

THE ENDLESS JOURNEY HOME

Post Traumatic Stress Disorder & Invisible Wounds
Symptoms and Resources

An Iraq Veteran and family's story, suggestions for support, healing and for changing the system

By: Specialist Joe Collins, USAR (Ret.) OIF Veteran

Table of Contents

Some Personal History on PISD/Invisible Wounds	3
Physical Symptoms	6
Psychological Symptoms	6
Sleep Problems	6
Isolation	7
Anxiety	8
Hypersensitivity	9
Memory Problems	9
Suppressed Traumatic Memories	11
Mood Swings	12
Addiction/Self Medications	13
Personal Hygiene/Housekeeping	14
Self-Mutilation	14
The Importance of a Strong Support System	15
Successful Recovery and Living with PTSD/Invisible Wounds.	15
<i>Summary</i>	17
Family's Story	18
Changes Needed to Help Prevent, Intervene and Treat	
PTSD/Invisible Wounds	22
Learning from War	26
References, Reviews and Special Thanks	27
Resources	28
Helpful Numbers	29
Where to Begin	30

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Our Story

In January 2003, 19-year old Army Reservists Joe Collins, announced that he had volunteered for duty in Iraq with another unit and would be leaving home in 24 hours. The post 9-11 wars had shifted from Afghanistan (Operation Enduring Freedom – OEF) to prepare for Expeditionary Forces to enter Iraq.



Everyone assumes that because you made it home without any obvious injuries that everything is back to normal. For me, with PTSD this is the beginning of my long and painful journey home.

Joe left in January 03 for premobilization and then officially deployed to Iraq in March 2003 for the first wave of Operation Iraqi Freedom (OIF). His 366 days in Iraq were interrupted by a one-week leave in February 04, and a final return home in April of the same year.

When he got off the plane, he looked as healthy and strong as ever, walking with confidence as people stopped to shake his hand and thank him for his duty. It "appeared" that Joe had weathered the storm well. As a family, we were vigilant, but relieved he was home.

Within four months, he had found a great job. Within the following three months, he had purchased his own home. By the age of 21, Joe had served for a year-long deployment, got a great job and was a home owner.

But unbeknownst to us, he was slowly unraveling. He avoided sleep because of the memories it would bring, and when he did sleep, it was in the walk-in closet of the home he had purchased. He was becoming more isolated and irritable, but his disciplined military training kept him pressing forward despite all odds, until he could hold on no longer.

In April of 05, Joe's boss notified the family that he had not shown up for work (very unlike him). Responding with alarm, we found Joe in the home he had purchased, paralyzed with exhaustion and invisible wounds he had tried hard to ignore and/or overcome on his own.

Veterans' Families United (VFU) began because of one family's effort to understand and advocate for this proud young American who had pushed forward despite all odds. Through the process, he lost his job, his home and his health, but not his hope.

VFU was created to reach out to veterans and families of all generations and conflicts who have faced the same challenges. Since 2008, we have shared this booklet that Joe wrote. In this update, we have also added a new section on

"Family Issues" to share common struggles that families face with the wounds of war. You can find some resources to help with these issues on our website at www. VeteransFamiliesUnited.org under "How to Get Help" and on our Resources page at the back of this booklet.

JOE'S STORY

I now consider myself an expert on the signs and symptoms of PTSD and related illnesses. I have suffered from it all for more than 13 years, not nearly as long as many, but I have suffered to the most extreme of each of the symptoms listed within this booklet. I believe that merits my understanding of the debilitating effects. For the first two and a half of those years, I was so ill and devastated from its effects that I was bedridden, only leaving my room maybe seven hours a week to see my counselor and psychiatrist.

My reason for writing this guide is to better educate and spread awareness of PTSD and other invisible wounds and their effects. In my own personal experiences, I have gone through countless doctors in the military, VA and civilian



With PTSD trying to be "normal" after living in the "extreme" of a war zone is very difficult. I am thankful I have a good support system of close friends and family.

sector. While showing "text book" signs of PTSD, I was once given a 15-minute (mis) diagnosis and quickly written a prescription.

On two separate occasions, I went to see civilian psychiatrists in the earlier stages of my illness (for fear of losing my military status).

The first time, I filled out a True-False survey and then spoke with the doctor for 15-20 minutes. I was told I had Attention Deficit Disorder and was prescribed Adderall.

Another time, I was accompanied by my mother who is a Licensed Professional Counselor. When I spoke with the doctor myself, I basically went through the exact same process, except he spent less time with me and (mis)diagnosed me as Bi-Polar Disorder, sending me off with three different prescriptions. I now know that my mom was in such shock herself, that it was hard for her to be objective and we both relied on the doctors to help me.

Luckily, after enough unsuccessful attempts, I found an excellent psychiatrist. He did a great job of communicating with me, my mother and my regular counselor (who I was fortunate enough to find on my first attempt and has helped me tremendously). From the combined effort of all three working together on my behalf, I was able to begin the journey of recovery from PTSD and other invisible wounds of war.

It has now been 13 years of ongoing recovery. I have learned that there are some very caring people who want to help. I have also learned that there is no "magic pill" that will "cure" me. I learned that we still don't know everything about the effects of shock, trauma and other exposures and injuries of war and that it is wise recognize that and to very carefully participate in the healing process.

From my experience, it is hard to find the types of doctors who have knowledge to properly diagnose you from the symptoms you might be suffering. My experience has shown me that I was MORE OFTEN misdiagnosed and sent down the wrong path of recovery...and even worse; I was put on an addictive medication that only masked the problem. Then, I had two battles to fight; ADDICTION AND PTSD.

I think, when it comes to PTSD, the most positive and effective way of treating it is to catch it early on and to have a good support system (family and friends) and a treatment team (a group of professional healers) who are all on the same page when it comes to what the illness of PTSD and other invisible wounds brings and what steps are needed to get you back on track to living a healthy and fulfilling life.

To help soldiers and/or their families and friends REALLY understand what PTSD (and other invisible wounds) looks like, I have described the symptoms and how they look in the following pages. Hopefully, if you see something familiar in yourself or someone else, you can get treatment soon and not have to experience as much suffering as I have.



Any person who has witnessed a traumatic event may suffer some degree of PTSD. The most important thing to remember is not to ignore the symptoms.



PTSD symptoms usually do not begin to surface until 3-6 months after the deployed soldier returns home. (Check off symptoms to take to your primary care physician if you think you may be suffering from PTSD or other invisible wounds).

Physical Symptoms
Headaches
☐ Stomach problems
☐ Changes in breathing patterns (i.e. shortness of breath)
☐ Lack of energy OR
☐ Sometimes being very active and over-energetic
☐ Sleep problems
☐ Feeling of emotional pain that you have never felt before
☐ Anxiety problems
Hypersensitivity
☐ Hyper vigilance (always on alert)
Psychological Symptoms
☐ Mood swings
☐ Memory problems
☐ Addiction/Self Medication
Loss of personal hygiene/housekeeping
☐ Risk taking behavior
☐ Isolation
Depression (thinking "what's the point")
☐ Paranoid thoughts
Sleep Problems
Insomnia (not being able to fall asleep or stay asleep)
Having nightmares
☐ Waking up covered in sweat
☐ Kicking during sleep
Constantly waking up and falling back asleep, possibly due to bad dreams
Waking up and being easily startled and/or being confused about where you are
☐ Irregular sleep cycles

Often these symptoms will lead an individual to avoid sleeping as much as possible or turn to alcohol or other drugs to try and self- medicate the problem.

An important thing to remember is that EVERYONE has some of these symptoms, some of the time. It's when an individual has a LOT of these symptoms, most of the time and they are affecting family, work, finances and social life, then it may be a good idea to seek help.

Following is a list of some of the most difficult problems that I have had to face and my experience with it. I hope that it will help others understand what is happening to themselves or their loved one.

Isolation:

Early Stages:

The individual will begin to slowly start isolating himself or herself from society. These symptoms can be evident by a lack of wanting to go out to social places that they used to find enjoyable. The individual may not show an interest in meeting new people or they feel uncomfortable or alert if placed in a situation with a large crowd of unknown people. They might begin eating meals alone or may become workaholics, throwing themselves into materialistic things rather than people.

At this stage, the person usually begins to sever many social ties, only leaving those close members of family or closest friends who he/she trusts and feels enough comfort around to allow the relationship to last. Human interaction is an important part of emotional growth and recovery. Without it, the soldier will continue a downward spiral.



Anxiety builds from the unknown that was faced on a daily basis.

<u>Later Stages</u>:

Usually by this time the person is nearly crippled by other symptoms and often can be diagnosed as being depressed, which is part of the illness but not the whole picture. By this stage the person has most likely completely cut him or herself off from society including friends and family and will most likely surround themselves only with materialistic things.

They usually will only go out on a required basis (to get food or medication).

Often, to reach this level of isolation, the person is in a severe, deep stage of PTSD and needs immediate medical attention. Without it, things can very often get worse if left untreated.

Anxiety:

Anxiety can be tied in to nearly every symptom of PTSD. This is another symptom that often leads to an incomplete diagnosis. This can lead to the wrong type of medication, which may seem to help at first, but often can lead to addiction problems. Anxiety medications can be more of a band-aid solution and very often, do not really solve the problem.

The strongest symptom of anxiety for PTSD sufferers is remaining in a constant state of hyper vigilance (on "alert"). This happens at a subconscious level. Often, the returned soldier is not even aware that they are stuck in this hyperactive state. They will sometimes seem on edge and always be prepared as if something is about to happen.

Good warning signs for this is that the soldier will never seem to be calm or in a relaxed state, especially in a public place. They may appear to constantly be looking around and sizing things up.

Another good sign is if you go to a restaurant to eat, the soldier will always request to sit in a corner or with his/her back to a wall. From personal experiences and those of others who have suffered from PTSD (or other invisible wounds that effect the nervous system), if put in a situation when UNABLE to sit in a comfort zone (a back/corner booth), then the soldier will feel uncomfortable throughout the entire meal while people walk behind him/her. The soldier will be constantly looking around feeling uncomfortable or insecure.

Other symptoms of anxiety are shortness of breath in stressful places or situations, rapid heart rate, muscle tension (often in the jaw area, which could lead to grinding of the teeth and severe headaches) and severe stomach problems.

Anxiety often leads to many avoidance activities, and in some cases can be the cause of isolation. For example, in many cases returning soldiers who are suffering from PTSD will stop watching news about the war or even can't handle watching movies or TV shows with war in them. These things trigger anxiety levels that go "through the roof" and bring back unwanted or unpleasant memories that they are not ready to deal with or face yet.

It's very important to keep a watchful eye for these symptoms because they are easy to notice at first, but if immediate action is not taken, a domino effect will occur at a rapid pace and make it much harder to help the soldier the longer it goes on.

Hypersensitivity:

Hypersensitivity and anxiety usually go hand-in-hand. The most common symptoms are sensitivity to bright light, loud noises, large crowds, unfamiliar places and/or being easily startled.

At first, these symptoms may appear to be slight or almost unnoticeable, but a soldier that begins to feel an increase in an anxiety levels and discomfort when exposed to some of these elements may need immediate help.

Over time, and without treatment, symptoms can get worse. In several cases, those who suffer from PTSD and have not sought proper help can suffer severe anxiety attacks (panic attacks) and often complain of migraine headaches if they are triggered by one of these symptoms.

Memory Problems:

Memory problems are probably the most commonly shared symptoms of PTSD sufferers. At first, memory problems may be somewhat hard to diagnose, but often it is a progressive symptom and will get worse as time passes without proper treatment.

Early Stages:

The first stages of memory problems might show up as absent-mindedness like easily forgetting things like important dates, appointments, and names of new people that they meet. Constantly misplacing or losing things are also some examples. If the returned soldier never had problems in any of these areas before he/she deployed, it is important to keep a watchful eye on them. Without proper care, memory problems can become progressive and debilitating.

Later Stages:

By this time, the returned veteran is most likely showing many other symptoms of PTSD. Late stages of memory problems will be very obvious. The person most likely will forget things on a day-to-day basis. They might even have trouble remembering things from the past. Sometimes the returned soldier may be in the middle of a sentence, then pause and forget what they were talking about. Or, they might tell you something and minutes later tell you the exact same thing because they forget they have already said it in the first place.

Memory Problems that can also be caused by other issues:

Over the past 13 years, I have learned that memory problems can come from other invisible wounds. Undiagnosed Traumatic Brain Injury (TBI) can also affect memory. There are not many good tests to help determine TBI unless it is severe. TBI can affect parts of the brain that process memory.

Another thing that can effect memory is lack of sleep. As a soldier, we are trained to do without sleep so that we will be prepared for combat at any time. However, the long-term effect of sleep deprivation (whether its learned from our military training or because we avoid sleep because of unwanted memories) can be severe. There are often completely different treatments for disrupted sleep than for PTSD and other invisible wounds.



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The long-term effect of sleep avoidance can cause an individual to live in a sort of "twilight" which is like being awake and asleep at the same time. This can become "normal" to the soldier, but to those around the soldier, they can see an increased distance, irritability, and lack of healthy engagement in life. Unless the sleep issue is addressed carefully, it will continue to create a downward spiral.

In my experience, it does not seem like a lot of care providers understand the huge impact that long term sleep deprivation can have on memory and on recovery itself. It seems like sleep doctors, psychiatrists and other care professionals have an opportunity to work more closely together with treatment of this or it will continue to be a huge problem for returning combat veterans.

Another thing to be aware of is that soldiers are trained to adapt and to keep functioning. In many cases, if a returned soldier begins to realize they are having problems with memory and they are unaware that it might be PTSD (and/or other related issues), or they are resistant to getting help, they might purchase note pads, post-it notes, or dry erase boards to try to compensate for their memory loss.

From personal experience and other soldier's experiences, when this level of memory challenges has been reached we often compare it to feeling like

our memories have been put into a blender and pulled out. It leaves a feeling like everything is mixed up. It can also feel as if some of the memories were left out of the blender, evidenced when we draw a blank trying to recall certain events. Others say they feel as if their memories are like a block of Swiss cheese, and they can remember things that happened in the order that they happen, but they have blank spots or there are holes of missing information.

It is very; very important if you are a soldier, a family member or friend of a soldier who reads this and are aware that you or someone you know is going through this problem, to SPEAK UP about it. Without intervention or help, this can continue to be progressive and be harder to treat the longer you wait.

Suppressed Traumatic Memories:

In many cases, when a person is exposed to a traumatic event, they will often suppress the memory of it. It is a survival mechanism built into us to help us continue to function and survive after being exposed to the trauma. The best way to describe what happens and how it relates to for those with memory problems. PTSD is by using an analogy.



A dry erase board may compensate their memory loss.

The brain works in similar ways to store memories as a computer does by burning information into a CD. When a traumatic event happens, this leaves a deeper impression in your memory (or a deep groove like in the CD). If you are in a war zone, you adapt after the traumatic event happens even though this deep impression or groove in the CD (so to speak) has already been burned in. You do this to survive. But you still must "drive" and function, still "burning information making new memories" after the traumatic event has passed. Depending on the level of trauma, it may start to become difficult to even remember the event.

Once the soldier has returned home, there is a good chance they will have suppressed the traumatic memory since it is too painful for them to confront. So, they will continue to live life as though nothing happened. Eventually something (a noise, something they see or smell or touch) will trigger (bring back) parts of that memory.

Like the "burning" of a CD, the traumatic memory would leave a deep groove. Once a soldier is triggered, it brings him/her back to that groove in the memory and it is like hearing a CD stuck on "skip". It just keeps playing over and over because it is stuck in that groove. This can often be the beginning of PTSD or what starts causing some of the previously mentioned symptoms. If this is happening, it is a good idea to tell your care provider. There are new and a growing number of ways to help with this that do not involve medication.

Mood Swings (risk taking behavior):

These are both common symptoms of PTSD and can be interrelated. Mood swings are very apparent and easy to notice. Usually, when it comes to PTSD and the soldier begins to experience problems with mood swings, it will almost always appear as aggressive or violent. One thing to keep in mind, as with all these symptoms, if you didn't notice any problems BEFORE deployment, but notice them after returning home, then you KNOW something isn't right.

Mood swings can often appear to be mild temper tantrums, or irritability towards others, but can often get worse. The best way to describe why a soldier might deploy appearing "normal" and return from deployment showing any of these traits is described below.

Let's imagine that a soldier grew up in a hot climate where there are long summers with temperatures usually getting into the low 100's. If the soldier had never been anywhere hotter than on a 100-degree day, he might think that the 100-degree heat is unbearable.

But now let's imagine that same soldier has been in the desert for a year or more, with temperatures from 110-130 degrees every day, (which seems insanely hot normally). Upon return home, the soldier thinks 100 degrees is much easier to bear.



What seemed "insane" or "unbearable" or "difficult" to adjust to when first thrown into the war zone, becomes normal as soldiers adapt to the event to survive. The soldier that deployed and then returned from duty, SEEM like the same person, but experience has made that person different.

The soldier that deployed and then returned from duty. SEEM like the same person, but the experience made that person different. What seemed "insane" or "unbearable" or "difficult to adjust to" when first thrown into the war zone, becomes "normal" as soldiers adapt to the events to survive; the "insane" becomes "normal". Then, when a soldier returns home, all those events are brought home as invisible baggage.

Violence, aggression and/ or risk-taking behavior is part of "everyday life" when a soldier is in a war zone because they are risking their life everyday for their country. So that behavior becomes "normal". If there isn't someone to show the soldier that the violence, aggression and risk-taking are "normal" for the war zone, but "extreme" when coming home, then they often don't know the difference.

Addiction/Self Medication:

This is one of the most important symptoms to watch for, and the most dangerous. If it is not caught early enough, or if the soldier is misdiagnosed, the soldier can be sent down a dangerous and painful path of drug or alcohol abuse.

For those soldiers who aren't abusing drugs and suffering from PTSD, they will often turn to alcohol to try and numb the pain of the symptoms and/or the painful



If you can start a path towards recovery without being prescribed ANYTHING, then take that opportunity.

emotional memories that they are suffering from and experiencing.

Other soldiers might start to become aware of their problems and seek medical help. But if they seek help with someone who does not have a full understanding of PTSD, it is easy to misdiagnose, and be given medications that can make things worse. This is tragic because the soldiers' "goal" isn't to become an "addict". But, if a soldier is given something that helps ease the pain, then before long, they can be abusing the drug or alcohol that they think is relieving it.

If you notice some of the symptoms listed, it is best to avoid alcohol and medications until you speak with a counselor or psychiatrist and entire care team. If you can start a path toward recovery without being prescribed ANYTHING, then take that opportunity.

If you are abusing drugs or alcohol, or you know of a returned soldier who is, then immediate intervention is needed. Be careful in the way you approach the intervention, because it is often met with anger and aggression and possibly violence, depending upon the level of PTSD and if the soldier is self-medicating. Take precautions if you plan to intervene by finding a counselor or expert in war related PTSD to help guide you.

It is important to remember that the soldier didn't just wake up one day and say, "I am going to become an alcoholic or addict." The soldier is in pain and trying to find something to take the pain away. They just don't realize that self-medicating only makes things harder to deal with in the end.

Personal Hygiene/Housekeeping:

This is another important symptom that is common among PTSD sufferers. It is often progressive, and the person can easily be diagnosed with depression when it can also a symptom of PTSD.

Early Stages:

The individual will begin to show signs of not maintaining a clean appearance, such as combing hair, shaving on a regular basis or wearing clean clothes. They might also begin to stop picking up after themselves on a regular basis and/or not keeping a clean and organized home.



Later Stages:

By this time the individual most likely has no regard for their own appearance, and most likely doesn't shower or bathe on a regular basis. They probably can hardly clean up anything after themselves since by this stage, even small, simple tasks seem overwhelming. If the soldier has reached this level of illness, then immediate medical attention should be sought. By this stage, if there is no one to care for the sick soldier, then it becomes dangerous because they are struggling to even make it day to day.

Self-Mutilation:

Self-mutilation, which can be burning or cutting of oneself, can be a symptom of PTSD sufferers. If you or someone you know is doing this, it is extremely important to seek immediate medical help.



I went from 180 lbs. and a clean appearance upon returning from Iraq to an un-kept 230 lbs. after being nearly bed ridden for 2 ½ years due to suffering from PTSD.

The only reason someone would purposely harm himself or herself is because they are in an extreme amount of pain. Often, it can be a cry for help, or in other cases, someone might be suffering so much that

they hurt themselves to try to take their mind off the pain they are always feeling and focus it on something else.

If a soldier is involved in self-mutilation, then IMMEDIATE intervention and possibly hospitalization is needed.

To reach the point of suffering where you begin to harm your own body can often be followed by suicidal thoughts if gone untreated. Therefore, it is EXTREMELY important to seek help if you or someone you suspect is doing this. (Crisis Hotline 1-800-273-8255 dial "1" for veterans).

The Importance of a Strong Support System:

I believe having a support system (family and friends) to be there for you when you are suffering from PTSD and other invisible wounds, is absolutely necessary for recovery. In my own personal experience, there was a time during my illness that I was suffering so much from the symptoms of PTSD that I was no longer able to advocate for myself.

I had to move back to my mother and stepfather's house. My mother had to fill out most of the necessary paperwork for me to receive disability from the VA. They drove me to and from all my medical and counseling appointments because I was too ill to do it on my own. On top of that, they assisted me with ordinary tasks such as running errands or getting groceries while I focused on my recovery.

Without their assistance, there is no telling where I would be or what situation I would be in today. Without strong support systems, people like me would most likely end up on the street or in a hospital somewhere, or in other ways furthering our illness.

Obviously, the most severe result of these illnesses is suicide. In extreme cases, soldiers are in so much physical and mental pain that they feel there is no hope. Thinking this pain may last forever, they often begin to believe that the only peace they can find is to end their life. If you are a soldier or you know a soldier suffering from PTSD or some of the issues described here, it is important to seek support. Whether it is family or friends or some of the resources listed in this booklet, there are people who care, and it is important to ask for their help.

Successful Recovery and Living with PTSD/Invisible Wounds:

With proper counseling and medical treatment and support, it is possible to make a functional, ongoing recovery from PTSD and other war related wounds and function as a member of society again. Although when I say "recovery", I don't mean that PTSD and other wounds will magically disappear from your life. I mean that you will have the symptoms under control.

PTSD/invisible wounds are something you will live with for the rest of your life, but you can learn tools and coping mechanisms through treatment to assist you when you are triggered by something. Plus, overtime, you will begin to know your own limitations and how far you can push yourself before symptoms will begin to arise.

Knowing this information and working with your local VA (who will assign you a disability rating for financial compensation) and other knowledgeable care providers can allow you to still live a fulfilling life without having to worry about the financial loss this disability has or can cause. It is always good to ask any care provider if they have experience working with combat veterans. This can help you to get targeted help and make the road to recovery less challenging.

The main thing to remember to continue recovery is to keep hope, faith and to NEVER give up no matter how much pain you might be experiencing. Believe me, I have been there, but I held on at all costs and sooner or later, if you don't find help, then help will find you.

Other Symptoms:

Over the past 13 years, other symptoms have appeared. It is very clear that I have PTSD, but these symptoms are more visible wounds, and seem unrelated but very important to speak out about.



Sleep problems can be long lasting and troublesome unless addressed and treated properly.

In 2009, my teeth began to disintegrate. Little by little, my teeth dissolved. Year after year, I continued to get dental help but now I do not have any of my original teeth left and have dental plates. Some doctors think it is due to medications I have taken. Some think it is Acid Reflux (GERD) caused by my anxiety. Some say it is dental hygiene and others wonder if it could be delayed reaction to exposures I might have had while "in country". It is important to seek immediate attention if this begins to happen and to file with the VA Burn Pit Registry, so more information can be gathered.

In 2012, I got lower extremity Lymphedema. This condition is rare in young patients and often is a result of cancer treatments or

physical injuries. There is no "cure" but it can be managed. Again, it is a mystery why I have lymphedema and I will have to wear and use special equipment and/or have surgery as time progresses so that I can continue to walk.

In 2016, I was diagnosed with Planter Facscitis with Fibroma. These are huge lumps in the arches of my feet. When I walk, it feels like I am walking on needles.

I have special insoles now to help offset the lumps so that I can walk with less pain.

None of these other health issues are directly related to PTSD. It is possible that I was exposed to something (like the Vietnam Veterans with Agent Orange and the 1st Gulf War Veterans with Gulf War Syndrome). It is very important to speak out about any additional physical problem so that your family and care team are aware of the complications and it helps with greater understanding.



This condition is rare in young people and often a result of injury, after surgery or radiation therapy. It can also be certain diseases or problems that keep the lymphatic system from functioning properly.

Summary:

Post-Traumatic Stress Disorder and other invisible wounds of war can be very serious issues if left unattended. Any person who has

witnessed a traumatic event may suffer some degree of PTSD. Then, there is the possibility of undiagnosed TBI, sleep disorders and toxic exposures, as well as addictions, that often complicate the issue. The most important thing to remember is NOT TO IGNORE the symptoms. The earlier symptoms are identified and addressed, the sooner that helpful intervention and the journey to healing can take



place. If you are personally experiencing any of the symptoms mentioned in this guide, or if you know anyone who may be, please don't delay in investigating any of these resources on our website at www. VeteransFamiliesUnited.org or listed at the back of this booklet under "RESOURCES".

"Keep Pedaling On!"
Though the journey may be difficult, there is support through caring and helpful people, sometimes in places you might never expect.

FAMILY'S STORY

By Cynde Collins-Clark, mother of Joe Collins and 2018 Elizabeth Dole Foundation Fellow for Oklahoma (www.HiddenHeroes.org)

One of the most difficult things about being a family member is experiencing the feeling of deep gratitude for the veteran and their service and recognizing the feeling of frustration and helplessness when you notice the changes taking place when the veteran returns. It is often very confusing and disorienting. If you recognize any of the following symptoms, it may be time to seek help. (Active Military seek help with the Family Readiness Groups or Military One Source. Veterans' families can seek help with the VA Coaching Into Care Hotline or the Vet Center nearest you. You can google any of these resources or see the back cover for contact information).



Cynde Collins-Clark, mother of Joe Collins and 2018 Elizabeth Dole Foundation Fellow for Oklahoma (HiddenHeroes.org)

Symptoms of Family Members

Extreme anxiety
Inability to communicate effectively
Sense of complete "overwhelm"
Uncharacteristic fear
Confusion
Lack of sleep
Unhealthy habits or change of habits/activities
Irritability/Anger
Loss of work productivity
Withdrawal and Isolation

Extreme Anxiety:

This can feel like you are "walking on eggshells" around the veteran. An example can be changing your behavior so that you do not "trigger" the veteran's unwanted memories or hypersensitivities. Often, the veteran does not demand it, but the family member is acutely aware of the unexpected and unpredictable responses of the veteran due to issues for which they may, or many not even be aware.

Inability to communicate effectively:

It sometimes becomes challenging to know how to express concerns that you may have. Sometimes, veterans are in denial or defensive about their behaviors. After

all, they have been trained to "suck it up" and "drive on" no matter what to survive a combat situation. This is helpful when in a combat zone. It can be challenging in the civilian sector. It can also be threatening if the veteran is a career military

member whose service may be cut short if they admit they have an issue. If you find that you cannot share your concerns honestly with the veteran in your life, or that they are minimized, it may be time to seek some outside support. (For no cost civilian care see www.GiveAnHour.org or contact a patient advocate at the VA).

Sense of complete "overwhelm":

Many civilians think that help from the military or VA is automatic. This is not correct. The veteran may not be willing to seek help if still in the military because of stigma. Registry in the VA system is NOT automatic and is often overwhelming for a veteran. When these things occur, then it is often the family member that is trying to



It is often the family member that is trying to navigate the very complex system of care.

navigate the very complex system of care in both the military and VA systems. Many times, family members can be denied input. Family members are also not trained in the language of the military and VA so on top of the issues that they face with the veteran, they are also overwhelmed with the task of "how to support and find appropriate help" for the veteran. When I could not find the help that I needed after multiple efforts, I contacted my Congressman and filed a Congressional Inquiry. This should not have to happen and should always be the last resort. It took 7 years to get my son's GI bill/student loan information and that was only possible with the help of our Congressman.

Uncharacteristic Fear:

If you have noticed strange behaviors in the veteran that were not present before deployment, but are now and/or are increasing, it can create an unfamiliar fear. This could be for such things as being fearful if you notice the veteran sleepwalking, having night terrors, engaging in high risk taking or addictive behaviors, etc. If you notice that you are more fearful about the financial, emotional, and social well-being of yourself or your family, it is a good sign to seek outside assistance. (See RESOURCES at the back of the booklet).

Confusion:

Sometimes the processes to help you and the veteran have contradicting information. This is not purposeful, but the result of a huge system that is not adequately prepared with a "customer friendly" way of seeking resources. There have been countless times that I was told one thing by one party and something different from another, put on "hold" for long periods of time, "transferred" from one entity to another to loop back around without any conclusion, given information that did not make sense, or not acknowledged at all. This can be very confusing. If you are faced with any of those issues, it is good to seek help. (See previous suggestions for seeking help and our RESOURCES page).

Lack of Sleep:

Every new parent knows that the schedule of a new born will cause disruption to sleep. That is because the baby is growing (needing food), needs a diaper change, doesn't feel well, or other expected behaviors.

However, most family members are not prepared for the disruption to sleep from the returned veteran. Veterans are accustomed to being "on alert" in every way for their very safety. Because of this, they often have extremely different sleep/wake patterns. Most of the time, veterans are not "re-acclimated" to a normal sleep cycle. They go from being hyper alert to being expected to sleep like a "normal" individual. This is unrealistic and often confusing for them as well as the family.

Just like with a new baby, you may be experiencing the odd sleep patterns of a returned veteran. If you can talk about it and create ways that are on a healthy path for you both, that is great. Otherwise, it might be helpful to seek support.

Unhealthy habits or change of habits/activities:

If you notice that you are sleeping more or less, gaining or losing weight (15 lbs. either way in 6 months), are running late for appointments, have little or no energy, have started self-medicating to numb yourself to the changes in your life or are escaping through any activity that compromises the well being of yourself or your family, it may be time to reach out for help.

Irritability/Anger:

Often, drastic and unrelenting changes can cause exhaustion. The exhaustion, unchecked, can turn into uncharacteristic irritability and anger. If you were patient and handled anger well before the deployment, but now have very little patience and anger easily, it could be that the transition home is taking its toll and

that some outside guidance and support could be helpful.

Loss of work Productivity:

All of the symptoms listed above can cause or contribute to loss of productivity at work. It is difficult to "stay on task" and work successfully in traditional civilian jobs when faced with growing anxiety, exhaustion, and worry for the well-being of the veteran, yourself and your family. When your work habits begin to change for an uncharacteristic period of time, then it may be time to explore options to deal with the issues differently. I had to go from full-time to part-time work which effected my salary and ultimately, my retirement pension dramatically. I could

not sustain the caregiving of my son and the work that I was doing. It was making me sick. I had to make a hard and costly choice. Now, there is the option of applying for the VA Caregiver Program which can be helpful if you are approved. If you are the caregiver, consider applying for this program with can be found on line at https://www.caregiver.va.gov/support/support benefits.asp

Withdrawal and Isolation:

The combination of some or all of the factors listed above can lead to the desire to withdraw and isolate. It's as if our bodies are seeking any "down" time to restore and replenish. That makes sense if it is a short period of rest and then you are able to return to



It might seem like "thumbs up, I'm ok" to some, but these symptoms may be telling you that help is needed.

balanced functioning for yourself. However, if you are withdrawing and isolating more and more, it can be a sign that you could benefit from support.

Sound Familiar?

Many of the symptoms listed above were also mentioned in Joe's story. The impact of untreated combat trauma, both visible and invisible, ripples out. Some would call this "secondary trauma", although that is not an official diagnosis. Neither the veteran nor the family member started the journey of "service to country" with the intent of carrying the wounds home and to their loved ones. However, the lack of adequate transition services for combat veterans and seamless services for assistance for veterans and families has created an unworkable situation. That is why we feel very strongly about the next section.

Changes Needed to Help Prevent, Intervene and Treat PTSD.

Post Traumatic Stress Disorder can happen to normal people who have witnessed a traumatic event. Military training does not cause a person to be immune from trauma. THERE IS NO MEDICAL TEST FOR PTSD, meaning that it is BEHAVIORS that are SYMPTOMS which are used by professionals to determine the likelihood of PTSD and other invisible wounds.

War, by its very nature is a series of traumatic events. Currently, an estimated 1/3 of all veterans returning from current conflicts are suffering from some form of mental health challenges AND only approximately 30% of ALL veterans are registered for VA Medical assistance. Left untreated, the long-term effects may include:

- Increased relationship problems and divorce
- Increased violence in the home, thus a potential for intergenerational violence and abuse
- Increased possibilities of legal issues (at one time, ¼ of the prison population was veterans)
- Increased possibilities of homelessness (at one time, ¼ of all homeless were veterans)
- Increased suicide risk and completion

Following are issues that we are aware may have opportunities for improvement. After an UNPRECENTED length of war time in American history, fought by less than 1% of the population, it is essential that these challenges be addressed for our future.

Challenge 1:

Inadequate Transition Programs from the Combat Zone to Home for Veterans AND their families.

In "Joe's Story" he says, "Violence, aggression and/or risk- taking behavior is part of "everyday life" when a soldier is in a war zone because they are risking their life every day for their country. So that behavior becomes "normal". If there isn't someone to show the soldier that violence, aggression and risk-taking is "normal" for a war zone, but "extreme" when coming home, then often they don't know

the difference "

There are currently few and/or inconsistent programs in place that provide adequate structure to help the returning veteran to learn and practice skills to transition from "extreme" behavior to "normal" behavior when returning from a war zone.

Many civilians assume that there is a very thorough process in the military to help veterans return home, to de-brief and to find "balance".

That is NOT correct. There are "some" things in place to help the service member, but they are not consistent in all branches of the service or even from base to base. It is even more challenging for the National Guard and Reserve who do not return to a daily routine that active duty members have.

Very often when a veteran returns home, the mind, body and spirit are used to the high alert and adrenaline overload that is necessary to stay alive in a combat zone.

For the most part, veterans and their families DO NOT have the skills to re-gain balance back home resulting in many of the issues discussed in this booklet. History is full of cultures and traditions that have very specific transitions for warriors. We can revisit this wisdom and begin new ways of welcoming home our veterans

Possible Solution:

Create a consistent "Transition Program" to systematically address common "coming home" issues for veterans AND their families.

Veterans and their families are incredibly resilient and have learned tremendous skills to survive tours of duty. Unless there is as much effort in transitioning veterans back into a non-combat environment, it is reasonable to expect them to operate using the "extreme" behaviors that they learned to go into harm's way and stay alive during combat.

It is incomprehensible to imagine that a veteran could return from war and transition back without significant support and accepted/encouraged processes for re-integration. It is equally incomprehensible to imagine that family members would have the skills and knowledge for the transition period.

Training veterans to "come home from war" is as important as training them to "go to war" and will take as long and require the same rigor and commitment from leadership as boot camp or basic training. Funding for this type of "re-boot camp" should also include full pay until the veteran has transitioned successfully into a job or continued education. "Success" could mean at least 6 months on the same job and/or completion of a semester in school...the options are limitless.

We owe it to our veterans to teach them the skills of regaining balance no matter much money it costs or how long it takes. We owe it to their families to give them the structure and support system to make re-integration efforts more inclusive of them.

Challenge 2:

Easy-to-access, immediate, and high-quality medical care.

Many civilians "assume" that military members who return from a combat zone have immediate access to medical and mental health, and dental treatment. That is not correct. It is extremely complex because it depends on where you live, which branch of the service you are in, and if you are active, reserve and/or the service discharge status.

These are just a few reasons that veterans may not seek medical care, mental health or dental care.



Many civilians assume that military members who return from a combat zone have immediate access to medical, mental and dental treatment.

Possible Solution:

Offer every eligible veteran a LIFETIME medical benefit card that allows access to ANY medical, mental health or dental practitioner PRIVATE, PUBLIC, COMMUNITY OR VA (their choice) to use as needed.

An expanded list of providers could include PRIVATE and PUBLIC providers (non-VA) who have met Medicare

eligibility requirements and who file claims to and/or through the VA so that they can collect more information about veterans health issues.

With new technology, this is a possibility and could allow veterans in both urban and rural areas, to have more easy access to services as well as develop a broader data base about our veteran's health.

It is estimated that only 30% of veterans have registered for VA Medical service. Not only would more accessible service be helpful to veteran's, but it may increase critical information that can help with research of veteran needs.

Challenge 3:

Inconsistent and often unreliable ways to define PTSD and TBI.

Many people believe that PTSD and TBI (traumatic brain injury) are determined from biological tests (blood tests or other medical procedures). This is NOT correct. PTSD and mild to moderate TBI are defined by symptoms (except severe TBI). There are some testing procedures that can be used, called neuropsychological evaluations. They are very helpful, but often still leave room for questions in diagnosis. Also, they can take long periods of time that can be stressful to administer to the veteran also, adding to the layers of issues. An accurate diagnosis is most helpful to determine the most helpful treatment.

Possible Solution:

Continue to research methods of more accurately diagnosing and treating "invisible wounds".

There are some public and private efforts that are being made to find "bio-markers" (biological identifiers) of PTSD and TBI. Research can be a slow and difficult process. We can encourage this research through our support of these efforts with emphasis and focus on non-pharmaceutical solutions (not medicines that alter our bodies) and focus on the most <u>natural</u> options for healing, once an issue is identified. We can also encourage research that does not <u>add</u> to the stress of the combat veteran (like home health or better access for rural veterans to private clinicians in their area).

Challenge 4:

Seamless Services for both married and single veterans and their families.

Nearly 45% of our armed forces are single service members. Often, their only support system includes their "family of origin", meaning their parents, siblings, grandparents and even aunts and uncles. The same is true for fiancés of single service members.

When something happens of importance, like a deployment or coming home ceremony or informational newsletters, emails and events, the families of single service members are often "in the dark" about important ways to support their loved one.

Families of single service members need the SAME type of information and services as families of married service members (including mental health support through Military Family Life Consultants or other DoD services)

Possible Solution:

Include "designated" family of the single service member in the same system of support as MARRIED service members.

Notify family members designated by the single soldier of their status and keep them updated in the same manner as married veterans. Provide the same services to those designated family members such as notifications, events, medical information access, medical/mental health support and care, etc.

This may be occurring in some branches of the service, and if so and if it is working, use the process to make it consistent for ALL branches of the service.

Learning from War:

We learn something from every war. From WW2, we learned about "shell shock" and "battle fatigue" that was later named PTSD. From the Vietnam War, we learned that veterans needed each other as support systems to deal with the aftermath of trauma and the "Vet Centers" were born. From the Gulf War, we learned that no matter how long a war lasts, there are casualties from emotional, physical and biological contaminants that affect the veterans and their families for a lifetime.

It is our hope, that the legacy of OEF/OIF is one that recognizes the need for traumatic intervention IN THEATER and the need for creating new and more personal and efficient processes for supporting veterans and families through the

challenges when coming home.

With growing mental health statistics, suicide rates, homelessness and incarceration among combat veterans and the resulting financial impact to veterans, their families and our country, we can't afford not to change.



Joe visits the 911 Memorial in New York City in 2014.

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Resources

Veterans' Families United Foundation – 405-535-1925 www.VeteransFamiliesUnited.org

VFU is an all-volunteer, not-for-profit organization that offers a comprehensive website and resource bank that helps veterans, families and their friends to find information to help with post combat support. Look for "how to get help", "wellness resources" and other links on our site. We list and describe specific resources that may be helpful. We are not a VSO and do not offer financial assistance, but we have compiled and created a comprehensive list for easy access.

Suicide Prevention Lifeline – 1-800-273-8255 (option 1 for veterans 24/7/365) http://www.suicidepreventionlifeline.org/

This is a part of the SAMHSA network dedicated to immediate needs. There are people available to direct you to help 24/7/365.

Military One Source – 1-800-342-9647 www.militaryonesource.mil

You may call this number and request to speak to a counselor. Contracted mental health counselors will speak with you about your concerns and offer information to help deal with difficult situations. This is an excellent resource for immediate 24/7 person-to-person information if the military member is still in the service.

Hidden Heroes – www.hiddenheroes.org

If you need any additional information or have any questions, please contact the Elizabeth Dole Foundation at info@hiddenheroes.org or call (202) 249-7170. This is a non-emergency closed group for caregivers of veterans.

Give An Hour – www.GiveAnHour.org

Give An Hour provides a list of PRIVATE therapists who offer their services at no cost for one session a week for up to a year for veterans and their families. Identify yourself as a Give An Hour client and ask if the therapist has experience working with veterans and families.

Make the Connection

www.maketheconnection.net

This VA website has specific information about PTSD and includes videos, assessments for PTSD, information sheets for families about where to get assistance and many other helpful items.

SAMHSA – Substance Abuse and Mental Health Services Administration (press "9" to speak to someone)

1-877-726-4727 - www.samhsa.gov/militaryfamilies

You can find community mental health care in your areas that is often offered at a reduced rate as well as links for crisis, jail diversion programs, and mental health and substance abuse networks.

National Alliance on Mental Illness (NAMI) – 1-800-950-6264 (M-F 10-6 EST) www.nami.org/veterans

This link describes common mental health issues and resources for veterans and families who may be in need.

VA – www.va.gov

The VA is divided into 3 areas; 1) Medical, 2) Benefits and 3) Burial. If you are a veteran, you must REGISTER for VA services. You can do this by beginning an on-line application at http://vabenefits.vba.va.gov/vonapp/main.asp (VONAPP - veteran's online application). These benefits are NOT automatic, and you must start the process yourself. This is essential immediately upon qualification. DO NOT DELAY. You may never need to use these benefits, but you have EARNED them, so it is good to use them! (See Vet Centers for issues specific to PTSD)

Vet Centers – www.vetcenter.va.gov 1-877-927-8387

Vet Centers guide Veterans and their families through many of the major adjustments in lifestyle that often occur after some Veteran returns from combat. Services for a Veteran may include individual and group counseling in areas such as Post-Traumatic Stress Disorder (PTSD), alcohol and drug assessment, and suicide prevention referrals. All services are free of cost and are strictly confidential.

Archives.gov - click on "Veterans' service records" to obtain copies of DD-214's or other military records that may help filing claims and seeking assistance.

Tragedy Assistance Program - www.taps.org 1-800-959-8277 Offers compassionate care to all those grieving the loss of a military loved one.

The Soldiers Project - www.thesoldiersproject.org 1-877-576-5343 Free, confidential and unlimited mental health services for Post 9-11 Veterans, active duty service members and their loved ones.

Visit www.VeteransFamiliesUnited.org for assistance or use these Helpful Numbers:

Helpful Numbers:

 Coaching into Care:
 1-888-823-7458

 Crisis Hotline:
 1-800-273-8255

 Homeless Veterans Hotline:
 1-877-424-3838

 Reachout Hotline:
 1-800-522-9054

 Military One Source:
 1-800-342-9647

VA Assistance to sign up for Medical Benefits 1-877-222-8387 (M-F 8a-8p EST)

 VA Caregivers Support Line:
 1-855-260-3274

 Vets 4 Warriors (peer counseling)
 1-855-838-8255

Where To Begin:

- 1). Any <u>veteran</u> seeking assistance at the VA must register for VA medical benefits. The Veteran will need an up-to-date DD-214 (this can be found at Archives.gov). Then call your local VA Medical Center OR Vet Center and tell them you need to register for VA medical benefits. Ask where to go and what to do, then do not delay. The Veteran has earned these benefits.
- 2). If a <u>military member</u> has not achieved Veteran status and needs help, follow the protocol of your branch of service. If you are concerned about confidentiality, you might seek assistance with Give An Hour or Soldiers Project (see contact info on Resources page).
- 3) If you are a <u>family member</u> and the veteran is resistant to seeking help, you may call "Coaching into Care" (1-888-823-7458). If you need personal support, go to our website and click on "How to Get Help" and select from the area you need assistance for options. You might also review "Support to help combat veterans" under the "Family Tab" on our home page website.

"When my dad was in Vietnam the second time, I was a child. I remember the fears that plagued me while he was there. Many years later, we have identified that Post Traumatic Stress Disorder is the price many vets and military families have paid for sending a loved one to war.

My family was no exception to the effects of PTSD on the soldier and on us. We now have an opportunity to acknowledge and support soldiers who have come back from war and are not the same, and their families, in their journey home."

~Loving daughter of a Korean and Vietnam War Veteran

NOTES





Helping Veterans
and Their Families
with Resources They Need
to Move Forward

Dedicated to:

SGM Phillip E. Cozort, US Army Reserves

For his integrity, selfless service and sacrifice demonstrated while fighting for my rights as a disabled veteran. For showing me that I was not alone in my darkest hours and restoring my faith and hope when I needed it most...a legacy I now follow for other soldiers.

- Joseph Scott Collins

Veterans' Families United Foundation P.O. Box 14355 • Oklahoma City, OK 73113 • 405-535-1925 www.VeteransFamiliesUnited.org