Mind Matters Podcast - Caregiver Support

Introduction:

Welcome to another episode of the Mind Matters podcast where we talk about brain health, dementia care, and so many topics in between. Today we're focusing on a topic that touches many people, both in our greater society as well as within our Acts communities, and that is providing care and support to loved ones living with dementia.

Whether you're a caregiver yourself or maybe you know a caregiver or are simply tuned in to learn more about this journey, you're not alone. We have resources available to support you, so in this episode we're going to talk about what support for caregivers really looks like. We also hope to be able to provide some practical tools and tips that you can take away and implement in your own caregiving journey to help support both yourself and your loved one.

Caregiving is love in action, but we often don't talk about the invisible weight of caregiving. It can be exhausting – both physically and emotionally draining. Caregivers can feel isolated and overwhelmed, and we often don't talk about these things. When dementia is in the picture, it can be even more of a challenge to be that primary caregiver. When you are the primary caregiver of a loved one, your role changes, your relationship changes, the way you connect changes, and that can be a challenge. It's normal to feel loss. Grief is part of that relationship because the dynamics have changed.

It's very important to know that you're not alone in this. A lot of times caregivers feel isolated because they feel like they need to handle this all alone and carry this weight as the 'healthy' one in the dynamic. But it's OK to talk about it; that's how we grow. That's how we can be better caregivers, by taking care of ourselves and making ourselves a priority. That will ultimately help you support your loved one.

So today, we're going to break this down into four core areas where caregivers need support. We're going to talk about emotional support, informational support, practical support and that supportive connection and how important that is for the caregivers to get that within their community.

Emotional Support:

Let's start off with emotional support. It's so important when we talk about emotional support to recognize that caregivers experience many emotions: loss, grief, guilt, fear, frustration, maybe even anger. They can experience them sometimes all at the same time, with so many emotions swirling at once.

Caregivers can also experience emotions as the relationship with their loved one changes. Maybe it's a spousal caregiver and they used to have that partnership with their spouse for 40, 50, 60 years, but now that dynamic starts to change to caregiver and care receiver. Or maybe it's an adult child and they're taking care of their parent, and they start to take on a little bit more of that parent role and that dynamic shifts. So, you can experience loss or confusion or grieve that former relationship. Many adult children are in the sandwich generation too, where they're caring for their own young kids and also take on caring for a parent who needs more support or needs caregiving as well. And that compounds the situation and the emotions that come along with it.

What's important to first do is just recognize these emotions and that it's okay to have them. It's also important for caregivers to give themselves grace; we are all only human after all. A key component for caregivers is to know what your emotional limits or emotional bandwidth might be. And that's going to be different for each person who is a caregiver. You need to know your limit so that you know when to seek support at the right time for you.

After we recognize and acknowledge emotions, we can look at what supports are available to help us through this emotional time. The primary resource for emotional support will be talking through how you are feeling. This can be one-on-one through counseling or through talking to a therapist. A therapist or counselor can help caregivers to both process their emotions, but also to learn where their limits might lie so they know when to ask for help. At ACTS, we offer mental health clinicians for residents to have that formal support available.

Emotional support can also be seeking out commonalities with other people going through the same situation. Talking with others who have the same experiences with their own loved ones can offer validation for how you’re feeling. They can also offer tips and strategies to navigate this journey, as well as an opportunity to vent to someone or a chance to simply laugh together. Caregiver support groups offer this opportunity to connect with others, and many of our Acts communities have groups that meet on an ongoing basis. The Alzheimer's Association is another great resource for support groups. They offer groups that are in person but also have virtual groups, which can be a great option for a caregiver that might not be able to get out to a group regularly.

In addition to formal support groups and therapists, just having someone to talk to who can listen without judgement is so integral to that emotional support component for caregivers. This can be a trusted friend, family member, someone in your church, or a neighbor.

Informational Support:

The second topic we are covering is informational support. There is lots of information about dementia out there but caring for a loved one that has cognitive change or that is going through a dementia journey is not something that you tend to learn about until you have to. Most people are not proactively learning about what it would be like to care for a loved one that might have a dementia diagnosis.

In some ways, learning about dementia can be like learning a foreign language, especially if you're already in the middle of your caregiving journey. Being able to be a little more proactive in this situation and start to gather more information about what dementia is, what it is not, how you can properly care for someone, and what might they experience as they're going through the disease process will be highly beneficial in the long run.

From a caregiver perspective, you take on not just the emotional toll, but the physical toll of caring for someone as well. You might not be able to leave them alone for long periods of time, or maybe you're having to assist them to use the bathroom or to get changed daily, and that's more physical activity than you're used to. When you get into that position of physical and mental exhaustion, it becomes a lot more challenging to take a step back and say, "OK, what do I need to learn at this moment in time?" Because of this, being proactively informed can help you to feel more in control of the situation.

The best way to become informed is to seek out information provided by reliable sources. A previous Mind Matters podcast discussed that dementia is an umbrella term that encompasses a lot of different diagnoses. What specific diagnosis a person has can impact what you might see from your loved one over time, especially when it comes to symptoms and when they might appear in their journey. Learning specifically about what type of dementia they have is a really great way to inform yourself ahead of time so that you might know what to expect down the line and you might know how to navigate those challenging situations when they arise.

One of the best sources of information is the Alzheimer's Association website. They have a really wonderful portion of their website that's dedicated to caregivers where you can get help with everything from finding a support group (as previously discussed) to learning about the different types of dementia, and learning about how to give proper care to someone in the early stages of the disease process versus the middle stages and versus the late stages. Because what we do know is that as they change over time, the needs for a caregiver are going to change as well.

Another great resource for information is the National Institute on Aging, which is the primary federal agency supporting and conducting Alzheimer's disease and related dementias research. Their website can help you learn about current research and what's out there right now from a treatment perspective. These studies and information can help support your understanding of the disease process as well as seek out opportunities for better care and treatment for your loved one.

There are also some really great books geared towards caregivers. A highly recommended book is called *The 36 Hour Day*. It is based on the concept that as an individual, we all live a 24-hour day; but as a caregiver, you pack more tasks into that day, so it's almost like you're living 36 hours in a single 24-hour period because you're doing so much for someone else. Another great book is called *Living in the Moment*, which supports the idea that your loved one is going to change and by default you must change with them. Caregiving requires you to be in the moment with them and to be willing to do things differently than you're used to.

The last resource for information is right within your own community at Acts, as there are many great supports available. There are social workers who can provide clinical guidance and information. The Primary Care Office is a great place to get facts on disease process and diagnosis. Lastly, there is the Memory Support Team, which produces this podcast and a variety of other educational tools to learn more about the brain, dementia, and caregiving. Our team is always willing to be a sounding board to offer support for residents going through this journey.

The goal here is, ultimately, that understanding the disease process and understanding what your loved one is going through will help you make better decisions for them and for you and hopefully making you feel more confident in being a caregiver as well.

Practical Support:

Practical support is tangible help with daily tasks for both the caregiver and for their loved one who's living with dementia. This might be helping with preparing meals, medication oversight, helping with everyday care for your loved one, or transportation help to an appointment or doctor visit. Or maybe it's simply just spending time with a loved one who's living with dementia to give that caregiver a little bit of a break. It's important for caregivers to really know their limits when it comes to identifying what practical support they need. No one can do it all 24 hours a day, every day. Understanding your own boundaries can help you to know when you need to seek support and what it should look like.

There are two types of practical support. There's formal support, which is going to be trained companions and caregivers who can come and help in the home when a caregiver can't be there or when a caregiver needs a little bit of respite. Formal supports can also include respite care, such as adult day programs. At Acts, many of our communities have Home Service companions available within the community. Many communities also have Memory Cafés, which offer the opportunity for engagement and support for both the caregiver and their loved one.

Then we have informal support, which is going to be things like family members pitching in or friends or neighbors stopping by. Even something as simple as offering to pick up prescriptions or dropping off a ready-made meal can relieve a task burden from the caregiver’s plate. With this informal support, it can be helpful to ask for specific assistance rather than assuming that others will know how to help. It may be helpful to have a short list of ways that you need support so that when someone says, “How can I help?” you have a reference point to give them a task or situation they can assist with.

A key component of putting these formal and informal supports in place is being proactive. It is important to know what is available to you and have a plan for how to put that support in place when the time comes so you can alleviate the stress of being reactionary once a situation has become too challenging.

Community Support:

Maintaining positive community connections is so vital and has so many benefits for caregivers. A strong connection within your social community can offer stress relief, better physical and mental health, opportunities for informal support, and an outlet for self-care. It is important as a caregiver to take care of yourself as well and give yourself permission to make yourself a priority so you can be the best version of yourself when caring for your loved one.

Often, it can be challenging as a caregiver to set appropriate boundaries, but the natural inclination to take on more and keep saying ‘Yes’ to new challenges can overextend your physical and mental limits. When caring for someone else, you cannot pour from an empty cup. It becomes increasingly important to do things that feed your spirit and give opportunities for meaning and purpose throughout your days other than being a caregiver. This could be spending time in nature, getting a massage, reading a book, or just sitting down with a nice cup of tea. Acts communities have many wonderful clubs and special interest groups to join, whether for socialization or to engage in a favorite hobby. Scheduling time for this connection on a regular basis is a great way to ensure you don’t forget about your self-care.

Practice saying ‘No’ as part of your self-care and caregiving journey. This can be very challenging to do but it ultimately helps to protect your well-being by reducing stress and likelihood of burning out. One way to put this tip into practice is to reply to someone’s request by saying “let me check my calendar and get back to you”. This affords you the opportunity to politely take a moment and reflect on whether agreeing will bring you positive outcomes or more potential stress.

As previously mentioned, Memory Cafés within our communities also offer a way to socially and meaningfully engage with the person you're caring for in a supportive atmosphere. It is common to forget how to have meaningful moments of engagement with your loved one, as caregiving can feel very task based. Memory Cafés can help to frame your interactions in a positive light and help find that spark again of who you were as a duo before this journey began. They also offer opportunity to connect with other people that are going through it, so you can socialize together and build a bond over shared experiences.

Conclusion:

Today’s podcast has reviewed four key areas of support for caregivers. This information may seem overwhelming, so let’s touch on some easy ways to put these tips into practice.

If you are a caregiver for someone who has cognitive change or dementia, focus on trying to do one thing this week to support your journey. One simple idea is to purchase a book about caregiving, such as *the 36-Hour Day* or *Living in The Moment,* which are both great options and are available on Amazon. Once you have the book, you can read little bits whenever you have a moment. Even five minutes of reading will give you practical information to incorporate into your caregiving routine.

Another idea would be to make a call to explore formal or informal support options. This could be to explore Acts Home Services, to find out if there is a Memory Café at your community, or to investigate other respite options. One simple phone call can give you lots of information that you didn’t have before, and that you can save for the moment you truly need it.

Lastly, try to schedule a quick check-in with yourself to focus on your well-being. Maybe you spend a few minutes reading that book on caregiving you purchased or take a short walk. Even just sitting on the patio to get some fresh air can feel rejuvenating. It’s all about making a little pocket of time for yourself where able, because every little bit counts.

On the flip side, if you're not a caregiver but you know someone who is, there a many simple things you can do to show that person you are thinking of them and offering support. You can send them a card, handwritten note, or even an e-mail or text message just to say, “Hey, you were on my mind. Hope you're doing well.” Offering that simple social connection can go a long way.

You could drop off a meal for someone, especially if you notice they are going through some changes in this journey of caregiving with their loved one. Perhaps you've not seen them regularly down at dinner, so you pick up dinner for them and drop it off saying “I just wanted you to have a hot meal tonight because I didn't see you down at dinner at all this week.” This is a thoughtful way to show you are looking out for them.

Lastly, think about specific ways you can offer your help or time. Sometimes just asking "do you need help" can be overwhelming to a caregiver. But a specific offer can give them the opportunity to say 'Yes' very easily without having to think about how to direct your help. This could be offering to pick up their prescriptions or giving a block of time where you are available to sit with their loved one while they take some time for themselves.

A key takeaway for all these practical tips is that asking for help or offering help does not have to be perfect, it just needs to be done. When the intent is there, the connection will follow. And it is important to remember that asking for help does not mean that you are weak, and offering help does not mean you are trying to take over. It means that you have the best interests of the person receiving care in mind and you are looking to support them in the best way possible.

Thank you so much for joining this episode today. Hopefully you have learned some new strategies and practical tips to support you along your caregiving journey. Please join us next time for our Mind Matters podcast.