

Inclusive care: The road to empowering and supporting military and Veteran caregivers



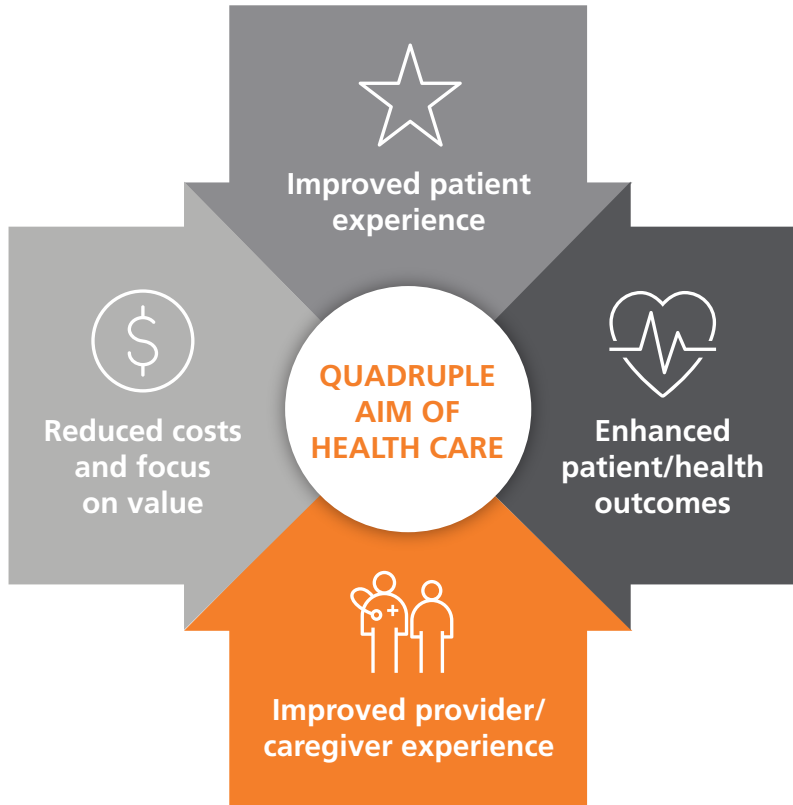
When Colleen Johnson's husband Thomas, a national guardsman, returned home from Afghanistan in 2014, he was a completely different man. "One dark evening in late 2014, my very capable husband — my rock, my mountain, my warrior — could not make a simple decision and said his whole world was upside down," she recalls. "His invisible wounds of war manifested as we transitioned with him from combat to civilian life. Issues arose that are all too recognizable to the military community: memory issues, bouts of anger, severe fatigue, debilitating migraines and so much more."

Navigating the U.S. health care system can be a challenge for anyone, whether it's understanding your benefits, scheduling appointments, coordinating with specialists, keeping prescriptions straight or, of course, paying the bills. But Veterans and Military Service Members face additional hurdles. Their injuries are often severe and they suffer disproportionately with disorders such as post-traumatic stress and other complex, comorbid illnesses directly related to wartime service.

Because of their unique needs, about 25% of VA enrollees rely on the support of a caregiver like Colleen Johnson. And roughly half (49.3%) of all Veterans who rely on caregivers today would need to be placed into a skilled nursing home or assisted living if they no longer had that support, according to a 2017 Disabled American Veterans (DAV) survey.¹ The survey also found that military and Veteran caregivers consistently experience worse health outcomes themselves, as well as greater strains in their family relationships and more workplace problems than non-caregivers.

OptumServe™, the federal health business of Optum and UnitedHealth Group, is committed to learning the best practices of inclusive care for military and Veteran caregivers and incorporate those best practices into the care delivery system.

Inclusive care and caregiver support have many benefits that align with the Quadruple Aim — improving the provider experience in order to provide higher quality care with greater efficiency at a lower cost. At the Elizabeth Dole Foundation, they have embraced and expanded the model by adding caregivers as a recognized and respected part of the care team.



The premise of the Quadruple Aim helps caregivers feel included in their Veterans' care by listening and supporting them in meaningful ways and ultimately improves the care experience for patients and their caregivers.

When it's easier for caregivers to schedule appointments for their Veteran, the results are fewer missed appointments. When caregivers are educated and trained on how to administer complex treatments, such as injectables, there is better medication adherence and fewer errors. When robust support solutions, such as access to adult daycare or respite care are offered, caregiver stress is eased, which allows them to continue in their crucial role. And, when health care providers recognize the value of a clinical partnership with caregivers, they can reconnect to what inspired them to become health care providers.

Bringing Veteran caregiver support to the fore

The Veterans Health Administration, which serves more than 9 million Veterans at 1,255 inpatient and outpatient facilities, has a long history and a deep commitment to serving not only Veterans, but also their caregivers. The VA is working hard to better understand and meet caregivers' needs.

But they can't do it alone.

Enter the Elizabeth Dole Foundation, which was founded in 2012 to empower, support and honor the nation's 5.5 million military caregivers: spouses, parents, other family members and friends who care for America's wounded, ill or injured Veterans.

The Foundation's Hidden Heroes program shines a spotlight on military caregivers and helps connect them to resources and support. It includes a network of cities and counties that have pledged to streamline services to military caregivers and share best practices, an online support group for caregivers and grants for innovative programs that make a direct impact on the lives of America's military and Veteran caregivers.

The Elizabeth Dole Foundation and the VA have teamed up on the newly launched Campaign for Inclusive Care. Backed by research from both organizations, it aims to integrate military and Veteran caregivers into their Veteran's care team from day one of the care process. Supported by a generous philanthropic investment from USAA, the program will create a model intervention that results in a culture of care that is inclusive of military and Veteran caregivers.

"To me, inclusive care means that my care recipient and I, as his caregiver, have a team of people supporting his healing and recovery from the immediate onset of wounds, illnesses and injuries," says Johnson, an advocate for Veterans and their caregivers, and fellow at the Elizabeth Dole Foundation.

"Inclusive care is about respecting each other's contributions — clinical and non-clinical — to healing, recovery and wellness; about listening to the care recipient's needs and wishes; and about advocating when physical and/or mental health compromises the care recipient's capabilities. Inclusive care reminds us of the power of compassion and deep empathy we hold for one another. Our Veteran did not experience the wound, illness or injury alone; we do not heal alone," she says.

Caregivers are an extension of the health care team both at home and in the clinical environment, working to ensure continuity of care while advocating for their care recipient, who may have difficulty advocating for themselves, says Jill Wachtler, director of Military and Veteran Caregiver Support at OptumServe, a federal health services business that supports the VA's Community Care Network. She's also the primary caregiver for her husband, a retired U.S. Navy Veteran with Gulf War Illness.

"We think it's important that caregivers are recognized, respected and included at every possible touch point where it makes sense, because we understand that any time there's a barrier for that caregiver, there's a barrier for that Veteran," Wachtler says. "This is such an important issue for me and for OptumServe and we look forward to partnering with the Elizabeth Dole Foundation on an initiative to get this right."

Inclusive care should be a given

Even as the VA and other organizations seek to support the estimated 5.5 million military caregivers in the United States, those caregivers are giving back to the health care system, as well. The RAND Corporation estimates the cost savings of the work of military and Veteran caregivers at a whopping \$14 billion annually.²

"Inclusive care is not only the right thing to do, it's the smart thing to do," says Rashi Venkataraman Romanoff, vice president of Programs and Partnerships at the Elizabeth Dole Foundation. "Beyond being a warm, soft-touch program, everything about inclusive care is also a very smart business decision for any health plan or hospital system or clinic setting. Because when you're really engaging all the members of your treatment team — including caregivers — then you're going to get patients who are adhering to their treatment plans and taking their medications."

Wachtler agrees: "We know that if a caregiver is well-supported and has the right resources, that Veteran is going to live their best life. A respected and a well-supported caregiver can really add years to someone's life."

The Campaign for Inclusive Care is a national initiative to integrate caregivers into their Veteran's health care team. It is a joint initiative between the Elizabeth Dole Foundation and the Department of Veterans Affairs.



OptumServe looks forward to working with the Elizabeth Dole Foundation on the Campaign for Inclusive Care, says Chief Medical Officer and retired Navy physician Dr. W. Mitch Heroman, with an eye toward implementing real-time learnings from the initiative within all of the services it provides for the federal government and beyond. “Today, we have the honor and opportunity to serve over 7 million Veterans throughout their health care journeys. From providing military entrance exams when first joining the service, to caring for them as Veterans through the VA Community Care Network, we understand the continuous clinical care these individuals need. We are constantly testing and mapping out opportunities to improve the care experience for our service members and Veterans. Integrating a committed focus and strategy around caregivers is a huge priority for us.”

Unprecedented benefits

The Elizabeth Dole Foundation, the VA and OptumServe believe that inclusive care could improve outcomes and experiences for caregivers, patients and health care providers. Caregiver inclusion can improve care quality and patient safety through, for example, greater medication adherence, better care transitions and lower readmission rates. What’s more, as health care provider burnout becomes an increasingly recognized challenge, inclusive care, by resetting the conversation with caregivers, can help reduce burnout and return joy and focus to the work.

Inclusive care is a system-wide approach to Veteran care that embraces, engages and empowers caregivers, clinicians and Veterans throughout the entire care journey, the Elizabeth Dole Foundation notes. Inclusive care increases the capacity and competency of the entire care team to deliver appropriate, efficient, effective and high-value services.

Inclusive care must be team-based to work: health care is a partnership among the clinical Veteran care team and family caregivers. It’s centered on sound communication and secure feedback from all care partners.

The road forward relies on cultural change

The evidence-based Campaign for Inclusive Care is organized into three phases: first, understanding challenges and opportunities and identifying the key components of inclusive care followed by creating evidence-based solutions informed by health care providers, caregivers and subject matter experts. The third phase entails testing and measuring on-the-ground solutions, including the launch of an online resource — the Academy for Inclusive Care — which will equip clinicians and other VA workers with toolkits, videos, improvement reports and other educational and training resources.

In particular, the Academy will host four 15-minute videos to help the VA community and others better understand the importance of inclusive care and key elements to integrate. They’re designed for quick and easy implementation and consumption by clinicians and staff who may be wary of adding “one more thing” to their workload.

“We spent a lot of time thinking about the best way to transform how inclusive care is done at the VA,” says Romanoff. “We saw this training opportunity not only for clinicians, but for staff, for social workers — for anyone who is interacting with Veterans and their families at facilities.”

Caregiver inclusion isn’t yet widespread. According to the DAV survey, more than half (56%) of VA caregivers said that in the past six months, the patient’s health care team never asked for their ideas about managing their Veteran’s health. Even more were never asked if they have the skills or training they need to help their Veteran (69%) or if they needed help at home in managing their Veteran’s health condition or conditions (72%).³

INCLUSIVE CARE IMPROVES:



Health outcomes



Relationships



Quality of life



Clinical performance



Health care provider work experience

The harsh facts and figures in the DAV survey, the RAND report and other evidence of the importance of military caregivers inspired what is, in some senses, a simple idea, says Rachael Barrett, the campaign's project manager who, along with her sister, is a caregiver for her Veteran brother.

"Health care providers go into this work for all the right reasons and they want to do right by patients and families. But somewhere along the line, things got tripped up," says Barrett. "So, what can we do to challenge providers and create a smooth path so they can recognize caregivers and see them as partners? What can we do to turn this into a consistent practice across the board?"

The answer, she says, is to create a cultural shift. "It's about raising awareness and bringing health care providers back to that space that brought them into this career, into this field, into working with Veterans, into working with caregivers and remind them of the value of that work," Barrett adds.

In addition to the VA, veterans service organizations (VSOs) play a key role in the lives of Veterans and their caregivers.

"Ongoing support and communication, where people are telling their real stories, talking to people who are in your situation and getting peer support is important," Wachtler says.

But sometimes community-based efforts are scattered and largely uncoordinated. They also, for the most part, do not measure quality, effectiveness or outcomes.

According to the RAND report, caregivers of all ages would use more community resources were it not for the maze of different service and support options with varying eligibility requirements.

And then there's the military culture itself.

"It's not true of everyone, but you do have a culture where Veterans and military populations don't always want to ask for help," Wachtler says. "They don't want to be seen as weak. So, having to ask for help and having to put yourself out there in this way can feel very vulnerable."

Further, being a Veteran — and caring for one — can be isolating, she says. "Less than 1% of our country actually participates in military service. There's just a real lack of understanding from people who don't have a service member in their family."

Transforming the patient, privacy paradigm

In many ways, the caregiver-inclusion movement is an extension of the existing trend of family-centered care.

"Everyone talks about wanting to do family-centered care, but there's not a lot of tools to help achieve that goal," Romanoff says. "There's been a real gap. To me, the Campaign for Inclusive Care is the answer. It's the foundation and the VA saying, 'we really want to transform how we're thinking about family-centered care.'"

One key is to identify and involve caregivers from the very first point of contact and throughout the care pathway. "It starts when they're filling out all the paperwork. It starts the second that they walk into that facility, that day when they go off to the front desk to check in," Romanoff says.

Moreover, staff must learn to recognize caregivers in order to ensure they can include them properly.

FIVE FACTORS OF INCLUSIVE CARE

There are five key components of inclusive care, according to the Elizabeth Dole Foundation:

- 1 System-level policies of inclusion:**
Looking across workflows, policies and every step of the Veteran and caregiver experience to identify opportunities for inclusion.
 - 2 Clear role definition of caregiver:**
A caregiver is an extension of the health care team both at home and in the clinical environment who works to ensure continuity of care while advocating for their care recipient, who may have difficulty advocating for themselves.
 - 3 Caregiver capacity assessment:**
Providing screening tools for providers to help understand where the caregiver is at and what additional education or resources they need.
 - 4 Explicit caregiver involvement:**
Lean on opt-out policies vs. opt-in.
 - 5 Mutual caregiver/professional communication:**
Create user-friendly communication vehicles as well as an environment of openness and respect.
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"If we can give these front-line providers, be it clinical staff or administrative staff, more tools to be able to recognize and identify these caregivers and really engage them from early on, the process will be smoother throughout," Romanoff notes. "So, while the campaign is really focused on clinical interactions, the broader aim of what we're trying to do is promoting a whole-systems change approach to thinking about how we can better involve families and caregivers that are doing so much of this 24/7 care behind the scenes."

Another barrier is a lack of understanding about how to appropriately enforce HIPAA and other privacy regulations. HIPAA was originally intended to protect the confidentiality of digital health care records, but never intended to prevent caregivers from having access to the health information of their loved ones. Due to the fact that there are penalties in place for those who wrongly disclose medical information, many health care employees are hesitant to share information, even with caregivers who are providing for that patient, fearing they will get reprimanded. As long as the patient agrees to have their medical information shared with their caregiver, HIPAA allows for the health care provider to do so.

"Over-interpretation of privacy rules makes it really easy to shut down conversation, engagement and inclusivity," Barrett says.

While Romanoff notes that privacy rules shouldn't be ignored, she also urges providers to understand and explore. Caregivers should be able to get an update, whether that be in person or over the phone, as long as the patient has given consent for them to be involved in their health care conversations. Thankfully, the Caregiver Advise, Record, Enable (CARE) Act has passed in 37 states, the District of Columbia, the U.S. Virgin Islands and Puerto Rico. This legislation requires hospitals to record caregiver names in the medical record if the patient has opted to include them. It also requires hospitals to provide knowledge to the caregiver on how to perform medical tasks that need to be done in the home and inform the caregiver of a hospital discharge.

"People get so nervous about breaking a rule that they forget about common sense and thinking about what a patient really needs from a health care perspective and how can we achieve that in the most effective way," Romanoff notes. As more education is brought to health care professionals about the importance of the caregiver role, further progress will inevitably follow. Both health care professionals and caregivers have the common goal of bettering the health of the patient — by working together, they can better the odds of making that goal a reality.

Striving for ultimate impact

While the Campaign for Inclusive Care is just getting started, its ultimate goal is to expand its impact beyond the pilot phase to inform changes to the health care system at large.

"There's an opportunity to really move the needle on this with the VA because you have so many patients with such complex conditions. And it's easier to make the case for including someone who's doing wound care or is managing tens of, if not dozens of, different medications. Obviously, this person should be included in the treatment plan," Romanoff says.

Additionally, there will be benefits to these efforts beyond the VA population, she notes. Civilian patients and caregivers face these kinds of challenges, too.

"The hope is that if we can make this work for the most complex patients, it will then cascade down and be helpful to patients in other situations."

To learn more about the Campaign for Inclusive Care, please visit: elizabethdolefoundation.org/campaign-inclusive-care

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Sources:

1. "America's Unsung Heroes: Challenges and inequities facing Veteran caregivers," 2017, Disabled American Veterans.
2. "Military Caregivers Share the Costs of War," 2017, RAND.
3. Ibid.