I see the bulk of my patients a year or perhaps many years after they have been discharged from the hospital. All the attention essentially goes to the physical recovery. This can be at a rehabilitation centre, or at home assisted by physiotherapists or occupational therapists, but the fact remains that the body is central, and the mental aspects are overshadowed. Once the physical rehabilitation process is on track, other issues start becoming noticeable. There are basic complaints such as poor sleep, nightmares or disrupted structure to the day, and later on difficulty returning to work, difficulty participating in social situations with large groups of people, and becoming easily irritated.

I have seen people who have experienced a delirium and are plagued by nightmares, but I also regularly see feelings of guilt or shame. It is good to know that some of the patients do not remember their ICU stay, but they hear from family or doctors how they behaved during the delirium. Many of them have great difficulty with this after the fact. For example, I had a patient who in his delirium was convinced that the doctors and nurses were plotting against him. He made a kicking motion against the belly of a pregnant doctor, and later experienced great shame about his behaviour during the episode of delirium.

It is important to realise that when someone is experiencing a delirium in the intensive care, that patient is at a greater risk of developing post-intensive care syndrome, also known as PICS. This is the collective name for the physical, cognitive and mental problems that occur due to serious disease and the subsequent ICU treatment. I have been dealing with this group of patients for years, first as an ICU nurse, then at the follow-up care outpatient clinic in the hospital, and now again for several years as coach and counsellor in my own practice, Gezondheidszorgcoach. What I see in all of my clients is that they no longer recognise themselves after an ICU admission. There is an enormous difference between how someone was before and after a stay in intensive care, especially in an emotional sense. Whereas some people ‘flatten out’ and feel fewer emotions, others are less inhibited and are extra sensitive to external stimuli, often also with a shorter fuse than before – they are quicker to be consumed by their emotions, so to speak.
By the time people come to me, they have already worked so incredibly hard by themselves, physically as well as mentally. But because there is still such relatively low attention given to the consequences of a delirium, certainly in combination with PICS, patients sometimes end up receiving mental healthcare. They so much want to be their old selves again. The first thing I try to instil in them is that, when something dramatic happens to you, the expectation shouldn’t be that you will go back to being your old self right away, if ever. It is a process that takes years, and which in many ways resembles that of a loss and grief: the loss of a part of your health, the confidence in your own body and sometimes also the loss of relationships, friends, work or hobbies.

On top of that, people may get signals from their body that they do not recognise. Like I said, many former ICU patients have no memory of their time in intensive care, but that doesn’t mean the body does not remember it. People are sedated but also reach the surface. As a result, perhaps much later suddenly a certain song on the radio or the smell of a perfume that a family member wore when they visited becomes a trigger. And then your body gives a sudden and extreme stress reaction that you cannot place immediately, and which can even lead to anxiety and a panic attack. I had a client who was convinced that she had been floating around in a boat, alone at sea. I advised her to go back to the intensive care, to her room, to the environment where she had been at that time. It turned out that at the time she had been staring at a blue ceiling while lying on an air exchange mattress, but the delusion from the delirium made her utterly convinced that she was on a boat at sea.

I also have a number of stories of patients who have experienced a hyperactive delirium, and as a result of that delusion climbed out of bed or pulled out their drip or ventilation tube. As a last resort, the intensivist may decide to restrain the patient to protect them from themselves, but this can have lasting consequences. I would therefore recommend that ICUs should also have a policy to identify a delirium as quickly as possible so that the treatment can be adjusted accordingly. Because people often carry with them the consequences of a delirium episode for years, and we should jointly do everything possible to limit those consequences as much as possible.

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