

## Critical care patient discharge summary training pack



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## Introduction

*National guidelines recommend that critically ill patients should be “offered information about their condition and encouraged to actively participate in decisions related to their recovery...tailored to individual circumstances” (NICE, 2007: p16). The importance of providing appropriate, timely and accurate information during critical illness rehabilitation is further endorsed by the National Institute for Health and Clinical Excellence (NICE, 2009).*

The concept of using a ‘patient discharge summary’ was conceived and developed during research conducted by Bench et al (2012, 2014). A patient discharge summary describes what happened to a patient in critical care, and helps them to make sense of their experience.

Findings from our research suggest that writing a ICU patient discharge summary is feasible, if staff are given adequate training and support to ensure that summaries include sensitively written information that patients will understand and find helpful. Based on our experiences of working with critical care staff to produce patient discharge summaries, this training pack is intended as a guide to help other health care staff write summaries for their own patients.

We thank you for your interest and hope you find the material contained in this training pack useful.

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# The context – why is a patient discharge summary needed?

by Catherine White, former ICU patient, Information Manager, ICUsteps.

*Being critically ill is a very distressing experience. While in ICU, patients can experience:*

## **Partial awareness when under light sedation**

During light sedation, patients can have a level of awareness. Sometimes they can hear people speaking to them; they know enough to get a sense of time passing, but they may not understand where they are, not know that they are in hospital and be unable to communicate.

## **Delirium**

ICU delirium is well documented, and it is believed that 2 out of 3 ventilated patients suffer from it. It can be a terrifying experience and delirium can be obvious (hyperactive) or silent (hypo-active), so for some patients there is no outward sign of what they are experiencing. With delirium, your mind creates scenarios which are not true but they are not dreamlike - the world you create feels absolutely real because of the clarity in which the hallucinations happen. Your mind is desperately trying to make sense of this strange world you are now in and often the hallucinations are based on some reality – the feeling of being restrained because of the lines, noises you can hear etc.

## **Paranoia**

It is quite common for patients with delirium to think they are being harmed and to not believe what staff or even their families are telling them.

## **Confusion, disorientation and an inability to retain information**

If you are an emergency admission, you have no time to prepare or to understand what is happening to you. You can't engage in your treatment or discuss with the medical staff about what is required and why. Worse than that, a complete inability to make sense of your surroundings can cause profound distress. Even after someone is out of sedation and the delirium may have improved, they may still have a very flimsy understanding of where they are and what is happening. If they are able to hold a conversation, they may not remember it afterwards, and they may not understand how ill they are.

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### **Inability to communicate**

Patients may be sedated, unable to talk due to a tracheostomy or to make themselves understood if they can talk. This adds to a person's confusion because they can't hold a conversation to explain what they are experiencing.

### **Alien environment**

ICU is a very alien environment for patients. It can be noisy, with activity 24 hours a day and machine noise. It can feel like the machines alarm every time they move position. Sometimes there are no windows, so there is no daylight and the unit can be brightly lit, so patients can often be disorientated as to whether it is day or night.

### **Lack of real sleep**

Patients can find it very hard to sleep because of the noise and activity around them; they may find it difficult to get comfortable and have to lie in one position; they may need treatment in the night and the sleeping tablets they are given may react with other medication and give more strange dreams.

More information and personal accounts of patients and relatives experiences in ICU can be read at [www.icusteps.org](http://www.icusteps.org).

Some patients have no memory at all of their time in ICU and it might be thought that this is preferable. However it can be that these patients are more distressed by the idea of this 'lost' time than if they have confused memories. It can feel very frightening to have had no awareness at all of what happened to you.

Transferring to a ward after ICU can be a worrying time for patients and relatives. The patient may still be very ill – they may still have delirium, paranoia and be very confused. They are likely to have very confused memories from their time in ICU and may not be able to distinguish between what really happened and what were delirious memories. Arriving on the ward, they will be very weak, have poor concentration, be exhausted and may have no real understanding about how this has happened to them. Recent research by the UCCDIP project group (Bench et al 2012, 2014) found that 54% of patients had little or no understanding of their critical care experience.

From my experience, and from talking to other patients, I believe that the only way to start to rebuild your life after critical illness is to try and understand what happened to you – but patients need help and information to be able to do this.

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In the research undertaken by Bench et al (2014) 93% of the patients who received the patient discharge summary found it helpful stating:

**“It helped me to know what had happened to me.”**

**“I had no memory of leaving my brother’s home or travelling to hospital so this has again given me some concrete information... it helped to fill in the gaps in my memory.”**

**“It explained the emergency.”**

**“Helped me to accept what was happening.”**

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# The patient discharge summary

## What is it?

The patient discharge summary provides patients with information about their critical care stay when they go to the general ward. This is vital because patients:

- may have no idea how ill they have been
- may not be able to distinguish between what really happened and what was delirium
- may have very confused memories of their time in Critical Care
- will be physically weak, exhausted, confused, have limited concentration and recall - and have no clear understanding what has caused this.

The idea of the summary is for Critical Care staff to write a brief explanation of why the patient was in Critical Care and what happened to them while they were there. It should be given to the patient when they are ready to leave Critical Care, before they move to the general ward.

The summary is mainly for the patient, to fill in the gaps about what happened to them, what treatments they had and to give a sense of the order of events. However, it may also be useful for:

- close relatives, as it gives a clear explanation of what happened. Although they were probably with the patient much of the time, it can be very hard to absorb and understand information when they were so worried about their relative
- general ward staff, who may not really understand what the patient has been through
- GPs, who may be the only link to any help once the patient gets home. The summary may help patients to discuss with their GPs what has happened to them
- family and friends, to help them understand what the patient has experienced.

This summary will be the first step to help patients make sense of their experience. Writing it and helping your patient understand what they have been through could make a real difference to your patient's recovery once they leave Critical Care.

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# Patient discharge summary guidelines

The idea is not to give a lengthy explanation, but to give an outline of what happened by using the structure and examples given below. When writing the summary, the main points you need to remember are that:

- patients may not understand how ill they have been, so try not to be too blunt in what you write
  - there could be sensitive issues about why the patient was in Critical Care, which they would not want written on the summary
  - the summary needs to be easy to read, so please don't use any medical terms/jargon that the patient may not understand.
- 1. Begin with which hospital the patient is in, the length of their stay and the dates of their time in hospital**

This is very important because the patients are often disorientated and confused and may not know where they are. Include the day and date they were admitted, and the date they were discharged from ICU. This helps the patient understand how much time has passed.

**Example:**

**“You have been in the Critical Care Unit at Milton Keynes Hospital. You came in on Tuesday 3rd July 2011 and have been here for 11 days and were discharged to McGregor Ward on Saturday 14th July 2011.”**

- 2. Why was the patient admitted and how did they get to ICU?**

It is important to say how they arrived in hospital, if you know that, as it helps piece together what happened, and why they needed to come to hospital. Also if the patient came to Critical Care from the ward, write why they were in the ward in the first place.

**Examples:**

**“You came into Critical Care after a road traffic accident.”**

**“You came into Critical Care after going to A&E after feeling very ill at home.”**

**“You came into Critical Care because there were complications while you were having your surgery.”**

**“You came into Critical Care because you became very ill while you were on the general ward. You were in hospital to have your appendix taken out.”**

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### 3. What was the diagnosis? What were the patient's main symptoms ?

This is a medical explanation of what was wrong with the patient put into non-medical language. Below are some examples of common problems translated into lay language:

Condition	Lay language
Traumatic brain injury	You hurt your head very badly because of an accident.
Subarachnoid haemorrhage	You had bleeding in your brain.
Stroke	You had a stroke, which means that blood could not get to a part of your brain for a short time.
Polytrauma	Your body was seriously hurt in many places and stopped working properly. You also had some broken bones (list which bones – leg, arm etc).
Sepsis	You had severe blood poisoning, and you became very ill while your body tried to fight an infection. The infection came: <ul style="list-style-type: none"><li>- from your chest</li><li>- from a wound in your leg</li><li>- after your treatment for cancer</li><li>- after your transplant</li><li>- after your operation for...</li></ul>
Multi organ failure	A number of your organs such as your heart, liver or kidneys stopped working properly.
Liver failure	Your liver stopped working properly.
Aortic aneurysm	You had a problem with one of the pipes (blood vessels) that leads from your heart. This blood vessel became weak or burst and caused bleeding inside you.
Renal failure/Acute Kidney injury	Your kidneys stopped working properly. This was because of an infection <b>or</b> this happened after your operation. We needed to use a machine to replace the work normally done by your kidneys.
Heart attack	Your heart stopped working properly and could not pump blood around your body.
Attempted suicide: Overdose	In these cases, concentrate on the symptoms: You were unconscious when you were brought to hospital and needed to have ...
Attempted suffocation	You had an injury to your neck, which needed...
Airway problems & respiratory failure	You were having problems breathing. We needed to put a tube in your throat to help you breathe or You had a very tight mask on to help your breathing.

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#### 4. What treatment, procedures and operations did they have?

It is very important to also say the length of time the patient was sedated; what treatment they had (strong drugs, breathing machine etc); any operations etc.

**Examples:**

“You were kept asleep with strong drugs for 10 days.”

“You had a breathing tube put in your throat and a machine has been helping you breathe. This meant you couldn’t talk.”

“A machine and strong drugs needed to help your heart keep going.”

“You have been fed by a tube in your nose and have had many tubes attached to you.”

“A tube was placed in your head to drain the blood that was building up.”

“You had a special helmet put over your head to help you breathe. You didn’t like this because it was uncomfortable.”

#### 5. How did the patient seem to react to their ICU stay?

Did the patient seem upset, distressed, try to pull their tubes out etc? Do mention if the patient had delirium as this would have been a significant part of their Critical Care experience.

**Examples:**

“While in Critical Care you seemed...

...uncomfortable - you didn’t like having the tubes in you and would try to pull them out.

...very confused at times and didn’t know where you were.

...upset - the strong drugs gave you bad dreams and you were frightened because you thought the dreams were true.”

#### 6. Any other information that would help the patient understand and make sense of their time in Critical Care?

**Examples:**

“While in Critical Care....

...you found it difficult to sleep.

...you have not been out of bed or been able to sit up.

...you found it difficult to sit up and felt very dizzy when you tried to.”

“Your arm is very weak because of the illness.”

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## Example of a patient discharge summary

You have been in Intensive Care Unit at x Hospital. You came in on 14th July 2011 and you have been here for 67 days to the 19th September 2011. You were taken to A&E, then transferred to ICU. You were brought in by ambulance from home after you had severe blood poisoning, which means your body became very ill while your body tried to fight an infection. The infection came from your stomach where you had a hole in the small intestine and there was a leak inside your body. You had an operation to close the hole.

You had a breathing tube in your throat and a machine has been helping you breathe. This meant you couldn't talk. You were kept asleep with strong drugs for more than 30 days. You were very uncomfortable and didn't like having the tubes in and you would try to pull them out. The strong drugs that you needed gave you bad dreams and you were frightened because you thought the dreams were true. You also found it very difficult to sleep in ICU. The hole in your throat was closed up three days ago to get you ready to move to a ward. You could not eat normal food because of your surgery, so when you started eating again, you were on a very soft pureed diet.

### Additional notes:

- Staff should be given the opportunity to practice writing summaries and receive feedback on them.
- The information written in the summary needs to be sensitive to the fact that the patient may have no idea of how ill they have been. The severity of their condition while they were in Critical Care may be a shock to the patient.
- Staff should be given the opportunity to discuss any issues that arise from completion of the summaries. It is important to talk about how to manage sensitive situations and to set some scenarios for group discussion. For example, where there has been a suicide attempt, or where the patient may have AIDS but not told their family. In these cases concentrate on the symptoms and treatments rather than stating the cause of why treatment was needed.
- We strongly recommend that summaries are checked by a nominated person before being given to the patient to ensure they are easy to understand and that they contain appropriate information.
- Not all patients will want to read the summary immediately. It might be helpful to place it in a sealed envelope, which can be opened by the patient when they feel they are ready to read it.
- Having a qualified health care professional (for example, an ICU outreach or follow up nurse) available on the ward who can discuss the contents of the summary with the patient is recommended.

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# Information for Patients (Computer version)

## Why was I in Critical Care? What happened to me?

*A Microsoft Word version of this sheet can be downloaded from the ICUsteps website.*

Name: <input type="text"/>
You have been in <input type="text"/> unit, at <input type="text"/> Hospital
You came in on (DD/MM/YYYY) <input type="text"/> and have been here for <input type="text"/> days. You were discharged to <input type="text"/> Ward, on (DD/MM/YYYY) <input type="text"/>
You came into Critical Care because <input type="text"/>
You got to hospital by (please tick): <input type="checkbox"/> ambulance <input type="checkbox"/> husband, wife, family or friend brought you <input type="checkbox"/> transferred from another ward / transferred from another hospital.
Please complete below details of the patient's diagnosis, treatments and procedures, how the patient has seemed and any other relevant information. <div style="border: 1px solid black; height: 150px; width: 100%;"></div>

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## Information for Patients

### Why was I in Critical Care? What happened to me?

Name: \_\_\_\_\_

You have been in \_\_\_\_\_ unit  
at \_\_\_\_\_ Hospital

You came in on (DD/MM/YYYY) \_\_\_\_\_  
and have been here for \_\_\_\_\_ days  
You were discharged to \_\_\_\_\_ Ward  
on (DD/MM/YYYY) \_\_\_\_\_

You came into Critical Care because

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You got to hospital by (*please circle*): ambulance / husband, wife, family or friend  
bought you / transferred from another ward / transferred from another hospital.

Please complete overleaf with details of the patient's diagnosis, treatments and  
procedures, how the patient has seemed and any other relevant information.

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- **Bench S et al. (2014)** Providing critical care patients with a personalised discharge summary: A questionnaire survey and retrospective analysis exploring feasibility and effectiveness. *Intensive & Critical Care Nursing* 30 (1): 69-76
- **Bench S et al. (2012)** Developing user centred critical care discharge information to support early critical illness rehabilitation using the medical research council's complex interventions framework. *Intensive & Critical Care Nursing* 28(2): 123-131

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