



Caregiver Focus Group Results

June-August 2023

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I. Overview

1. **Virtual focus group with a group of caregivers** in June 2023 who had participated in an on-line caregiver support group organized by Age Well. Age Well staff member who had led the support group also organized and facilitated the focus group.
2. **Focus groups by phone with two families with limited English** with an interpreter translating. These families had been caregivers of their elderly parents and had experienced trauma because of mistreatment and negative interactions with providers during their parents' end of life care, as well as funeral preparations. Focus groups were facilitated by the VDH Evaluation Director who is on the project team.
 - a. A State of Vermont staff member involved with this project knows these families personally (is themselves a member of their community) and thought it was **essential for us to hear their stories**.
 - b. At least two of these participants are **also older Vermonters themselves**, so their comments have also been included in the write-up of the Equity focus groups.
 - c. Some of their experiences are included here, labeled as **Equity**.

II. Things Participants Like About Being a Caregiver

Learning new skills, role:

*"I am **learning how to cook**, for one thing. I didn't cook much at all. My wife has [diagnoses] so I am **learning new things I didn't think I could.**"*

*"I am **learning new skills my husband used to do.**"*

Don't have to worry like I would if someone else was caring for my person, somewhere else:

*"Because I am **taking care of her**, I am not worried 'cause the thought of someone else taking care of her that I might not trust is kind of unnerving. I don't have to worry."*

*"I like **having him home and knowing he is safe**. He has that [dementia diagnosis], and his behavior can get out of control, and he can start screaming, but I feel he is safe here."*

Appreciation is received, felt:

*"It **gives a whole new appreciation for what loving someone is** and, on another side, it **makes me appreciate all the efforts she made** as a housewife and mother taking care of the home while I came home and had a beer on the couch."*

[Equity] *"My mom was **always smiling at me**, and even though she couldn't talk, when I would come in the room, she would always wave to me – "come over! come over!""*

Love and closeness:

*"In many respects, it **brought us closer together.**"*

*"[I learned from a course I took that] **love is a decision, and you don't think about yourself as much as who you love. You are giving of yourself and not thinking of what you are getting back and that is pertinent of my situation.** That is true. It's not all cherries and all that stuff and it's a whole process and **I wouldn't trade it for anything** for what we have gone through together and what we are going through right now."*

[Equity] Role fits with what my culture, my religion, my community expects of me, I am doing what I am supposed to be doing.

III. Things Participants Dislike About Being a Caregiver

It is overwhelming, all-consuming:

*"The main thing is I think it is **all consuming being a caregiver. I quit working. I take care of my wife 24 hours a day, 7 days a week.** I dislike that it is all-consuming."*

*"I find that I **never have any time to myself** – I also work while I take care of my mom. ... I am the only one in my family that can work days and I haven't had a vacation for over 3 years. I work every other weekend and have had two full weekends off in 3 years."*

*"One of the things I find is that I **become overwhelmed with paperwork**, for example the state's long-term care, Medicare, etc. I have written government grants that were easier to write."*

"I also care about a lot of other people [my husband's sister, friend, one man in church] and also run a food shelf."

Resentment, rejection of my help, lack of appreciation:

*"Being **rejected for trying**. In my late wife's case, she had both [two dementia diagnoses] and in the end, it was all brought together under the diagnosis of [diagnosis]. Someone mentioned I had often described her as having a Jekyll and Hide personality and, **on a dime, she would change her personality from docile to a raving maniac.** She was a strong girl and was difficult to handle and it didn't always work. **It left you feeling very depressed (you being me) with the fact that your best efforts weren't getting very far at the moment.**"*

Person is different, has a different reality (dementia):

*"With [his] kind of dementia, it is behavior, and **he is not the same man anymore.** If I offer a suggestion, he can get really angry, and I don't know if he knows what is going on or where they're headed at."*

Having to constantly watch over their person:

*"I spent the last four months as her primary caregiver and I **couldn't leave her alone** and when she had the opportunity, she would wander off. She wandered off at [a] Mall and the police had to find her, and she fell in love with the police officer."*

Lack of help, challenges can lead to isolation, depression:

*“Isolation because I **don’t have any help**. My kids are too far away. It is hard to get out to see people...”*

*“I’m getting counseling for **depression**, and they say I **need self-care** - which I know I do, **but how am I going to get it?**”*

Financial fears, challenges:

*“The **fear of being financially devastated**. If you feel you need some decent long-term care, and some options are poor and other options are outrageously expensive and you could become homeless yourself. Very scary to think about that.”*

[Equity] *“Insurance would only pay for certain kinds of things – things that didn’t work for my mom – so we were **forced to rely on donations** to help us get the things she needed, which was humiliating.”*

[Equity] Providers not listening to us about what our loved ones desperately needed, and not communicating with us in ways we could understand:

These were traumatizing experiences. Full stories need to be heard and solutions enacted immediately.

IV. Times When Felt Work & Contributions Respected & Valued

When I receive acknowledgements and thank-yous from others and the one I am caring for:

*“When I hear from my kids acknowledging what I am doing for my husband and their girlfriends and wives **give me nice kudos** sometimes.”*

“Also the **Age Well volunteers** – my wife enjoyed the volunteers that showed up every Thursday afternoon for 3 hours and they had a ball talking with each other – there should be a million of them out there. **She had nothing but great comments about how well we were doing.**”

*“My mom’s siblings **always thanked me for taking care of her** and said **I am going to heaven for being so patient.** Mom also **tells me she loves me and thanks me for helping her and taking care of her.**”*

When I took a caregiving class and no longer felt alone:

*“When I took that **class on caregiving** (Powerful Tools for Caregiving) [it showed me that] **I am not alone**, and other people are doing the same thing.”*

V. Times When Felt Work & Contributions **Not** Respected & Valued

When the one I am caring for is negative, screams at me:

“Many times, it’s like (she says) “I just want to die” because I have given up my life to take care of her and that negativity just kills me. So, I say, “if you are going to talk like that, just don’t talk to me at all” because it sends me over the edge.”

When it feels like society doesn’t value your caretaking efforts:

*“My [parent] is in a very expensive facility that my [sibling] makes enough money to handle that. [This is in contrast to our situation.] I had to retire from my job and am essentially providing that \$14,000/month service to my wife with no compensation. We are forced into this poverty because someone gets dementia, and you can’t send someone to a facility. I would prefer to have her stay here until it is too hard. **It feels like society doesn’t value your effort at all in taking care of people.**”*

When you feel like you are on your own:

*“Friends, you don’t want to burden them by complaining all the time, but you are on your own pretty much – that is the bottom line – **you are on your own**. Everybody’s got their problems...”*

[Equity] When providers didn’t listen to us about what our loved ones needed; when they didn’t respect our caregiving efforts.

VI. Resources Participants Were/Are Able to Access

Participants were asked about education, training, counseling, respite, and support they had been able (or wanted) to access.

"It's important."

Caregiving Class, Seminars, Educational Videos:

- **Powerful Tools for Caregiving class**
- *"I have gone to every **seminar** I can find around here that deals with Dementia."*
- *"I learned about **Teva Snow**...she has all kinds of **educational videos on YouTube**."*

Support Groups:

- **Alzheimer's Association, Support Group:** *"The **Alzheimer's Support Group** is very helpful – you learn from other people, share concerns, learn from other folks what they have done."*
- *"I participated in [the **CARES**] **group** sponsored by the **Memory Center at UVM** over Zoom where we all supported one another and helped one another..."*

UVM Memory Center:

- *"We go to the **Memory Center** and they **gave me a social worker** because we have no family support. I was very lucky."*

SASH Services:

- *"**SASH** helped me... they came and interviewed me and I could see the big picture and more clearly what I was up against. They helped with a will, the final directive thing, getting a handicap parking thing, they were helpful. I learned about that through the **Blue Cross Blue Advantage**."*

Therapist, Counselor:

- *"I have that **counselor** that's just for me..."*
- *"I have a **therapist** that I **talk to on the phone** every two weeks so that is helping me. I started doing that when COVID hit."*
- *"I too have participated with a **social worker at the Memory Center** and initially the participation was with my son. I am glad he participated. He went off on perspectives that I would not want to share about myself, his old man, about not taking care of myself. Since my wife's passing, I am continuing to see her, and she is looking out for me and how to take care of myself."*

Respite:

- **Age Well – Volunteers, “Grant”**

*“So, I have the fortune of working with the **Age Well** folks and qualified for a **grant** and had **respite for 4 weeks or so** and it allowed me to go to some of the **CAREs meetings**. That will continue until the end of June. Having just the 3-4 hours a week is a blessing, to focus on things around the house even, like mowing the lawn.”*

- **Family and Friends – “daughter-in law,” “cousin,” “my kids,” “a friend”**

- **“A lady”**

*“The **lady** I have on Tuesdays and the one I have on Saturdays **I have known since I was a little girl** didn’t want me to pay her, but I pay her \$10/hour and I am blessed to have her for those hours.”*

Other Supports:

- “[I also have] my poor blind **girlfriend** who tries to take me out to lunch every other week while I also take care of her.”
- “Super helpful **dementia care.**”

VII. Things that Made it Possible (Facilitators)

- **Cost** is “*nominal*”, “*modest*,” or insurance covers completely
- Held **virtually**
- “**Age Well** *helped* with the course I took advantage of (*Powerful Tools for Caregivers class*)”

VIII. Barriers to Accessing Resources

Couldn't get away, would need care for my person:

"If I need to go to a support group, I would need to find some care for my wife."

Working another full-time job, so can't participate during the day:

"I would have loved to take classes like that, but I am working at the same time I am taking care of my mom, so basically working two 40-hour jobs and during the day I can't participate. I am watching her now, so running to see what she is up to."

Lack of information on classes, other resources:

- *"I hadn't heard about [the group sponsored by the memory center at UVM] until I was in my 3rd or 4th year of dealing with dementia."*
- *"Why wasn't [Teva Snow's] name mentioned at the very early stages of this process?"*
- *"I don't know of anybody, other than Age Well, who might help."*
- Participant didn't know the Caregiving class was offered virtually until the Focus Group

Cost of respite services, have to sign contract:

- *That's all stuff I pay for [people coming in to provide respite]. I talked to so many companies and they **wanted you to sign a contract** with a minimum of 20 hours/week at \$35/hour. That is ridiculous. My mother has some money, but I don't know how long this is going to go on and how long the money will last. It's **just not affordable.**"*
- *"I got the grant too although I **wish it was more.**"*
- *"There are income things too as there are **groups that get stuck in the middle.**"*

Don't trust, uncomfortable:

*"There was another company that was less money with no contract or minimum. Somehow, we got on the topic of if someone has ever stolen from someone and they said that doesn't happen that often. You **don't trust if they are going to steal from you or how they are going to treat your mom** and I don't know if I want to risk that."*

*"I heard stories of people who come in and are totally inappropriate with your loved one. It's a whole different attitude that you get and **makes me really uncomfortable about who is walking through the door.**"*

Don't want to ask others to deal with person's challenges:

*"Mom has Sundowners, so at 2:00 or 3:00, she has that look in her eye and you don't know if she is going to know you or not. Part of it is **you don't want to put anyone else through that** because it is hard to deal with. I would rather have someone in the morning when I feel she is better."*

Couldn't find people; workers not paid enough:

*"I called everybody that Age Well recommended and they all said "no". Even though at the time I had money, **I couldn't find people.**"*

*"A lot of those **workers are only getting paid half of what the companies are taking in.** some of the companies work more easily with long term care arrangements than independently. I had one caregiver who drove a long way for her stint through a large national group. It's **not fair to the caregiver to get paid that sort of rate.**"*

Rare disease means information difficult to find:

*"[Their] **disease is so rare** and [social worker from Memory Center] will try to find you information, but **there is no one holding your hand.**"*

*"There are so many different types of [this condition] so **I may not find any information that is helpful.** Aphasia is totally different from behavioral, so "good luck"."*

So much to do, tired, no longer have a partner to help:

*"There is a **shopping list to do this, do that, etc.,** and we are **tired.** We **don't have that other person in our lives as a partner to do things anymore.**"*

Only support group far away

Government makes it so difficult, have to fight for everything:

*"[He] is young to have such a serious dementia and we **had to fight our way through disability stuff,** and I **had to demand** a brain scan to determine dementia and that was all we needed to prove he had dementia. Now Dr. [Name] is providing care and got all the documents we needed. The **diagnosis was a long time coming and the disability insurance -** I had to apply online, and they kicked me out of the system and then had to wait months to talk with someone. The **government makes it as difficult and as long and drawn out as possible.** Caregivers should be given **funding.**"*

IX. Solutions

“Everything.”

Financial assistance, budgets:

“Do something to subsidize families that are going through this – it is a lot of work. ...and it is unaffordable for long term care options, and it is so out of whack and if there was something that could help us financially, that would be great.”

*“I have a sister who lives in [another country], and she doesn’t have to worry about stuff like this. It is all taken care of. The health care system in this country is way out of whack, and insurance companies rip you off. The **healthcare plans could include long term care** in them. It is the same thing as childcare and seems like old folks are expendable.”*

*“Make **funding budgets** a priority in government. “A budget is a moral document” is a quote I heard. Political people make decisions about that.”*

Publicize resources more effectively, make a “one-stop shop”:

*“Find ways to make these programs that are out there **more publicized**. Like I participated in a group sponsored by the Memory Center at UVM over Zoom where we all supported one another and helped one another, and I hadn’t heard about this until I was in my 3rd or 4th year of dealing with dementia. We need to, as a community, to **make these things more known**.”*

*“We need a **one-stop-shop for information on services** available. I don’t know of anybody, other than Age Well, who might help. You should be able to have **one huge neon sign** on everything you need to know.”*

“Why wasn’t [Teva Snow’s] name mentioned at the very early stages of this process?”

Provide more care - in home or at day-care centers:

*“Also the **Age Well volunteers** – my wife enjoyed the volunteers that showed up every Thursday afternoon for 3 hours and they had a ball talking with each other – **there should be a million of them** out there.”*

*“My mom is pretty mobile so pretty agreeable so **she could have a “babysitter” while I take a class**. To have someone to be with her so I can do this conference [focus group?] would be really handy.”*

*“If they provided some sort of **group care for people who were bringing their person they are giving care to with them**, like a babysitting group like they have at church.*

*“They used to have more **adult day care centers** open before covid and they closed. The ones that are open have a list a mile long. That seemed like such a nice option to drop their loved one off and have some flexibility in your day.”*

Treat need for adult care like need for childcare:

“Daycare has subsidies for the exorbitant costs, and this is the same issue.”

Figure out how to get more people - provide better pay:

*“You also need **people**, and they are hard to find. I called everybody that Age Well recommended and they all said “no”. Even though at the time I had money, I couldn’t find people.”*

Offer support groups, more classes:

*“**Support groups** sponsored by the state maybe in each area of the state that **would offer just encouragement, good ideas, and being able to meet other people**. That **class** I went through was an escape from reality and a positive boost every time I went to class. Something like that would help.”*

Fund Alzheimer’s research

State – provide what you say you are going to:

“I would like to add to that that the state really needs to back up and ensure the implementation of the things they say they are going to do. My wife was on the waiting list for adult day care for five years and then died waiting for it. There are many things proffered for support but not actually available.”

Provide administrative manager:

*“One of the things I find is that I **become overwhelmed with paperwork**, for example the state’s long-term care, Medicare, etc. I have written government grants that were easier to write. I have to collate it and send it off. Dealing with the **administrative piece** of this – **would be great to have a program manager to help coordinate it all**. You have no clue **what words to use** so insurance companies don’t lead you down the wrong path, etc.”*

Equity – Many Things Must Change:

- Allow family members to use the interpreter they understand best, and they are most comfortable with, that speaks with their dialect/accents (is from the same country originally)
- Don't speak with parent (through interpreter) without a family member also present
- Translate documents they are asked to sign so they understand what they are being asked to sign (especially waiver of life-saving measures)
- Explain services or decisions they are unfamiliar with, especially hospice, using a trusted interpreter who understands cultural not just language translation.
- Make sure Advance Directives are filed with the Registry so that they can be located by any provider when needed.
- Remember that they know their loved one well.
- Remember that they are people going through an incredibly difficult time with their loved one, who happen to speak another language and come from another culture.

X. Impacts on Caregivers

*"I am here so much, but **my self-care time is so short**. I want to spend time with my family and my dog that I like to walk, and I don't have time. ... I just don't have time between working full time and taking care of her full time. I like to go kayaking and I haven't done it in 3 years, and I would like to do something fun for me to change my attitude a little bit."*

"I forgot how to be a social animal and take care of myself. It took everything you've got so now I have to reintroduce myself to the world again as I am not taking care of my wife anymore. Sometimes I am wishing for some of the difficult times we had together compared to what I have now."

*"I have been **living with drama for a long time** -this disease starts in your 40's so we have been living with it for 20 years, and it's all behaviors like giving your money away, scams, having to get a lawyer... **A social worker suggested I get counseling and an anti-depressant**. His case is drama, drama, drama..."*

*"I found also through all this that **my health declined**. I am on blood pressure meds now, am Type II diabetic and my health has declined."*

*"There is a shopping list to do this, do that, etc., and **we are tired**. We **don't have that other person in our lives as a partner** to do things anymore."*

*"My **health is deteriorating**... I am **very depressed**."*

*"There is **no thought of what happens to any of us when this happens**. I just had to finish a course ... and it talks about what we are going through, and the sheer numbers of women who are leaving the workforce. We are losing a lot of people who are unpaid and unappreciated and financially devastated."*

XI. Coping Strategies

Participants mentioned a variety of coping strategies throughout the discussions.

Keep things in perspective, positive self-talk:

- *"You have to remind yourself **this isn't forever.**"*
- *"But you know, **I am surviving and so is my wife.**"*
- *"I am pretty blessed because **I could have it a lot worse than I do.**"*
- *"I am a **Vietnam Vet...**and saw combat up close and personal, and surviving that helps in this situation somehow, and helps me get through it pretty much."*

Other coping strategies:

- *"I learned early on that the person's reality is **THE** reality, no matter how crazy that is, and you have to **go with that flow.**"*
- *"I am in the **church choir.**"*
- *"I am **learning to draw stuff and draw a picture every day** – that's another therapy I guess."*
- *"I was a Phys Ed teacher at middle school for 36 years and have a **routine for exercising** which helps also. When you are teaching if you don't take care of yourself, you aren't going to be effective, as the kids suck the energy out of you. I learned that before this."*
- *"I **called the police** to tell them what he's got."*
- *"**Music** On YouTube – following this girl... the way she can communicate the song and tell the story; she is talking just to you."*
- *"**Run the Food Shelf**"*
- *"**Run the guest services department at the [town's] fairgrounds.** It is a very loving, supportive group... we are a support group."*
- *I'm trying to train other people to take on some of these [caregiving] roles.*