

DLAAB

Disability Living Allowance Advisory Board

NEWS & UPDATE.

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Topics for Future Issues

- ◆ Epilepsy
- DM's suggestions for topics welcome. Please contact us.

INTRODUCTION BY THE CHAIR

Hello everyone,

In this spring issue, there is a very interesting article on Post-traumatic Stress Disorder, a condition which has consequences for DLA and AA, and is particularly topical at the moment. Being specific about the potential care and mobility needs is not easy as you will read, however, the article does explain the types of problems people with PTSD might suffer from and the available treatment.

I do hope you find it informative and that it helps to give some clarity to this important condition.

As always we continue to welcome any comments or suggestions you may have, particularly for further articles which you would like to see in the DLAAB News and Update.

Best Wishes
Anne Spaight
Chair DLAAB

POST-TRAUMATIC STRESS DISORDER

The defining feature of post-traumatic stress disorder (PTSD) is a history of having experienced an event or situation that most if not all people would consider exceptionally threatening or catastrophic. The person may have experienced the event directly (for example, being subjected to a violent attack, or being victim of an earthquake), or have witnessed it (for example, seeing somebody seriously assaulted, or murdered). The examples just given are of single, sudden events. However, PTSD may also arise from situations in which the threat is sustained, such as having been tortured. The key characteristic of events that may give rise to PTSD is that they involve actual or threatened death or serious injury. As noted below, a very distressing reaction is almost universal after a severe trauma, but this is not PTSD- PTSD comes some later, some weeks or months after the trauma.

Characteristic features

The features of PTSD fall into three main groups.

Re-experiencing the event: The person experiences aspects of the trauma in vivid detail while asleep or even when awake. These experiences are sometimes termed *flashbacks*. For example, the victim of a rail accident might have great difficulty returning to travel by rail, or even going past a railway station. Even seeing a rail company logo on the television might trigger a flashback. When somebody has

nightmares of the previous trauma, this may make them feel very frightened and it is not uncommon for the sufferer to feel safe only if somebody else is with them. In some cases, this will reflect a preference to be accompanied when going out. In other instances the person will be unable to go out at all unless accompanied, as might happen in severe agoraphobia.

Over-arousal: In essence, the person suffering from PTSD tends to remain in a state of high alertness, ready to respond to further threats or dangers. Because the person is perpetually scanning the environment for threats, it becomes difficult to concentrate on other things. For a similar reason, sleep is often disturbed. The combination of being constantly vigilant for threats in the environment, plus fatigue from maintaining this alertness and the lack of sleep, also contribute to another common feature - irritability. Sometimes, the person and family or friends try to manage this irritability by having someone with the person, to calm him or her down when the irritability arises.

Avoidance:

Because of the tendency of cues to the previous trauma to trigger flashbacks, people with PTSD commonly try to avoid situations where such cues are likely to arise. If going out of the house is likely to expose the person to such cues, then he or she will often avoid going out unless accompanied by someone else. Even when accompanied, the person may experience not only flashbacks but also panic attacks. The extent to which the person might expect to encounter cues to the previous trauma will vary from case to case. Thus a person whose trauma involved a boat capsizing might be able to go out as normal provided he or she avoids expanses of water. On the other hand the victim of an assault might become very wary of people coming too close to him or her, and might then be unable to go more than a few steps out of the house, unless accompanied. Also, the person with PTSD commonly experiences what has been described as 'emotional numbness'. Previous positive emotions, for example towards family members, are no longer present, and the person may feel as if they can no longer experience pleasure. Needless to say, those close to someone with PTSD will often describe the person as having gone through a 'personality change'. For the sufferer as well as for loved ones, it often feels as though the person has changed permanently, because the changes are so striking and pervasive.

How common is PTSD?

PTSD is, unfortunately, relatively common. In the United States, community surveys indicate that approximately 8% of adults experience PTSD during their lifetime. In groups of people who have been exposed to specific traumatic incidents, such as rape victims,

combat veterans, or the victims of torture, the likelihood of developing PTSD is substantially higher, as high as 50% in some studies.

Time course

Most, if not all, the features described above are very common immediately after experiencing a severe trauma. For the majority of people, these distressing symptoms gradually decline, usually over a matter of days or weeks. These initial symptoms are not part of PTSD. However, for some, the symptoms persevere, and for others, the symptoms decline immediately after the trauma but then return, and remain. This is when PTSD is diagnosed. Most commonly, PTSD starts within three months of the trauma, but in some instances, the onset of symptoms can be delayed by months or even years.

Treatments

There are treatments available that are effective for many people who have PTSD (see below). The key to effective treatment is the initial recognition of the symptoms as features of PTSD. If PTSD is not diagnosed, the symptoms may persist for many years.

Who develops PTSD?

The pattern and presentation of PTSD is consistent with psychological theories that identify the basis of PTSD as being a failure to properly process the memories of the original trauma. In essence, the person suffering from PTSD has a conviction that the trauma has either continued, or will return. It appears that the more severe the trauma, the more likely that PTSD will follow.

Help seeking and diagnosis

People with PTSD may come to the attention of healthcare professionals by a variety of routes. PTSD may be misdiagnosed as anxiety, panic attacks, anger, irritability, or depression. To complicate matters further, it is quite possible that someone with PTSD will, in addition, develop some of these other problems, to the extent that the person seeks help for these problems rather than for the PTSD, which may be overlooked. In extreme cases, neither the person suffering from PTSD, nor family or friends, recognise the PTSD as a clinical syndrome that requires treatment. In cases where PTSD has become longstanding, it is appropriate to seek specialist assessment, with a view to using the treatments outlined below, either individually or in combination.

From the perspective of claimants for DLA or AA, the key point is that if the claimant has not been referred for specialist help, he or she may

be quite unaware of the diagnosis of PTSD, even though the symptoms give rise to considerable distress.

Treatments

Treatments may involve using medicines, or involve psychological interventions.

Medicines for PTSD

There is research evidence that some antidepressants can be effective in treating PTSD. Some people may have been treated with medicines to assist in managing anxiety - these usually belong to a class of medicines called benzodiazepines, which includes diazepam (Valium).

Cognitive therapy

Cognitive therapy, also known as cognitive-behavioural therapy (CBT) is, considered to be commonly effective in treating PTSD. Trained, experienced therapists carry out CBT. These may be clinical psychologists, but could also be nurse therapists, occupational therapists, or psychiatrists.

Eye movement desensitisation and reprocessing (EMDR)

This is a relatively new form of treatment. The aim of EMDR is to desensitise the person to the distressing thoughts and feelings resulting from the original trauma.

A key advantage is that in cases where it is effective, its benefits can be rapidly achieved. However, at present, EMDR availability is poor overall, and patchy at best.

Outcome

With effective treatment, the outcome is expected to be favourable. However, particularly if PTSD remains undiagnosed, and if the person does not come to specialist attention, the condition may endure for many years.

Conclusion

PTSD is often very distressing for those experiencing it as well as for family and friends. Despite the fact that the symptoms are commonly distressing and intrusive, PTSD may remain undiagnosed. There are effective treatments, but their availability on the NHS may sometimes be limited.

DLAAB NEWS

MEETINGS WITH OUTSIDE ORGANISATIONS

The Board meets regularly with outside organisations. At these meetings Board Members with relevant skills, expertise or interest have discussions with representatives of various groups.

The Board invites specific groups and also welcomes approaches from any group who feels it would benefit from meeting the Board.

We use the News and Update as a means of directly informing DM's of changes that are new or brought to the Board's attention. This is in addition to the information already available in the Disability Handbook.

Updates to the Disability Handbook are being made via ICT where appropriate. Meeting with the Board gives access to representatives of outside organisations to inform us of issues needing clarification.

NEWS

Since the last issue of DLAAB News and Update the Board has met with representatives from BLESMA and will be meeting Aphasic and MIND. Our Research Group has been monitoring new developments and treatments for various conditions with the focus being on subsequent changes in the level of Care and Mobility needs. Our website has been redesigned with focus on clarity and accessibility. We now have an internal search engine giving easy access to articles from all past issues of the News and Update as well as all Annual reports.

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THE REMIT

The Board has three main functions:

- To give advice to the Secretary of State on matters referred by him/her.
- To give advice to Department of Work and Pensions Medical Services doctors on cases referred for expert advice.
- To present an Annual Report on its activities over the year to the Secretary of State.

INVITATION TO DM'S

If you have any specific questions or general queries please contact us via the Secretariat.

We wish to use the News & Update as a forum for discussion.

FOR YOUR INFORMATION

Please note- the articles contained in this news- sheet are written for the benefit of Decision Makers, to help them with their job.

Although these articles are now in the public domain they are advisory only and therefore **must not** be quoted in any decision or communication with a member of the public or their representative.

GETTING IN TOUCH

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