Dementia Care Management Program

Report to

Chairman of the House Appropriations Committee
Co-Chairwoman and Co-Chairman of the Senate
Finance and Appropriations Committee

Virginia Department for Aging
and Rehabilitative Services

Commonwealth of Virginia
Richmond
November 1, 2023

COMMONWEALTH OF VIRGINIA
DEPARTMENT FOR AGING AND REHABILITATIVE SERVICES

Kathryn A. Hayfield
Commissioner

8004 Franklin Farms Drive
Henrico, VA 23229

Office (804) 662-7000
Toll free (800) 552-5019
TTY Toll free (800) 464-9950
Fax (804) 662-9532

November 1, 2023

MEMORANDUM

TO: The Honorable Janet D. Howell and the Honorable George L. Barker
Co-Chairs, Senate Finance and Appropriations Committee

The Honorable Barry D. Knight
Chairman, House Appropriations Committee

FROM: Kathryn A. Hayfield
Commissioner, Department for Aging and Rehabilitative Services

SUBJECT: Annual Report on Dementia Case Management Program

Pursuant to Item 331 J of the 2022 Appropriation Act, the Department for Aging and Rehabilitative Services (DARS) is pleased to submit the report on the status of the Dementia Care Management Program. This program is built on work undertaken at the University of Virginia's (UVA) Memory and Aging Care Clinic since 2016 through a partnership with DARS. This document provides a brief description of this previous work and information about the program through the second year of funding from July 1, 2022 through June 30, 2023.

If you have any questions about the report, please do not hesitate to contact me.

KH/gw

Enclosure

Report on Dementia Case Management

A Report to the Virginia General Assembly *November 1, 2023*

REPORT MANDATE

Item 331 J. of the 2022 Appropriations Act: *Out of this appropriation, $262,500 the first year and $262,500 the second year from the general fund shall be provided for an interdisciplinary plan of care and dementia care management for 88 individuals diagnosed with dementia. This service shall be provided through a partnership between the Memory and Aging Care Clinic at the University of Virginia and the Alzheimer's Association. The Department for Aging and Rehabilitative Services shall report the status and provide an update on the results of the dementia case management program to the Chairs of the House Appropriations and Senate Finance and Appropriations Committees by November 1 of each year.*

BACKGROUND

During the 2020 Special Session, the General Assembly appropriated funding for a pilot program of dementia case management starting July 1, 2021. In the 2022 Special Session, the General Assembly appropriated additional funding starting July 1, 2022. This funding was appropriated to support the implementation of a program for dementia care management at the University of Virginia's Memory and Aging Care Clinic (UVA MACC) in partnership with the Alzheimer's Association.

KEY ACCOMPLISHMENTS

- Dementia Care Managers (DCMs) support families using an evidence-based program.
- 91 persons living with dementia and their caregivers enrolled in the second year of the program.
- A bicultural, bilingual (English and Spanish) DCM was hired in 2022.

DARS AND DEMENTIA

DARS' mission is to improve the employment, quality of life, security, and independence of older Virginians, Virginians with disabilities, and their families.

Under the Code of Virginia § 51.5-152, DARS has several powers and duties with respect to Alzheimer's disease and related disorders (ADRD). These include evaluating the needs of individuals with ADRD and their caregivers, and identifying the services, resources, and policies that may be needed to address such needs for individuals and their caregivers, and recommending policies, legislation and funding necessary to implement the state plan for meeting the needs of individuals with ADRD and their caregivers.

The most recent plan, the *Dementia State Plan 2020-2024: Building a Dementia-Capable Virginia*, was developed by the Alzheimer's Disease and Related Disorders Commission in consultation with stakeholders and citizens and includes five main goals. Goal Four is to provide access to quality coordinated care for individuals living with dementia in the most integrated setting. The Commission is due to publish the next four-yearly iteration of the Plan on October 1, 2023.

The Dementia Services Coordinator, housed within the Division for Aging Services at DARS, supports the Alzheimer's Disease and Related Disorders Commission, disseminates information on systems, services and related activities, and coordinates services and activities of state and local agencies, service providers, advocacy groups, first responders and law enforcement, as well as other entities throughout the state that engage with people with ADRD and their caregivers, specifically the Alzheimer's Association, Area Agencies on Aging and Adult Protective Services.

BRIEF HISTORY

Dementia Case Management began at UVA MACC in 2016 with support from a grant awarded to DARS by the federal Administration for Community Living under the Alzheimer's Disease Initiative—Specialized Supportive Services program. UVA MACC collaborated with the Jefferson Area Board for Aging (JABA), the Area Agency on Aging serving the Charlottesville region, to jointly hire and manage two dementia care managers serving a total caseload of 100 families. Over the nearly three years that the program operated through August 2018, the program served a total of 220 people living with dementia and their caregivers.

The project reported on several measurable outcomes highlighting the benefits of care management. Among both people living with dementia and their caregivers, these included: decreased depression, improved quality of life, reduced problematic behavioral symptoms and lower severity of dementia symptoms, and reduced health care utilization. In addition, caregivers reported a reduction in caregiver burden. Overwhelmingly, both people living with dementia and their caregivers felt the program was beneficial, helping prepare them for the future, improving clinical care and treatment, improving access to community resources and reducing stress.

These results help explain why dementia case management has maintained a high profile in Virginia's Dementia State Plan since the first plan in 2011. The Alzheimer's Disease and Related Disorders Commission has consistently advocated for state funding to support dementia case management with an ultimate goal of having these services available across the Commonwealth. Since the DARS-supported grant projects ended in 2018, UVA's two dementia care managers have continued to serve about 100 families annually with the support of additional grant funding from the Administration for Community Living and the Department of Defense. Under the former funding project, UVA successfully incorporated the evidence-based Benjamin Rose Institute Care Consultation (BRICC) program. Through the Covid-19 pandemic, dementia care management continued to be provided virtually, with similar outcomes in terms of depression, quality of life, symptom management and health care utilization.

IMPLEMENTATION

Partnership with the Alzheimer's Association

As directed in the budget language, UVA MACC continues to partner with the Alzheimer's Association to carry out the project. This is accomplished under a Memorandum of Understanding (MOU) that covers the DCM's time and effort.

The Association's DCM has now worked on the project for more than a year, and is a solid member of the dementia care management team. Her experience now allows her to help onboard and support new DCMs as they are hired.

How the program works

Most participants are first offered information about the program by their health care team at the UVA MACC, at diagnostic visits or follow-up care visits. They are given a brief description of the program, and if they are interested, their contact information is shared with the program coordinator. The coordinator then follows up with a call to the family to provide further information and enroll the individual living with dementia together with a primary caregiver willing to meet regularly with their assigned DCM.

Once enrolled, the individual and caregiver are asked to complete a comprehensive set of questionnaires addressing depression, anxiety, quality of life, healthcare utilization, dementia-related behaviors and caregiver reactions, and others. Caregivers are additionally asked to complete measures of caregiver stress and burden, dementia knowledge and self-efficacy. These questionnaires are used to inform the person-centered care plans developed by the DCMs in consultation with the individual and caregiver, as well as to gauge the effectiveness of the program.

The assigned DCM then contacts the individual and the caregiver. The degree of interaction with the person living with dementia will depend on their own preferences, as well as the stage of the disease process, with people early in the disease process more likely to engage regularly with the DCM. DCMs use the BRI CC program to guide their interactions including structured assessment conversations in the first few weeks of participation to help formulate the care plan. Over the twelve months after enrolling, participants are contacted at least once a month by their DCM, with additional contacts determined by the individual and caregiver needs.

At the end of the 12-month enrollment period, a second set of questionnaires is sent to the caregiver to complete. This includes the same questionnaires completed at enrollment and the Satisfaction with Care Survey. Six months later, an abbreviated set of questionnaires is sent to the caregiver to complete.

How the DCM helps

One of the primary goals of the DCM program involves coordinating care around their dementia diagnosis, with an emphasis on providing person-focused support, education and guidance as they navigate healthcare and community providers. An equally important, but less obvious role involves providing validation and emotional support at a time in life where things can be particularly overwhelming. DCMs validate the participants' emotional experience, while also providing disease-specific education and helping them to identify supports and strategies that would be beneficial for their unique needs. DCMs have the flexibility to meet the participants where they are physically and emotionally, and allow space for building a sense of rapport, safety and trust early in the relationship.

Most of the program's interventions can be organized into seven main categories: 1) care coordination, 2) education on diagnosis and dementia progression, 3) guidance and education on community resources, 4) guidance and education on financial resources, 5) guidance and support for long term care planning, 6) emotional support, and 7) behavioral symptom management and safety strategies. Appendix A provides specific examples of activities undertaken by the DCMs in each of these areas.

While the goals and anticipated outcomes of care are unique for each individual living with dementia and their primary caregiver, DCMs can broadly anticipate helping to prepare individuals for the challenges associated with living with dementia, reduce the need for unplanned medical treatment, decrease the emotional and physical burden of living with dementia, and improve emotional outcomes for individuals and caregivers.

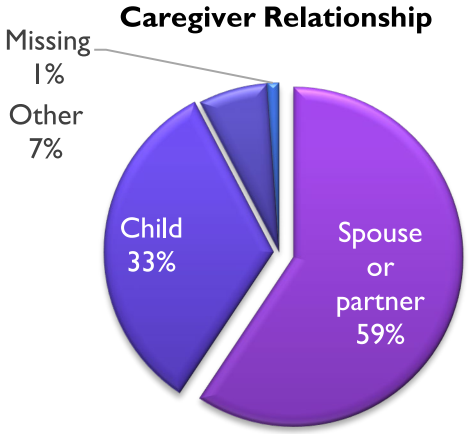
DCMs use a variety of means to maintain contact with the participants including phone, email, videoconferencing and in-person visits. Typically, DCMS will also accompany participants while they are in the MACC for follow-up care visits, providing another set of ears in often emotional and sometimes overwhelming appointments. Clinic visits usually entail meeting with a number of members of the care team that can include neurologists, neuropsychologists, nurse practitioners, social workers and others.

Program enrollment

Through the end of June 2023, the program enrolled 91 individuals living with dementia and their primary caregivers. Demographic information about the participants is in Table 1. Caregivers are often younger than the person living with dementia and generally female. By relationship, 59% of caregivers were the spouse of the person living with dementia, followed by 33% who were adult children, typically daughters.

Table 1: Participant Demographics

	Individual Living with Dementia	Primary Caregiver
Female	48%	71%
Black/African-American	9%	8%
Hispanic/Latino	2%	3%
Veterans	9%	11%
Age Range		
Under 60	10%	35%
60+	87%	65%
Lives alone	10%	n/a
Rural	50%	50%



Services provided

Care coordination is provided in a variety of settings, including during participants' visits to the clinic and DCM visits to the participants' home, and through phone calls, emails and telehealth visits. Home visits are an important component of the program as they typically provide a wealth of information to help the DCM support the participant more effectively, as well as providing an important opportunity to develop rapport.

At a minimum, DCMs contact each participant once a month, with an average of three contacts per month. DCMs record the time spent assisting participants as direct hours and indirect hours (see Table 2). Direct hours are actual time spent with the participants including at clinic visits, in-person home visits, phone calls, telehealth visits, and emails. Indirect hours are time spent working on tasks for the participants such as leaving or answering voicemails, time spent locating resources, time spent communicating with providers about specific patient needs, travel to and from visits, and time spent documenting interactions with participants.

Table 2. SFY 2023 DCM Outputs

Total Service Hours	1,961
Direct	1,027
Indirect	934
Total Contacts (#)	2,216

Program outcomes

Program outcomes have started to become available as participants complete the 12-month assessments and separate from the program. However, full analyses are not yet available. Appendix B contains information from the baseline assessments that further describes the participants and their caregivers. Notably, participants tend to be independent for activities of daily living such as bathing and dressing, while needing assistance with instrumental activities of daily living, such as housekeeping and medication management. This reflects the relatively early stage of the disease process for most participants.

Subjectively, the DCMs report a decline in healthcare utilization for enrolled participants. They reported a reduction in the need for in-person appointments at MACC and emergency room visits as they are available to problem solve, answer questions, help caregivers navigate the health system, and help caregivers implement behavioral intervention strategies.

DCMs have also been able to facilitate positive changes for participants that allow the individual living with dementia to remain in the home longer. Examples of such changes include the following:

- Creating a safe environment (i.e., making suggestions to make the home safer and help with fall prevention) while finding community volunteers and grants to make the home more accessible (i.e., installing ramps and shower bars, fixing mold issues, helping with roof repair, and finding and delivering durable medical equipment);

- Connecting families with local individuals and home health agencies to provide respite;
- Addressing cognitive changes with the treatment team, as needed, rather than the participants needing to wait for the standard yearly follow up visit;
- Providing education and emotional support;
- Connecting families to community-based services for free durable medical equipment or other adaptive devices (e.g., bathtub chairs, disposable briefs, wedges to make shifting someone in the bed easier on a caregiver's back, etc.);
- Helping connect caregivers to support groups, therapists, or other mental health support to combat caregiver fatigue/burnout;
- Ensuring caregivers are aware of their local community support agencies, including their Area Agency on Aging, Department of Social Services, Senior Centers, and others.

Letters of support and testimonials provided by families receiving care coordination through this program are included in Appendix C to further illustrate the positive impact care coordination has on families.

Lessons from the second year

The DCMs and the team have learned from caregivers that they are concerned about losing care coordination after 12 months. Caregivers and PWD are so satisfied with the program that they have requested services to be extended beyond a year. The program team has been examining whether it is of greater impact to limit the program to 12 months to provide services to more people, or to extend services to current participants and limit the number of additional participants who can be provided the service.

An additional lesson learned is that enrolling Spanish-speaking participants has challenges beyond the need for having DCMs on staff who are fluent in Spanish. Many of the Spanish-speaking participants were not born in the United States. They have less familiarity with the health care system and cultural factors that enable service provision. As a result, more phone calls and home visits are required to help people understand the program and how to use the resources provided. In addition, there is more of a need to sit down with participants and read the questionnaire items aloud to them or to do so over the phone. This may be related to reading ability, education level, and/or familiarity with filling out questionnaires. It has also been found that while many of the Spanish-speaking participants have strong family support, they frequently have few external resources. With rates of dementia typically 1.5 times that of the white population, this population is important to reach. The program team looks forward to increasing its understanding of how best to serve them.

Program reception

Reception of the Care Coordination program has been overwhelmingly positive within UVA MACC and with associated partners. The team has found that the great majority of caregivers receiving clinic care are interested in care coordination. As such, the team has had to be strategic in how the program is advertised to prevent the waitlist from being flooded with people desiring services. Demand for services has far surpassed the current availability of DCMs.

Care coordination is a highly desired service in the UVA MACC. The limited number of funded DCMs has restricted the provision of this service to all interested patients and families.

APPENDIX A

Table 3. Action types and examples of DCM interventions

Action Step Types	***Examples***
Behavioral management strategies	E.g., for sundowning, hallucinations; using dry erase boards for scheduling; dementia clocks.
Safety strategies	E.g., grab bars in the shower, removing rugs from the home; reviewing how to call 911 in the event of an emergency; reviewing personal safety equipment (e.g., medical alert device); contacting APS about concerns of abuse or neglect.
Strategies for both behavior management AND safety	Discussing strategies for managing/reducing the likelihood of wandering (e.g., alarms on doors); camera systems for in-home safety and monitoring; strategies for discouraging persons with dementia (PWDs) from driving.
Strategies for activities of daily living	Discussing automatic pillboxes/pillboxes with alarms; educating about incontinence care; putting water bottles on the counter as a visual reminder to hydrate throughout the day.
Administration/case management	Initial chart review; scheduling visits; consulting with other providers (e.g., on the team) with whom the PWD is already established; completing paperwork.
Referrals to other providers	E.g., to speech therapy, physical therapy, psychotherapy, palliative care, hospice.
Providing education about navigating diagnosis and disease progression	Reviewing the diagnosis of Alzheimer's disease and what might be expected for MCI or the relevant stage of dementia; educating about the difference between depression and apathy, or about anosagnosia.
Guidance and education on community resources	Discussing Silver Sneakers program; directing a care partner to the local area agency on aging; connecting them with Meals on Wheels or another specific community resource; sharing information about the Alzheimer's Association 24/7 Hotline.
Guidance and education on financial resources or benefits	Discussing Medicare/Medicaid benefits, long-term care insurance, VA benefits, or FMLA benefits; making the care partner aware of grants; assisting with affordable housing vouchers or respite care vouchers.
Guidance and support for long-term care planning	Discussing options for assisted living versus in-home help; providing guidance about questions to ask home health agencies or facilities.
Providing emotional support	"Above and beyond" active listening and typical counseling skills, such as validating and discussing anticipatory grief, ambiguous loss, or guilt about transitioning the PWD to an assisted living facility.
Guidance and education about research/clinical trials	Providing information about local research opportunities/clinical trials; helping to coordinate brain

	donation/autopsy for research purposes.
Guidance and education about legal resources	Discussing the importance of updating wills and advance directives, designating an agent under power of attorney; connecting the PWD/Care Partner (CP) dyad with an elder law attorney.
Rapport-building	Different from “above and beyond” ongoing maintenance of rapport/usual empathic care. Initial establishment of rapport; could also occur after an issue or conflict between the DCM (dementia care manager) and the PWD or CP (e.g., if the care partner is frustrated with the DCM about a conversation or resource).
Lifestyle, quality of life, and enrichment/engagement resources	Memory scrapbooking for the purpose of enrichment and reflection on the PWD’s life; encouraging increased use of respite to improve quality of life; discussing the benefits of a specific enrichment activity (e.g., arts/crafts).

APPENDIX B

Preliminary data from baseline assessments of program participants

Care Partner Reports about Care Recipients (Person with dementia—PWD)
ADLs (Katz Index of Independence in Activities of Daily Living). Care partners reported the following about their care recipients/PWDs' basic self-care activities of daily living:

Table 4. Activities of daily living (ADLs)	Dependent %	Independent %
Bathing	27%	73%
Dressing	36%	64%
Toileting	17%	83%
Transferring	6%	94%
Continence	34%	66%
Feeding	9%	91%

IADLs (Lawton-Brody Instrumental Activities of Daily Living Scale). Care partners reported the following about their care recipients/PWDs' instrumental activities of daily living:

Table 5. Instrumental activities of daily living (IADLS)	Dependent or needs assistance (%)	Independent (%)
Ability to use telephone	77%	23%
Shopping	92%	8%
Food preparation	89%	11%
Housekeeping	87%	13%
Laundry	77%	23%
Transportation (drive or use public transportation)	88%	12%
Responsibility for own medications	87%	13%
Ability to handle finances	95%	5%

Quality of life in AD (Quality of Life in Alzheimer's Disease; QoL-AD). On average, care partners rated their care recipients/PWDs as having "fair" (=2) to "good" (=3) quality of life (*M* = 2.38, *SD* = .47, sample range = 1 – 3.46; measure range = 1 – 4).

Total neuropsychiatric symptoms (Neuropsychiatric Inventory Questionnaire; NPI-Q). On a questionnaire of neuropsychiatric symptoms, on average care partners endorsed that their care recipients/PWDs exhibited 4.19 symptoms (*SD* = 2.76, sample range = 0 – 11; measure range = 0 – 12).

Caregiving Logistics
The vast majority of care partners (74%) reported that they provide 81-100% of the care for their care recipient/PWD.

Fifty-one percent of care partners reported being the sole informal (unpaid) care partner, whereas

19% reported having one other care partner, 16% reported having 2 other care partners, 4% reported having 3 other care partners, and 10% reported having 4 or more other care partners.

The majority of care partners (71%) reported not having a paid care partner involved in the care system, whereas about one quarter have one paid care partner and 6% have 2 paid care partners involved.

In addition to their caregiving responsibilities, almost half (44%) of care partners work for pay.

Care Partner Self-reports

Wellbeing (WHO-5 Wellbeing Index). Care partners' average wellbeing/quality of life was 46.4 (SD = 23.43; sample range = 0 – 92), where 0 represents the lowest quality of life and 100 represents the highest quality of life.

Caregiving preparedness (Preparedness for Caregiving Scale; PCS). On average, care partners reported feeling "not too well prepared" (=1) to "somewhat well prepared (=2) for caregiving (*M* = 1.9, *SD* = .71, sample range = .13 to 4; measure range = 0 – 4).

Depression (Center for Epidemiological Studies Depression Scale; CESD). On average, care partners reported a subclinical level of depressive symptoms (*M* = 12.3, *SD* = 9.9, sample range = 0 – 44; measure range = 0 – 60).

Anxiety (Geriatric Anxiety Inventory; GAI). On average, care partners reported a subclinical level of anxiety symptoms (*M* = 7.0, *SD* = 5.6, sample range = 0 – 20; measure range = 20).

Caregiver Burden (Zarit Burden Interview; ZBI). On average, care partners reported experiencing a mild to moderate caregiver burden (*M* = 19.6, *SD* = 9.5, sample range = 0 – 39; measure range = 0 – 48).

APPENDIX C

Testimonials provided to program staff directly or through the satisfaction surveys.

- I wanted to thank you, as head of the department. We were assigned to AB and Nurse C. They have both been such an immense help to me, supportive in so many ways. When I had a problem or question, they were on it and responded immediately. I didn't have to go to "My Chart", try to remember my password (or reset it) and then wait 24 hours for a response. I got answers immediately. AB is just a "font" of information and had an answer or source for every need I presented and was so encouraging and sympathetic. Nurse C has been both sympathetic, knowledgeable and persistent, helping us find the appropriate medication for my husband when we he was going through some very difficult times.
- I wanted to let you know that the information you sent me on self-confidence and dementia, and my subsequent change in behavior to support my mom, had a huge beneficial effect….. Based on the information you gave me on self-confidence, I took a different approach. Physically everything was the same, SUV, step stool, me, my mom BUT rather than directing her, I let her decide how she would get in and when she said she felt like she was going to fall instead of saying I'm here, I can support you I told her Take as long as you need. You make very good decisions on keeping yourself safe and the evidence is that you haven't fallen. Let me know where you want me to stand and hold the door. The first time it took her a few tries but she made it in. She ended up getting in and out three times and each time it was easier for her than the other. What a gift.
- I must express my full appreciation for the Care Coordinator service that was provided for the last year. From simply prescription support, to managing hospital interactions, to providing encouragement, my care coordinator provided a valuable service. I only wished that this could be a regular service that could be covered by the insurance companies.
- This program has been so beneficial to me and my Care Coordinator, AB, has been beyond wonderful. I do hope that it will be continued and I will miss the psychological and emotional support that I have received. Thank you.
- Working with the care coordinator gave me the tools and the confidence to use the tools to care for my mom. Also learned to set realistic expectations and be grateful for the moments of connection that spontaneously occur. I can avoid taking things so seriously that all I do is worry which leaves time and emotional space for myself and for my relationship with my mom.
- I think that UVA memory center is a godsend. When I walked out of our 1st meeting I felt a load lifted from my shoulders. Having a team is such a bonus compared to the other neurologist in town. And having the ability to call on a sympathetic and knowledgeable care coordinator without having to worry about the cost is a gift. I am much more capable of dealing with his illness than earlier. Taking anxiety medicine certainly helped and being in this journey long enough that I have acquired more caregiver skills has allowed me to help advise other caregivers. I cannot say enough good things about the way UVA has helped me so consequently helping my husband.
- Appreciated the program that provide the Care Coordinator. Find myself recalling helpful information we received. I am working on more information available in my area to continue to help me to do a good job for the patient. Thank you for the program.

- I am extremely grateful to have had the opportunity to participate in this study. This past year would have been so much harder without DF to talk to. She has helped me hugely by supplying resources and interfacing with the UVA Neurology care team. A Care Coordinator is a wonderful service to offer as part of the Memory Care Clinic! The caregiver support study was a great experience. DF was great to talk to and I miss having the opportunity to speak with her once a month. Having that service as part of the UVA Memory Care Clinic would be amazing!
- Thank you for all the assistance. I look forward to perhaps participating in the program at a later date as well.
- My family and I are so grateful to DF, our care coordinator, and this beneficial research program. Nurse C and Dr. G and others on staff have been super helpful. We feel blessed to have your support.
- Having a care coordinator for the past year made a huge positive impact on my life! I hope that having access to such an individual will be an available resource for all care givers in the future.
- Our care coordinator has simply been invaluable this past year. I have learned so much and felt so supported. Thank you for the opportunity to participate! I truly hope the benefit of providing this service is found so it becomes an option for everyone caring a loved one with dementia.
- I've gained so much from this study! And from talking with and learning from AB throughout this process.
- I simply do not have words to express how much I appreciate what you are doing to help me.
- Thank you for everything you've done for our family in this challenging year. We have been so blessed by your help, so many times! Like gold, you are!
- You have been the Angel that God choose for us to get through this rough time. I am sadden by the fact that our time is over, but I am still hopeful that things will change later that we can get back together again in the future.
- I so appreciate all the information/resources you have provided to me. I will be looking into everything and figure out what best works for us at this time. I am encouraged.
- Because you suggested that I ask about financial assistance at JABA, we have already saved about $1,000. Last month, it was a bit over $400.00 and, this month it was $600.00 plus something. That's not something to ignore. Thank you so much for that suggestion.
- I am so thankful for you and all that you do for us.
- Thanks so much for being there for us. I certainly am feeling better about our situation. I also enjoyed talking with you the other day. Refreshing! You listened and heard me. I don’t usually experience that in medical appointments.