(MUSIC PLAYS)

MATT BRANDENBURG:  
You are listening to the AOTA podcast. Here is your host, Matt Brandenburg. Alright. Today I am joined by Jill Cigliana, occupational therapist and the executive director of Memory Care Home Solutions in Saint Louis, Missouri. Also, joining us is Scott Trudeau, the Director of Practice Engagement at AOTA. Jill, Scott, thank you both so much for being on the show today.

SCOTT TRUDEAU:  
Thanks for having us, Matt.

JILL CIGLIANA:  
Thank you, Matt.

MATT BRANDENBURG:  
It is my pleasure. I've been looking forward to catching up with you both and learning from you about some pretty exciting and important topics for really OT practitioners in a lot of different settings. But before we dive into our theme today, Jill, I wanted to ask if you could introduce us to Memory Care Home Solutions and what your role is there.

JILL CIGLIANA:  
Sure, happy to. So, Memory Care Home Solutions is a non profit community organization based in Saint Louis, Missouri, and we are entirely mission focused. The mission is to improve dignity and quality of life for people living with dementia and their families. And we achieve this mission by transforming evidence-based interventions into accessible health care solutions. So, I lead a team of program, operations, and fundraising staff, and we all work together to provide four specific dementia services in and around Saint Louis, but covering both the states of Missouri and Illinois. And if you like, I can describe those services for you.

MATT BRANDENBURG:  
That would be wonderful. Yeah. What are those services really look like?

JILL CIGLIANA:  
So, our core service is dementia navigation. And this is based on, because everything we do is evidence-based, our navigation program is based on the care ecosystem, which was developed at the University of California, San Francisco. And in this program, we pair families with one of our dementia navigators, and they stay in touch for, together for a year or longer. And it's really about helping families learn how to manage dementia progression at home. And that team of navigators is supported by a clinical team of occupational therapists, social workers, and pharmacists. We also offer in-home occupational therapy services, and the evidence-base for that is COPE, care of persons with dementia and their environments, which was developed by an OT, Dr Cathy Piersol and Dr Laura Gitlin. Our third service line is individual counseling to support the mental health and coping strategies of family care partners. This is a team we people with dementia and care partners. We consider a dyad, really an inseparable unit.

So, we have services that support all the members of the family. And then lastly, our fourth service line is education and outreach. So, we provide a lot of training and education to professionals on best practices in dementia care, because no one gets enough of this in school. So, we try to provide a lot of great continuing education.

MATT BRANDENBURG:  
And that is wonderful. I love those four lines that you mentioned. And it really sounds like your focus is on the individual or the person experiencing dementia. Also, on the family, and even taking it a step further in scope to really creating an organization and a system to educate care providers and educators and researchers to really cover all the bases in promoting best outcomes for people who do have dementia. That's amazing. How did you really become interested in working with caregivers and working in all these different aspects of care for people with dementia?

JILL CIGLIANA:  
Well, Matt, I had a grandfather who had dementia, but I think, I discovered my passion for family caregivers even earlier than my passion for dementia as a condition because I have a cousin with profound autism. And throughout my cousin's life, I have watched my own aunt struggle to advocate for her daughter. And I saw the tremendous toll this took on the entire family. So, my cousin's autism behaviors actually have much in common with dementia behaviors. She frequently tries to exit the home. She constantly repeats her words and actions, and with the wrong approach, she can be easily triggered to total agitation or meltdown. And sadly, very few people see past these challenges to see her incredible abilities and strengths. And that's really similar to the case for dementia, families and other people really see the abilities that are slipping away to dementia because they're grieving and because it is striking when people lose abilities. But they fail to see the beauty and the strengths that remain and the opportunity we all have for meaningful connection.

What I began working as an OT, my first job as an OT was in home health, and I quickly saw the parallel between autism and dementia caregiving. And I was pretty shocked by the ways that health care often does more harm than good for people living with dementia and their families through some really traumatic experiences that I saw my patients go through. So, the medical system is really good at treating acute health issues, but doesn't often address the actual challenges related to dementia. So, for example, we're really good at rehabilitating broken hips or treating dehydration. But health care doesn't often help the patient or family cope with the symptoms of the dementia that were contributing to those problems. So, the more, yeah, so when I was working in Home Health, I learned about memory care home solutions, and I thought, well, I need to be involved in that work. And at the time, memory care didn't have any occupational therapists on staff. So, I wrote a letter to the founder and asked if the organization would consider adding an OT to the team.

And that's how I ended up here. Yeah, it was just going out on a limb and saying, "Hey, I'd love to be a part of this. It's such a need."

MATT BRANDENBURG:  
That's a wonderful example of advocacy for yourself and really just having that attitude and willingness to say, "Hey, like, OT can fill this gap and fill this need and can fit here." How would you describe or what would you say that OT services do for the families that they serve within Memory Care Home Solutions? Sorry, (LAUGH) I got the acronym confused in my head.

JILL CIGLIANA:  
It's not an easy name. So, you know, I think, our OT services at Memory Care Home solutions are different because we are very lucky to have the privilege of serving this population exclusively. So, we don't have to shift gears and go from treating, you know, an orthopedic injury or a pediatric patient. We get to focus specifically on the unique needs faced by these families. Also, our staff have training in three different evidence based programs. They're kind of all from the same body of research developed by Cathy Piersol and Laura Gitlin. So, we're, our OTs are trained in the tailored activity program, skills to care and cope. Kind of what all of those evidence-based models have in common is that they address both the functional challenges in the daily routine and also the behavioral and psychological symptoms. And actively engage family caregivers to brainstorm and problem solve and think about ways to address those functional challenges and behavioral symptoms. And we also help families see those preserved strengths and abilities so that they can find new ways to engage in daily activities.

Because by engaging people in meaningful activities, that is our first line of approach to preventing or de-escalating the challenging behaviors.

SCOTT TRUDEAU:  
I think, if I could interject too, I just wonder, Jill, if you have any thoughts. I think, for me, one of the things that's most exciting about your program is that it is truly community based. And when we think about, when you talked about your experience in home health and sort of the, some of the negative experiences that these families experience in more traditional medical model service delivery, I think, that the memory Home Care Solutions framework being community based is really a core component that allows the person to thrive in their own environment within the context that they should be, if you will. I guess, I wonder, have you thought about that? Do you have any thoughts about that? Because I know it's not always easy to run this kind of a program in at the community level.

JILL CIGLIANA:  
No, I think, that is the unique strength of our organization is that we are deeply ingrained in the community and we are at every level governed by the voices of people living with dementia and family caregivers. So, I think, those, you know, that we are a community based non-profit, that the voices of the people we serve pave the way for us. So, caregivers of people living with dementia are on our board of directors. Almost everybody on our team has been personally affected in their own families by dementia and caregiving. And then at the community level, because we're out and in the various neighborhoods and regions and in and out of people's homes, and working very closely with the village that is required to support a family who's managing dementia at home. So, we actually visit adult day programs. We meet with train educate in-home care providers. We work with, you know, when home is no longer a safe option for either the caregiver or the person living with dementia, we work to know what communities, long-term care communities, senior living communities might be a more supportive environment when a transition is needed.

And those are never, for us, those are never one off referrals. It's about being in real relationships with other service providers and our community, with our local chapter of the Alzheimer's Association, with our local area agencies on aging. And I think, what's also unique is because we follow people longitudinally and it's not, it's about an ongoing relationship, not an acute experience or a brief episode, then we know the outcomes of any referrals that we make. And we see which partners in our community are dementia capable, like who can serve this community well? Because every adult day program doesn't do a great job with clients with dementia, and every in-home service provider isn't excellent at the creativity that's required of providing care to somebody living with dementia. So, I think the fact that we are really ingrained in our community and led at every level by the voices of the people we serve are two unique elements of a community based organization delivering this service.

SCOTT TRUDEAU:  
And it seems to me that that's also why that fourth pillar that you talked about in terms of education and outreach actually allows you to accomplish that. I would guess that part of your education and outreach into the community is building those relationships.

JILL CIGLIANA:  
Right. And helping, you know, and kind of not only walking the journey with families, but walking the journey with care providers too, because this work is challenging and complicated. And it's kind of sharing our own vulnerabilities with other community organizations that, I think, that helps us all get better together. So, something that we always like to include in our education and training is that, you know, dementia care includes many failures, and every day, we will experience failures. And in health care, you know, we like to have right answers and we certainly don't like to have experience failure. You know, when you're working to support a person who is living with brain changes, the same logical, rational approach that we take with other patient populations is not effective. There is so much trial and error and we like to demonstrate that, hey, even our team who does have the luxury of working with this population all day, every day, still has to have a lot of trial and error to figure out what works.

So, the brainstorming and problem solving piece of this is really important, and just acknowledging that is very validating to other care providers. Because everybody, you know, at our core, I think, the vast majority of people want to do right by these clients and families. But it's just, it's not easy. And we don't get a lot of preparation for how to work in this kind of creative way with patients and families in our traditional training.

MATT BRANDENBURG:  
Having that adaptability and growth mindset within your program, on top of all the other aspects you've described, really illustrate how this is kind of a gold standard for dementia care. And it makes so much sense that you have been working closely with AOTA, including Scott, who you have a background in clinical and research experience, working with people with dementia and their caregivers across the continuum of care to advocate for the role of occupational therapy in the guide model, which is our main topic for today, and was recently announced by the Centers for Medicare and Medicaid Services, or CMS, as you'll hear us refer throughout this discussion. And GUIDE being the acronym for guiding an improved dementia experience model. So, Jill and Scott, could you introduce GUIDE to us, really, what is it and why is this important for practitioners to know about?

SCOTT TRUDEAU:  
I think, that the GUIDE model sort of is the culmination. So, for me, having been around the block for a while now, working with folks with dementia and their care partners

SCOTT:  
And doing some of the research that has hopefully contributed to our understanding of best practice. The idea that the guide program is now trying to take a lot of that evidence and put it forward into an improved payment model that will allow folks to do some of the important work that Jill was alluding to. So some of the community outreach, the care navigation, the caregiver support in a real way, will be baked into this new payment model. So that folks will be paid with an expectation that those types of services will be supported for any beneficiary who's participating in the model. But what has to happen, what's a little tricky about this right, is that because it still is Medicare and Medicaid, they're going through the primary provider, primary medical provider. So basically a primary care physician or a nurse practitioner is going to be responsible for doing the billing and getting the payment for the services that are provided. But they're then expected to contract with programs beyond the medical model, to support the people with dementia in their community and their program.

So it's a little bit complicated. It's considered a demonstration project, because of that they're looking to see what kinds of creative solutions there might be out there in the world. And hopefully part of what we've been trying to do at AOTA, is to really advance the awareness that this model is coming, it's happening. And that we as occupational therapy providers who have an interest in supporting quality of life and keeping people functioning and participating in context in community, we really need to find ways to step up and participate and contribute to this demonstration project. So we're really hopeful that a lot of OT practitioners and maybe even some of our listeners will be thinking about, Wow, how could I connect with with a guide dementia management program in my community? And where would I look to even make some of those initial connections? Jill's probably got a little bit more boots on the ground perspective in terms of how they're thinking about Memory Home Care Solutions.

Is thinking about actually partnering with or implementing. But one of the things I just wanna say before I forget, because this is my take home message, so I'll get it in here now. Maybe it'll hear it again. But one of the things that's very exciting about this model is that CMS came to AOTA over a year ago and said, "Hey, we're thinking about this model and we'd like to understand how we should be thinking about occupational therapy participating in this model." And it was through that, that we began to share evidence about occupational therapies contribution to dementia care. We brought in experts like Jill to meet with CMS, to begin to help them to see that occupational therapy can be part of this solution. And the best news to report so far is that when this program was announced and Jill and I were texting each (LAUGHS) other at the time. When this program was announced by CMS, one of the slides specifically shows a primary care provider partnering with an occupational therapy practice in the community and putting this model together.

So they are very clearly looking for models that support, and include the principles of occupational therapy in the guide program. So this is a tremendous opportunity for us as a profession to stake our flag in this work that is so important to so many of us.

MATT:  
Yeah, that's amazing. I'd love that. And I wanna take this opportunity to thank you both for your advocacy efforts and working with this model and helping others to recognize and learn about how it can fit within it. And how it can really make a huge impact for people who have dementia and providing community care that really goes beyond the individual. And works with caregivers and other important factors of life. Jill what are your thoughts on this model and can you introduce us to its purpose and your feelings on when it was introduced?

JILL:  
Sure. So to start that answer, I should probably backtrack to explaining a little bit about how my organization is funded to do the work that we do. Because this has been a real limitation. Because people ask us all the time, "Is there a memory care home solutions in my community?" Like why isn't there one of these in every state? And really the reason why is and why more of these non-drug dementia interventions have not gotten into the hands of people who need them is because there have not been payment and sustainability mechanisms. So, most people are familiar with the drug discovery pipeline and we even see new Alzheimer's drugs coming to market now. So we kind of understand that process. There's research. There's randomized controlled trials based on the outcomes. Then there's an FDA approval process and then Medicare decides if it's gonna cover the drug and then patients get access to the drug. So that pipeline is not as well established for non pharmacologic interventions. But and a lot of people also don't know that the same decades long research has been occurring for non-drug dementia treatments.

Kind of parallel to the drug research has been all this great research, not only OT focused research which we draw heavily on, but lots of disciplines of research on how to best support people living with dementia and their care partners. But again, because there is no payment for these services in the real world, are no easy payment mechanisms. Nobody gets to take them off the shelves in academia and provide them in their communities. So we are funded through grants, philanthropy and some health insurance reimbursement. So our OT service line and our individual counseling service line, we're able to reimburse for some of those services. But even what we are able to collect in health insurance billing does not cover our costs even to provide those services. So our dementia navigation services have been entirely grant and philanthropy funded. With one of our largest sources of funding being the Administration for Community Living, has a grant portfolio called their Alzheimer Disease Project Initiative.

So, that funding mechanism has really supported us in taking evidence based programs and delivering them in our community. But we can't grow or scale and few other organizations can do this work because it's very hard to fundraise and and write grants. So we're excited. We're first and foremost excited that the guide model is a care model. That fills a total void. Something that health care is not currently offering. And it will help patients and families navigate the progression of dementia at home through education, training, advanced care planning, coordination of care, and importantly access to respite. So, caregivers can have the time they need to manage their own health and well being. So, that's why it's really exciting. But equally as exciting, it is a payment model. So that providers who want to offer these services can be reimbursed for their work on behalf of these Medicare beneficiaries. So, this care and payment model won't be available to everyone because this is a test.

And it's an eight year test that will only be available to beneficiaries of traditional Medicare Part A and B. It will be billed under Part B Medicare benefits. So only time will tell if this will become a permanent benefit within Medicare. And we certainly hope that it will.

MATT:  
This is fascinating and eye opening to me as still a young and at times ignorant practitioner in terms of my knowledge related to the medical system and billing and reimbursement and and payment models. But it kind of sounds like this is a way for future practitioners, if the test goes well. To be reimbursed for providing care that's not one on one direct care with someone who has dementia but being reimbursed for working with caregivers. And working with families. And working on the overall health of caregivers to really promote better outcomes and overall well-being for everyone involved in the care for someone who has dementia. Am I missing any large aspects of kind of the purpose of of this model and what it could lead to?

SCOTT:  
CMS is setting forth that their overall outcome has to do with improving the quality of life for people with dementia and their caregivers. Delaying avoidable nursing home long term placement and enabling more people to remain at home through the end of life. Those are again not traditional acute medical model outcomes that we're invested in a lot of the work that we do, right? We look for cure. We look for fixes. We look for for improvements. But this is just at its very core, looking at quality of life and making things better for people who are traversing the trajectory of neurodegenerative disease of dementia. So that's one important piece. The other piece that I think is really critical to think about is that, not only are they are they asking us to demonstrate the care, the intervention strategies that are gonna be effective. But they're also encouraging us to think about the business models and how are we gonna pay this and sustain this type of model going forward. As I said, occupational therapy will not be direct billing CMS for the services that are provided under this model.

That business arrangement has to be made through the primary provider. These are being billed as E/M codes, which are evaluation and management codes that are currently only billable by a physician or a nurse practitioner or a physician provider. That in and of itself is forcing us to think creatively about the entrepreneurial model and the business model of how this could be sustained going forward. And that quite frankly is also part of what's being tested here.

MATT:  
It's fascinating. I love that emphasis on kind of reframing how we view medical outcomes within systems. And it sounds like there's a lot of creativity involved in workshopping solutions to how to implement this model and make those connections. I think, Jill you mentioned some of these earlier. But what are some of the main factors that CMS identified as drivers of poor quality dementia care that can be addressed by this new model?

JILL:  
Well, specifically, they're looking to measure the strain on family caregivers. So this to my knowledge is the first time a Medicare benefit has ever... Medicare is a health insurance which is tied to a beneficiary. So that would be the patient. But this is the first time that a Medicare benefit is extending to somebody outside of the patient, being the primary caregiver. So for the first time ever, we're measuring caregiver burden. So, how is the well being of the care partner? Because we know that if care partners aren't supported, then that predicts nursing home placement for a person living with dementia. And as Scott mentioned, we're also looking to improve quality of life for people living with dementia. Medicare is also interested in understanding does an intervention like a dementia care model keep people not only out of moving into a nursing home for a residential stay, but also does it prevent falls, trips to the emergency department, hospitalizations? Because we know that people living with dementia have two and three and sometimes four times the medical utilization and then expense of their same aged peers who do not have dementia.

And that's no quality of life for anyone to spend. Years of your life in a vicious cycle between emergency department, a hospital, admission, rehab stay. Come home for a little bit. repeat the cycle. That is is not how the vast majority of us would ever define having an acceptable quality of life. And we know we've been analyzing our data for for 20 years and the randomized controlled trials that test non-drug dementia interventions have proven this also that this sort of help really does keep families together longer. It really does reduce the amount of time people have to spend in the miserable environment of a hospital. Which is we know that it's not fun for anybody to be in a hospital. But when you have a person who's living with some pretty major brain changes, and you take all of their familiar environment and their the coping mechanisms they have and that familiar environment away from them. By being in the very disorienting environment of a hospital or rehab setting, that it only exacerbates the confusion and disorientation and agitation.

So this is really saying like what can we do to make everybody's life better and honor the wishes of people who are living with this condition and their families. So for that reason the the metrics that the model will test are really interesting. And the fact that the model will also include it's an annual benefit up to $2,500 for families to use an in-home care provider. To get some respite for the caregiver, an adult day health program or a facility based respite stay if the caregiver needs, for example, to take a week off to have their own medical procedure done. This acknowledges and validates the very significant role that unpaid informal caregivers have in their contributions to care for this population. And this Caregivers are always under-recognized and unappreciated. But this goes a step toward saying, "Hey, like, we don't have the workforce to provide this level of care. We don't. 80% of the care for people living with dementia is provided for by unpaid informal, that means family member or friend caregivers." And if all of those people just decide one day to stop caring for the people they love, I mean, we would all be sunk.

There aren't enough care settings or care providers to do this care. I mean, it is only possible because people who love other people show up every day and sacrifice to make it happen. And a model like this, you know, is a first step in supporting that whole system of informal care.

SPEAKER:  
Well, thank you for highlighting that. That's really exciting to hear about this model and hear about the implications that it may have moving forward. Can you talk to us more about kind of your advocacy efforts? What is kind of the process that you've gone through to understand the intricacies of this new model, and what are the next steps in advocating for (UNKNOWN) involvement or advocating for the model's implementation?

SCOTT:  
So, right now, we're at the phase where the model has been announced. Due September 15th, they requested non-binding letters of interest from providers who were working on setting up a dementia care model. I say that emphatically that those were non-binding. So, the fact that somebody might be listening to this and didn't get included in or didn't supply a letter of interest does not exclude you from being part of an application that goes forward. The application call will be coming out this fall, and that's a specific as we've been able to get from them from CMS. So, I can't say exactly when the applications are gonna be due, but we expect that folks will be, you know, working now to try to identify potential models. One of the interesting things is that the expectations for these care models will be more defined in what's called RFA. The request for applications. And so we've asked questions from CMS about specifics, and we've been told that we can't hear the answers yet but that they will be illuminated through the RFA.

I know I'm not being particularly articulate right now, but the point that I really wanna make for people is that if you've had some preliminary conversations with folks in your community about participating and they haven't been responsive to you, they may be more responsive when they see all the things that have to be included in the model in the RFA. So, for instance, we know that comprehensive functional assessment is gonna be part of the expectation. Once folks see that explicitly, they're gonna have to say, "Well, who can do that?" And if you step up and say, "Hey, I'm an occupational therapist, I can not only do the comprehensive functional assessment, but I'm also gonna be able to go into the home and do a nifty home evaluation and safety evaluation in the home." Those are two things that are gonna be expected that then gives you the leverage to negotiate the contract and the business model with the primary provider. So, that's what I'm trying to say here, is don't be too put off yet until the RFA comes out and you see the details because we really, really don't want OT to walk away from this because I do think and Jill, I hope I can speak for you, we agree that occupational therapy needs to be part of this solution.

And if we miss the opportunity to get into these programs now, we potentially are putting ourselves again out of potential for the future here. So that's why we're trying to do as much as we can to mobilize the workforce to respond.

JILL:  
And I completely agree. As far as what are our efforts now and what is the timeline, we are anxiously awaiting the release of the RFA. And right now, we as an organization are thinking through various models. For example, we have some great physician groups from primary care and from specialty care who refer a lot of their patients to us at Memory Care Home Solution. So, with the right application for us, be a partnership with those providers who are already sending a lot of patients to us. Or should our approach in an application be... We have a lot of these pieces in place already. We're already enrolled and credentialed with Medicare to provide outpatient occupational therapy and outpatient psychotherapy services. We're not enrolled because we don't have a physician on staff to provide the group of codes called evaluation and management codes. So, should we hire a provider who can build those codes and make that the model in our application? So, right now, I think it's the right time.

I mean, that's what we're doing as an organization. And I think anybody who's interested in this and who might already be delivering some care to people living with dementia should really be connecting with other partners, with referral partners, with community partners to see how to put forth the best application that makes the most sense for your community. Because every region and community is unique. That's where we are. And, you know, nobody knows who will be selected to be a test site. But preparing to submit an application is the next step. And I think, as Scott has mentioned, it will be so interesting to see all the different models that come out of this. But I hope that people aren't too intimidated by the process because we need OTs, and we need people with community expertise. We encounter a lot of groups that are really interested in tech solutions. For example, like how can we remotely monitor this population? And I wanna say there are a lot of great tech solutions. There are a lot of great AI-driven products.

But dementia care really does come down to human connection and contact. I mean, there is a point in dementia progression where no amount of remote caregiving technology can substitute for a human being. So, we actually do need community partners, people who can show up in the homes of people who are living with dementia. So, I encourage everybody at the community level to think creatively about this and to start conversations with partners and other organizations in your community. And I'd also like to add that there is no other discipline that in a performance-based way, will help families figure out the daily challenges in the functional routine. So, if OTs don't stand up and do this, then it will be people reading off of strategy lists, you know, reading about dementia education and then relaying that to a family. And what I always like to say is if families could read about a strategy and solve a problem like resistance to bathing or some really difficult incontinence problems like urinating in the closet versus the bathroom, or the paranoia that goes around with not recognizing your family member, but instead thinking they're there to harm you.

Everybody else is just sharing education, but it's OTs who have walked this walk with patients and families and who have gone in, you know, in partnership with families and changed the environment, modified the activities and taught people how to change their care approaches. And those are the unique contributions of occupational therapy, and we need OTs. So, OTs might not have to be the hands-on providers for all families who participate in these models, but OTs need to share their experience and wisdom with the team of people who do this work. And that's why I feel really fortunate Memory Care Home Solutions because for people in our navigation program, they don't all need an OT, but they all have a navigator. And our navigators are supported by occupational therapists. Some of the most difficult problems we encounter are around resistance to bathing, and it's not that the person physically can't transfer in and out of the shower. This is not a problem solved by a tub transfer bench or a grab bar.

This is a behavioral challenge that the person with dementia really believes they are bathing as independently as ever. And they're really offended when a family member tells them, "Hey, it's been a while, and you're starting to smell bad." That's a real insult to their dignity. So, resistance to bathing is one example and the need to retire from driving or driving cessation. These are communication issues and behavioral challenges that no discipline outside of occupational therapy is as prepared to address with families in a real performance-based way. So, I hope OTs will stand up and join a team or think about submitting an application in partnership with someone to really bring forth these values to families who desperately need the help.

SPEAKER:  
Absolutely. Those are wonderful examples of how occupational therapy practitioners could fit into this model's application and really highlights the importance of doing so. It sounds like practitioners who are established care providers and have experience working with people with dementia may already know where to go to kinda make these connections and who to contact about starting a team or starting one of those applications. What about someone who maybe is an independent practitioner or someone practicing outside of a large organization? What recommendations would you give to an OT practitioner in that circumstance?

SCOTT:  
So, I think if someone's an individual practitioner, they're getting referrals from somewhere. So, if you are working with older adults and a portion of that older adult population is going to be folks with dementia. So you have some connections. It's really looking at those referral sources and trying to figure out, I think Jill alluded to that earlier, trying to figure out where do you make those initial connections. This is a unique opportunity because I think most of us would agree that complex care. So, even though this is not acute medical care, it is very complex care, and complex care is best done by an interprofessional team. And so we wanna respect the fact that OTs aren't gonna be doing it all by themselves, but also, in these business models, we can't set up the relationships that are needed to build directly for an OT-led model. It's gotta be done through the primary provider. So that really puts us in a situation where we're required to be creative, not only creative problem solvers in terms of how do we meet the needs again, from an intervention level, but also creative problem solvers in terms of what business models might actually be viable for us and for the folks that we're working with to move this forward.

And that's the piece that I think is gonna be maybe the most challenging, is to make those connections and to sort out what is actually possible. One thing I will say is that we'll provide few links to some guide content information. And in the content information, there's a description and actually a payment schedule so that going into that contracting relationship, you would know that in the first six months of enrollment in the guide program, the beneficiary is going to... or the provider is gonna be reimbursed for each beneficiary at a certain level. And so from that, you could extrapolate, "Well, if OTs gonna take this much of that to do a comprehensive functional evaluation and a home evaluation, this is gonna be what I'm gonna build the provider for, and that's reasonable within the payment schedule that becomes really important." So you can get kind of practical when you look through the guide materials that are already published to begin to see what options there might be for setting up that business model.

But it really is going to, you know, there is not going to be one approach. Jill mentioned before does her program contract with a primary provider or do you form a business relationship or a contractual relationship and have a subcontract with that provider, a referral source in the community? Those are both viable potential options, and there probably are a lot more that go beyond my business sophistication. But really, this is a time to be creative and be open and to really step up and maybe take a risk. This is kind of uncharted territory, literally. But we need people to do that.

SPEAKER:  
I love that. And Jill, are there any additional recommendations you would give to practitioners who find themselves wanting to learn more and learning or yearning to get more involved with this guide model?

JILL:  
Sure. So, I mean, a quick Google CMS guide model will take you right to a really wonderful web page where CMS has linked all of their webinar materials, fact sheets, FAQs. It's really great content, and it's easy to find. So, I would start there. My other recommendation is for AOTA members or for people who are considering membership, we have a great AOTA community of practice on dementia practice, and we're kind of as a group of peer learners, you know, it's not a class - we're all learning together. That's what a community of practice is. So, I encourage people to join. I help facilitate with some really great people. Kate Keefe and Kathy Piersol, and with Scott's help, this community of practice. And these are the kind of issues we talk about. I've also just learned a lot from following the legislation, and through AOTA's advocacy and education to me as a member, I've learned how to... Submit public comments and just kind of have a voice in these big policy level changes. So I'd say connect with AOTA.

Connect with the CMS guide model page and get talking to colleagues and partners in the community. And those are the ways to get involved.

MATT:  
I love that. That's wonderful recommendations. Wonderful resources. I will be sure to include those links in the episode description. Let's move on to our wrap-up, our call to action additional steps or recommendations that you can give to our listeners. Scott, how would you recommend OT practitioners get involved in advocating for OTs role in guide? And maybe you can highlight again why it's so important.

SCOTT:  
I remember back in the 1990s, so similar experience to what Jill referenced earlier. I remember going over and meeting with the Medical Director of our Dementia Care program in the health care system I was working in and I said, "Geez, you know I notice you don't have occupational therapy here in your dementia program." And he said to me, "Oh, we don't need occupational therapy. Our patients don't have any rehab potential." And I remember that just being so profoundly wrong (CHUCKLES) to me at the time. And, within a year I was helping him write a book on enhancing quality of life for people with dementia, of which the center core of the quality-of-life model that was being posited was meaningful activity engagement. And so, when you think about advocacy, you think about getting involved. Don't expect the doors to be open. I was talking to someone this morning who said, "If there's not a seat for you at the table, bring a folding chair." And I really do think that this is one of those times when people have to maybe go outside their comfort zone and take some risks and reach out and ask some questions.

You may very well be surprised it may not be, "Here is your seat at the table", but it may be over time you're able to navigate and negotiate something that's actually gonna be not only in your best interest in terms of your feeling productive and contributing to the profession of occupational therapy and the greater good. Right? That's why we all became OTs. We wanted to do good. But you're also going to be advocating for the profession at the same time. And that's really, really important right now.

MATT:  
Absolutely, and it just brings to light the importance of Jill, you've lived the experience and you've lived the example of writing a letter to Memory Care Home Solutions. And everything that has resulted because of that willingness to take the risk and learn more and step up and advocate for occupational therapy and working with this population. You mentioned that the applications are opening in fall. The deadline for the letters of interest has passed. What's kind of the next deadline or timeline that practitioners should be aware of and what kind of requirements should they be looking into to prepare to hopefully advocate and be involved in the guide model?

JILL:  
We're not exactly sure of the specifics on the next piece of the timeline, but everybody should have their eyes open in November when we'll see the details in the request for application. And then to be as prepared as possible by November so that you can get right to work at putting an application together with partners. And then something that's nice about this model is that for people who are forming new programs. So, for those of us who are building new partnerships to put forth an application, there will be a one year ramp-up period that acknowledges that a lot of capacity building work needs to be done before people can roll out a brand new program like the guide model. So, for some people who are already established and prepared to build for this might be able to start delivering the model as soon as July of 2024. For people who are building new programs, we will have until July of 2025 to be ready to deliver the program. So, there is there's still time. Any good idea and good partnership work that can be done now will help people have the time that they need to build capacity for delivering a model like this.

So, the time is now to get those conversations started. And I would just encourage everyone, if you see a need that OT can fill in your current work setting as far as people living with dementia are concerned, be a voice, shine a light in the area where more support and service is needed. We all see these voids in our work settings. Keep asking questions. Work with your management and your leadership team to say, "Hey, this could be better. We could be providing better care for this population that not only supports them, but also supports their families and keeps them all together longer." So, everybody has a voice in this work.

MATT:  
I love that. That's a wonderful message, and I have a follow up too. What are your hopes for how occupational therapy can really feel those voids? How do you envision OT practitioners being involved in the model and making a difference to help people living with dementia and filling those voids, as you mentioned?

JILL:  
Well, I think a model like this is ideal because it allows people to have support throughout the journey. So, it's our vision at Memory Care Home Solutions that everybody gets t. Including people with dementia, gets to live a life of dignity on their own terms. So, what I would like to see for OT is that means people have access to OT at points along this journey when they need the help. And as with any neurodegenerative condition, that changes gradually over time, the types of OT help that people need will also change over time. So, I think a model like this will help people access the right supports and the right services at the right time to live life on their own terms. And to live a fulfilling life which people with dementia can still live a joyful life full of meaning and connection long into the progression of this condition. Occupational therapists in particular is the profession that will help people define what their best life looks like and how to engage in meaningful activities, meaningful relationships, and how to maximize function at every stage of dementia progression.

MATT:  
I love that. What types of resources would you recommend to practitioners who wanna learn more? We've mentioned CMS.gov. Are there any other resources or research articles that you would recommend our listeners look into?

SCOTT:  
So, I would just put out another plug in Jill mentioned the Community of practice. I think that that's a really important avenue for people to connect with one another, and part of this creative problem solving will be enhanced by sort of the opportunity to share a network with other providers who might be doing similar work. And so, I think there's a lot of potential not only for creativity but also for feeling some support, because as I said, this is a little bit of a step out of our comfort zone to try to figure out this business model on this approach. I really do think that that community of practice is a really important and valuable resource. I also would just alert people to the fact that the dementia practice guidelines are being reviewed and updated as we speak. So that the AOTA practice guidelines will give a fresh look at the literature and the evidence for occupational therapy interventions with folks with dementia. So that's not available right this second, but it will be forthcoming and you certainly can refer back to the previous, the existing practice guideline for evidence-based programming.

And then some of the programs specifically that the evidence-based programs that Jill mentioned, cope and skills to care and tap the tailored activity program. Those have research articles that are available for folks to look specifically and directly at the evidence if they're interested in getting that granular. Or if that argument would be useful in your business model planning to show that there is sound and substantial evidence to support OT programming in this in this space.

JILL:  
Yeah, and I'll add a couple of our favorite resources that we use every day at Memory Care Home Solutions. The Family Caregiver Alliance has wonderful tip sheets and in multiple languages. Material that professionals can use. Materials that are family and caregiver-facing. Really great stuff on Family Caregiver Alliance and the Benjamin Rose Institute on Aging maintains a best practice dementia caregiving resource. kind of like a library of evidence-based dementia caregiving interventions that it has a nice summary of many evidence-based programs, including some that are very occupational therapy specific. And links to all the primary source articles on those interventions. And from a video perspective, I will say, we at Memory Care Home Solutions maintain a YouTube library of really simple and practical videos on best practices in dementia caregiving. And Teepa Snow, another OT, does beautiful work in the dementia space and has wonderful videos on a positive approach to care for dementia.

All great resources and I'm sure I'm missing many that are also wonderful. But these are good starting places, and the Alzheimer's Association. The national organization does so much to make great educational content available. And to their advocacy arm, the Alzheimer's Impact Movement does so much to advocate for treatment options for this population.

SCOTT:  
Can work halls work with Dementia Care. Dementia Care Specialists is another OT-driven resource that people should be aware of if they're not already.

MATT:  
I Love it. We've got a full buffet of resources for our listeners. I've been interviewing people for a while for AOTA and every time I learn so much, I feel edified. I feel more educated. I feel more inspired at the end of every interview. But this one in particular, I feel just a fire about, wow, this is such a great opportunity for occupational therapy and I'm so glad to be a part of this profession and to get to know people like both of you who advocate for our profession. And provide these opportunities and kind of education for people to move forward. And I just wanna end with a Golden Nugget segment and ask you both if you could share one tip recommendation for OT practitioners. What would it be?

JILL:  
Oh, that's such a hard question. (LAUGHS) There's a lot of pressure, Matt.

SCOTT:  
I have an answer. One of the things that I've learned as I've gotten involved with AOTA more and I've reflected back on my own career. The idea that opportunities to innovate really require us to first look at our core values as occupational therapists and then look at the opportunities that are available and how do we fit those core values into the opportunity innovatively. And that sounds a little complicated, but I do think that sometimes human nature is to chase the shiny object, and so there's something new. So, I wanna do something new to respond and to innovate. And sometimes that means leaving what's tried and true and what our core beliefs are. And I think as I think about this model, I think how critical it is to keep the core values of occupation and client-centered care and occupation-based performance at the center of whatever models folks are able to navigate and how important it is to stay true to that core while being creative and being solution minded and stepping outside of our comfort zone.

That to me is really the essence of what we're talking about here.

MATT:  
I love that. That's a wonderful nugget Scott. And Jill, same question to you.

JILL:  
I would say let the voices and the experiences of the people you serve be your guide. And if you acknowledge that you will learn more from every patient or client encounter then they will learn from you. You will put yourself in a position to use your occupational therapy lens to make life better and to meet their needs through a better experience. So just remember that it's a gift when you get to have time and experiences with the people you serve. They are the real experts and they will guide you to new applications for occupational therapy.

MATT:  
I love that. That's amazing. Thank you both so much for everything you've shared today and for these golden nuggets to really send us off. Thank you so much for your time and it's been a real pleasure speaking with you both.

JILL:  
Well, it's been a lot of fun. Thank you, Matt, for caring about this issue and for highlighting the new model and the needs of patients with dementia and their families.

MATT:  
Absolutely.

SPEAKER:  
Thanks for listening to the AOTA podcast. Tune in again next time. (UPBEAT MUSIC).