Crystal Nicely, Caregiver and Spouse of OEF veteran

Statement of Crystal Nicely
Before the
Senate Committee on Veterans' Affairs
Hearing: "Examining the Lifetime Costs of Supporting the Newest Generation of Veterans"

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Good Afternoon. Chairman Murray, Ranking Member Burr, Members of the Committee, thank you for inviting me to share my and my husband Todd's experiences with you today.

I hope, through my testimony today, that those looking in will feel my frustration and heartache. Ever since my husband was injured I have assumed a higher responsibility to care for him and support him as we transition into a new life. I'm sharing my personal experiences and feelings which I hope will be useful to you in creating a better system of support for wounded warriors and their families. My husband lost his arms and legs while serving his country in Afghanistan. During a combat patrol through the village of Lakari, which is in the southern Helmand Province, Todd was hit by an IED.

It has been a long journey since that day in early 2010. Under normal circumstances, one would think that it would be quite easy for someone to lose hope and motivation after such a catastrophic injury. But my husband has been a fighter since day one. In recovery he displayed the same irresistible warrior spirit for which the Marines are so beloved. First fighting off infection and disease, then working aggressively with his physical medicine and rehabilitation, through progression in prosthetic training, and also fighting for me and our future together.

Although my husband is one of only three surviving quadruple amputees in the Marine Corps, his struggles and hardships are very similar to other Wounded Warriors, regardless of their injuries. I am here today, not only on behalf of my husband, but also the countless other wounded Marines and their caregivers.

Coordination and Transition

The process of transitioning out of the military has been particularly difficult. Todd has been part of the Integrated Disability Evaluation System (IDES), which I understand is supposed to be a faster, more efficient way to complete the evaluations and transition servicemembers. That has not been our experience. At one point, a very simple narrative summary of how my husband was injured sat on someone's desk for almost 70 days waiting for a very simple approval. I thank Chairman Murray for her help in getting that resolved, but it should not take my talking with a United States Senator to make that happen. More importantly, what about all the other wounded Marines who have not had the chance to ask for that kind of help?

Coordination of care for Todd has also been a problem. There seem to be so many coordinators that they are actually not all on the same page and sometimes doing things opposite of each other. Though she was trying to help, I rarely got to see our Federal Recovery Coordinator, who seemed to have too many people she was responsible for. The lack of communication also

extended to benefits and programs. While I'm optimistic for the new VA caregiver program, I have gotten hardly any information on how to participate. There has been a similar lack of information about a variety of VA and other benefits.

For the benefits we know about, we are also faced with problems in getting these benefits. Periodically the stipends stop, which makes things very difficult. I do not know why this occurs, especially as it is difficult to get a clear and definitive answer, but we need help.

Caregiver Needs

The community of wounded Marines at Walter Reed is diverse, and each has their own particular needs. Many of them are fortunate to be accompanied by their loved ones. For most of the family members, we were thrown into this new role unexpectedly and unprepared, but we have taken it in stride with determination and hope of the future. What we have discovered is that we could never have prepared ourselves for what we face on a day to day basis while taking care of our loved ones.

For me, I am not only my husband's caregiver, non-medical attendant (NMA), appointment scheduler, cook, driver, and groomer, but I am also his loving wife faced with my own stresses and frustrations. To be clear, this is not an issue of being overwhelmed with caring for my husband for there is no other place on earth I want be other than by his side. I am sure that many of the other caregivers would agree. What is upsetting is the lack of support, compassion, and benefits for these individuals. It needs to be just a little bit easier. Many of us, left our lives back at home, and assumed a new role and life at Walter Reed, as many caregivers have done across the country. Simply put, life here isn't a picnic. It is a bittersweet struggle of coping with new identities and new norms, whatever those may be.

I first wish to address the most difficult and disheartening issue that continues to be a problem and barrier at Walter Reed. There is not much these days my husband can do without me or someone at his side. We attempt to function independently, but the reality of his injuries requires that I be close to his side, and even if I am away for only short periods someone must be there. This is part of our new normal. Without his prosthetics Todd is unable to perform many of the very basic Activities of Daily Living (ADL) that are taken for granted by so many.

The process to serve as an NMA is tedious, particularly at a time when we must oversee all the other parts of our household and our lives. I am not enlisted so it is frustrating when I'm expected to carry on as if I were, when the circumstances I have now are so much bigger than that. This is an additional and unnecessary burden for the spouses and family members.

This continual process of reapplying to be an NMA feels as though I am being assessed on my love and care for Todd, or my value to him and his condition. But helping him through his treatment is what I want to do. How could I ever ask someone else to step away from their lives to come do what we so proudly do, loving and caring for our husbands. It's almost disheartening to think that someone no matter how willing they may be can care for my husband more than I can. It hurts just to consider having someone else there instead of me sharing and growing in this experience with my husband. A lot of us come from jobs or school, and there are those that have children to look after as well. Personally, I was attending school before this. Now I have to

consider the very expensive life that lies ahead for my husband and me. However, none of these factors would change my decision or take me away from my involvement in helping Todd's recovery. I believe it is helpful when we can be there learning together to learn these new life skills so, in the near future, I can step away without worry knowing that he can perform everyday activities safely and, eventually, without someone else there.

Many of us caregivers are unable to work, there just are not enough hours in the day, and in my case, leaving my husband's side is just not an option. Thus, I do rely on the compensation that comes with being an NMA to assist with maintaining my household and saving for our future. With Todd's injury the bills did not stop coming and, to be honest, things have become more expensive. We are grateful for what assistance we do get from the Marine Corps, but had we not been guided by our case managers, other volunteers like the Semper Fi fund, and other families of wounded warriors, we would have been lost in this recovery process.

Warrior Transition Units

Frequent rotation of section leaders in the warrior transition units is another problem area. When the new leaders take over, they know less about what is required than the spouses. This is no fault of their own, for most of these individuals that are sent here to support the wounded come from military occupational specialties that are unrelated to what there are about to be asked to do. So it is a learning process, but by the time they understand, it is time for new section leaders to take over, again without the requisite skillsets, and the challenges continue. I have to seek out other sources and individuals to assist me. Additionally, in these situations, trust is a key part of an effective relationship, but the continual turnover hinders the development of that trust.

Conclusion

It should not take a newspaper article or appearing at a Senate hearing to address these problems, but I am glad to have the opportunity to express this to you and seek your help. I want to take a moment to express my appreciation for what is being done now to aid in future assistance of the wounded and their families. I know that issues are being work towards and I will never be able to fully express my appreciation for what assistance we do get and for what is available to us now for every little bit counts. I hope my testimony today has been helpful to you as you continue working to address these issues. Thank you very much and I would be happy to answer any questions you have.