

Information for patients and carers

Delirium on the Critical Care Unit

What is delirium?

Delirium is a state of mental confusion that is common in patients who are critically ill. A patient with delirium may:

- See, hear or feel things that are not actually there (or hallucinate). The things they see and hear are often frightening
- Have very suspicious thoughts (or delusions). For example, they
 may believe that staff are not who they say they are or are trying
 to harm them
- Not know what day it is or that they are in hospital. They might think they are somewhere else
- Not remember or understand what is said to them and might not be able to follow a conversation

Delirium can change quickly, so a person may seem to be having a normal conversation and then suddenly appear confused.

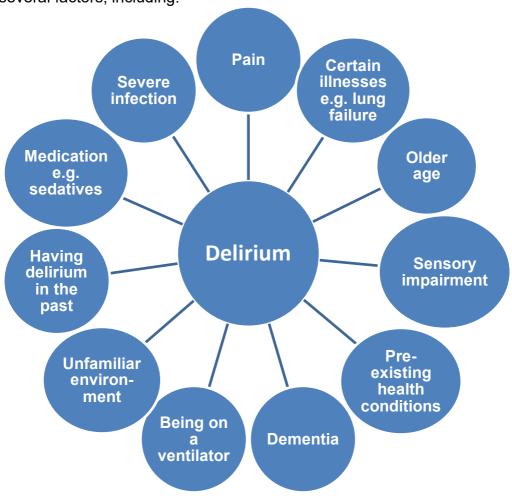
As these experiences can feel very real and frightening to the patient, they may try to leave their hospital bed or ask to go home. It can be even more distressing when patients cannot talk about what they are experiencing, for example if they are on a ventilator (a machine to help them breathe) or cannot speak normally. This can also be very distressing for friends and family.

When delirium is obvious to others, this is called **hyperactive delirium**. Patients may become very agitated or even aggressive because of the frightening things they are experiencing, and they can be very restless. However, delirium is sometimes hard to notice; this is called **hypoactive delirium**. It might not be obvious that the patient is having frightening thoughts. They may appear to be very still and quiet and withdrawn from others.

Delirium is usually reversible. This means that, as the patient starts to recover, the delirium also usually goes away. It may take from a few days to several weeks before it fully improves.

Why does delirium develop?

Delirium is the brain's reaction to a serious medical problem. It is common when someone is critically ill and it is estimated that approximately two thirds of patients on a critical care unit will experience delirium at some point during their illness. It is very difficult to pinpoint exactly what causes delirium and it is likely to be a combination of several factors, including:



Checking for delirium

Staff on the unit will check for delirium with patients regularly, usually more than once a day when they are awake.

They may complete a short assessment that includes asking the patient to squeeze their hand when they say a certain letter, to respond to questions or to carry out certain actions. This will give staff an idea of whether the patient can pay attention and whether their thinking is clear or confused.

Support during delirium

If you are visiting someone who is experiencing delirium, there are things you can do to help:

- Reassurance. For example, let them know where they are, who you are and that they are safe
- Talk calmly to them and use short sentences. It may help to read them some of a favourite book or play their favourite music if they are not able to respond
- Let staff know if the patient wears glasses or hearing aids.
- Bring in familiar objects or photos from home that the person may find comforting

Staff will also help patients with delirium. For example, they will try to address any medical problems that might be adding to the delirium, get the patient into better routines with sleep and eating/drinking and get the person moving when they are able to do so safely.

After delirium

Some people will not remember their time on the unit or what happened to them. Others may have distressing memories about it. The following are common reactions in people who have been critically ill:

 Fear or anxiety: reminders of the experience might lead to anxiety e.g., sounds, sights, smells or reminders on the news or TV. However, anxiety might also feel like it comes 'out of the blue'

- Reliving experiences: a person may have unwanted memories, thoughts or images about the delirium. These might be very vivid, so that the person feels like it is happening again (flashbacks), or they might have nightmares
- Emotional changes: common feelings are sadness, anger, fear and guilt. Alternatively, some people feel numb, detached and unable to have positive feelings
- Being 'jumpy': being easily startled by things like loud noises or sudden movements
- Difficulty falling or staying asleep, or restless sleep
- Trying to avoid thinking about the experiences they have had or avoiding anything that would remind them of it
- Relationships: difficult experiences can bring people closer, but they can also put a strain on relationships. For example, the person might feel that others don't appreciate what they have been through, or friends and family may be struggling with their own reactions to their loved one having had delirium
- Coping: some people might turn to alcohol or drugs to cope, which can lead to other difficulties

There is no right way to react after being critically ill and having delirium. Everyone's reaction will be different, and you may experience all, some, or none of the above reactions.

Patient experiences

These are some experiences real patients have shared about having delirium on the Critical Care Unit:

"I thought they were getting ready to take me up there to experiment on me and they were going to kill me. And that was horrible. And my family was coming in and I didn't tell anyone and that was a horrible feeling...I just kept it to myself...I thought I was going to die."

"I apparently had a fight with some male nurses. I don't remember a thing about that, and that's not me. I apologised profusely on that one because I just can't believe I did anything like that."

"I felt like an asylum seeker trying to get into the country because I was on a ferry, hiding on top of a pile of pallets... Someone was saying, 'She is pulling the tubes out, pulling her tubes out,' and they were dragging me across the top of the pallet. But you see I wasn't seeing them as saving me or helping me. I felt I was in an alien place, that's the word for it."

What can help?

Whilst delirium is common on the Critical Care Unit, it may leave patients feeling distressed. If that is the case, then there are things that can help with managing distress more effectively:

- Routine: Getting a sense of routine back is important. It might help
 to draw up an activity schedule for yourself each week to make
 sure you pace yourself at first and are not trying to do too much.
 Rest is very important for body and mind during recovery from
 critical illness
- Look after yourself: Look after yourself by eating well, reducing alcohol use, exercising where possible and getting into a routine for sleeping
- Try not to bottle your feelings up: It can really help to talk about your experiences with someone you trust. If you find it difficult to speak to friends and family, it may be helpful to speak to someone else such as a GP, work colleague, member of a religious group or mental health professional
 - Some people find it too painful or overwhelming to remember their time in hospital and may need time before being able to speak

about it. You may want to try other ways to express your feelings in a way that feels safe for you - some people find exercise, drawing, writing or a creative class helpful, but there are many other ways you could try

- Going over your experiences: It can help to go through what happened in hospital and have a timeline of events. Sometimes loved ones keep diaries of what happened in hospital and this can help you piece together what happened and what was real or not
- Grounding' exercises can help at times of intense distress or if you are experiencing flashbacks. These can ground you in the here and now, which may help you to feel less distressed. 5 4 3 2 1 is an example of a simple grounding exercise:
 - o Notice 5 things you can see around you
 - Notice 4 things you can hear around you
 - Notice 3 things you can feel or touch
 - Notice 1 or 2 things you can smell or taste
 - Take one or two relaxed breaths if you are able to and remind yourself that you are safe now

You might also use relaxation methods, such as breathing exercises. One simple breathing exercise is **'Rectangle Breathing'**. This works by making the outbreath longer, which can calm the nervous system. Breathe in for the count of 3 and breathe out for a count of 5.

Or imagine breathing around a rectangle. Breathe in through your nose along the short side, and out through your mouth along the long side.

Further support

If you find that you are experiencing some or all of the things described above for longer than one month without improvement, you may wish to seek further advice.

Most areas have a psychological wellbeing service which you will be able to access. If you are registered with a GP in England, you can discuss your options with your practice.

The Critical Care Unit at Royal Preston Hospital also offers an outpatient follow-up clinic. This is available to answer any questions you may have about what happened in critical care and to check on how you are doing from a physical and emotional perspective. Patients who were on the unit for four or more days are automatically invited. If you haven't been invited and would like an appointment, then please contact the unit on the telephone number under 'contact details' below and they will be happy to arrange this for you.

Contact details

Should you require further advice or information please contact:

Clinical Health Psychology Service on 01772 523252. If there is no answer then please leave a message with your name, contact details and reason for calling and someone will get back to you.

Critical Care Unit reception on 01772 521600.

Sources of further information

www.lancsteachinghospitals.nhs.uk

www.nhs.uk

www.accessable.co.uk

www.patient.co.uk

www.lancsteachinghospitals.nhs.uk/veteran-aware

<u>https://icusteps.org/</u> ICU Steps is a charity which aims to provide information and support to patients recovering from critical illness, and their friends and relatives.

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