USofCare COVID-19 Webinar Series
Realities of Eldercare During COVID-19
Thursday, July 30 | 2pm ET

0:00 - Natalie Davis

Hi everyone and welcome to this United States of Care webinar - Realities of Eldercare During COVID-19.

I'm Natalie Davis, co-Founder and Managing Director for Public Engagement for United States of Care.

I'd like to start by thanking the sponsor for today's webinar, **AARP**.

AARP is the nation's largest nonprofit, nonpartisan organization dedicated to empowering people 50 and older to choose how they live as they age.

With a nationwide presence and nearly 38 million members, AARP strengthens communities and advocates for what matters most to families: **health security, financial stability and personal fulfillment.**

We are lucky to have AARP's **Nancy LeaMond, Executive Vice President and Chief Advocacy & Engagement Officer** and **Megan O'Reilly - Vice President of Government Affairs** joining us today. You'll hear from them both soon.

United States of Care is a new non-profit organization founded a few years ago by a diverse group of policymakers, advocates, regular people, providers, entrepreneurs, public health experts, community leaders, and many more.

Our mission is to ensure that every single American has access to quality, affordable health care regardless of health status, social need, or income.

Our country is at a pivotal moment and our mission has never been more relevant or more important than right now.

The COVID pandemic and national movement for racial justice have shone a light on longstanding gaps and critical inequities in our health care system.

Since the pandemic began, we shifted our resources fully to support COVID-19 response efforts.

We have coalesced our expertise, content, network of experts, and listening research to the release of a number of valuable resources and recommendations to health care leaders, as well as providing 1:1 technical and expert assistance to Federal and state policymakers.

We rely on our Founders Council members, Entrepreneur Council, and Voices of Real Life - **3 of the speakers today are a part of these groups** - to guide and amplify our work.

Today's webinar will focus on the realities of eldercare, and specifically the role of caregiving, during the pandemic.

Caring for our nation's elders and managing their significant needs was already a huge challenge for families and for our health care system.

COVID-19 has put this population at even higher risk, and brought additional complications to an already fragmented system.

There is no doubt the pandemic has thrust these serious needs even more squarely into the spotlight and strained the people caring for the elderly ... their loved ones, community members, providers, and advocates.

It's my pleasure to welcome and thank all our speakers for joining us today and sharing their expertise. I am honored to introduce them.

**Rebekah Azaylia Alexander** is a member of USofCare's Voices of Real Life, which is a group of everyday people who bring their life experiences and needs to help us shape policy solutions. Rebekah is a millennial caregiver to her maternal grandmother from Puerto Rico while maintaining a fruitful career, as well as advocating for broader support for caregivers.

**Alexandra Drane** is an United States of Care Entrepreneurs Council member and is CEO and co-founder of Rebel Health/ARCHANGELS, and the national Wellness Expert for Prudential.

**Nick Loporcaro** is also a member of the USofCare Entrepreneurs Council and CEO of Landmark Health, one of the nation's largest health care companies focused on in-home care of complex, chronic patients.

**Megan O'Reilly** is Vice President of Government Affairs at AARP.

As the webinar title reveals, the challenges of caring for our elders have been magnified by COVID-19 and we're honored these experts are here today to share where we are and what's to come.

It's a big topic, eldercare, so to keep things manageable, I have asked each of our speakers to focus their comments on the reality of eldercare during a pandemic, and what they wish for the future of caring for the elderly.

They'll each take about 5 minutes to speak from their personal points of view as caregivers, providers, advocates, and changemakers.

After we've heard from all speakers we'll open the floor for your questions. Instructions for how to ask a question will be given at that time.

For more information on our work during COVID, as well as our USofCare Entrepreneurs Council and Voices of Real Life, visit our website unitedstatesofcare.org. On our website, you'll also find the recording and transcript of this webinar in about 24-48 hours.

With that,

I will now turn it over to Nancy Leamond to say a few words.

4:31 - Nancy LeaMond

Thank you Natalie and thanks to USofCare's for your leadership and for including me in this conversation. I am a former caregiver and a serial caregiver and this is an extremely important issue to me personally and an extremely important issue to AARP. As Natalie said almost overnight the pandemic has laid bare a simple truth many of us have tried for years to bring to light. That our economy breaks down when people cannot balance work with caring for their family and their loved ones.
Up until now, family caregiving historically has been a personal matter but the challenging reality of caregiving are suddenly on display due to [INAUDIBLE] crisis, now more than 48 million families caregivers are [INAUDIBLE working from home while caring for children or aging parents and worrying what happens if they get sick. There is no backup system. Millions of the central workers must make impossible choices, such

as live without a paycheck, come home to a sick child, an aging parent or a spouse with a disability and put vulnerable lives at risk.

Even before the pandemic the work of caregiving was costly to families. 1 in 5 caregivers report hard financial [INAUDIBLE] and after all family caregiving is not a short term commitment. The average length of care is 4 and a half years. The pandemic is also changing the future of caregiving. An entire generation today is watching and experiencing the crisis unfolding in our nation's nursing homes and long term care facilities.

As of today more than 59 thousand nursing home residents and staff have died from Covid-19, that's 40% of all Covid related deaths in the United States and the number is rising every single day.

At AARP these realities are nothing new to us, but now with the Covid-19 pandemic highlighting [INAUDIBLE] we see a rare opportunity born out of this crisis to do something bold and lasting as our nation responds. Is not enough to return to our patch work system[INAUDIBLE] of public and private support for people who provide care. We can cease this moment to create meaningful sustainable change and state and federal policy, business practice and community response.

In the short term we need to provide immediate support and we need to demand answers, in the longer term we should address the barriers that prevent older adults from remaining safely in their homes and communities and consider new models for care. As the nation's largest organization dedicated to empowering people 50 years and older, we know a goal like this requires bold action. That's why we need to ensure all working people have access to paid sick and family leave. We also know we should provide tax credit for resources in return for time spent providing family care and we should increase the availability of home and community base options. We need to urge policy makers and businesses to invest in making it affordable , accessible and acceptable for all to care for loved ones as they age. We can mobilize entrepreneurs and innovators to pilot new solutions for older adults.

I look forward to working with many of you, to continue to draw much needed attention to this issue as we really look to find solutions for millions of caregivers who are depending on us to do so.

I'll now turn it over to Rebekah Alexander, a member of USofCare's Voices of Real Life, to share her experience as a millennial caregiver and advocate.

8:27 - Rebekah Alexander

Hello everyone, it's a pleasure to be with all of you today able to use this platform to share the perspective of a millennial caregiver. My journey began nine years ago when my maternal grandmother moved up from Puerto Rico to live with us after my abuelo passed away. Neither myself nor my mother could have anticipated all of the extraordinary challenges to managing my grandmother's care that would come our way. She was with us at home for the first seven years but unfortunately, approximately 2 years ago in May, my grandmother was admitted into rehabilitative care after a fall in our kitchen and never came back home - she never fully regained her strength and became bed ridden. Since her initial admission, she has been placed on and taken off hospice care – ironically, the latest stint ending in November 2019 just before the pandemic began. Prior to the pandemic, my mother and I went to visit her nearly every weekend – myself, every other weekend as I live and work in New Haven, Connecticut now. This was challenging in and of itself, but we were happy to do it knowing we could keep eyes and ears on the ground maintaining some degree of control over the quality of care she received. With the onset of the pandemic, all our connections to her have nearly evaporated. And the guilt pangs, anxiety, insomnia, and yes depression that we already lived with have intensified, easily by ten fold, as a result.

My grandmother is too frail to reach for the phone in her room so calling her directly to speak to her is out of the question and despite repeated requests to have her phone simply placed on her tray table so we can reach her, they have been ignored. We are able to currently schedule FaceTime calls to see her but that's when and if the staff are able to coordinate these videos, many requests have been missed. For the first few months, we weren't even permitted to bring her food which is a problem because I know she doesn't eat a lot of their food – she wants and needs her 'comida criolla', the foods we were raised on, not hospital food. We are limited in our ability to request regular updates regarding her care and we are asked to trust that the healthcare professionals are able to meet all of her needs – but we know they are not. Ensuring she received quality care required near constant supervision during normal circumstances, the current situation has only amplified these concerns. And because she's a Medicare/Medicaid recipient, we are terrified of complaining to the point of her possibly getting kicked out of one of the only decently rated institutions close to home that actually accepts Medicare and Medicaid alone. Let me be clear, this is not an insult or affront to the facility itself, rather on a system that was already fraying at the seams before this public health crisis and now promises to completely tear under the weight of the pandemic.

I wish I could say that bringing her home would be an answer, but the truth is we are unable to meet her level of need from home. My mother, who is a stroke survivor herself, can no longer manage care for my grandmother's needs by herself. And I cannot stop working to care for either or both of them full time. I cannot do that because I am an only child, only grandchild,and the reality is the entire economic security of my family rests squarely on my shoulders.

When my parents begin to deteriorate and require assistance, it will be my sole responsibility to look after them. There is no back up, I am it. I moved to New Haven to pursue a career and economic opportunity I could never have dreamed was even possible just a few short years ago, it's a dream my family of Caribbean immigrants worked tirelessly for decades to make possible. I cannot erase their sacrifices and allow my family to be plunged into poverty in a system that already expects us to fail and is not built to support this level of need. Yet still I am
plagued by the costs this decision has had on the wellness of my loved ones. I am constantly tortured by the idea that they could both be in danger or in

desperate need for full time care and it is not happening because I cannot give up on our only hope for a prosperous future. I refuse to be demonized for this ‘choice’. I’m here today and everyday that I choose to participate in caregiver advocacy because while I may not know what to do or how I’ll handle the weight of my loved ones care while juggling a full time career, and maybe one day a family, I can be the voice for those already living with the challenges of these responsibilities as well as those who aren’t even aware if this hasn’t hit their home yet, it certainly will. It is my sincerest hope, families like myself, will have their voices amplified during this extraordinary period and that we are able to galvanize around policies that will support all of our long term care needs for aging seniors as well as desperately needed support services for caregivers themselves.

Thank you very much for your time! Next up, please welcome Alexandra Drane with Rebel Health/Archangels and the USofCare Entrepreneurs Council to hear more about her experience and as well as her fantastic work.

13:23 - Alexandra Drane

Thank you, Rebekha. You are truly extraordinary. Thank you for sharing your story and the reality of what so many caregivers are going through and you share it so beautifully. We talked a lot at Archangels about the importance of having a combination of data and stories because data engages your brain and gives you [algo] to believe, but it’s really the stories that engage your heart and that's where behavior change happens.

I want to build on the incredible story that you had by backing it up with some of the data. I know AARP is beautiful data, [INAUDIBLE] incredible data on the reality for caregivers right now and hopefully using it to inform policy for the best of all of us. I know that's what we are all pushing toward. We did some analysis, we ran a study in May of 2020 on caregiving intensity which is the metric that we use to look at the impact on caregivers across the number of different variables. One of these was really surprising to us [INAUDIBLE]. 61% of the national sample indicated that their caregiver when defined as ‘worrying about, taking care or looking out for a friend, neighbor or family member’ during Covid-19 and 55% of that 61% actually said this is a new role for them during Covid-19.

57% of those caregivers overall are experiencing clinically significant levels of stress, anxiety and or depression and Rebekha listening to your story, I feel that on your level of stress. You are what we call a high intensity caregiver and the number of those experiencing clinically significant levels of stress, anxiety or depression constant 92% when you are looking at high intensity caregivers. I think often times we pretend is great to be young, I actually love getting older, but that not true if you’re a caregiver, 56% of millennials caregivers are reporting Covid-19 related loneliness or isolation due to pandemic and gen z caregivers believe it or not are feeling this even more with 69% reporting loneliness or isolation because of the pandemic. We do see that age has a potentially protective effect with 42% of boomer caregivers reporting loneliness or isolation potentially indicating maybe they're gaining some resilience over time. I had a hysterical conversation the other day where I actually by accident used the word only before saying 42% and then I had to apologize a million times, I cannot believe I just said 'only' before 42%. That's 42% of boomer caregivers are reporting loneliness or isolation and that's horrifying. When I used the word intensity, for us at Archangels that's really a combination of the caregiving load we are very careful not to use the word burden there are so many negative connotations to the word burden a lot about being a caregiver is hard a lot about it is glorious and extraordinary and we want to be finding and celebrating those things. It's the burden, it's a load and then it's the buffers you have or don't have to mitigate that load. Examples of the load or things like time, finances, family, conflict, self-doubt; examples of things to buffers of feeling supported being informed finding meeting and then there's also the impact that this has on you. Obviously, a huge impact from a mental health behavioral health perspective and of course we see that manifest physically and those examples would be things like self-neglect withdrawal emotional distress work impairment all things that Rebekah has already spoken to so beautifully. Rebekah, you also just mentioned the issue of insomnia and for some people across the country, Covid has meant that they get to sleep more, that's not necessarily true for caregivers, 25% of caregivers are reporting sleeping less than usual, and we can imagine this is less than their already diminished levels because we know caregivers sleep less. The level of intensity also has a huge impact on age, again not productive, Gen-x women 48% and 50% of millennial men with high levels of intensity are sleeping less than usual. Caregivers are reporting, as you would expect, using alcohol and medication but it’s not as much as you would think because it’s really hard to be a caregiver in the middle of the night if you are drunk or if you are hungover. We see the highest rates of coping with alcohol for 26% of Gen-X men; with medication we see about 30% of millennial men and 23% of millennial women. What we do know, I’m going to share this statistic because most of us work so hard we know that the best, one the best treatments, one of the best lines of care is to help people feel less alone. So, any of you who have personally gained the Covid-19, don’t feel badly if you are a caregiver because the Covid-1919 is very real for carriers stressed out caregivers are turning to food at an alarming rate. Half of caregivers report they were coping through food for women, Gen-Z women are at the highest risk, 72% and for millennial men at 53% are turning to food to cope, so it’s less for boomer women and lesser boomer males, and that is a relationship that you can see as it goes through the generations.

When we start to talk about what we can do about this, there are some folks who are holding out hope individually well when Covid is over this is going to get better and everything's going to get better. People who were caregivers before Covid that is decidedly not true more than 80% of caregivers who are taking care of someone before Covid, expect their caregiver responsibilities to stay the same or even increase after the pandemic has abated 46%. I’m sharing all these because hopefully anyone out there who’s an employer or working with a health plan or working from a policy perspective, these are the things that lever that we can start to pull to be supporting caregivers in their very real reality. 46% believe that their responsibilities will increase because they expect to have less help either paid or unpaid, 36% believe their responsibilities will increase because they expect to have to make different choices for their care for example, to leave their loved one at home rather than a care facility and about 20% because they believe that the health of their loved one is going to decline. Rebekah, you talked a lot about your worry about money and finances and having to be able to keep your job and we know that there's a lot of fluidity between caregivers who are employed and not employed because it's hard to have two jobs at once and it's hard to be doing your job in a formal setting when you have a full-time job as a caregiver as well. We are seeing that income is actually not protective in that, I hear this all the time I'll hear essentially the same story from the CEO of a health plan and how much trouble they're having being a caregiver even though they're supposedly an expert and then obviously we hear from folks who are, my fellow associate caregivers from when I was at Walmart for example. I'm going to talk about bright spots really quickly and then I'll pass it off to Nick.

Caregiving is really hard but it also can do some beautiful things like help give you an enormous sense of purpose and purpose is protective. These buffers are really important because they can reduce the intensity but the absence of them can increase it. Caregivers who do not have a lot of buffers are actually 55% more likely to be depressed, anxious or highly stressed versus those who don't. All you entrepreneurs out there, we need to start companies to Nancy’s point. How can you use your passion? Go start companies that help support these buffers.

The buffer that’s most likely to have a protective effect on the mental health of caregivers, is having someone that they can turn to for support and anyone who’s had that experience personally knows how valuable that can be. Over 80% of caregivers, who don’t have this buffer are clinically depressed, anxious or highly stressed. Next up, is having access to information, 90% of caregivers with high intensity say that just, just knowing that respite services exist in their area that could give them a break would reduce their stress. They don’t have to access the respite they just need to know that it exists. Let everybody out there know that these services exist.

I want to make another comment on that which is, for most humans out in the world the term respite doesn’t mean anything ‘I don’t know what respite is’ ‘What does respite actually mean’. Caregivers are struggling themselves to define that so even as people in the space, I think many of us can’t agree on what it qualifies as respite. Caregivers do respond to the idea of getting a break which can come in a number of ways and for most of the caregivers we find, is not necessarily transportation services, they’re asking for coverage, back to that point, 70% of caregivers are asking for someone they can trust to take care of their loved ones so they can go to do the things that they need to do like; exercise, just take a break, take care of their own medical needs, go to lunch.

I’m going to close out and pass off to you Nick by saying, I think an easier question for all of us right now, then who’s a caregiver who isn’t a caregiver and a time of great division this is actually that’s a beautiful thing, because it means it’s something that bring us all together.

Nick Lopocaro, fellow entrepreneurial council member CEO of Landmark doing amazing things in this space. I pass it off to you.

22:00 - Nick Loporcaro

Thank you, Alexandra and thanks for having me on. I’m to speak to you from two perspectives, one is the CEO of Landmark Health and maybe spend 30 minutes on a quick commercial on Landmark, we are what we do and then share some you know, quick personal story as well on why this is real for me and has been what’s guided me and taken me to landmark. We affectionately refer to our patients, we serve as our Joes and Josephine’s. I’ll speak to you about my Josephine, my mom.

First and foremost, here’s the quick commercial. Landmark is an in-home medical care provider and as per my statement we take care of very complex chronic frail seniors in their homes. We currently have the responsibility to care for approximately 115,000 Joes and Josephines in the U.S. In 15 different states, 50 different communities. We have close to 400 providers, physicians and app’s but we have a whole team and we call an interdisciplinary team composed of social workers, care coordinators, nutritionists, pharmacists who look after our patients in a very holistic longitudinal personal perspective. The average profile average patient is 77 years old with eight or more chronic conditions on several meds several of our patients have cognitive impairments, hearing impairment, visual impairment and I'll come back to why I mentioned especially in the context of Covid and we are talking about telehealth.

I just want to give everybody an appreciation of who we were. I'm going to go on a tangent and come back really quick. I spent the better part of the previous 16 years with Landmark now two years at a large organization at Mckesson, very senior roles and I had met one of the co-founders of Landmark a couple of years back and I happened to meet him while I was in the process of transitioning my mom to an assisted living facility and I shared this with Rebekah earlier. Rebekah is on her own, there's four of us, I have three siblings and we are from Montreal. Unfortunately, my mom got to a point where we needed additional services and getting her to an assisted living facility was the best option for us. I will share the day that I had to bring her to the assisted living facility, she was aware enough that she knew why she was there and I'm from an Italian immigrant family and she looked at me in Italian with tears rolling down her eyes and in Italian said 'you're leaving me here to die' and I know after I pulled the dagger out of my heart, stood there and stood strong and I knew this was the best thing for her. I went down to the parking lot and wrote myself a note which I still have on my iPhone, and what I wrote to myself was 'doing it wasn't the hardest thing, it's why I had to do it' was so hard, this was the best thing I could offer her. I go back to when I met Adam Baller, the founder of

Landmark. He is telling me the story how they go into home to care for people and verbatim looked at him and said ‘so you're telling me this is like the old days’ where the doctor used to go make the house calls like you didn’t have to go to the clinic they would come and see you. I will tell you, to this day that’s what only got me at Landmark but has kept me here. Why we do what we do and what’s really powerful here is and before this session talked with some of my providers and out chief medical officer and asked because I get the stories we get the thank you notes from the caregivers and daughters, sons, neighbors and people that work with our Joes and Josephines and I’m going to share with you two quotes. I’ll combine them, this is from a caregiver ‘when we call they know who I am, they know our story I feel very connected to the whole system as a Caregiver Landmark gives me peace of mind’ and what we pride ourselves is we really are part of that, we really are part of the family, we really get to know, we built this intimate relationship with our Joes and Josephines.

Just to sort of get to Covid and how it’s exacerbated the need and the risk of sounding a little shameless has really put us in a spotlight on what it is we do and the importance of what we do. I’m going to borrow something Nancy said in her opening, we deal with people that are typically homebound or home limited and a lot of them they’re saving grace as they’d have family or friends they will come over, the grandkids have come over. As soon as Covid hit and we got proactive and tried to protect our Joes and Josephines what are we telling them? One you are already isolated, now we’re telling them you can’t see the grandkids, you can’t see your friends, no one can come visit you have to stay in your home. Just the behavioral health impact of that and then the caregivers. It’s really really tough, and not to create an ultra-somber mood here but we lost our Josephine just a little over two months ago. I lost mom to Covid related complications in Montreal. Fortunately, there are a lot of angels in the system as Rebekah mention earlier we had, every once in a while, when they could one of the nurses aides would go over with their own Iphone and put us on Facetime with mom, so we could at least see her but no contact with her for the weeks prior to her leaving us. The night she left, again an angel one of the doctors that took his own phone put us on Facetime so we could communicate with her and that’s what Covid has really brought to the surface and I say exacerbated the need for better coordination, better systems and how we as a network. What Alexandra said earlier, it is not necessarily the son, the daughter, the granddaughter, it’s the neighbor, it’s anybody in the community.

We do our best to work and do outreach and work with the community and make sure we stay connected with the caregivers, get to know the families and continue to support them.

So i'm going to stop there and hand it over to Megan O’Reilly, vice president of government affairs for AARP and I’ll join you all back for the Q & A.

28:55 - Megan O’Reilly

Thank you, Nick. As we've already heard from the tremendous speakers we've had you know family caregivers have long been the backbone of this country and with the current pandemic the economic pressures they face are only increasing. For family caregivers with loved ones and long-term care facilities we've heard you know many have been largely cut-off from in person visitations now for more than four months. We know they provide not only a source of comfort and care but they're also a really important safety check. Since the pandemic began AARP has received thousands of stories of family members who report calling, emailing, pleadings with facilities for information on their loved ones. In too many cases we heard from families unable to visit who got the call to come say goodbye to their loved one. This is unacceptable. In our addition to our advocacy work which I'll touch on at the end of my remarks, AARP has been working hard to help empower family caregivers with information and tools to help them navigate these uncharted times. For example, we've put out six questions to ask if your loved one is in a nursing home, such as has anyone tested positive in the facility? What is being done to prevent infections? Does the staff have the PPE they need to stay safe and keep residents safe? Is the facility full staffing levels? We also have questions if your loved one is in an assisted living facility. For caregivers with loved ones living in their homes and communities, they too face new challenges particularly when home care is necessary. As we've heard at a time when we're quarantining and trying to limit in person contact, how do you keep your loved ones safe? While also making sure they get the care they need. AARP has also put out a set of questions for family caregivers to ask when balancing those health and safety concerns again including, What care is necessary? Is telemedicine an option? Is the staff caring for my loved one? Caring for any Covid-19 positive individuals? And is so, what safety protocols are being taken? What infection protocols are in place? Do they have enough PPE? As we look to the future, we must invest and support family caregivers and ensure that there is a quality of care and quality of life for their loved ones across care settings. Challenges around long-term care have long existed but as we've heard this pandemic shows the time for bold action now. This is particularly true as we both have a growing aging population but also an expected decline in the availability of family caregivers in years to come, the 85 plus population those most likely to need assistance with daily activities is projected to more than triple between 2015 and 2050. Greater support for our family caregivers must be a key component of any effort to address long term care, we need policies to help alleviate the economic challenges family caregivers take on when caring for a loved one. In addition, as we heard greater access to respite care even just the availability of that is greatly needed. We also need to make it easier for family caregivers to take time off from work for caregiving and make sure that they have access to relevant information and resources when they need it. In addition, for families that want to keep their loved one in their home and communities, we need to expand access to HCBS and remove the institutional bias in Medicaid that prevents many families from having that choice. We know that on average for every one person residing in a nursing home Medicaid can fund three individuals receiving community-based long-term care. We also need to expand access to home medicare home health so that more can receive the care they need at home is appropriate. For families with loved ones and long-term care facilities we must do more to ensure that those facilities are safe and the residents are well cared for. We know from Covid-19, the critical importance of infection control yet we also know that infection control was a challenge even before the pandemic, poor working conditions including low pay creates significant staffing challenges and we know that strong enforcement of regulations that impact residents health, safety and well-being are essential.

While we have many long-term challenges to tackle, I want to touch on three immediate steps that are needed and can be taken now to help family caregivers and their loved ones. First, you know congress is in the midst of a debate right now on the next Covid package, they must make nursing homes and long-term care facilities a priority in this package. We have close to 400 residents and staff dying every single day. We need required testing, PPE and staffing. That's not only essential to slowing the spread and saving lives but it's what's needed so that we can safely reopen facilities to their family caregiver and loved ones. We know virtual visitations and that ability to connect as we've heard while those in-person visitations are largely halted is essential to keeping that connection between family members and loved one.

Number two, congress should provide for greater investments in home community-based services to help more, older adults remain in their homes and communities if that is where they want to be.

Third, we've talked about this already today but the financial support is desperately needed for family caregivers who on average pay about seven thousand dollars out of pocket annually when caring for loved ones. There's a bipartisan bill in congress the credit for caring act that would provide a targeted tax credit. In addition, the medical expense deduction helps alleviate high health care costs. That is actually reverting back to 10% at the end of the year. Again, there is bipartisan legislation that would keep it at that 7.5% threshold that should be enacted. I'll just finish by saying while there's much to be done there's also significant opportunity here and I think our conversation that we've been having just shows the tremendous support that we all have for our family caregivers and this is incredibly an opportunity for all of us to seize. Thank you and I turn it back to Natalie.

35:09 - Natalie Davis

Thanks so much Megan. And a big thanks again to Nancy, Rebekah, Alex and Nick - and specifically Nick and Rebekah sharing their very personal stories. And to AARP for their support of this webinar.

We'll now open up for questions. Please use the Q&A button at the bottom of your screen to type in your questions. We'll give a few seconds for folks to get their questions in.

*(Alex - You mentioned loneliness, I have been following your work for years and you have talked a lot about loneliness. Do you have more to say on your studying of loneliness)*

*(Nick - You have providers across the country, how are they fairing. Our health care workforce are the heroes, alongside our caregivers)*

*How do we think about telehealth and virtual care for the elderly and caregivers during COVID)*

35:47 - Natalie Davis

Our first question comes from…
This is actually for anybody on the panel.
How do you think about telehealth and virtual care for the elderly and caregivers?
We did have already of course talked about that as a great way to connect when you're not able to be in person. If people have more to say about that or other uses of telehealth and virtual care would be great to kick off with .

36:09 - Nick Loporcaro

I think when we did our prep, I shared some of this. I've had a couple of interviews where people have focused on telehealth and all the rage and I preface by saying hopefully I don't come off as a luddite, you know I just crawled out of the cave and discovered fire. For us telehealth is a tool, we've embraced it, we use it but it's not a panacea especially when you look at the population we've been talking about or the population we've served. I mention it in my opening, 40% of our population have hear impairment, visual impairment , cognitive impairment or we've even joked when we get on these zoom calls, the number of times your bandwidth freezes up or your volume isn't working. Can you imagine going through a process like that with an elderly individual that's in crisis.

Now, they're not always in crisis and there is where I think we've learned to embrace telehealth. When Covid hit and we reverted right away the first thing we did was get on the phone to reach out to all our Joes and Josephines just to let them know we're here for you. We got our community coordinators and others on the phone just keeping them company, have a conversation right?. We leverage telephonic and then we leverage video where we could and then we started leveraging what I referred to as facilitated telehealth, where we don't necessarily need a doctor to go in but someone can sit down with Joe and Josephine and get the doctor on the video and they can exchange. If you are going through and exacerbation of any sort you need someone there. I think we can get into all the behavioral health issues around not having that sort of touch as well and in particular again with the population we serve. So, great tool it's allowed for us for a higher number of touches. That being said, there's still a need to be able to go in and intervene and coordinate with others to make sure that at least in our case our Joes and Josephines are getting that care.

38:10 - Alexandra Drane

I just want to add one point. I agree with that. I would remind people that for a lot of people they don't have access to anything even close to that but what they do have access to is a phone. One of the first and most important things each of us can do is reach out to somebody who's a caregiver, reach out to somebody who's isolated in their home and just love on them, love on them on a regular basis. You don't have to be a professional to do that. I think the reason why i get so obsessed with that data, and I'm sorry I went so fast I wanted to share so much with you guys, is because behind every data point is somebody who is suffering  and I think we can use that data to drive action and hopefully ultimately to drive impact. Obviously we need to have a huge amount of impact in that notion of connection, Nick that you're speaking to an enormous loneliness we see elders are having in their homes and obviously that loneliness is going all the way down to Gen-Z and below that. No one is spared right now.

39:06 - Nancy LeaMond

I wanted to have one thing on telehealth. There are very few benefits of Covid but one has been to kind of supercharge the telehealth movement. My husband was ill and in the home for over five years and was very computer savvy but we never did telehealth because the doctors didn't want to use it. As we move ahead we have the challenges of broadband, we have the challenges of educating older americans especially with technology and we need to focus on that. But I think for me is how will the medical profession adapt in an ongoing way ? Will the reimbursement system support it?  How can we be clear about when telehealth is an advantage and whether it's just going to be another activity for billing and frustration?. I think those are the kind of critical things for telehealth moving forward at least for our constituency.

40:04 - Natalie Davis

Yes Nancy, we've been talking a lot at USofCare about and how virtual care exacerbated existing disparities and we are here to watch for that.

40:14 - Nancy LeaMond

Absolutely

40:19 - Natalie Davis

This question is for AARP for Megan or Nancy.
You are leading the nation and advocating for new nursing home protections and investments. What is the outlook for passing legislation to protect you members and americans in nursing homes?

[CROSSTALK]

40:34 - Nancy LeaMond

I’ve learned that it’s really important to empower people you work with, so I’m going to let Megan answer that.

40:39 - Megan O’Reilly

Thank you. Yes, I think we are in the cross up, in the middle of an upcoming negotiation where we have a house bill that includes some provisions on nursing homes and the bill released this week by senate republicans. Also, has some provision. First and foremost the message that we have is that this has to be a priority. We have 59 ,000 residents and staff from long-term care facilities who have died and everyday we’re losing 400 more. It’s that sense of urgency that we brought to capitol hill and I do think it’s amazing when you talk with policy makers many of them too have stories like we’ve heard. I think the prospects are good, I think there is a lot that is on the table right now and so what our charge is to make sure that this is top of mind. That we truly see meaningful progress. We’ve put forth a sort of five point plan of what we think congress needs to do to really make a difference here, both to slow the spread within the facilities but there is also corresponding spread within the community surrounding communities.
This is a really important issue from a resident perspective and the health and safety and the families, the peace of mind. This is also going to our larger effort to combat Covid and flatten a curve.

42:07 - Natalie Davis

Great. This is a nice segue to a question.
Do you have recommendations about testing for clinicians and providers particularly those going into homes and facilities to provide care to patients?
Should testing for Covid be done regularly with clinicians and providers as preemptive or is it better to watch for symptomatic exposure?
What do you think about testing and maybe Nick this is a good question for you.

42:33 - Nick Loporcaro

The general answer is yes to all. Where we've struggled and you've all seen it and I think it's in the question, are some of the delays. As I met with our chief medical officer we're fortunate we actually have an infectious disease specialist on our team.
Ideally the antibody test would be the best indicators for us on our clinicians and knowing whether or not they have the antibodies. Unfortunately, we're still at a point where even if you test positive we're not sure. We're reliant just like everybody else on making sure our providers have sufficient PPE when they go into the homes. My opinion in order of priority, antibody testing, Covid testing if you could get results within 24 hours that would be great and if you could do it frequently, not very costly.

As well as we've also started looking at it from the patient perspective if you can determine that would be great. If and when we get there, I believe priority should be given to clinicians and the front line, definitely.

43:44 - Natalie Davis

Great, Thank you.
This question I'm going to start with you Rebekah and Alex and Nick you must have some interesting thoughts here.
Many entrepreneurs have tried to innovate and do direct consumer apps to support family caregivers that these have failed.
What nuances and user adoption can be shared to help create useful tools for caregivers?
Rebekah, What kind of apps or technology would be helpful for yu ? and then Nick and Alex as entrepreneurs it would be great to hear your perspective.

44:15 - Rebekah Alexander

Wow, that's such a great question. I would have to say I think one of the biggest obstacles is really just reach. Making sure that we are promoting these apps as much as possible especially, I hate to say it but through social media is probably going to be one of the biggest connectors really to the faces on the ground and the folks really struggling with this. Especially if we're talking about engaging younger generations that are starting to struggle with this a little bit more. I would say an app that would be useful would certainly connect us to other caregivers in the area, and support groups of anything of that nature. Also, I would say very honest, anything that connects us to legal assistance as well in terms of trying to work through all the paperwork that is required for quite frankly any level of care.

When my grandmother was home there was a period where it was just the three of us and there was a period where we had home health aides and that now with institutional care and I have to say through each phase we really benefited from having folks with legal expertise in our lives to help us navigate that.

Even if it were maybe just kind of one-on-one guy to make sure that your checklist of legal proxies and living will and testaments even just having someone walking us through that will be very beneficial because I do find that a number of caregivers that I've connected to are really unaware of the nuances of those steps and how important they are to protecting yourself and your loved one.

45:55 - Alexandra Drane

I'll add to that quickly. Rebekah, I love listening to you. I could listen to you all day long. The peer-to peer thing we know is incredibly important. I think that's something that we can't emphasize enough particularly around these , you know, somebody who's been a caregiver knows a lot so everybody out there first should hire caregivers or multitaskers. If you are currently in a caregiver situation go find someone  who's been a caregiver or they're going to have been through everything you've been through before they can help you starting by just helping you feel less alone in what can feel like a [INAUDIBLE].

I think one if the biggest challenges with these apps is you got to find a caregiver and a lot of folks don't self-identify as a caregiver, they say ' Well I'm just a son, I'm just a daughter, I'm just a neighbor, I'm just a friend or I'm just a partner'

Number one is to increase awareness and we can do so by getting leaders across communities, across employers, acrozz health plans to stand up and tell their own stories so that others can see themselves reflected in them and through that process. Self-identify and then feel seen.

Number two, I love apps, I'm not a technological only technologist entrepreneur. I love technology, I think it can help a lot. It's not panacea and at the next point I think that we have to do first and foremost as employers, as health plans, as communities is to stop and look at what we already have. We already have so much to support caregivers. We need to unbundle that stuff and rebundle it, repackage it in terminology that resonates with folks right. Don't use the term respite care, broaden your definition of what care is to include what's kind of logical. If you define it in the way that a real human out there who doesn't work in the health care system would .

Number three, we have to showcase an ROI and that feels guilty. I always feel dirty when i start talking about money when i'm talking about caregiving, I do it for love, I know all the other caregivers out there are doing it for love but in order to be able to be scalable and sustainable we have to start sewing and return on investment for that. We actually talk about how you have to be able to productize what you're doing and productize love in order to have the impact that will get folks to invest in it. We use and there's any number, recruiting for employers, recruiting retention, lower healthcare cost, higher productivity, same things for health plans. For the state the unpaid value for caregivers this was a five-year-old number before Covid hit. It's 490 billion, Nancy I think that's a number from you guys, I'm not sure, thank you for that. Please do the next generation of that research, that's a huge amount of dollars and that is a real cost so just because we're not saying it, just because we don't pay it to someone doesn't mean it's not there. I think we are going to see that impact on states, in the very near future.

48:26 - Nick Loporcaro

I'll make a quick comment because I don't know how we are going to solve this because now close to 20 years in health care and I know, we've been debating it for a long time.
I would have loved to be able to have access to my mom's chart every day. We'd call up and say was the last time the doctor came by, he came by two weeks ago and can you tell me what he did. We'll call you back tomorrow, fax over the sheet. We live in a day and age where we talk about technology and yet none of it's seamless and there's a lot of regulatory hurdles here and

legal issues. I think if there were a day or an app where i could just check in every once in a while and just know. I think it would help caregivers a ton.

49:10 - Alexandra Drane

Ok, everybody. Write down open notes. In full disclosure, I’m on the board of advisors for open notes but they have close to, I think 50 million individuals now covered and they have very special features that you can just check and give access legally and with control by the person from your caring to the caregiver. There is actually enormous research supported evidence that has an incredible positive impact across the board: clinical impact, financial impact and it exists right now for a lot of people essentially for free, so open google notes.

49:46 - Natalie Davis

Thank you. I want to just acknowledge how many people are sharing very personal stories about being caregivers in the chat. Thank you guys for sharing those stories with us.
Megan people have brought up this a couple of times.
What if the likelihood of caregivers being paid and congress or states really thinking about supporting financially caregivers?
What’s your outlook?

50:10 - Megan O’Reilly

We’ve been working for a number of years now on a family caregiver tax credit bill. This is something that we’re working both at the federal level and there’s efforts at the state level as well. It's a bipartisan bill in congress, bipartisan efforts across the country. I do think that there is a recognition and the dollars speak for themselves, the amount of money I think I mentioned seven thousand dollars annually that family caregivers are paying out of pocket. The 490 billion dollars that Alexandra mentioned to our economy so I think there’s a real recognition of the financial impact that family caregivers have and I’m optimistic that we can make progress to look at those types of proposals to help alleviate some of those financial challenges.

50:58 - Natalie Davis

Thank you. Rebekah you have a lot of fans in the Q&A.
As a fellow only child, whose parents are still living independently but will one day likely need care. How do you recommend to prepare in advance ? This is for everybody but they specifically ask for Rebekah.

51:19 - Rebekah Alexander

Really good question. It’s interesting, I actually just started having these conversations with my own parents and I think through our experience with caregiving, by the way my grandmother and my mother aren’t even the only family members that  we’re all caring for at the moment. We certainly realized that there was a lot more preparation to go in early. I hate to go back to legalese but i would say you really need to start thinking about talking to them especially if they have chronic health conditions. Who do they want to be in charge of their care? Will they actually give you access to their accounts? So that you can start looking at finances and really be a partner in terms of helping them with retirement. Understanding what the expenses could possibly be and start having conversations about what living arrangements are possible versus desired and being as practical as possible with those conversations.

In my own situation, myself and my partner have already kind of started the conversation about when we do purchase a home making sure that there’s a possibility of our moms especially being able to potentially stay with us. We haven’t even started a family yet and we’re already talking about taking care of our parents. It sounds a little crazy and especially for young people there may be a hesitancy to even engage in those conversations but start early and be as frank as possible. It’s difficult for your parents to start talking, there are definitely forums and panels online that you definitely check out where we can think of different ways to approach the conversation but it has to be had sooner than later. My parents are about 10 to 15 years away still from their own retirement and because of this experience, I’ve definitely pushed for us to as a family start coming to consensus about certain decisions and next steps so I'm not blindsided when next phases come.

53:26 - Alexandra Drane

I want to build on that Rebekah with three quick points.
One,  I love that you are thinking about that with your mom, let's not forget the guys out there 45% of caregivers are men and caregivers are often the last people to self-identify. They're the first to be like 'that's not caregiving, that's just what i do'. Men can sometimes have even less access to supportive infrastructure that's out there.
Number two, I think it's also fun. I'm such a big believer in having conversations. Many of us are now seeing all these tools and it's becoming more mainstream to have this conversation. Another way to approach it is, we can also think about who we would want to be our caregiver. Often when you become a caregiver it's kind of a thankless moment, nobody ever acknowledges that you just suddenly are a caregiver. What if you flip that a little bit and I could say to someone that I love " Will you be my archangel?". When the time is right, will you care for me?  Will you advocate for me ? Will you help me with all of these things? And so you turn it into something that is celebrated and acknowledged.
The last point is, one of the places that we see a humongous bump in intensity is stress with siblings. Rebekah, there is a lot that's hard about being an only child, I love my brother madly but let me tell you one of the moments that he and I are like. We are talking about our caregiving responsibility so i think this is a unilateral thing again caregiving something unites all of us in different ways but something we all share.

55:04 - Alexandra Drane

Okay, I have two more things that I'll add quickly. One, I know people are talking a lot about hospital at home and things around hospital at home that's an example to me I think it makes a lot of sense unless you're a caregiver who has a full time job and then of these hospital at home programs are saying " okay, we'll send someone to your home for during the day" but guess what ? If you are a caregiver you need to sleep at night , so you can do your job the next day. I just think we have to think about the unintended consequences of the push to care at home which is fantastic unless you're an unpaid family caregiver who is trying to hold down a job. Back to Rebekah's point to keep finances going because someone needs to have a job.
My second point is we talk a lot at Archangels about this concept of look, love, lift and I will ask all of you wherever you are looking for caregivers because they're everywhere and they don't look like what you would expect. Take a moment to love them and recognize the love that they're giving, all care counts and then give them a lift and that lift can be something as straightforward as just saying "thank you, I see you" it can be connecting them to a peer to Rebekah's point it can be connecting them to resources that you know exist in your community or that you know exist in your company. Look for love wherever you can, USofCare this has been such a gift to be part of, a huge lift for me. Super grateful to you guys for all that

you are doing and wish that we will enormous impact at this particular moment in time.

56:25 - Rebekah Alexander

Alex, I love all of your points and I just want to re-emphasize that it is so important that those of us who are aware of the caregivers in our lives make ourselves as available as possible to support them. That includes whatever you are able to lend whether it’s a listening ear or honestly just offering to fill in for a day, a weekend or whatever is at your disposal. Just offer that support. I will say one of the hardest parts of this experience for me is that it really took me plugging into these different organizations including USofCARE to start feeling that I had allies in this fight. There were so many other people with experiences like mine, it’s not exactly very popular for a 30 year old to say “Hey, I’m taking care of parents and grandparents” . It's not an experience that’s really kind of shared very vocally or through social media [INAUDIBLE].

The closer you get to engaging in these organizations and connecting to folks, once that connection’s been made offer help, be there be that support because that really is what is so required especially at a time like this. That isolation is so detrimental to honestly the mental and physical health of caregivers and right now we are in survival mode, we need to galvanize around each other and support this extraordinary period.

57:58 - Natalie Davis

Thank you everybody for joining us this afternoon. Special thank you again to all of our speakers.

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Thank you everybody and have a good afternoon.