

Understanding Post-Traumatic Stress Disorder after Intensive Care: Information for patients

If you have been treated in an Intensive Care Unit (ICU), you will know that it can be an intense and distressing experience. People are admitted to ICU when they are critically unwell due to an illness, accident or after a major operation. Treatment in the ICU saves lives, but it also normal to experience difficulties afterwards.

Physical recovery after ICU can take time. Many people also experience psychological changes like feeling low, anxious or irritable, or experiencing nightmares and intense memories of their time in hospital. This information sheet gives you more information about one common problem after ICU: Post-Traumatic Stress Disorder (PTSD).

What is PTSD?

PTSD is a common problem after ICU; at least **one in five patients** go on to develop symptoms of PTSD. For many people, the symptoms get better over time. However, if the symptoms last longer than a month and are distressing, it may be helpful to get some treatment for PTSD.



The symptoms of PTSD can include:



Nightmares and/or unwanted vivid, upsetting memories (flashbacks) of experiences in ICU.



Feeling upset or experiencing physical symptoms when you are reminded of ICU. Some of these reminders may be obvious. For example, you might feel very anxious when you go back to the hospital where you were treated. Other reminders might be subtle. For example, you might find yourself suddenly feeling upset or anxious and not know why. This can happen when you encounter a “hidden trigger” to your memories, such as a beeping noise that reminds you of machines on the ward, a smell of disinfectant which smells similar to the ward, or the sight of something which is the same colour as the gowns that medical staff wore.



Being jumpy or easily startled



Difficulty sleeping, poor concentration or being more irritable than usual



Changes in how you think and feel. Some people think differently about themselves and other people after a trauma. They may feel upset by the way that their body has changed, or feel worried that they have lost their mind because of the experiences they have had. Other people start thinking more about bad things that might happen to them or their loved ones or feel more anxious about their health. You may feel angry, guilty or ashamed about things that happened in ICU, or sad and hopeless about the future. All of these feelings are very common after ICU.

Here's what some of our patients who developed PTSD after ICU have told us about their experiences:

"It was very confusing, very scary, like a living nightmare. I didn't know what was true and what wasn't"

"I found it very hard because I couldn't speak to other people, they think I'm weird, they don't understand"

Making sense of your ICU experience

For most patients, the ICU is an unfamiliar environment. Some aspects of it can be confusing and frightening. Afterwards, you might find that your memories are jumbled and it can take time to make sense of what happened there. Talking to friends and family can help make sense of your experiences.

Here are some common experiences for patients whilst in ICU:



Periods of loss of awareness: You may have been conscious for some, most or hardly any of your time in ICU. You may have clear memories for parts of your stay, and no memory or confused memories for other parts of it.



Your sense of time may be very confused: For example, you may have felt like you were there briefly when actually it was a long time, or vice versa.



Difficulty moving or talking: Patients in ICU are often given drugs which might make it difficult to move, and you may be attached to different pieces of equipment. This can also make it hard to talk, especially if you had a tracheostomy or a tube down your windpipe to help you breathe.



Confusing memories: It is normal to have confused memories of your time in ICU. You might be unsure which of your memories are real, and which were dreams or caused by delirium. Read more about delirium in the next section.

Delirium

Delirium is a medical name for a state of confusion. It is a bit like a dream or nightmare, but the experience feels completely real at the time. Patients may see things or people that aren't there, or believe things very strongly which aren't true. Not all of these experiences are frightening, but some can be absolutely terrifying.

Here are some common experiences during delirium:

- Believing the doctors and nurses are trying to kill you and/or are only pretending to be medical staff
- Believing you have been kidnapped
- Seeing animals on the ward
- Feeling as if you are on a journey e.g. floating down a river, flying in a spaceship
- Seeing people on the ward who want to hurt you
- Believing someone has sexually assaulted you

Here are some useful things to know about delirium:

- ✓ It is extremely common in ICU. In fact, **up to 80% of patients experience it.**
- ✓ It is probably caused by the medication that people in ICU are given, as well as the impact of being so ill and not being able to sleep properly.
- ✗ It doesn't mean you are going crazy or you have lost your mind.
- ✗ It doesn't mean you will keep having delirium experiences afterwards. However, PTSD symptoms may mean that memories of your delirium experiences while you were in hospital may come back to you in nightmares and flashbacks.

Sometimes events from your past find their way into delirium experiences.

Also, we often find that real events in the ICU have got confused and muddled up with delirium.

For example:

- People often describe **experiences of moving, like floating or flying** which might be because beds in ICU move to prevent pressure sores.
- When medical staff are doing something as part of your treatment, like ventilating you, washing you or changing dressings, **it may feel as if they are trying to hurt you.**
- Staff may be wearing personal protective equipment like masks, visors and gowns. **This can make them look alien and strange.**

Other resources

- **ICU Steps** (www.icusteps.org) is a patient-led organisation to help patients and their families affected by critical illness. They have lots of useful information on their website, an online forum where you can ask questions and share experiences with other people who have been in ICU, and they also run support groups in some areas of the country.
- **The hospital where you were treated** may be able to help you make sense of your experiences. Some run intensive care follow-up clinics, and give patients the opportunity to come back to the unit (if you choose) and/or speak to members of staff. If you have questions or concerns about your treatment, you can contact the ICU where you were treated, or the clinical health psychology team at your hospital.
- If you are not receiving treatment, and think you may have symptoms of PTSD or another psychological problem, **please see your GP** or contact your local Improving Access to Psychological Therapies (IAPT) service at [https://www.nhs.uk/service-search/other-services/Psychological%20therapies%20\(IAPT\)/LocationSearch/10008](https://www.nhs.uk/service-search/other-services/Psychological%20therapies%20(IAPT)/LocationSearch/10008).