A LocAL Organization Helping LocAL Families

Fall 2019

Dementia Is Not a Diagnosis A PROPER DIAGNOSIS IS THE FIRST STEP IN CARING FOR SOMEONE WITH DEMENTIA.

The first step in caring for someone with dementia is to get the right diagnosis.

Dementia is not a diagnosis. Dementia is a general term indicating that thinking and memory are impaired enough that day-to-day function is compromised, such as difficulty with grocery shopping, preparing meals, using a telephone, or balancing the checkbook. Saying that someone has dementia is like saying that someone has a headache—it doesn't imply anything about the underlying cause. Headaches can, of course, be caused by things that are benign, such as muscle tension or migraines, or by things that are much more serious, such as a brain tumor or a stroke. Similarly, dementia can also be caused by things that are relatively benign, such as a vitamin deficiency or a thyroid disorder, or by more serious disorders such as Alzheimer's disease or frontotemporal dementia.

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There are many reasons as to why it is important to get the right diagnosis.

The first reason is the most obvious: we want to make sure that we check for those reversible causes of dementia, such as B12 deficiency, hypothyroidism, or a chronic infection such as Lyme disease. Many of these causes can be evaluated through blood tests. Depression is another potentially reversible cause of dementia. There are other causes of dementia that, once determined, may also lead to improved cognition or, at least, can stop its decline. Structural brain imaging studies such as MRI and CT scans can identify: subdural hematomas (accumulation of

blood between the skull and the brain), which may need to be removed; normal pressure hydrocephalus (accumulation of spinal fluid inside the brain), which can also be treated surgically; or large strokes that need to be evaluated to prevent future strokes.

The second reason to obtain a diagnosis is to identify those aspects of cognition that are likely to be affected early, and those aspects that are likely to be affected later.

In Alzheimer's disease memory problems are usually the first symptom, followed by wordfinding difficulties, trouble with complicated activities, and getting lost on familiar routes. Only later in Alzheimer's disease do other symptoms sometimes occur, such as a change in personality, agitation, incontinence, and aggression.

In frontotemporal dementia, changes in personality and behavior come first, along with difficulties doing complicated activities. Language problems and changes in diet typically occur next, followed by memory problems.

In dementia with Lewy bodies, visual hallucinations of people and animals may be an early symptom, as is acting out dreams (often kicking bed partners) while sleeping. The stiffness, tremor, and shuffling steps of Parkinson's disease are other early signs.

In vascular dementia, trouble with complicated activities is often the first sign, with memory problems coming later.

In normal pressure hydrocephalus, urinary urgency—needing to run to the bathroom—is an early sign, leading to incontinence when one doesn't make it on time. Walking slowly with small steps, and trouble with complicated activities are other early signs.

And there are many other causes of dementia in which different problems typically occur, each with their own order.

> The third reason to get the right diagnosis is so that the correct evaluation and treatment can be initiated.

Cholinesterase inhibitors, such as donepezil (Aricept), rivastigmine (Exelon), and galantamine, can improve patients with Alzheimer's, dementia with Lewy bodies, and vascular dementia.

SSRIs (selective serotonin reuptake inhibitors), such as sertraline (Zoloft), citalopram (Celexa), and escitalopram (Lexapro), are first-line therapy





Shine a Light on Respite Care 2020 Alzheimer's Art Calendar

Each month offers insights into the various daycare locations found in ACA's area. Receive a calendar for a \$10 online donation: www.alzca.org/calendar.

Surgical evaluation and possible intervention is needed for those with normal pressure hydrocephalus or subdural hematoma.

Stroke workup and treatment, usually with aspirin or other blood thinners, is necessary for vascular dementia.

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Lastly, there are research opportunities available for some causes of dementia. For example, new medications are being developed that may be able to actually remove the amyloid plaques that kill brain cells in Alzheimer's disease. Knowing that your loved one has Alzheimer's disease would, of course, be the first step in taking advantage of this opportunity.

So, don't let the doctor give you or a loved one a diagnosis of "dementia" without explaining what is causing the dementia. It's like walking in to the office complaining of pain in your head, and the doctor concluding, "Yes, you have a headache." None of us would be satisfied being given the diagnosis of "headache," and we shouldn't be satisfied being told the diagnosis is "dementia" either.

Andrew Budson, M.D., is a professor of neurology at Boston University, a lecturer in neurology at Harvard Medical School, and Chief of Cognitive and Behavioral Neurology at the Veterans Affairs Boston Healthcare System. He is the author of "Seven Steps to Managing Your Memory: What's Normal, What's Not, and What to Do About It.



Alzheimer's of Central Alabama





Walking to Remember

Saturday, November 2, Riverchase Galleria, 8 am

> Register (205) 871-7970 or www.alzca.org/walking

Alzheimer's in Alabama

Alzheimer's of Central Alabama's annual caregiver conference

Friday, October 18

Canterbury United Methodist Church, 8:30 - 3:00

Conference highlights include:

Brian LeBlanc was diagnosed with early-onset Alzheimer's in 2014 and is living with vascular dementia. Brian realized that we seldom hear from people living with dementia and he knew he HAD to talk about it. His story, I Am Still ME!, provides a rare window into the journey of a "regular guy" who is living with a progressive, degenerative brain disease.

Jamie Tyrone learned of her 91 percent lifetime genetic risk of succumbing to Alzheimer's disease. Her personal experience of living with this genetic status has been featured in the New York Times and the Washington Post.

The cost to attend is \$15 or \$35 for those needing CEUs.

Presenting Sponsor: Medical Properties Trust

To see full conference agenda and to register: www.alzca.org/conference

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ComfortCare







The Ministry of Alzheimer's of Central Alabama

Almost 30 years ago, local family and support group members joined to create Alzheimer's of Central Alabama (ACA) to promote research and provide services for local families living with dementia in its many forms. The heart of what we do is help families keep their loved one at home.

Through ACA's programs, education, and services we seek to help diminish the devastating affects a diagnosis of Alzheimer's or dementia can cause for an entire family. While research gives hope for the future, ACA's services give actual help now, with relief to specific challenges families face as their loved one progresses from needing supervision to custodial care to nursing care.

ACA is here to help!

Project Lifesaver Bracelets for patients at risk of wandering. The bracelet emits a radio tracking signal to help local law enforcement locate a patient who has wandered. 60% of

The statistics are staggering:

- Every 3 seconds someone develops dementia worldwide.
- Every 65 seconds someone in the U.S. develops dementia.
- Over 90,000 individuals in Alabama are living with dementia.
- They are cared for by 303,000 unpaid family caregivers.

patients are at risk for wandering, making it the most dangerous dementia behavior.

Respite Care Scholarships for patients to attend an adult day care center. This year over 59,900 hours of care will be provided for 104 people living with Alzheimer's.

Continence Products delivered to the home each month. Continence products are a medical necessity but for many families purchasing the products they need is a luxury. This year ACA will provide 105,840 products to families in need.

Supporting Arts Programming for those living with dementia: visit ACA's website for more information about our annual calendar of dementia art.

Education is a family's first line of defense when faced with a dementia diagnosis:

Call our helpline, visit our website, or attend a support group or a community education program. Contact us at aca@alzca.org and ask to receive our weekly Dementia Community Calendar.

Alzheimer's Research—ACA has funded 24 research grants and has established the Alzheimer's of Central Alabama Pre-Doctoral Scholars Program for Alzheimer's disease research at UAB.

100% of the Money Raised Stays in Alabama to Help Alabama Families





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