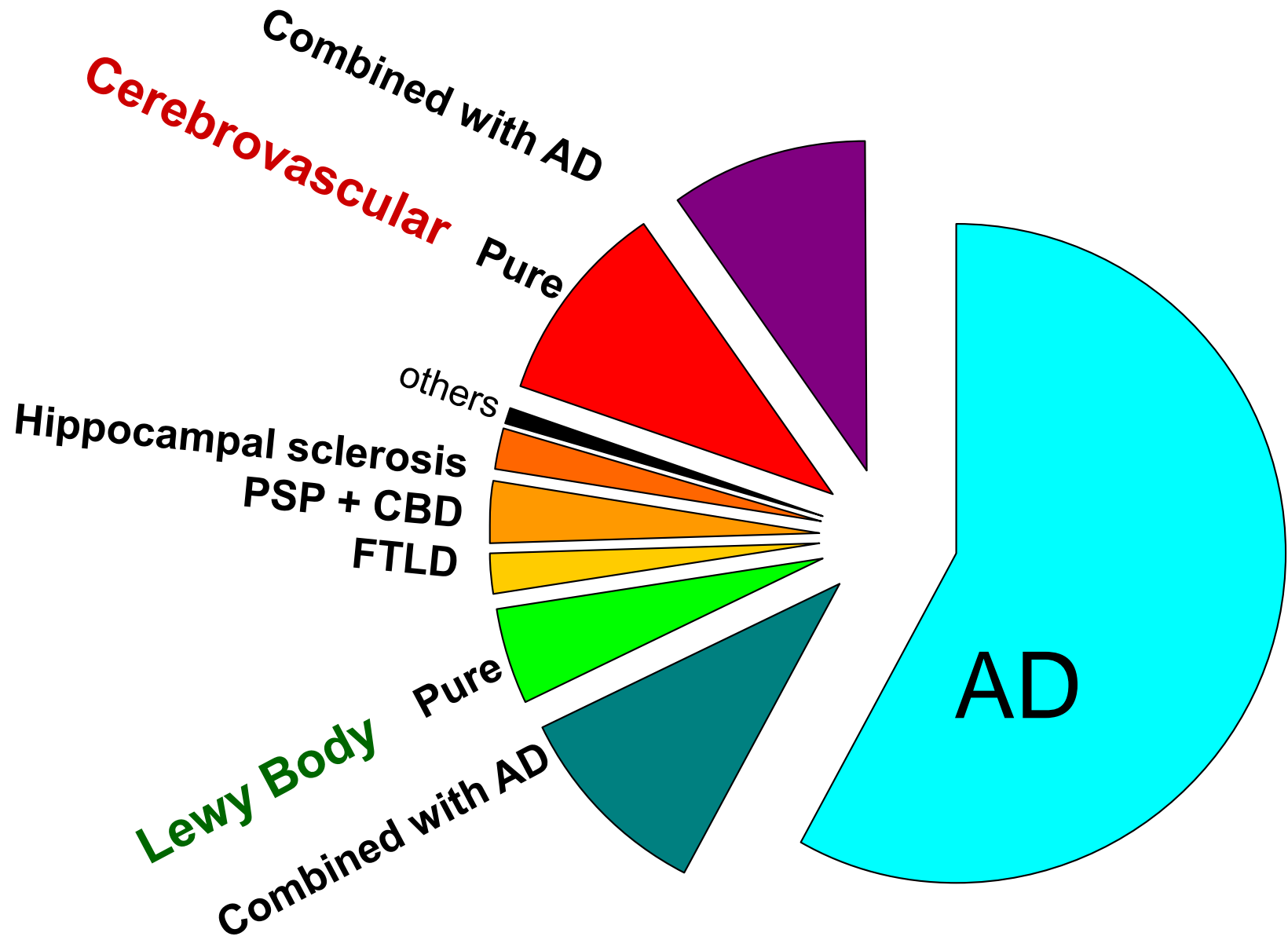
- Ask the patient permission to review the evaluation.
 - Review onset and course; any important ancillary symptoms.
 - What have others observed?
 - Often, little response.
 - Are there any particular concerns?
 - Briefly review the work-up.
 - Details aren't needed.
 - Families are often waiting for the diagnosis.

Sharing the diagnosis

- Be straightforward with the diagnosis.
 - Common question, “What’s the difference between Alzheimer’s and dementia?”
 - Avoid jargon
 - Watch out for preconceptions about “normal aging.”
 - Age is a risk factor, not a cause.
 - Just like many diseases, dementias become more common with age.
- A primer on diagnosis may be helpful.
 - Dementia/NCD is a syndrome, not a specific disease
 - An acquired cognitive impairment severe enough to interfere with function
 - There are over 150 causes of dementia. We break them into major categories [etiologies]:

Etiologies of Chronic NCD (Dementia)

- Neoplastic (brain tumor) – subacute, weeks to months; other symptoms (HA, focal deficits) and signs (seizure); evident on imaging
- Toxic/metabolic – typically subacute (delirium), fluctuating, and other signs, e.g., ataxia; GI, skin, other systemic changes.
- Trauma (TBI) – abrupt onset, improving then static course; imaging
- Infectious/inflammatory – subacute; other sxs/signs
- Vascular – like trauma, sudden (stroke), improving, then static; imaging
- **Degenerative – slow onset and progression (years).**
 - **Alzheimer's the most common – apart from mentation, nervous system is normal.**
 - **Parkinson's the 2nd most common – motor symptoms are present**



Cerebrovascular Disease
Neurology practice=common
Autopsy pure VaD=3-10%

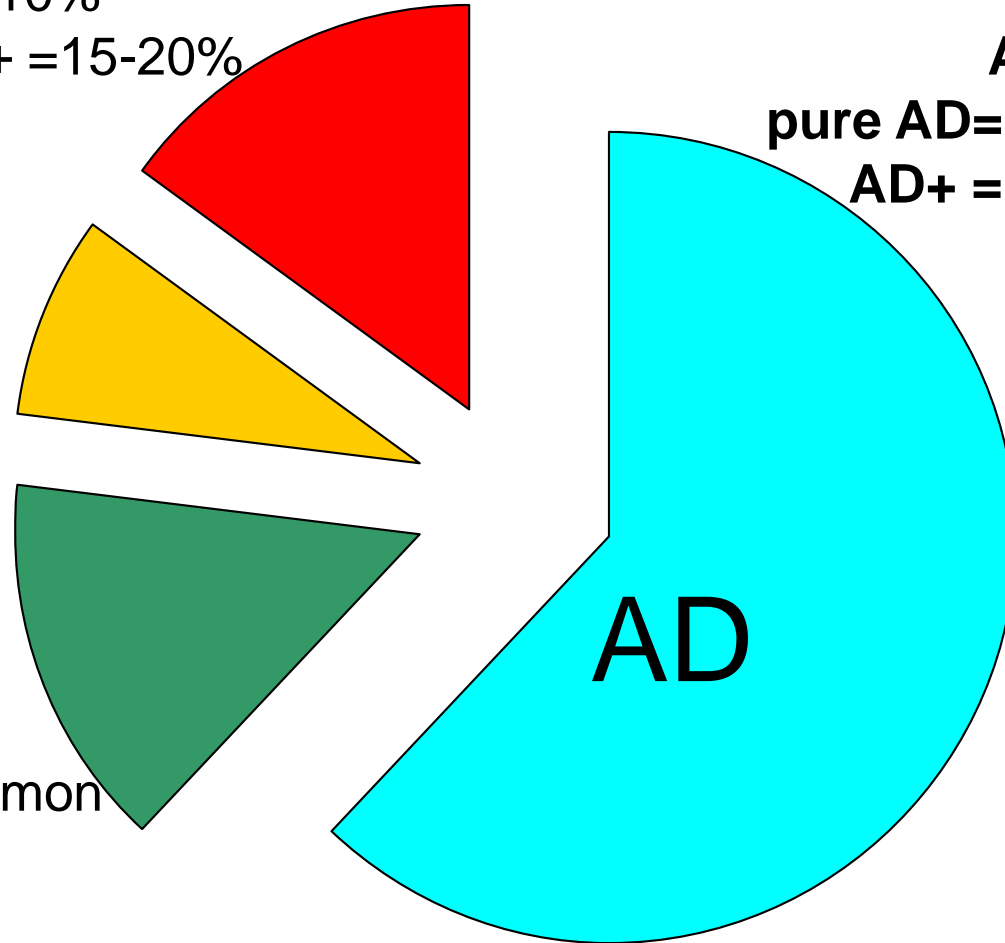
cerebrovasc+ =15-20%

Other=
7%

Lewy Body Disease
Neurology practice=common
Autopsy pure=8%
LBD+ = 26%

Epidemiological
estimate
AD = 60-80%

Autopsy
pure AD= 40-50%
AD+ = 65-80%



Vascular Cognitive Impairment

- Apart from post-stroke, e.g., aphasia, VCI is not well-defined.
 - Non-specific WM changes do not correlate well with cognitive impairment.
 - Vascular disease bad enough to cause dementia is severe vascular disease.
- Consequences of diagnosing VCI:
 - Focus is on treatment of vascular risk factors.
 - Likely NO impact on the course of dementia
 - But may give false sense of changing disease.
 - May divert attention from more important matters
 - Failure to pursue help for AD, other progressive dementias
 - “Mini-strokes” are TIAs. TIAs have nothing to do with dementia.

Sharing the diagnosis

- Try to give one primary diagnosis.
 - Avoid confusing explanations.
- Ask if family was expecting the diagnosis.
 - If unexpected, don't try to do too much.
- ***Point the patient and family in the right direction.***

Empowering the family

- You know more about dementia than patient or family, BUT...
- They know the patient better than any test can show.
- Every AD patient progresses at a different rate, but a given individual tends to progress at a constant rate.
 - Only about half of patients have significant change in bedside tests (e.g., MMSE, MoCA) over 1 yr.
- Each family is different. The patient and family must tailor interventions to suit their needs.
- ***Identify resources that may help.***

Empowering the family

- Dementia care is chronic disease management.
 - Encourage pro-active thinking; develop a 'plan B.' "What if...?"
 - To family:
 - What (worries) keeps you up at night?
 - "If you have plans you never use, so what? If you don't have a plan when you need one, that's a crisis."
 - Every family is unique. There is no cookbook.

Empowering the family

- To adult children:
 - Don't wait to be asked for help. Help is needed now.
 - *Build visits/contacts/'help' into your schedule.*
 - *"Call me if you need me," often means every call is a crisis. Caregivers hate making the call, adult children hate getting them.*
 - Develop a plan, re-assess every 6-12 mos.
 - *Dementia is slow moving. Don't second guess every day.*
 - Be able to look at parents and say, "Don't worry, we've thought of that. We've got it covered."
 - *Demented parents may be forgetful, but they still know when you're lying.*

Empowering the family

- Identify a family member familiar with patient's health care to come to every medical visit.
- Identify and divide other tasks, e.g., finances, transportation, shopping, home repairs, meals; exploring ALFs and LTC.
 - Out-of-town relatives can do a lot on-line.
- Demented patients have trouble making a plan for the day.
 - Don't recommend to the patient what they should do. Family/friends should plan an activity and invite the patient to join.

Follow-up visits

- Have a check-list of issues:
 - Management of:
 - Caregiver stress
 - Medications
 - Finances
 - Home safety
 - Meals, diet, exercise; sleep
 - Socialization [The default is to sit at home, watch TV.]

Surprising Things at Family Meetings

- Who shows up.
- Perception of impairment by family.
 - Some families clearly identify problems when testing is normal.
 - Some families are oblivious to obvious problems.
 - Recognition of cognitive impairment seems unrelated – even inversely related to – level of education/socioeconomic status.
- Your perception of onset, course, nature of sx's may change.
 - Patient/caregiver may have provided an alternate/unreliable hx.

Surprising Things at Family Meetings

- Understanding of dementia
 - Dementia is often perceived as more benign than Alzheimer's.
 - AD is sometimes assumed to be associated with violent behavior.
 - Demented Dad has “normal aging.” Mom, the same age, is not demented. “What's your point?”
 - Some people that claim to understand dementia clearly may not.
 - For e.g., they explain what you have told them about a patient's dementia to the patient, but in a less understandable way.

Surprising Things at Family Meetings

- “Good news” may not be well-received.
 - Testing that looks normal may not be reassuring.
 - *“Oh, great. Now what am I supposed to do?”*
 - Often, patients return years later with obvious sx's of dementia.
- Reactions to diagnosis
 - Often, patients are least upset and most appreciative of diagnosis.
 - Sometimes the diagnosis triggers a very upset reaction despite a caregiver and family living with the disease for years.
 - Siblings may be the most defensive, take it the worst.

Useful tips for families

- If you have plans you never use, so what? If you don't have a plan when you need one, that's a crisis.
- If you think you need help with it now, you probably needed it 6 months ago.
- Think of the worst nursing home you can imagine. They have a bed.

Final Thoughts on Family Meetings

- Some family meetings go better than you ever hoped.
- Some go worse than you ever dreamed.
 - Don't let patients leave alone.
 - Don't let families stay after the meeting without staff in attendance.
- You go into health care to make a difference.
 - Family meetings do that.

Ron Chester, 89 years of age, was stopped by the police around 2 a.m. and was asked where he was going at that time of night.



Ron replied, "I'm on my way to a lecture about alcohol abuse and the effects it has on the human body, as well as smoking and staying out late."

The officer asked, "Really? Who's giving that lecture at this time of night?"

Ron replied, "That would be my wife."