

Introduction

Many patients who have been sedated and ventilated in Critical Care have little or no memory of their stay. Some patients suffer with nightmares and depending on their content; they are sometimes convinced the events have really taken place because they seem so vivid. Any true memories they may have are usually jumbled and often difficult for them to put into order, especially if they have been in a number of locations within the hospital. This lack of recall may contribute to unrealistic expectations about their speed of recovery as they will not necessarily appreciate the severity of their illness nor understand the range of debilitating symptoms they may suffer following their time in Critical Care.

Some patients report spending considerable time trying to remember what has happened to them and trying to piece together events from what others tell them. The distress caused by their memory gap appears to be a negative factor in coming to terms with their illness and return to normal life.

The intention of a diary would be to describe and explain the real events in a chronological order. It is hoped this will not only help the patient make sense of their memories but also give them a better understanding of their illness and enable them to set a more realistic timescale for recovery and minimise the risk of adverse long-term problems.

When to start a diary

It is difficult to know when is the right time to start a diary because we can never be sure how quickly a patient will respond to treatment, or if indeed they will at all, as unfortunately some do not survive due to the critical nature of their illness. If families are able to take charge of a diary the sooner they are started the better.

Diaries tend to be started two to three days after admission, with a summary of events so far. A nurse may be able to help with this. It may be necessary to leave a few empty pages at the beginning to do this later, and you may also want to summarise the events leading up to the admission.

Consent

It is very helpful if families can take charge of a diary but sometimes the nurses may suggest a diary. Although the patient is probably unable to consent for themselves, we want you all to feel comfortable with the decision to start a diary and we would also like to take photographs. The procedures for the taking and storage of photos is explained fully in a separate leaflet, (please ask if you cannot find one). Photos will not be printed without the patients consent. If you object to the diary and/or photographs we will respect your wishes.

Who writes and what should be included in the diary?

Anyone can write in the diary and should sign their entry with at least their first name. Reading previous entries can encourage people to contribute, and sometimes be a method of communication for the family, with each other and the patient. Remember to write things that are important to the patient eg results of sporting events they may be interested in, world affairs or family events. However, be careful not to include too much trivia, like the weather every day.

The nurses can write or help families to write medical items in non-medical terms so the patient can understand. It is important for everyone to describe the patient's reactions and also how serious the situation is, or the meaning of the concept will fail. When the patient reads the diary, they can see how ill they were, and read about themselves getting better, which in turn aids recovery. The diary should remain by the patient's bedside, so it is owned by the patient and available for all contributors.

Ownership of the diary

Once the patient leaves Critical Care, the diary may be continued on other wards and the patient may become interested. The patient should read the diary only when they feel ready to do so, and the timing for this should be their own decision. It could be some months after returning home and some may never want to read it at all.

As the diary belongs to the patient, no copies will be kept by Critical Care or in the patients notes and therefore the responsibility for its safe-keeping rests with the patient and relatives after leaving Critical Care. The Critical Care Follow-up nurse will be available to answer any questions at any time during the patient's recovery, and also about diary writing, please phone 01206 742687 (or internal extension 2687) and leave a message.

If the patient dies

The diary should be brought to a close by a nurse or a member of the family if you prefer. It will then be offered to you to keep and read whenever you want to, as some families find this helpful in remembering events and coping with their loss. If you do not want the diary it will be stored with the patient's notes, in case you change your mind at a later date. However, please remember medical notes for deceased patients are stored for eight years from the date of death and then destroyed.

Please ask if you require this leaflet in an alternative format.

Leaflet number	729n4
Created	1 August 07
Reviewed	August 2014
Next review	August 2016

Creating a patient diary in Critical Care

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Information for relatives and friends