

Clear communication about the program's purpose, goals, and process are essential to setting Caregiver expectations from the beginning.

more about the program itself.

BECAUSE...

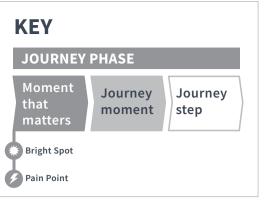
## U.S. Department of Veterans Affairs CAREGIVER PCAFC JOURNEY MAP

The Department of Veterans Affairs (VA) Caregiver Support Program (CSP) provides education, tools, and services to Caregivers of Veterans, including the Program of Comprehensive Assistance for Family Caregivers (PCAFC), which is a program that provides training, support, and a stipend to Caregivers of the most severely wounded

Large life changes, like quitting a job and spending more time in the

with other duties.

The Veterans Experience Office (VEO), in collaboration with CSP, has conducted human-centered design (HCD) discovery work to capture the voices of Caregivers, Veterans, CSP staff, and providers. The Moments that Matter, bright spots, and pain points for currently eligible Caregivers of Veterans are shown below. The purpose of this Journey Map is to illustrate Caregivers' current experience with the PCAFC to inform opportunities for program and system improvements.



## **ACRONYMS & TERMS**

**ADL** Activities of Daily Living **CSC** Caregiver Support

Coordinator

**CSP** Caregiver Support Program **Dyad** A Caregiver and Veteran pair

**PCAFC** Program of Comprehensive Assistance for Family

Caregivers

may still harbor the same feelings as when they learned about the decision that caused them to appeal.

MIS MOMENT  Physics of the residence of the control		AWARENESS AND APPLICATION			ELIGIBILITY AND APPROVAL			DAILY LIFE			ASSESSMENTS			TIER MODIFICATION OR DISCHARGE					APPEAL		
REGIT  RE	WHAT OCCURS IN THIS MOMENT	Veteran/Caregiver dyad or VA staff member tells us		to discuss eligibility	participates in	conducts an in-home	approval letter with tier	for their Veteran		participates in	receives a call to schedule 90-day or annual	evaluation is	evaluation is	come in for a clinical	for clinical	a letter about a tier change or discharge and	new financial situation and decides what to	changes 90 days after tier change	evidence to		Dyad receives decision letter
MAIN  The State of the Control of th	PROGRAM MPLEMENTATION VARIANCES BY SITE			in-person or letter  CSC may meet with  Caregiver prior to initial		doctor  CSC may meet with  Caregiver prior to	letter  Signatory: CSP or Office			and frequency of other CSP programs varies by		Personnel: CSC, nurse, or	<b>Personnel:</b> Nurse and/or CSC							and appeal processes (including the configuration of the appeals team) vary by	
ANN properties and the second time of the second ti	BRIGHT	friends, [I] found out about the program"  "this is what I do. I do this because I love my husband, and I can't have him anywhere else."  I am excited to learn about this important		benefits of the program and the resources that are available to me if I am accepted.  I feel hopeful about our	my Veteran were validated, and I also learned how to take better care of myself in	VA and it's not anything against the system or the peopleHaving them come to the house is just		Veteran is rewarding.  "My daughter [will] pop up [and tell me]'I am so glad Daddy is here	"Instead of working 8 hours a day and then coming home and making dinner, cleaning, picking the kids up from practice, we actually get to sit down and watch TV	one place where it's about me and my needs.  "I am [less co-dependent because of] the support from the program. Sometimes that's the only place I have to turn."  [After getting connected with the support groups] you don't feel like you're alone. That was my start, [when I began] feeling like I'm going to survive		speaking with my nurse because she puts in referrals for the things I need.  My social worker makes me feel supported when she	social worker provides me is helpful and also				to stay at their tier or in the program by appealing. Hopefully, we				
Clear with racts.	PAIN	know about [the program]you know, if their family members would just know about		are eligible because I didn't fill out the application correctly.  Phone call catches me at a bad time during working hours.  I couldn't think of all my questions, so I called back and no one answered.  Someone told my Veteran there was a VA program to support Caregivers but it turns out that we are not	since the day he got hurt. I've been the one	a lot of just random people coming, and he hates it. I don't like it either."  "All the contact was mainly them to us. We had to come in and do an interview here, [after which] they came to	work. Like everyone always says you live paycheck to paycheck"  I don't understand how I	'you have PTSDI panic when the phone rings if it's not the right time [of day]."  "The hardest part about being a Caregiver is when peoplesay, 'You don't even have a job'. Trust me, it's more than what you think it is."  "I'm his Caregiver. It's in your notesI just kind of push through [when providers won't talk with me] because I'm super frustrated."  "I felt that I was losing my life's work. I felt I lost my life because [being a Caregiver]	about money.  "If I could financially, I'd totally leave my job today. I'm tired, I'm exhausted, I'm burnt out because [husband] is like first in my head."  I'm feel nervous when I think about how I am going to afford retirement with no	getting things here in the program. That's supposed to be [the point of] it: help the Caregiver to help the Veteran."  "When I do get to talk to [my CSC], she has the information that we need. It's just trying to reach her is the problem."  "I don't [go to many support groups] because I am so busybeing a		but sometimes I never get a call from them.  Sometimes it feels like a checklist, not a conversation intended to help me.  "The rules about whether you know if you qualify or you don't qualify the program [are unclear]: who they take in, who they don't take in, what tier you fall in."  "Supposedly I answered 'no' to some questions, so that's how we got our	from them unless something bad has happened or if something is changing.  How can they make an assessment when they see us so infrequently? They don't know what it's like everyday.  "All we've asked is for peopleto help guide usso we can get the help we're supposed to	asked to come into VA.  I received a letter, but I wish I could speak to someone on the phone	need to be here. Nothing about my situation has	and you can't even give me a reason why to validate it at all? So it's infuriating [when they] stare at you blankly and they say, 'Oh [CSC] said no."  I wish someone would have called me to tell me so I could ask questions.  "It was like, 'Wellyour husband just washed dishes' And I was like, 'What do you mean washes dishes? It's not about that.' My husband has PTSD. The slightest	ourselves without the stipend amount we have been relying on?  "I'm having to go through an appeal process to get things back where they need to be."  "If I threw in the towel and quit [being a Caregiver], we would cost the VA a whole lot more money than we are costing the VA now."  I was moved up a tier, but even my new stipend amount does not reflect the work I do		to feel like you're on trial and have to prove every single thing."  "She didn't list that our [ADLs] changed because he had to be helped to be bathed [and to] get [in and out of] the bed. None of it was listed. Nothing else had changed."  "Someone said they came to our house for a home assessment. We have security cameras. We brought [tapes] to our appeal [proving] no one came to our house. You're lyingsaying you came to our house when		The explanation didn give me any more cla  "So then they judge y and they're putting in comments andthen say, "You don't qualify when you did before!  "[Because you rely on program! you're wors off than you were [before]."  I feel like our years of service and sacrifice a not being recognized  "I would have like to have seen an official report on what took place when we went before the board! gut that's just the way my military mind works. I deal with facts."

needs for a while.

In-home visits serve as a rare moment to speak with staff in a one-on-one

Clear communication from VA before, during, and after tier modifications and discharges are critical to helping dyads understand and accept the decision, especially given financial implications.

uncertain about our future.