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Meaningful Lives As We Age

Journey to GUIDE: One Practice's Road to Implementation
Momentum Discussions podcast
Transcript



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Announcement:
Welcome to the Gerontological Society of America's Momentum Discussion podcast, where we explore the groundbreaking topics and advancements that are generating significant excitement in the field of aging.

Jen Pettis:
Welcome to this GSA Momentum Discussion podcast episode titled Journey to GUIDE: One Practice's Road to Implementation. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Eisai, Genentech, Lilly, and Otsuka for their support of The GSA KAER Toolkit for Brain Health and today's podcast episode. My name is Jen Pettis. I'm the Director of Strategic Alliances at the Gerontological Society of America or GSA, and I'm recording this podcast episode live in the podcast booth at GSA 2024 in Seattle, Washington.

Jen Pettis:
This year brought the implementation of the Guiding an Improved Dementia Experience (GUIDE) model, a Medicare payment and service delivery model. During this podcast, we'll learn about that model and how one practice has made its journey to being a GUIDE provider. My guests for today's podcast are my friends and colleagues, Dr. Carolyn K. Clevenger, a Professor at the Nell Hodgson Woodruff School of Nursing at Emory University and the Founder and Director and a practicing nurse practitioner at Emory Integrated Memory Care, a nurse-led primary care practice for people living with dementia. Dr. Clevenger is joined by her colleague Laura Medders, a licensed clinical social worker and the Administrative Director of Emory Integrated Memory Care. Welcome, Laura and Dr. Clevenger. I'm so glad you could join me.

Laura Medders:
Thank you so much for having us.

Carolyn Clevenger:
It's always a pleasure, Jen.

Jen Pettis:
Thanks so much. Laura, could you tell our listeners about GUIDE and the services it will provide to people with dementia and their care partners?

Laura Medders:
GUIDE or Guiding an Improved Dementia Experience is an alternate payment model through the Centers for Medicare and Medicaid Innovation (CMMI). They wanted to offer a different way to pay for comprehensive dementia care. They looked at what other programs are doing across the country that are already providing these services to patients and families. What types of elements are really featured and highlighted and necessary if you're providing really good comprehensive dementia care services? They looked at several programs throughout the country. They came up with certain elements that they noticed were pretty consistent with really good dementia care and put that into this new alternate payment model for people who are receiving traditional Medicare benefits. Part of the elements are making sure that people have a diagnosis. They are getting those cognitive assessments, diagnosis, and some idea of what stage their person may be living with, as well as the disease process.

We know that sometimes that's really difficult to do. It's really important that people have an idea of where they are on their journey. A critical piece of providing excellent dementia care is doing those assessments and making sure that the patients and families have heard that as well. Care coordination and care planning is also a critical piece of providing good dementia care. You can't just give the diagnosis and say, "Okay, bye." Families need a lot more support and handholding when they get this diagnosis. You need to be able to connect them to community resources. You need to be able to connect them with a plan for how they will address the symptoms that their person may experience and be living with. You also have to provide access to 24/7 care through a care team. That has been very important for our patients and families, particularly in our practice. We've had some people say, I've never had to use your after-hours line, but just knowing that this is available has given me so much comfort and the confidence that I'm in the right place. They feel like you have a team that is supporting them and will be there when they have an emergency. Providing caregiver support and education is also really important.

Laura Medders:
At Integrated Memory Care, we believe that our caregivers are our best intervention for our patients living with this disease. Having a well-educated care partner really impacts the trajectory of the person living with dementia and the experience that they'll have.

If you can provide that education and support for families so they are not scared or frightened or making rash decisions when a new symptom comes up, it helps everybody remain calm when they're in the middle of this crisis. If a family member does not know that it is normal for the person living with dementia to forget who they are, it can be so alarming. For them it is an emergency because this has never happened before. How could you not know who your spouse was? How could you not know who your daughter was? And we're all like, "What did you expect? This is a normal part of the disease." But if you have not been told the diagnosis and do not know that this is a typical symptom this is very alarming. Again, providing caregiver education and support is important.

For the first time, Medicare has acknowledged that caregivers sometimes need a break. For eligible care partners or patients, care partners will get a $2,500 respite to use towards services in-home care, potentially an adult day program, or potentially just respite care at a congregate living setting as well. That is cool and unique to the GUIDE program.

Jen Pettis:
That's terrific. I have a couple of follow-up questions. Is GUIDE available for people with all different diagnoses of dementia?

Laura Medders:
Yes.

Jen Pettis:
It is any type of dementia due to any cause. That's terrific. Then how many sites are there, Laura?

Laura Medders:
It is a program that people have to apply to participate in. Health systems, clinics, different health providers, or services had to apply with CMMI and say, "This is something we are interested in doing." They could apply and either be an existing site, which started in 2024, or they applied and will be a new site, which will start in July of 2025. There are approximately 75 existing sites throughout the country right now. We expect that there will be about 390 GUIDE sites when the new sites go live next July.

Jen Pettis:
Dr. Clevenger, on what care models did CMMI base its required services that Laura just reviewed for us for the GUIDE model?

Carolyn Clevenger:
As Laura said, when Medicare, CMMI specifically – the Innovation Center, was looking to create this alternate way of being paid and delivering care, they based it on the best practices out there. There are comprehensive dementia care practices across the U.S., and many of them were started with funding from the Innovation Center. I would say no comprehensive dementia care practice that I've spoken to created their model to keep it local.

Carolyn Clevenger:
Everyone created this model because they wanted to either replicate what they're doing by supporting other sites to do that or by modeling best practices and publishing and disseminating. Medicare wants to create a nationwide program, which they're basing on published outcomes. These are evidence-based practices, meaning they look at practices found in the literature. They invested in these practices starting with a long-term eye toward whether we can test, which is indicative of the Innovation Center, we develop innovative practices or practice models, we test them, we look at outcomes, and if they're effective, we talk about scale. This is the scaled phase of that.

Now, six practices have joined together and were identified in a report by the Milken Institute titled *Scaling Comprehensive Dementia Care*. There's an appendix there and you can see a side-by-side table of six comprehensive dementia care practices. None of us are the same. We all offer care differently; the models are different at every site, but we agreed on these common elements. These sites include the Benjamin Rose Institute (BRI) Care Consultation, Care Ecosystem, MIND at Home, the Aging Brain Care (ABC) Medical Home, the UCLA Health Alzheimer's and Dementia Care Program, and Integrated Memory Care.

That chart has been helpful. There's a side-by-side comparison for people who are interested to see how they're staffed, what the services are that they deliver, and what their outcomes have been in terms of what they've published on patient outcomes, caregiver outcomes, and cost, as well as an idea of what the investment is to create a model like that. You can imagine a very high-touch model like ours, in which we have a lot of contact with our patients, we have really robust outcomes, but it's a robust investment mostly in the team, and we love our team, so we are happy to make that investment. We all feel like it's the right model for our health system. There's a recognition that the model that each of us has might be different and ideal for different systems, different communities, different cultures, and so forth. Those six are published in a couple of different places, but all of us are interested in some degree of contact. That may be by telephone, online, or a consultation one time, or the extreme end of that, which is when we begin with people and stay with them until it's time for hospice.

Jen Pettis:
I understand that the six of these evidence-based models have come together to form the National Dementia Care Collaborative. Tell me about the collaborative and how its members can support other organizations seeking to become GUIDE sites.

Carolyn Clevenger:
Each of us in these six comprehensive dementia care models developed and tested this. Many of us, not all, come from academic centers as well. We publish and are pretty open about what we deliver, which can be found in peer-reviewed literature, podcasts, and webinars. We want other people to take up our best models, our best practices. We've formed this collaborative, the National Dementia Care Collaborative or NDCC, with the generous support of The John A. Hartford Foundation so that some of the practices and some of our models have already been replicated their model in other health systems across the country. Some have done it many more than 10, more than 20, some have had just a few. And not everyone has that infrastructure created for it. If you look up Integrated Memory Care, you will find information about our practice itself that's patient-facing. You will find our outcomes and things that we've tested and developed. If you look at the academic or published literature, you would not necessarily realize that there is a pathway to replicate an IMC type of practice in your system with our support. There's that infrastructure that we started to pull together.

Carolyn Clevenger:
The collaboration has worked pretty closely with the Innovation Center, the CMMI team. We offered one summit last year when GUIDE was initially coming out, and there's another summit at the end of this month in 2024. They've created a web presence for practices or systems who are interested because they are setting up a new GUIDE site in July 2025 and it would be helpful to learn lessons from those of us who are already in established GUIDE practice or to implement a model rather than coming up with something on our own in our health system to look at an evidence-based model that has been tested.

We have workflows, position descriptions, note templates, and billing guides. We can share all of the lessons we have learned through some pain points of our own so others don't go through those pain points. There are logistics and practicality in following an established model. But there's also the fact that we have demonstrated outcomes, which are the same outcomes that your GUIDE site will be measured against once you are live. We've been successful in avoiding hospitalizations. We've been successful in de-prescribing, especially high-risk drugs. We've been successful in reducing caregiver distress and burden. We've not measured quality of life; that would be a new one, and that's a tough one to measure. Everyone is clear that with GUIDE, the measurement tool that we'll use is probably not designed for the purpose that we're using it for now.

Based on our outcomes, and I would say with the other five models as well, we would expect we will be quite successful in meeting the goals and the outcomes that the Innovation Center is holding us to. That has implications for the overall success of GUIDE. It has implications for your payment amount because this is a payment that is adjusted based on outcomes after the first few years. The idea of collaboration is to say to practices, especially if they're standing up GUIDE, but if any system or practice locally is saying, "We have this population of people living with dementia. We know we could do a better job supporting them. We know we could offer more comprehensive services." If they want to move forward to do that, then we also want to support them in doing that, whether they're in GUIDE or not.

We created this more centralized resource where people can go to one place to learn about these six models. They have a resource to talk to and learn more from. They get an idea of how these fit into their system or not. In the next year, we will begin to have affinity groups for other practices who are interested in adopting the IMC version or the Benjamin Rose Institute's practice (for example), they can listen to those and learn lessons in that way. Each of us has different sorts of ways to support those practices, and that's the idea behind the collaboration. It is one centralized place versus each of our models independently. We are trying to let folks know, "Hey, we're here to help you, we're here to support you, and we just want to see better dementia care for everyone."

Jen Pettis:
Excellent. I want to spend the rest of our time discussing your team's journey together—Emory Integrated Memory Care's journey to becoming a GUIDE site. I know you're going to publish some of that journey in a poster here at GSA 2024. I also know you enrolled your first patient in July. I'd love to learn about your experiences since then. Who wants to get us started?

Carolyn Clevenger:
Integrated Memory Care (IMC) means integrating primary care, dementia care, and caregiver services all under one practice. You would think this is already a very comprehensive dementia care model.

Carolyn Clevenger:
Clearly, we were involved in these conversations back in the days of that initial report about scaling comprehensive dementia care. We created that label or term for our practices, ours and the other five, what that means, and what the core elements are.

We knew about GUIDE before it was called GUIDE. We sensed that it was coming, and we should be the most prepared. There are still a lot of processes and workflows and adjustments that we've had to make, and I'm glad to do it. But it's a journey. It's aptly named.

I would say that, of those three columns, that's how I think about our practice when introducing it to patients and families, and that these three different services happen under one practice. We shared a poster today, and I'll walk you through how we've made those adjustments. From the primary care side, I would say that's the least adjustment that we've needed to make because we are still doing that chronic illness management. We're still dealing with acute respiratory illnesses in the season that we find ourselves in now. We are still looking at that bladder medicine and how it's affecting your sleep, cognition, and all sorts of things. Because, as I like to say, your brain is connected to the rest of your body. The fact that we're doing your primary care, but in the context of dementia, maybe is the least of an adjustment.

But there are still adjustments there. What we put under primary care are things like annual wellness visits. Annual wellness visits are included under GUIDE. That's included in your dementia care monthly payment. We are still doing the annual wellness visits, but we had to tweak the billing because that's a disallowed code now. And you never want in any of these changes of codes to rely on everyone in our practice remembering, "Oh, this person is a GUIDE patient." There's some automation. There's been a lot of ongoing counseling and support with the IT team, the billing team, the coders, the finance team, and the medical record folks. There's a lot of automating those sorts of things. The same thing is true for care management/care coordination.

We are doing care coordination for all kinds of reasons, primarily dementia, but lots of other things, too. We've been doing chronic care management, complex care management, principal care management, and transitional care management. Since those codes went live with Medicare in the year we opened in 2015, we are still doing those activities, but the way we capture them is different since it's another disallowed billing code. We just have to make sure we don't bill for that if we're already doing that. We think about de-prescribing under the umbrella of primary care. These are all the things that are still happening. We're still following up with folks in terms of post hospitalization. We're still coordinating with other specialists and services, but we're not billing for that.

You would think dementia care would be identical. The services we're doing by and large are similar, but staffing is slightly different. One thing to think about with GUIDE is that you have a monthly payment, you have these required services or care elements that you need to include, and then you're held to these outcomes. Beyond that, it's pretty flexible in how you deliver the care, but there are requirements for your staff. Your practitioners need to be dementia-proficient clinicians. There is specialist training that we've offered again through the support of The John A. Hartford Foundation and GAPNA, which is called the Dementia Care Specialist. All of our nurse practitioners have completed that training. However, there needs to be a dementia-proficient clinician; in our case, all of them have met those criteria. Then there's the role of Dementia Care Navigator, and people might staff that differently. For us, one of our registered nurses fulfills the official role of Dementia Care Navigator.

Carolyn Clevenger:
While she's not the only one doing all the care navigation and coordination, she holds that role in our practice. In our staffing, we've carved time for one of our nurse practitioners to be the GUIDE Manager and one to be the Dementia Care Navigator.

Jen Pettis:
Is there a training requirement that's specific for the Care Navigator?

Carolyn Clevenger:
Yes. We had to identify what we had done to train our registered nurses. Again, I just can't say enough about everyone; everyone on our team is amazing. We all just adore our registered nurses. They were the first two in the country to complete a program called Dementia and Palliative Education for Nurses (DPEN), which was out of the University of Washington. They completed that training, which included some online asynchronous didactic and synchronized meetings with faculty to review cases. But they've also completed a few pieces we had put together locally. I would say the bulk of what they did primarily for their training was that. There is a list of required content, but I wouldn't say there's one source today that you go to this one training. I anticipate there will be a few of those coming.

The only thing I would say in terms of our dementia care changes is that you have to do comprehensive assessments, including cognition and behavioral function, which we've done for almost 10 years. There are different measures, though, because there are some standardizations. We had to switch to the Clinical Dementia Rating scale, which we've not used before. There is a home safety check that we've figured out a way to incorporate. We have a significant number of patients who reside in congregate living, assisted living, senior housing, and so forth. For those people, we already do some home visits with potentially. But just staffing and the logistics, and also asking patients if they're okay with you coming to their home, which has been okay for us because we have a relationship with people. It's not always easy for beneficiaries to say, "Sure, come to my house." The last piece under caregiver services is that we offer in-house support groups and classes and will now administer a respite program. I know other practices will potentially be using different community agencies, but we've provided support. That's probably been the biggest lift, I would say.

Laura Medders:
It's been really interesting to try to pitch GUIDE to our current, existing patients because we have said, GUIDE is this new program that's being offered, you're eligible, we've screened our patients, we know which ones have traditional Medicare and live in the zip codes that we will be serving through the GUIDE program. They're perplexed. They say, don't you already do this? It's been difficult for our families to say, "Sure, I'll agree to these extra things" because they're getting most of the comprehensive care. They've already been getting that within the Integrated Memory Care program. It has been a little bit perplexing for people. It allows us to have a stronger partnership with families because it means they are saying, "I agree to be contacted by you regularly. I agree to talk to you. I'm agreeing to allow you to come into my home and do these things, do this safety check."

I think it is a stronger partnership or a more official partnership with our patients and families than we have had in the past. And we are a pretty high-touch clinic to begin with. It's quite a privilege to be able to serve in this way. I do think the respite piece is what attracts a lot of our patients and families to this. With additional in-home care, it's always difficult to try to get families who think respites will be covered. They think assisted living is going to be covered. And now, we can say, "Here are some options for you," which is so nice as a social worker not to always have to deliver the bad news.

Jen Pettis:
You mentioned zip codes. Can you tell me if you chose zip codes or if CMS assigned them to you? How do they align in your geographic area? What does it mean for the number of folks you can serve?

Laura Medders:
We mentioned zip codes. You have to tell CMS where you will serve, but they did not prescribe that for us. With our respite partner, we thought it would be too big of a heavy lift to have Emory Healthcare or myself personally partnering individually and directly with private duty caregiver agencies and adult day programs. We may still do that, but it's as large of an area as the Atlanta Metro is, as many of those organizations are in the Atlanta area. We partnered with Jewish Family and Career Services in Atlanta. They have been running a voucher program very successfully with AgeWell Atlanta, the local agency on aging, with other programs in the Atlanta metro area. They were a natural and obvious choice for us to reach out to. The only reason we are restricted to zip codes is because these are the zip codes where they have partners already providing these services. For us, we said we will serve patients. This is how you're going to do it. This is how we're going to implement the respite benefit, and we're only serving patients who are living within their territory.

Carolyn Clevenger:
It's important for people to know there's a lack of clarity about how the respite works. The $2,500 is the cap that you have that we can spend on one person in a year. And it's not like a voucher or a gift card, where you can get your home care agency and spend the gift card. That's the total amount. But if you're doing in-home respite, which is the required respite to offer, that is in a unit of four-hour blocks. There's a set rate that Medicare will cover for that four-hour block. I'm glad we've been friendly partners and collaborators for a long time because here's what I'd like you to accept as payment. For example, the four-hour respite costs $125, but the agency charges $160. You cannot bill the patient for that remaining $35.

You are figuring out if it will be more than that and if the group will accept Medicare payment. If there are any fees beyond that, your practice must cover that. The thought is you're receiving this monthly payment, and you have a lot of flexibility with how you manage it. It's entirely possible, I would say likely, that if you're working with a partner, even if you're doing administration yourself, you're probably going to have expenses above and beyond those costs. That will come out of the overall budget, and it is with the agencies under contract. You don't get to shop around. It's part of the program. That said, having some amount of covered respite will not cover you for a year. It's not going to cover you for six months. It's going to be like some number of days.

We estimate 20 units of that respite for our folks, which is about what we're estimating. But let's say your husband has surgery and he's taking care of his wife; that is exactly the time he's going to need some home respite, or this gets you through until some other option is available. It's still hugely valuable. The fact that we've never had coverage for respite before and now we have something is a huge deal. But there are some logistics to work through.

Jen Pettis:
I imagine. Thank you both for joining me in the podcast booth in Seattle at GSA 2024. I want to ask you each to leave our listeners with one final thought.

Carolyn Clevenger:
GUIDE is an exciting program. I'm most distressed when people have never heard of it. I'm really glad to get the word out. I think it's very exciting and a big move by Medicare to recognize that there are tremendous needs for people living with dementia and their caregivers and an effort to try to address some of those through this test. And we sure hope it works.

Jen Pettis:
Laura, how about you? Final thought?

Laura Medders:
I am so excited about GUIDE and the acknowledgment that good dementia care is more than a diagnosis. Good dementia care includes wraparound services and support for the caregiver. I am hopeful that this will have a huge impact on the many families who are living with dementia in America.

Jen Pettis:
Again, Laura and Dr. Clevenger, thank you for your time and insights today. It is always a pleasure to sit down with you ladies, especially when we can do it in person at GSA 2024. Thanks so much for those listening to the podcast. I hope you found it enjoyable and informative. Thanks again, ladies.

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