

ROBERT VERBEKE, FATHER OF DANIEL VERBEKE

STATEMENT OF ROBERT VERBEKE
FATHER OF DANIEL VERBEKE
FOR PRESENTATION BEFORE THE?
SENATE COMMITTEE ON VETERANS' AFFAIRS
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Mr. Chairman and Members of the Committee, thank you for this opportunity to testify.

My son and I have a unique association with this committee as Dan was born in 1983 in Illinois and we have been residents of the Commonwealth of Pennsylvania since 1988. We both have served in the U.S. Navy.

I appreciate your time and interest in my experiences with the military and the VA and my views on what can be strengthened or improved. My immediate thoughts upon receiving the invitation are that there are many areas of care and support that are severely lacking. It is important to note that my needs for support are directly tied to Dan's needs. That is, take care of Dan's needs and most of my needs will be met. Dan's experiences are my experiences.

My son, ABE3 Daniel R. Verbeke, was injured on December 5, 2005 during combat operations in Operation Iraqi Freedom while serving aboard the USS Theodore Roosevelt, CVN-71. Dan sustained critical and life-altering injuries, which included a head/brain injury, collapsed lung, fractured vertebrae and fractured ribs. Dan has progressed with the healing of his physical wounds but suffers from severe Traumatic Brain Injury (TBI). He has steadily improved over the course of the past twenty-seven (27) months. He does not have functional use of his arms or his legs; he cannot eat, drink or speak though he has begun to vocalize basic words - 'Hi', 'Uh-Huh', 'Yea' and most recently 'No'. He is able to express emotions of anger, sadness and he will laugh. He attempts to use his left hand to help in brushing his teeth and shaving. He is able to communicate very reliably through eye movements and blinking. Oh, he has a great smile too!

Immediately after Dan's injury he was flown to Kuwait and then moved to Balaad in Iraq. It was in Balaad where a craniotomy was performed that resulted in saving his life. Days later he was flown to Landstuhl and then immediately moved to a private German Hospital, as there were no neurosurgeons at Landstuhl. He then was moved to Bethesda NNMC and subsequently to the Richmond VAMC polytrauma unit. While at the Richmond VA location I became unsettled with the type and level of care my son was receiving. I subsequently removed him from VA care to a private care facility that specializes in and has years of experience in Traumatic Brain Injury Rehab. We soon learned that this decision was the best decision I have ever made for my son.

My experiences with the military have been superb. Dan has received a tremendous amount of ongoing support from his shipmates. There have been numerous visits and interactions and in each case they have served to 'perk him up'. He really enjoys being with them. There is a very real bond with them that will never go away. I would also like to point out that his ship's Captain, Captain Haley, has been a big supporter and I thank him. Immediately after Dan's injury Captain Haley authorized and dispatched a CACO who joined us in Germany and remained with us until after Dan had been medivac'd to Bethesda. Senior Chief LeTourneau was

exemplary in her role supporting us. I would also like to mention that the ongoing assistance from Navy SafeHarbor has been invaluable. I have many words of praise for LCDR Ty Redmon and the team working with him. The military has acted and continues to act as part of our extended family.

My experiences with the treatment at the Richmond VAMC can be characterized as not good - not good at all. For the most part, the people who treated Dan were nice and caring people. What I learned immediately after leaving there, however, was they didn't know what they didn't know. That is, their skills, capabilities, resources, staffing, treatments, therapies and therapy techniques all fell extremely short of what we immediately experienced at the Bryn Mawr Rehabilitation Hospital. The Richmond VAMC was not accomplished in coma emergence and severe TBI and did not have the cutting-edge experience with a case as severe as Dan's.

The VA therapists and physicians had little or no experience with patients of the condition of Dan. The level of therapy and the techniques cannot be compared to the therapy Dan received while at the Bryn Mawr Rehab. The Bryn Mawr Rehab therapists are much higher skilled; they focused on stimulation constantly while performing therapy. The techniques in each of the disciplines of Physical, Occupational and Speech Therapy are far more advanced. Although the Speech and Physical Therapists at Richmond tried, they just did not have the expertise and they were very lacking in the techniques and resources that Dan received immediately upon transfer to Bryn Mawr Rehab. The Richmond Occupational Therapist is another story. Recovery from a TBI is about therapy and stimulation. While this therapist treated Dan she very rarely spoke to him, I continually witnessed sessions that would last longer than 45 minutes where she would not say more than a few words to him. When I commented on this, the VA reaction was to shift Dan's therapy sessions to a time when I could not be present. They didn't fix the problem - they ignored it! I escalated the issue to the attending physician and but were no changes.

After we returned to Pennsylvania I learned that while at Richmond VAMC, Dan was misdiagnosed on a medical condition that resulted in receiving medications that masked a very serious condition. He was ignored while in significant pain with the explanation that it was 'tone'. He was unable to get blood work done over a weekend to properly treat him following a seizure and we were told they could not have the results analyzed over the weekend as people were 'off'. Private care hospitals across this country perform these routine tests 24x7 and within minutes. He had an open wound that penetrated all the way to the bone on his right foot the entire time at Richmond (4-5mo) where the condition worsened and was only treated by a nurse. Immediately after being placed in private care, he was treated by a doctor specializing in wound care and under his treatment the wound closed in one month. Dan was in pain the entire time at Richmond.

The medical treatments and diversity of physicians treating Dan dramatically changed when we arrived at Bryn Mawr Rehab. At Richmond, Dan was treated by the resident physician and the attending. No specialists treated my son other than the neurosurgeon who performed his cranialplasty just before we left Richmond. Immediately after arriving at Bryn Mawr Rehab Dan was seen and treated by numerous specialists. It was a real eye opener and completely different level of care and aggressive effort invested in my son's accurate diagnosis, treatment and recovery.

Very shortly after moving Dan to Bryn Mawr Rehab he was seen by a physician specializing in 'tone management'. Tone is explained as the elasticity or tension of Dan's muscles. His TBI injury resulted in tone problems, that is, certain parts of his body muscles tightened up and would not move freely. It is a by-product of the great condition his body was in at the time of his injury. I clearly remember the physician's words when he first saw Dan. His words were 'Who did this to him?' That physician is also a member of the Armed Forces and has served in Iraq. He was angry at how my son had been treated.

The Richmond VAMC personnel very quickly scaled down Dan's therapy and for some disciplines discontinued his therapy sessions. They stopped therapy at a time when therapy and stimulation were most important in helping him progress, despite my efforts to persuade them to continue these treatments.

Quite frankly, the VA personnel were much more concerned about training the family than treating my son. Just one of the far too many examples is the very first meeting that was held to update me that occurred about two weeks after Dan arrived at Richmond. The entire agenda was to discuss family participation and training. I was with Dan and helping the staff nine to twelve hours each day - seven days a week. During that meeting I challenged them and asked why weren't we talking about what they would do to help my son. I stressed that should be the priority. My conclusion was they didn't know what to do or how to really help Dan. They simply did not have the knowledge, experience, skills, and resources.

On many occasions there were comments about cost and what items cost. Dan's care and treatment should not have been compromised by cost. Yet, it certainly was. - time and time again. I learned that lesson very quickly when I experienced his treatment plan outside the VA system.

I am prepared to provide many more examples far too much like these.

Dan was treated at Bryn Mawr Rehab until December of 2006. He emerged from vegetative state and progressed to a minimally conscious state. He was inconsistently responding and a decision was made to move him to a skilled nursing facility while awaiting surgery to correct contractures of both ankles. While in the nursing facility he continued to receive therapy.

While at Bryn Mawr Rehab I was contacted by the local Philadelphia VA and met with them to discuss Dan's status and possible future plans.

In September of 2006, Dan's neurologist and rehabilitation doctor advised me that we should begin to consider if we wanted to move Dan home because he felt we would soon need to move Dan from Bryn Mawr Rehab either to home or to a skilled nursing facility. Therapists from Bryn Mawr Rehab evaluated our home and we began to make architectural plans for modifications based on their recommendations. A representative from the Philadelphia VA was involved and their recommendations were included in the plans.

At this time I raised my concerns of next steps and my deep concern of suggestions of moving Dan from the rehab to skilled nursing with Congressman Jim Gerlach's office. I subsequently met with another VA representative in November of 2006. During this meeting I explained my

concerns and desires for my son. The VA representative listened and suggested he take me on a tour of the Coatesville VA Hospital Facility. I agreed and he proceeded to take me there and showed me a ward where Dan would be placed. It was a 'locked' dementia ward. He was quite proud of the facility and mentioned that because of my son's injury he would have a private room - when one became available. The entire ward stunk of odor from patients who needed to be cleaned. He wanted to place Dan in a dementia ward, indicating an appalling lack of understanding of the needs of a TBI patient. Immediately upon leaving the Coatesville VA facility I vowed my son would never be placed in a VA center again.

Dan had surgery to correct his ankle contractures and returned to the Bryn Mawr Rehab for two weeks in early March of 2007. The short stay was to confirm the surgery would enable the therapists to begin standing him. Standing has been found to help a TBI patient in their recovery and it has helped Dan. Following that stay he was moved to the Manor Care facility. Manor Care is a skilled nursing and rehabilitation center. The vast majority of the patients there are very aged people.

In March 2007, we decided to proceed with the home modifications and requested approval for a VA Housing Grant. The VA confirmed the strict requirements of the grant, which included that Dan's name be placed on the deed of the home. Because I declined, we subsequently had to settle for the very limited amount of \$14,000. Construction began in May 2007 with the VA knowledge of our plans and intent.

My experiences with the Philadelphia VA are extensive and uniformly quite frustrating. Every interaction with them has been arduous and verging on combative at times. They continually demonstrate their inability to establish and execute plans. They have been completely unable to meet Dan's needs.

During the spring of 2007, I met with a representative of the Independent Living and Vocational Rehabilitation and Employment group to discuss what opportunities that group had to help my son. During that meeting and in later interactions, I was advised by the VA person that she could approve financial assistance and was confident she could get a higher amount approved by the Philadelphia VA. She then decided that she could get a greater amount approved if she filed for a grant to the Washington office. The recommendation was that we halt the construction on our home until the approval was obtained for the grant. I refused and suggested that she expedite the approval process. At the time I also asked her to just get the Philadelphia financial assistance approved. She decided instead to proceed with the grant request from Washington. I waited five months until we received the decision that the assistance had been denied. Clearly my decision to proceed with the home construction was the proper decision. If I had waited, we would have significantly delayed the preparations for our home. The end result is Dan received nothing! There was no assistance. My conclusion is she either did not know what she was doing or she should have followed my direction and gained the Philadelphia approval.

On October 15 of 2007 I had a conference call with the Philadelphia VA and advised them the modifications to our home were nearing completion and that I intended to move Dan home on November 20. I requested their assistance in funding Dan's required ongoing therapy and in providing the necessary supplies and medications. Keep in mind they had full knowledge of the intent and had been in the loop on the home modifications since the preceding year. This call

was to advise them of the planned date. I very quickly learned they had no concept of how to establish even the most basic plan of action to transition Dan home. On multiple occasions following the call I asked for an executable plan - I'm still waiting. They could not tell me what actions they would take, when the plan would be complete or even who was responsible. November 20 came and went and I did not have the supplies or medications nor did I have a transition plan. It is inexplicable to believe they could not plan and execute. I have personally witnessed similar patients while at Bryn Mawr Rehab who were transitioned home in a matter of days yet the VA has not been able to accomplish this in many months.

After applying regular pressure on the VA, on February 21, 2008 I finally received the last of the initial supplies and medication items. It took more than four months to get these items. There were multiple instances of the wrong item or quantity being shipped, which required additional interactions with the VA. Why does it take four months to get items that are readily available?

During many conversations with them I requested a plan to re-fill Dan's medications and to obtain newly-prescribed medications. I still do not have an acceptable plan for newly-prescribed medications. The VA "solution" will take longer than 24 hours at best. It is completely unacceptable to wait that long. When I challenged them to deliver a more adequate plan their response was it was my fault because I had not identified a full service pharmacy for them to use. Their position consistently is that it is my fault. How can it be my fault that they cannot provide what my son needs? They can't plan or execute, they have known of our plans for more than a year. The only logical conclusion is that they just don't care.

After months I still have not received a transition plan for therapy and in-home assistance. They have received full evaluation reports on Dan's therapy needs and have received detailed orders from his physician about the type of care he needs and they continue to ignore them.

I could go on and on as I have numerous examples. Essentially my experience with the Philadelphia VA is:

- Make statements and do not live up to what they say
- Unresponsive - months to get transition plan in place
- Unwilling and unable to provide skilled care recommended by doctor
- Unable to fill supplies requests timely - takes many months
- Unable to provide medications STAT - takes more than 24 hours - they have no capability to meet an immediate need once he is transferred home. Their solution requires out-of-pocket cost for Dan
- Every decision that is made is based on cost impact - not what my son needs
- They ignore primary care physician's orders
- I have been informed by VA personnel that it is against the law for them to work past 4pm.
- Unable to establish and execute a simple plan - they can never tell me what, when and who is going to take actions. No dates - no commitments. All they tell me is they are moving as quickly as they can.
- They are already backing off any type of long-term therapy commitment - contrary to neurologist order
- Unwilling to fund his therapy needs - pushing the responsibility to private insurance

- Payment of his van to the dealer required my personal involvement and took three months after it had been previously approved by the VA
- Owe Dan money for reimbursement - more than 90 days - no one follows up
- No ownership. No one owns a problem to resolution
- Unprofessional - comments, can't plan, can't execute

It is clear to me that the focus should be what is best for Dan and what he needs. His needs for medications, supplies, therapy, etc. should be paramount in everyone's mind. Instead, the concern is where he can be shoehorned into the "system" and what an item or service, such as therapy, will cost and whether the VA or TriCare should fund the expense. It should be noted that since leaving the Richmond VAMC all of Dan's costs for care have been funded by TriCare with Dan paying the co-pays and cost shares. The VA has not participated in absorbing any of Dan's medical costs. That includes everything - surgeries, rehab, nursing, transportation, medications, disposable items, etc.

I'm dealing with VA personnel who have known for more than a year of our plans to move Dan home as recommended by his physician. They have had a very long time to assist with a plan for transition. Quite frankly, I regret getting them involved. They have turned a very simple transition into a complete debacle.

I have worked for a major corporation for many years and fully understand the requirement to have policies, processes and procedures that can be leveraged across organizations and businesses. But, there are always the 'big deals' that come along that require exceptions and actions that are not the norm. That's why the procedures and policies are there - to handle the norm and recognize when exceptions are necessary. The exceptions require a program office approach with a person or persons who have the responsibility and authority to make the quick decisions and direct the organizations on what is to be done. It requires a delegation of authority and shifts in accountability. It results in the 'big deals' moving quickly and smoothly. Dan and others like him are 'big deals'. They are the exceptions. There are not many who have been injured like my son. The VA can't cope with his needs and there is certainly no coordination within the departments and organizations of the VA. Complicate that with the inclusion of the private care element and TriCare and the systems and processes just break down.

For more than a year Dan's condition has been such that his neurologist and primary care physician believe it best for him to be transitioned home. To accomplish this required extensive modifications to our home and a huge out-of-pocket family expense. When this decision was made (in very early 2007) I engaged with the Philadelphia VA for assistance and once again I have experienced the inability of the VA at essentially every turn to execute even the smallest task without painstaking involvement and rework. They are not in the least bit concerned about serving and meeting my son's needs. They have repeatedly demonstrated they are unwilling and unable to assist.

Dan wants to and should come home. Yet, the VA has demonstrated they are unable to assist. This is unacceptable.

The problems and experiences clearly point to major systemic issues that must be addressed. Dan is a 'big deal', but he is not alone. These problems are not unique. They demonstrate major gaps and breakdowns in the level of care and complete failure to meet their unique needs. My son and others like him served their country proudly. The focus must be on what is best for Dan, the type of care he needs, deserves and earned in service to this country. Instead the military and VA have made and continue to make financial decisions. Those decisions are totally unacceptable if we care about the health and life of my son and others like him. They are 'big deals'. They need a different level of care and attention; they need regular stimulation and appropriate therapies, delivered by people experienced with this type of injury.

The level of care is complex and needs immediate and dramatic change but the issues we face are not. I constantly reinforce with the VA to do something for me don't give me more to do. Yet, they fail to understand. Their idea of help was to send me the link to a brain injury website. Give my son and those like him the in-home care they need - timely medication availability, nursing, ongoing therapy, stimulation, respite assistance, training, compensation for caring for their injured loved ones and relieve the huge financial burdens. We should not have to fight for these. Yet we do. Remember, one of the VA's first responses was that Dan should be in a dementia ward. Their most recent plan insulted me with a statement that they expected family participation in his care. Just what do they think has been going on? They really don't understand and quite frankly their attitude is appalling.

My belief is that the best ways to help the family is to dramatically improve the care for the injured. Stop the scrimping on care cost. Provide ongoing assistance to the families in terms of helping them - do things for them.

Thank you for the opportunity to share my experiences and my views on what can be strengthened or improved. I hope you understand that my only concern and priority is Dan and his care. I am not alone. Each of these serious injuries is unique and demand flexibility in care and cannot be served adequately with rigid processes and systems. The burden is placed entirely on the family because we do not trust the system to provide for our injured. Our experience has taught us that.

I'm asking for your assistance.

Thank you for allowing me to speak today.