

**DAVID CLARK:** I'm David Clark I am a behavioral neurologist at the Medical University of South Carolina. And I'm going to be talking about dementia, focusing on Alzheimer's disease primarily, but also some other causes of dementia, including the diagnosis and the management, from a pharmacological standpoint.

I think one of the most important things, when you're assessing a patient who might have dementia, is to have a good definition in mind. The definition that I was trained with was that dementia is a cognitive disorder that results in a decline in social and occupational functioning.

So when we say cognitive disorder, we're talking about problems with the computational things our brains do for us. Things like memory. That's remembering what we had for breakfast, as well as where we went to elementary school. Language, so being able to access and produce words, as well as understand words. Spatial orientation and navigation. And the recognition of important things in our world, like faces, places, and objects such as tools.

So this cognitive disorder, a disorder in one of those cognitive domains, must result in a decline in function. Now the way I operationalize this usually, is to diagnose dementia when I see little or no preservation of the more complex or instrumental activities of daily living. And these include things like cooking, driving a car, and managing medications or personal finances.

In addition to disruption of cognition and secondary loss of function, patients with dementia often exhibit changes in behavior, so what we consider neuropsychiatric abnormalities. These are not necessary for the diagnosis. But the different behavioral changes can help to decide which syndrome, or neuropathology, patients are suffering from. So these behavioral changes most often include things like depression, apathy, agitation or aggression, and psychosis, which can be hallucinations or delusions.

When we see our patient, those sorts of things, whether the patient is experiencing a disorder of cognition, and whether it's impacting their function, are the main elements of the history that we cover. And after we take a history, we move on to the examination of the patient.

In order to diagnose dementia, the most important part of the examination is the mental status evaluation. The Alzheimer's Association recommends a number of items for primary care providers. That is mental status tests. These are all freely available without concern of copyright violations.

And they include things like the Mini-Cog, which I will actually show you an example of in a moment. The GPCOG, or the general practitioners cognitive inventory. And a memory impairment screen, that's developed by the Alzheimer's Association. And the other mental status test that I'll talk about, that I use a lot in my practice, is the Montreal Cognitive Assessment, or MoCA. So I'll go into some detail about the mental status testing.

In addition to mental status testing, we like to look at the other elements of the neurological exam. Because they may help point us toward causes of dementia that are different from Alzheimer's disease. So that is to say, with Alzheimer's patients, the other domains of the neurological exam are typically normal.

And if they're not normal, then it may point you toward a condition with concomitant Parkinsonism, or cerebral vascular disease, or other comorbidities, that may be contributing to the dementia. So eye movements, for example, are often impaired in progressive supranuclear palsy. Blink reflex, or the reduction of blinking rate, may be altered in Parkinsonism.

From a motor standpoint, we may see movement disorders, such as rigidity and tremor, in Parkinsonian patients. Or myoclonus in patients with other forms of dementia, such as corticobasal degeneration. Reflex asymmetry and Babinski signs may point you toward a cerebral vascular etiology or another structural lesion of the cerebrum.

Coordination is not as often disrupted in patients where dementia is a concern. But it can be, especially in certain forms of multiple system atrophy that involve the cerebellum. And then sensory disorders may point you toward a polyneuropathy suggestive of an inflammatory disease, or diabetes, or hemisensory loss, as we might expect in stroke.

Gait disorder is common in patients with Parkinson's disease or Parkinsonism. In those patients we often see shuffling with unblocked turning, difficulty rising to a stand, or festination. And then there is a less common gait disorder, known as magnetic gate apraxia, that may suggest the presence of normal pressure hydrocephalus.

To focus in a little bit on mental status testing. This is one of the instruments that is currently recommended for screening in the primary care setting, known as the Mini-Cog. And this test just consists of three word recall and a clock drawing, which is used as a distractor task. As you can see, there are six different versions, each of which has three different words. So this is good for tracking the patient over time. It can reduce the learning effect.

The patient is asked to repeat back these three words. And once they've registered them, they're asked to draw a clock on a separate page. The second page actually has a large circle that the patient fills in to form the clock. And then after a three minute delay, that person is asked to generate the three words from memory. And this test gives a total score of zero to five points, where fewer than three points are considered indicative of dementia. And fewer than four points are suggestive of a need for further cognitive testing.

When we do more in-depth testing, and the testing that I'm more likely to do routinely in my clinic, I use a 30 item test, like this MoCA. This is also freely downloadable as a PDF file and can be used without fear of copyright violation. And as you can see, it has a number of stimulus items that are specific to the test. Including these line drawings of exotic animals, a connect the dots test, known as trails, or that is modified from the Trails B test, a space where the patient can draw a clock, and a space where they can copy a cube, as well as five item recall, tests of orientation, calculations, et cetera.

So this test gives up to 30 points, or patients can score up to 30 points. And scores below 26 are considered suggestive of cognitive impairment, with the higher scores in that abnormal range. That is scores of, say, 23 to 25 more suggestive of mild cognitive impairment rather than dementia.

Here in Charleston, and in South Carolina in general, one of the distinctions I'm often trying to make is the distinction between mild cognitive impairment thought to be due to Alzheimer's disease and cognitive changes related to cerebral vascular disease. And I've color coded some of the items here to indicate the patterns that I think I am more likely to see in these two different patient populations. So you see the green coded items are the items that I think are most often disrupted in patients with primarily cerebral vascular disease. The red items are more commonly disrupted in patients with MCI that I have a strong suspicion of being due to Alzheimer's disease.

And just to call your attention to the bottom of the test, where you see the delayed recall items. I believe that some of those items are commonly disrupted in both conditions. That is, the spontaneous recall is commonly disrupted in both conditions. Those are coded yellow. Whereas the loss of the ability to remember the items, even when the patient receives hints, is more suggestive of an amnesic memory disorder that often precedes clinical Alzheimer's disease.

There are a number of things to think about. Once we have good conceptualization of what Alzheimer's disease looks like, there are several things that I consider to be red flags. That give me the concern that a patient, even if they have dementia, has dementia from some non-Alzheimer's cause. So the red flags for me are primary language dysfunction. These would be patients who present with the complaint that they're having difficulty coming up with words, or understanding words in conversation, although they tend to remember recent events fairly well.

Prominent personality change. I want to point out that patients with Alzheimer's disease often have some personality change. But if you pin family members down about that personality change, it turns out that they're describing mainly a withdrawal from social activities or hobbies. So when I say prominent personality change, I'm talking about a really profound change in comportment or behavior to the extent that the spouse often says, this is not the person I married. So these patients may be lewd and very disinhibited or sexually disinhibited.

Parkinsonism is fairly uncommon in pure Alzheimer's disease and raises the possibility, to me, of dementia with Lewy bodies, cerebral vascular disease, or a number of other conditions.

Alzheimer's disease typically occurs in older patients, so patients above the age of 60. And when I see patients below the age of 50, to me, that's strongly suggestive that I might be dealing with something that is not Alzheimer's disease, such as frontotemporal dementia or perhaps a prion disease.

Prominent visuospatial disorientation is not typically seen in Alzheimer's cases. This suggests a syndrome known as posterior cortical atrophy. Probably about half of the PCA patients, that is posterior cortical atrophy patients, do turn out to have Alzheimer's disease at autopsy. But at least half of them have something else.

And last here I list rapid course, which may suggest some new structural lesion such as strokes, neoplasm, or a spongiform encephalopathy such as Creutzfeldt-Jakob disease.

I mentioned that neuropsychiatric changes are common in dementia, and that they can actually aid in the diagnosis. In Alzheimer's disease the neuropsychiatric changes that are most common are depression, which occurs most often early in the course of the disease, such as in the phase of mild cognitive impairment. Apathy and withdrawal are common throughout the disease course.

And patients with moderate to severe dementia often develop delusions of some sort, such as delusions of theft. That is thinking that someone came in their house and stole something from them, which, in fact, they have misplaced. Delusions of marital infidelity are very common and can be quite upsetting for both the patient and the spouse. And delusions of misidentification, in which patients no longer recognize their home and often insist that they want to go home. Or failure to recognize familiar individuals, including the spouse. And last, the failure to recognize the patient's own reflection in the mirror, also known as mirror sign.

The neuropsychiatric changes that are common in other forms of dementia include bizarre personality changes, which I touched on earlier. Including things like compulsions, sexually inappropriate behavior, increased affinity for sweets. So when I say this, I don't mean just that the patient likes ice cream more than they used to. I mean that the family members will complain that if they buy a box of cookies, or a bag of candy, the patient will eat the whole box, or the whole bag, in a single sitting.

Visual hallucinations are most suggestive of dementia with Lewy bodies. And actually I'm not sure I specified this, but the bizarre personality changes that I'm pointing out there are most suggestive of behavioral variant frontotemporal dementia.

So visual hallucinations, and hallucinations in other modalities, are most suggestive of dementia with Lewy bodies. These tend not to be stereotyped. But they are often animate and small figures. So the patients report seeing a dog, or a cat, or a grandchild, or people in the distance, such as people in the yard.

I mentioned REM behavior disorder. This is actually a parasomnia, or sleep disorder, more than a neuropsychiatric phenomenon. These patients act out dreams. So they may be dreaming that they're fighting someone. And they actually begin fighting and thrashing about in the bed. It can actually pose a danger to their bed partner. This disorder can actually occur as a harbinger of Parkinsonian disorders. So some patients with Parkinsonism, or Lewy body dementia, will report that they've been suffering from REM behavior disorder for 10 or more years before they develop the movement disorder.

Another important point of distinction is the distinction between delirium and dementia. Delirium is an attentional disturbance that results from a general insult to the brain. Usually, this is something inflammatory, or toxic, and sometimes may be metabolic, such as in cases of liver or renal failure. These patients don't show the patterns of cognitive change that I was alluding to earlier when I went over the MoCA for example. These patients instead show across the board difficulty with cognitive tests, including tests of simple attention like the forward digits span.

Fluctuations are prominent. So the patients may appear alert and appropriate for a period of time. And then they sink back into a confused state during which they may be sleepy or agitated. This phenomenon is often associated with urinary tract infections, or pneumonia, or metabolic disturbances, such as the ones I mentioned, liver and kidney failure. It's also common among older patients for sedatives, like benzodiazepines, or anticholinergic drugs, like Benadryl, to result in delirium.

The criteria for Alzheimer's disease have been revised in recent years. Prior to that we were using primarily the 1984 McKhann criteria. In which Alzheimer's disease was diagnosed, primarily in the presence of cognitive dysfunction, usually in the memory domain plus one other domain impacting function, and not attributable to some other pathophysiologic process.

Now, in the new criteria, published in 2011, there is a provision for probable dementia. Alzheimer's disease dementia, that is with evidence of an Alzheimer's disease pathophysiological process. And that evidence may come from MRI findings, cerebrospinal fluid findings, or PET scan. The PET scans may be fluorodeoxyglucose PET, which shows the pattern of metabolism across the cortex. Or amyloid PET, which can show the deposition of amyloid throughout the brain. There are also provisions for possible Alzheimer's disease, as in the old criteria, and possible AD with evidence of an AD pathophysiologic process.

Similarly the criteria for MCI have been augmented. In the past, we emphasized the first four things listed here. That there was a subjective change in cognition, with objective impairment in at least one cognitive domain, usually episodic memory. But the patient has preserved functional independence and can't be said to be demented. With the new criteria, there is a provision for saying, that you believe that the MCI is due to Alzheimer's disease because of evidence of some AD pathophysiologic process, like those I mentioned previously.

So I thought it would be useful to go through a brief case report. This is illustrative to me, because this patient was rather a puzzle. It was a 63-year-old white woman with a history of smoking, orthostatic hypotension, and carotid endarterectomy. So we knew that she was something of a vasculopath to start with. But both of her parents had late onset Alzheimer's disease.

Alzheimer's disease is not as genetically linked as many people believe. But having an affected parent does raise your risk somewhat, and I'm certain that having two affected parents raises your risk even more. This patient had a three year history of progressive memory difficulty. When her daughter would come to pick up the grandchild that the patient was keeping, the patient would be uncertain of how many diapers she had changed. And the patient's daughter felt that that was a change from the patient's previous cognitive state.

Also when they would be driving down certain streets, the patient would say that it had been a long time since she had driven down certain streets. But she was incorrect about that. She was still managing some of her instrumental activities of daily living. So she was still cooking. But she had made some mistakes with her medications and taken too much of one of her medicines. And because she got ill from doing that, family members agreed that she would move in with her sister for a while. Her primary care provider had recommended that she no longer drive.

The family members had noted some behavioral problems. For one thing, the patient said that she saw four bears in her backyard. At first they believed her because of the part of the state where she lives in, it wouldn't be too uncommon to see bears. But the family members grew skeptical when she started describing the interactions among the bears, which were distinctly human like. She also claims that she had done a back flip, although she had never been so agile in the past.

On one occasion she locked herself out of her house and was so frustrated that she took hold of a pair of hedge clippers, and started to try to break down the sliding glass door. But family members fortunately intervened. On another occasion, she was so angry at her primary care provider's office that the police had to be called I don't think that was the occasion when he told her that she had to stop driving. But judging from my own experience, I wouldn't be surprised.

So the things that I was thinking about, I listed here Alzheimer's disease and behavioral variant frontotemporal dementia. I would also propose that cerebrovascular disease could be a potential cause for these changes. The nearest psychologist who saw her felt that behavioral variant frontotemporal dementia was more likely.

On the MoCA, she exhibited primarily disruption of executive function, and loss of five points on delayed recall, with a total score of 14 out of 30. I felt that this score was suggestive of actual dementia. And I think that the cognitive decline that I was witnessing, or that the family members were reporting, could be consistent with the diagnosis of dementia. But still, we were wondering what the specific end diagnosis would be.

The MRI scan revealed a subcortical stroke in the left parietal region. At least it was read initially either as a cortical stroke or an area of inflammation. But as time went by, I became more concerned that it was a stroke or vascular disease.

Because of the concern of Alzheimer's disease and the lack of a clear diagnosis, I suggested that the patient have spinal fluid drawn so that we could get supportive data. And this is the result that we obtained from the commercial diagnostic test.

So this is a send out lab. And the way it's interpreted is the laboratory analyzes both the level of amyloid and the level of phosphorylated tau. Counterintuitively in Alzheimer's disease, the level of amyloid in the cerebral spinal fluid is actually reduced. Whereas the level of phosphorylated tau is typically increased. So if the patient's values are plotted in the lower right hand quadrant of that box, then that is considered to be consistent with Alzheimer's disease.

There are a lot of dots on the slide. Those are actually art work that was present in the older version of these reports they were sending out. The main dot to pay attention to is the asterisk there. That shows that this patient's adjusted amyloid level was approximately 0.4, and phosphorylated tau level was approximately 120. So these results were consistent with an Alzheimer's disease pathophysiologic process.

In terms of management, I always advise my patients to pursue a healthy lifestyle. It doesn't seem that there is anything that people have control over so much as these lifestyle factors. So seeing their primary care physician. Taking control of their medical problems, such as high blood pressure, diabetes, and high cholesterol. Abstaining from risk factors, such as smoking and illicit drugs. Consuming alcohol only in moderation.

The Mediterranean diet, in a nutshell, consists of a diet in which patients get their calories mainly from plant sources. So this includes olive oil, fruits and vegetables, nuts, seeds, and a few servings of fish per week.

Daily exercise is probably one of the most potent things we have for preventing or aiding cognitive impairment. And yet, it's very difficult to get people to comply with.

Social and religious activity both seem to be beneficial from a cognitive standpoint. And I don't necessarily suggest that my Alzheimer's patients pursue a foreign language or a musical instrument, but pursuing those things early in life seems to be beneficial in terms of overall Alzheimer's risk.

Beyond those lifestyle factors, there are two classes of medications that are approved by the FDA for treating patients with Alzheimer's disease. These include the cholinesterase inhibitors, such as donepezil, rivastigmine, and galantamine.

These are symptomatic treatments that do have long term repercussions that are beneficial. That is, patients who go on these medicines may stay out of the nursing home longer than patients who do not take them. There can also be neuropsychiatric benefits from the cholinesterase inhibitors. They can have some anti-hallucinogenic properties. And in this patient population, they're considered first line treatment for hallucinations. Unfortunately, gastrointestinal side effects are common. And there are other potential side effects, such as bad dreams and muscle cramps.

Memantine is the only medication in the other category of medications that has FDA approval. This medicine is a weak inhibitor, or antagonist of, the NMDA receptor. And the strongest evidence for its use is in patients with moderate to severe dementia. The cognitive benefits in this group are marginal, but they are present. The medication can be added on to a cholinesterase inhibitor. And there is some evidence for neuropsychiatric benefits with memantine as well, with some apparent reduction in emergent agitation. So it may not be a choice for your patient who's already agitated. But using the medication in patients with Alzheimer's disease may reduce the emergence of agitation.

Neuropsychiatric problems are a big part of what we treat in patients with Alzheimer's disease. And this is a list of some of the more common neuropsychiatric psychiatric problems and how we typically manage them.

For depression, SSRIs, such as citalopram or escitalopram, are the preferred agents. But those two that I mentioned are associated with prolongation of the QT interval in higher doses. So the high doses are not recommended in patients over the age of 60.

For agitation, there are some controlled studies that support the use of citalopram. Again, we're concerned about prolonging the QT interval and inducing arrhythmia. There is a phase two study supporting the use of dextromethorphan/quinidine in combination. A medication that is marketed for the treatment of pseudobulbar affect. A phase three study is under way. And if the phase three study is as much of a success as that phase two study, the manufacturers will probably seek FDA approval. Trazodone can be used. This is an antidepressant that has some sedating properties. And I have found it to be useful occasionally for agitation, usually milder agitation.

Psychotic features, such as hallucinations and delusions, can be treated with cholinesterase inhibitors first line. But in many cases, especially if patients develop problems such as aggression, then I have to resort to atypical anti-psychotic medications. This is also the case with delusions.

My reason for avoiding anti-psychotics, if possible, is that all of these medications have been associated with increased risk of death in this patient population. So I tend to use them only in settings where I feel that there are also risks, to life and limb, from not using the medicines.

Pimavanserin is a new medication that was recently FDA approved for the treatment of hallucinations in Parkinson disease or dementia with Lewy bodies. It has a completely different mechanism of action from the other atypicals. Nevertheless, it still carries the black box warning of the atypical antipsychotics.

And the last thing there, impulsivity. In the past, I have used Depakote to help patients to control their impulses. But this seems to be falling from favor due to concerns that valproic may actually shrink the hippocampus or be associated with other unfavorable outcomes.

The last thing I'll mention is that there are a number of clinical trials going on. Most of these are focused on reducing the burden of beta amyloid. At MUSC, we have started screening patients for the ENGAGE study. This is a phase three study of aducanumab, which is an infusion that's meant to reduce amyloid levels in the brain.

The IDEAS study is a study funded in part by Medicare. And for this study there's not a treatment trial. We're actually just looking for evidence that getting amyloid PET scans is useful for clinicians.

The third study there is a study we're hoping to get off the ground. It's a study of a beta-secretase inhibitor. This is one of the enzymes that generates the amyloid fragment.

And the last two studies listed there are actually studies of anti-amyloid agents, in patients who are thought to have Alzheimer's disease, but who have not developed any significant symptoms at the time of enrollment in these studies. The first one, the DIAN-TU study, is the Dominantly Inherited Alzheimer's Network Treatment Unit study. So these are patients with autosomal dominant mutations that cause Alzheimer's disease. And the last one is in patients with amyloid deposition confirmed through a PET scan. Yet these patients, apart from having amyloid, they do not have clinical evidence of Alzheimer's disease.

So that concludes what I'm going to be saying, and I think Sam Wiley will be talking next.

**SAM WILEY:**

Thank you Dr. Clark. Now we are going to hear a little bit about some resources. Resources for professionals, as medical providers. As well as we're going to talk about some community programs and services that are eligible for family members and individuals suffering from Alzheimer's and related dementia. We're going to speak about a little bit of online programs. And we're going to really talk about, what are the available resources that are actually there for individuals, maybe in the home, as far as they age and looking for their care in the home. And then we'll talk a little bit about potentially some pharmacological approaches in the presentation.

So starting out with professional support services, one of the first things we want to bring to your attention is that there is actually a referral pad with the Alzheimer's Association. These are free, actually, for any medical provider. And it's a pad that consists of all the services that the association provides across the state of South Carolina. And it's, quite simply, designed for medical providers to be able to check off on a pad and give to their patients, as conversation of Alzheimer's or a related dementia may come up. So this is something that's very unique. And it's something that can be attainable as a resource for professionals.

Another type of professional support services we want to bring into contact is, we actually have a web page. It's called, [alz.org/hcps](http://alz.org/hcps). And this is for our health care professionals. And what this is designed to do, is it's a web page created where medical professionals are able to access cognitive assessment information, dementia diagnosis. There's clinical trials. There's information resources that can be communicated and emailed, for patients and caregivers, right from this health care portal. As well as other different highlights, including the medical annual wellness visit, that you can gain information on. And among many other different types of information from. So there again, there's another particular piece that we're providing for professional support services. For medical providers and physicians to be able to access the information that they may be looking for.

To go a little step further, we actually want to show you what we have-- an app, which is very similar to the health care portal that I just showed you, but this Alzheimer's disease-- what we call Pocketcard app. Believe it or not, we just have won some awards on this, but this is another way to provide some convenient access for services for physicians and medical providers out there.

It has interactive cognitive assessment tools. It has information that can be emailed into packets directly to patients from this app. There's ways that you can access safety and driving clinical studies locator. There again, another way that we're trying to create making simple information easily accessible for professionals in the field for those dealing with Alzheimer's or related dementia.



And so those are, for the most part, for the professional support services that we're providing that on. We also do providing and services for the professionals in person as well. We come to offices as well to do the educational program as needed. But flipping over to community support services now something to be mindful of as we're working with families and individuals across the State of South Carolina.

We have six Alzheimer association-- six regional offices. And one of the first things I want to draw your attention to is that we do have a 24-hour help line-- 1-800-272-3900. This is 24 hours, seven days a week. It's licensed by nurse-- excuse me, it's licensed by social workers and counselors-- individuals-- families that are going through a difficult time, behaviors, or communications-- anything that may be involving Alzheimer's or a related dementia can call this number.

And they can call at 2 o' clock in the morning. They can call it at 10 o'clock in the morning on a Sunday before they may be possibly going to church. There again, it's there to enhance care and support-- provide the necessary information referral and care consultation that families need as they're looking for those enhanced care support services.

With the help call, you see information referral, and you'll see care consultation. Those are two main components that we provide in our helpline calls. Information referral is that we literally speak with families and ask them in a person-centered manner, what are their goals-- what do they like to see take place-- what are the services they're looking for. And we work to provide them all the information and services that are available to them in order for them to continue to map out their care plan for either themselves or the loved one that they're caring for.

Care consultations gets a little bit deeper into where we're able to really go into the behaviors, and communications, and really try to pinpoint why certain behaviors may be happening or triggers that may be calling certain situations-- some agitated person or other various different types of things and really getting into the care plan of that as well.

So those, for the most part, consist of our help line calls. Moving on, we have support groups for family caregivers across the State of South Carolina. There is a sitter service program that we actually have that actually provides us a little small amount of respite money for family caregivers that are providing that informal care to individuals in the home.

And what this does is this sitter service program actually goes and allows family members to be able to get a break and actually attend a support group, or an educational program, or some other type an event that the association is providing. So this is a sitter service that's available.

But we have the support groups statewide. We have about 100 support groups statewide, almost one in every county. Individuals can call and learn more about that through the 800 number. The educational programs are something that we provide out in the community. We provide anywhere from warning signs, to living healthy with brain and body, as well as all of the stages of Alzheimer's disease and related dementia, including programs for individuals with Alzheimer's disease, particularly in their early stages of the disease.

We go into legal and financial behaviors-- communications-- every communication aspect that we have for disease education, for Alzheimer's, and even related dementias. We have trial match program. Trials is something that you've heard of previously from Dr. Clark in the previous presentation. Through our trial match program, individuals are able to create a profile. And what this program does is it actually matches up particular clinical trials that are taking place, not only here in South Carolina, but potentially across the state.

And it matches these trials up with the individual that created a profile to provide them with the information to see if that individual or family is interested in possibly learning more and participating in these trials-- another way that we're trying to create access to individuals and gain more information as they're looking to advance in their care with Alzheimer's disease.

We provide safety services through the association. And the safety service program is really involved with the wandering program. We even have some driving videos that we have online that we'll discuss in a minute. But with the Medic Alert Safe Return program, it is a program that is designed that if individuals are lost or wandering, or have the potential to, they can enroll in this program.

And if someone goes missing under this program-- once a person goes missing, they are notified by first responders as well as the Alzheimer's Association in that state to be able to work with the families, to be able to work with the first responders, to get that loved one and individual back home safe and sound.

We have early stage engagement programs that we're working, particularly for individuals that are in early stage, as it says. Individuals in early stage, we recognize that still want-- or engage, and want to have fun, and want to be involved. And they even have stated many times I spoke with them and worked with them that we just want to forget that we have Alzheimer's disease just for a few minutes. And we just have fun and live our life.

And so we're recognizing that and realizing that we need and are continuing to work to put more engagement programs in place. And we're talking about fun things. We're talking about a walk through the trail in the mountains possibly. Or maybe it's a ballgame that's attended. Or it can even be something as an art class.

But we're really working to look at different ways that we can be creative in the early stage engagement. And one of the last of the core services that the association provides for the community is the respite care vouchers. And we'll speak more about that in just a few minutes.

So let's move on to our online programs at this time. These are online programs, again, that we have designed for family members and individuals with the disease, and any other person or professional that's just looking for general information. What we're looking at here is this is our caregiver centers-- [alz.org/care](http://alz.org/care)-- C-A-R-E. This is how you arrive at this website.

And what we've done with this program website is that we have put all of the information that we know that individuals, whether it be for the early stages, or just wondering if they have cognitive impairment, all the way to financial and legal care options, support, what to do about the future, everything that a person may be looking for, we have comprised all of that information on to one web page so that individuals do not have to search the entire website looking for information. So this is another great piece of information where people are able to access information and even access further services the more they look on the particular page.

We have another online program. We have ALZConnected-- [alzconnected.org](http://alzconnected.org). It's a free online community for everyone affected by Alzheimer's disease and even the individuals dementia. And we see a lot of individuals with the disease, and we see caregivers, and friends, and family members that actually utilize this information and utilize this web page and this website.

There are a lot of individuals that are not able to maybe get out to a support group, whether it be their job or the demands of their personal life and whatever it may be. So this is a way that people can access services and enhance their care and support looking for information connecting with others. And ordinarily, they may not be able to. But this is a way that gives them an opportunity to possibly do so.

Another online program that we're able to provide is the Alzheimer's Navigator. And this is a free online tool. And it really is designed for individuals with Alzheimer's disease and their caregivers. And a lot of times what we see with this information is that, a lot of times, individuals, whether it be due to the stigma still that we're dealing with, whether it will be to the lack of awareness of the disease process, a lot of times individuals don't want to call or don't want to reach out necessarily and have that conversation for whatever reason.

But the Alzheimer's Navigator gives individuals a chance to be able to go and, at their discretion, ask these questions-- look for information that they're looking for. And as they fill this Alzheimer's Navigator, and as they complete this information through this particular piece, it actually just starts to develop a care plan for the individual looking or entering information into this Navigator.

And so what it really does is it navigates so that it actually develops a care plan for individuals, answers a lot of the questions, and provides a lot of guiding information so that individuals can take this care plan. They can literally print it out. They can take it to their medical provider or their physician to say these are some of the concerns that I have in my plan. Or they use it for their plan as they're developing their own care, as they're moving forward for themselves, so another great tool for individuals that may want to connect through online services.

One of the last information on the online services we're going to talk about today is called the Community Resource Finder. And it's [communityresourcefinder.org](http://communityresourcefinder.org) quite simply. And this is a database that we have collected, an online tool, that literally does try to locate dementia resources, and programs, and services that are in the area for individuals. This is a national program.

This is the world wide web. But what you'll find is that, a lot of times, individuals will actually search for home health care providers. They may search for nursing home facilities. They may search for a legal elder law attorney. And this is exactly what this community resource finder is for is to try to take some of the hard legwork out of the family caregivers and individuals as what they're looking for to try to find the information as quick as possible without having to search for days.

So this is a community resource finder. And it's a good service to be able to access. And a great example is we were working with a lady that was literally living in London, England. And what she ended up doing is she went through the Community Resource Finder-- found the necessary information, because she was trying to arrange to provide care for her mother who was living in South Carolina. And so this was a great benefit for her, as she was able to locate the resources that she was able to need in order to continue to try to make that arrangement for care for her mother.

So we talked a little bit about what resources the associations offer. We talked about a little bit of the community resources that we provide. And we talked a little bit about the online resources that we have to provide. There again, we recognize that not everybody accesses the internet and online information. But we also recognize that a lot of people do. So it's really about creating more options of services and how people access those information services.

So a lot of times what we do is when we speak with families and we really talk to them about what are the short-term-- what are the resources in the State of South Carolina? And we find ourselves talking about two different types of areas. We talk about the short term care. What's available there?

And we talk about the long-term care. So let's spend a few minutes talking about the short-term care. There are three programs for respite programs, which is a break in care. There are three respite programs in the State of South Carolina. There actually are four. But we're going to talk about three today.

The Alzheimer's Association has a respite voucher program. There's money that comes through the Department of Mental Health that is received through the South Carolina legislation every year. And this respite program is designed to provide care in the home for individuals, whether it be through a home care provider or a private individual.

It can be utilized for adult day services. It can be utilized for a temporary short stay in a nursing facility, if a caregiver has to go out of town for some unexpected business. Or if a caregiver has some upcoming surgery, and they need their loved ones to be able to have that needed support in a facility while that family member goes through that procedure. So the association does have a respite voucher. Qualifications for that is that an individual has to have Alzheimer's or related dementia. And they have to have a family caregiver obviously to be able to provide that informal care.

Another program is the state respite funds. This is money that's set aside a couple of years ago, and it started ever since two years ago where the legislation has put money aside in the State of South Carolina to create some respite funds led the legislation and recognized that aging in South Carolina, there needs to be added benefits for family members providing care.

And so there's this pot of money that we call the state respite funds, which is very similar to the Alzheimer's Association voucher. But the caveat is that you can be a family member providing care for an individual or a loved one that doesn't have Alzheimer's-related disease. It may be that they just are aging, and they need more care, and that's where these funds come in.

The third program that we're speaking of is the Family Caregivers Support Program. This is actually a national program that's filtered through all the states. But in the state-- you don't know aging, which is the Lieutenant Governor's Office on Aging in the State of South Carolina, actually receives these funds and these funds are used in the same manner as Alzheimer's Association and state respite funds are.

There is a piece to the Family Caregiver Support Program funds that actually is what's called supplemental. So, believe it or not, individuals that are actually receiving some dollars from the Family Caregiver Support Program can use some supplemental services to help pay for such things as incontinence supplies, maybe some nutritional diet supplements, Ensure and Boost, maybe some small home modifications-- a wheelchair ramp or potentially a widening of the bathroom or doors in the home where a wheelchair needs to get through-- little things like that. So it's something to keep in mind.

So all these programs are very similar. And these are really the only short-term care that's available. And it could be anywhere between \$500 to \$1,500 a 12 month period. Individuals and families can reapply each year. Money is giving within the 12-month period until funds run out, and the new funds are received in the next fiscal year cycle.

Interestingly enough about these programs, they all are administered by that 10 regional area agencies on aging, or the ADRCs, which stand for Aging Disability Resource Centers. Now, the reason why these are minister together is that the state respite funds and the Family Caregiver Support Program funds are already administered by the 10 regional area agencies on aging.

And these 10 regional area agencies on aging are a stem from per State Unit on Aging, the Lieutenant Governor's Office on Aging, that I mentioned just a few minutes ago. So naturally, it was fitting that because the same clientele that these area agencies on aging are serving are the same constituents and clientele that the Alzheimer's Association is working with as well.

So in order to cut down duplication-- in order to streamline efforts-- in order to make all three programs most effective in serving more families-- we have been able to work with the area agencies on aging and state unit on aging where all three of these programs are provided to the families. And they are administered through these area agencies on aging. The best way to learn more about these programs is you can simply call the Alzheimer's Association. Or you can contact the State Unit on Aging, or one of the area agencies on aging in your area.

So we look at short term, and we say, OK, let's look at what we can get in place. And so we talk about what benefits may qualify through the Alzheimer's Family Caregiver State Respite Funds, as we just mentioned. So we tell families let's get in some short-term care in place. And then let's start folks in on the long-term care.

Now, what a lot of times will happen, particularly as we're speaking, of majority most of the individuals do want to try to keep their loved ones in the home. They work to try to do that. And we talk about both sides. What about this side? Keep them in the home. What is that going to require? But here's this other part of what if they do need to go into a nursing facility?

We'd really discuss those situations. But I'm going to focus on care in the home for the availability of South Carolina. And there's not much. One of the first things you see here is what we call the Community Long-Term Care. This is through the Department of Health and Human Services. It has a home and community-based waiver program. It is for individuals that are eligible for nursing home care-- they need nursing home level of care-- but who prefer to stay in the home.

And this is what this program is designed to do is to help individuals stay in the home as long as possible, meeting that nursing home level of care. Because it is a Medicaid cost, there is a financial eligibility that comes along with that. That means that not all individuals, and family caregivers, and families in the State of South Carolina actually qualify for this particular program. But this is one particular program that we do make sure that families and individuals are aware of, because it does provide a lot of in-home care support services that otherwise are not available in the State of South Carolina.

So we speak with them about Community Long-Term Care, but realize maybe they're not eligible for Community Long-Term Care. Then we'll always start to speak about what was the loved one a veteran. And if so, maybe that person is service connected and able to qualify for some aid and attendance through the Veteran Affairs Office. And so we do have this wartime veterans and their surviving spouses-- had to be 65 years and older-- that are entitled to this particular program.

What this means is that the wartime veteran has to have an honorable discharge at the time of his or her service. It also means that they have had to serve up to 90 days, if I'm not mistaken, in order to-- and it has to be at the wartime. In other words, if individuals were actually in Germany during Vietnam, but they were in a time of the Vietnam War, then they still will be considered a wartime veteran even though they may not even have seen conflict.

So something to be aware of that this is a program that's out there. It's a really good program. And we encourage individuals-- I encourage individuals-- that if they are a veterans to seek this long-term care service first and just see what they are able to qualify. And so that's something that we work and talk with families.

And so that is really it. When we look at short-term care, we talk about, OK, here's the respite care that we can try to get in place. And then when we look at long-term care, we look at the Community Long-Term Care. We look at the Veterans Affairs Aid and Attendance Program. And if you don't qualify for any of those, we obviously try to look to see if there's any kind of long-term care health insurance policy that may have been put into place.

And most people at this time and age don't necessarily have that, especially our older population. So in the State of South Carolina, there's the Alzheimer's services-- there's the short-term, and then there's these long-term care. Other than that, it's about really speaking with families about budget, and manging, and what can they do, and how can they do, and it is very difficult, as you can imagine.

So moving on, so that's the resources that we discuss. We want to be able to spend the last few minutes of the program today. I want to talk to you about those non-pharmacological things that we might can look at, particularly from the families and the way that we speak and work with the families when they contact us or when they come into the offices when we engage with them.

But before we feel like we can do that, we really need to talk about some of the communication and what's happening through the disease process in the early, and middle, and late stages. And that's how we look at it. We don't necessarily specify what-- there's 7 or 8 that we actually may recognize stages.

But I stick to early and middle late stages, because it's very difficult at times to sometimes to tell where a person may be, particularly if they have any other current health problems that are taking place that can really skew some of them the thought process of where they may be in the stages of the disease.

However, communication through the disease process in the early stage, as it states, we do see that individuals in the early stage are still able to convey their thoughts and feelings through their language. They're able to really engage, and they are able to make those decisions about their future care. It is not uncommon to see individuals in the early stage to misinterpret what others say. And a lot of times, we see where a person may get very frustrated, but it is all because they misinterpreted what was said.

But it's important to know that they're still intact where they're able to make those decisions. They are able to engage. They are able to have conversations. And so it's something to keep in mind.

When we move into the middle stage, that's when we start to see that individuals start to use really more the basic words and sentences. They really start to rely on the tone of the voice, and the facial expressions, and the body language. It's not uncommon. We've spent a lot of time working with professionals, particularly CNAs and nursing facilities.

And we really talk about be mindful of that tone of voice, and that body language, and even if there's a facial expression. And a great example is if there's an employee at a nursing facility who's just got out of a meeting, and the boss is really just got on to them, or they've just had a personal call that was very emotional for them-- maybe they were angry or had anxiety.

And then the next interaction that they have is with a patient at a nursing facility. And the first thing that this patient sees is they see the staff walk in. And they hear a tone in their voice. They see the facial expression. And they can pick up on the body language, and immediately, the person with Alzheimer's disease will start to believe, OK, what did I do to make this person mad? Are they mad at me?

And so it really starts a whole negative interaction for that day working with that person with the disease. So it's important to make sure that you shake off that body language and facial expression and really watch your tone of voice when you're working, particularly with individuals with the middle stage.

And as always, we really see that the emotional connection and the meaningful activity is extremely important. These individuals with Alzheimers-related dementia, but particularly Alzheimer's, they are losing more of their memory. And it's more emotional for them, and they're scared. And in anybody in that situation, we need to make sure that we-- we need to be loved. We need to be supported.

The same thing is going to apply here. And keep in mind the meaningful activities. There's so many things that can be done for a person with meaningful activities that they can engage in-- some of their hobbies. They may not be able to do it to the level that they were able to do it, but it's not necessarily focused on if you can complete the task. But it's actually just completing being engaged-- involved in the task.

So it's really important to keep that activity in play as much as possible. And as we move into the late stage, we will start to see that there is a response to familiar words, and phrases, and songs. And a lot of times you hear that where individuals can play older songs that the loved one that they're carrying for has heard-- maybe it's church hymns-- maybe it's some of those favorite old nursery rhyme songs.

And we do hear of so many good positive aspects where families are able to play these songs. These loved ones are able to hear the songs. And so we do see that they are able to pick up on these older memories that are formed long ago. You do see that individuals use that body language and the five senses to connect. You see individuals that may touch something that's hot. And they necessarily don't recognize that it's hot anymore, but they're trying to connect with their senses.

They may taste or put something in their mouth that they necessarily normally would not do. But there again, they're utilizing their senses. They're utilizing what they still have to try to engage that world around them. And so that's some of the reasons why you see some of these things that may take place that involves the senses that ordinarily may seem, wow, why are they doing that?

But they're trying to connect. And in the end, the emotional connection is even just as more important in the late stage-- even the physical connection-- a little hug or putting a hand over another person's hand or sitting down and just letting a person know that you're there for him, and you're going to be there for him. And that goes a long ways as your people are moving through the disease process.

So these are some of the communication pieces that we're looking for. So the last few minutes, let's look at some of the things that we can do when we see some of these behavioral changes that have these triggers. And one of the things that we see a good bit of is pain and discomfort as one of the high-- it's one of the highest things that we're able to see that where these behavioral changes start to take place.

And we a lot of times can pinpoint it back to where there is some type of pain or discomfort that a person is maybe dealing with. A great example of this is when working with a family one time, there was a gentleman who was almost-- he was 85 years old. He was in a wheelchair. And he had Alzheimer's disease.

And over a course of a couple of days, he became more frustrated, more angry, more lashing out at his daughter, who was his family caregiver. And she lived with him. And so he got to the point of three days had passed, and he literally started to chase her around in the wheelchair with a knife and said he was going to kill her.

And although she was probably physically able to not be harmed, she was emotionally traumatic. And so we discussed this conversation. And what we found out after doing a little bit of detecting is what we'll talk about in a second. We found out that this gentleman actually was constipated. He had been constipated for over three-- or possibly even a week. And we were able to pinpoint that this started to take place at a certain time each day.

And what we were able to do once we recognized that it could be involved with some bowel movements, the daughter got him back to the medical provider. And the medical provider was able to give the proper medication and be able to not be constipated anymore. And he actually became less agitated. He actually came back to his normal, happy self. And he wasn't in that pain or discomfort anymore. And so there's a lot of those that we see like that.

We also see overstimulation. We see boredom. People can be sitting around, and all of a sudden, there's just so much going on, they just get up and leave, and they walk out. And somebody will say, well, Sam has never got up and left like that. But there can be a lot of overstimulation or just flat out boredom. I don't know anybody now that doesn't get bored that doesn't want to get up and leave.



Fear of frustration is what we see that triggers some behavioral changes. A lot of unfamiliar surroundings definitely is something that's going to have some behavioral changes. And then we have some complicated tasks that could be frustrating for that person. So these are some of the main areas and triggers that we see that actually can cause pain. A lot of times people might mistake that, well, my loved one has reached a certain part of the disease. Now, it's time to put a lot of medication. And we're just going to get them all some medication. And that's what we always say. You need to speak with the medical provider.

But we also say, let's take a look back and see what's taken place and if there's something that we can look into the environment or some type of behavioral piece that we can look that we might can change or make better so that these behavioral changes are reduced.

So when we're understanding and addressing these behavioral changes, there are four areas that we like to try to work with families on. And the first is detect and connect, keeping in mind, you've got to know who this person is. You've got to know everything about them as much as possible.

Were they born in the South? Were they born in the North? Did they work on a farm? Or did they work in a factory? Or what was their type of work? What did they do? Who were they in the height of their life-- in the height of their career? Because we're going to be able to see, as you heard Dr. Clark say earlier, to some capacity that we're going to start seeing some personalities about the individuals that took place many years before.

And a lot of times it took place many years before a family member maybe even had known an individual. So they never saw the personalities that might take place. So we want to detect and connect. We want to address the physical needs first. Then we want to address these emotional needs. And then at that time, we want to reassess, and we want to plan for the next time.

It seems quite simple, but believe it or not, you put this practice in motion, and it does help. So when we detect and connect, we want to join that person to his or her reality. We want to understand the person's reality in the context of who, what, when, where, and how. Who was it that was involved? What happened? And when did that take place? When did that start? Did that start two weeks ago? When did you start to notice? Where was it? Was it around the bathroom? Was it outside? Or how did it affect that person? And how did it make them feel? We need to ask these questions?

We always want to make sure that we always approach a person calmly and respectfully, being in tune with what their actual body language and their facial expression is. So we want to make sure we do that detecting and connecting, keeping in mind who that person is.

We want to first, as we said, address these physical needs. We want to rule out any medical issues. Is there any other current medical problems that may be taking place that we need to go back to the medical provider to have a conversation about? We look at physical problems too such as hunger or thirst. Even a lack of social interaction-- you can even see individuals that may be dehydrated.

There's a whole host of physical problems that can take place. And as I said, I'm a big believer that a majority of the issues are physical when people really get into these behavioral problems. And then we need to look for the environmental triggers and what's causing discomfort. Is it a holiday setting where someone-- where the entire family is in the home? And it's off the routine of that person with dementia.

And we have plates clanging, and dogs barking, and babies crying, and the TV is so loud, and a lot of talking. And is that overwhelming for that person? Is that an environmental trigger where they get negative or respond negatively-- holler at the entire family. So those are things we need to be mindful of and how we can work to change maybe some of those environmental triggers as we look at that.

As we look at the physical needs, we want to address those emotional needs. We want to focus on the person's feelings. Sometimes that's harder than it sounds. But we don't want to focus on the facts. We don't need to worry about the facts. There again, connect with the person and their reality. And let's focus on their feelings.

It doesn't matter if they got the date right, or if they got the name wrong, or we don't want to focus on that. That's not what we need to be doing for these emotional needs. There, again, we need to know the person's knowledge of the preference. Who is that person? Because that's going to be very helpful as we work that into our intervention.

And then as always, redirecting is one of the biggest keys, and anything in energy, more soothing activity, positive activity, but redirecting is one of the biggest things that we can do. It's not so much about where is my husband who's been dead for 20 years. Where's my husband? Where's my husband?

But it may be more about is, tell me more about your husband. Who is your husband? Where did you meet your husband? Start using the who, what, when, where and redirecting individuals when they get into these behavioral or emotional pieces that we see.

And then last, we just reassess what we did. And we need to go back and detect and connect again. And we need to try to keep in mind, and we're in that person's reality. And trial and error is a lot of what it takes. What went well? What didn't go well? Who is that personality of that person? And what are their likes? And we need to make those adjustments as we can.