

# Recovery & Wellness post ICU: Using Patient Diaries

Lianne Humphries & Samantha Hagan

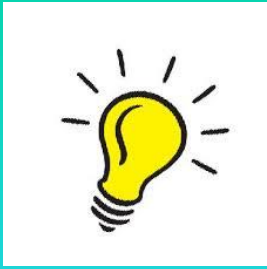


**Foundation of  
Nursing Studies**





- To share our experience in relation to the implementation of Patient Diaries
- To share patient and relative experiences
- To discuss current and future plans



# How it all began



- **Formation of the Practice Development Group**
  - Group work “sensory overload”
  - Aim established for the group;  
*“to improve the psychological aspect of care for ICU patients”*
- **Diaries**
  - Bridge the gap in memories; real Vs imagined
  - Psychological support for the patient
- **Application to FoNS “Patient’s First”**



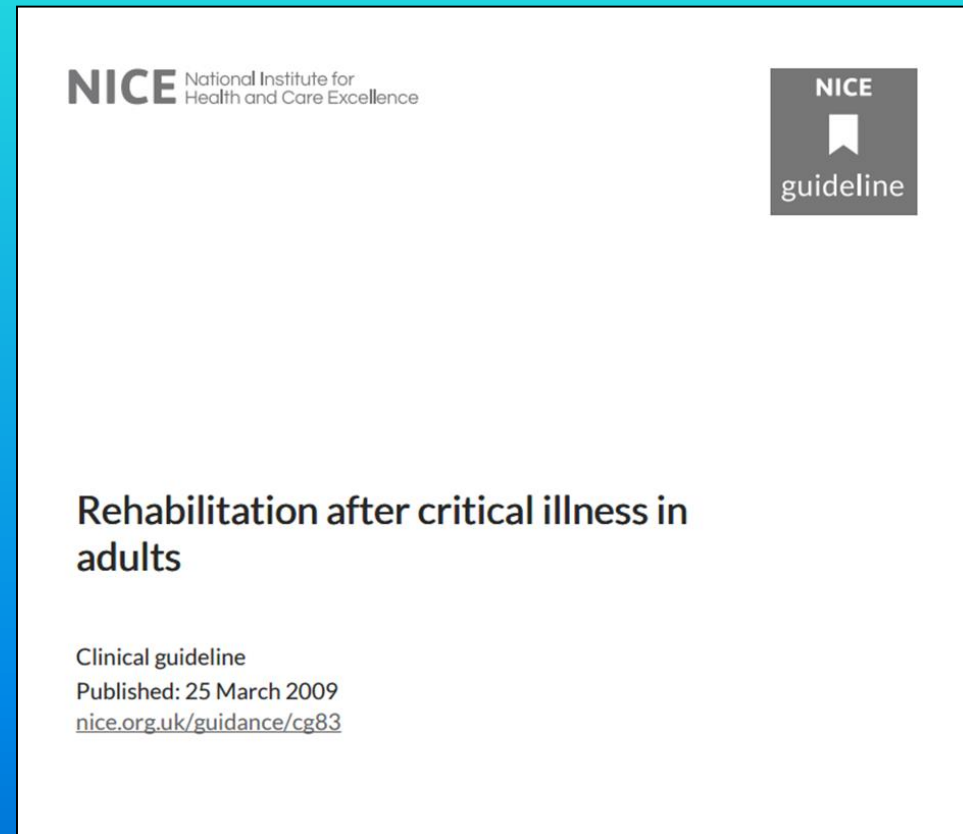
- Diaries have the potential to form one aspect of rehabilitation and make a positive impact on patients' recovery (Teece & Baker, 2017)
- Diaries may help relatives to cope (Nielson & Angel, 2016)
- ICU workers find diaries beneficial in providing comfort to patients (Perier et al, 2013)

# NICE Guidance

## (Clinical Guideline 83, March 2009)

Give patients/relatives the following information during their critical care stay;

- *Information about the patient's critical illness, interventions and treatments*
- *Information about the equipment used during the patient's critical care stay*



# Considerations



- Not all patients want to be reminded of the details of their illness
- Relatives may use the diary as a cathartic tool to express their emotions which may not be helpful to the patient
- Activation of diaries can lead to ICU workers developing strong emotional investment which may impact negatively on their wellbeing

Perier et al (2013), Teece & Baker (2017)

# Care & Support Post-Discharge

- Follow-up Clinic set up in 2010
  - Nurse-counsellor
  - Physiotherapist – physical rehabilitation
  - Intensivist – medical concerns
  - Recent funding for Clinical Psychologist
- Patient Diaries implemented to compliment and enhance this service



# Relative's Story.....

## Introducing "Niamh & Brian"

*"Niamh" had been married to "Brian" for over 20 years and was distressed when coming to visit him in Intensive Care. She recalls how his illness began and how it impacted on her and their family. We will now share an excerpt from her story that greatly influenced the direction of our project....*





# The Project



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Inspire Enable Improve



# Getting to know you

## What happens to the diary after intensive care?

Let your loved one know, when they feel better, that you have kept a diary of their stay in Intensive Care.

Explain to them that the diary is kept safely for them and let them decide if and when they would like to read it.

### Further Information


If you have any questions about keeping an Intensive Care patient diary please do not hesitate to ask the nurse looking after your relative s

Useful websites for more information:

[www.healthtalk.org/peoples-experiences/intensive-care/intensive-care-experiences-family-friends/keeping-diary](http://www.healthtalk.org/peoples-experiences/intensive-care/intensive-care-experiences-family-friends/keeping-diary)

[www.icusteps.org](http://www.icusteps.org)

[www.ics.ac.uk/patientsandrelative](http://www.ics.ac.uk/patientsandrelative)

 South Eastern Health and Social Care Trust

Keeping an Intensive Care patient diary for your relative

We hope you find the information in this leaflet useful

Information and guidance for friends and relatives

## What is an intensive care patient diary?

The Intensive Care patient diary can be an on-going record of events that have happened during a patient's stay in Intensive Care (ICU) to include things that happen outside of hospital as well as in ICU.

It can be written by a close family member, partner or friend so that the patient can see how their condition changed, who came to see them and what was happening at home whilst they were in intensive care.

## Why is the patient diary useful?

Patients may be in a relaxed, calm, or sleepy condition as a result of being given medication known as sedation which can lead to memory loss.

Additionally, ICU patients may suffer from a temporary state of confusion known as delirium. People with delirium may see and hear things that are not real and may lose track of their surroundings.

The diary helps to piece together the gaps in memory and make sense of what has happened while they have been unwell.

Diaries may help patients to understand their intensive care stay, which can help their recovery. If you choose to keep a diary, it may also help you to make sense of what is happening.

Often our memories are not good during periods of stress and anxiety and later you may wish to recall some of your experiences. Keeping a diary may also be useful as your relative might ask you questions about what happened to them.

## Can I keep a diary for my relative?

Yes. You can start a diary when you feel ready, if you feel it would help.

Patients who are in intensive care greater than 2 days may benefit most from a diary. There are notebooks available for you to use. One of the nurses will give one to you if you tell them that you wish to start a diary.

It is not permitted to take photographs of your relative while they are in ICU.

## What could I write in the diary?

When writing in the diary keep in mind that the diary is something the patient **may** like to read on recovery when they feel ready.

## Suggestions:

- You could write about thoughts or feelings that you would like to share with the patient
- You could write about things that have happened to you or the family which the patient would like to hear
- You could add messages from friends/family, for example children's homemade cards and supportive texts/emails
- You could add information from the outside world such as weather or favourite sports results
- You could write about milestones such as "today you sat up in the chair"
- Please take care to keep your diary safe at all times as it may contain sensitive or private information about your loved one

Name:

Age:

About Me

Place Photo Here



My Family and Friends

My Likes and Dislikes

Other Information

# “David’s” Story





# Stephen celebrates survival with care unit fundraiser

Julie Waters

j.waters@spectatornewspapers.co.uk

**"IT is a celebration of life, of still being here."**

These are the moving words spoken by brave Bangor man Stephen Wilson who battled back from the brink of multiple organ failure when he was diagnosed with swine flu just 18 months ago.

This courageous young man fought for his life spending a total of 75 days in hospital - 30 days of which were in the intensive care unit - with two weeks spent in a medically induced coma to give his body a chance to recover.

In a bid to thank all the medical staff that helped his remarkable recovery, Stephen has organised a beach themed fundraiser at Bangor Football Club this Saturday (22nd) night and hopes to raise £1,000 for the intensive care unit at Dundonald's Ulster Hospital.

Party goers are encouraged to don their T-shirts and shorts for this fun-filled beach night, that includes a host of ballot prizes and top DJ tunes.

Stephen said, "I would like to raise £1,000, just to give something back to

the hospital. There were a few pieces of equipment that I needed in hospital that due to budget restraints, they didn't have them readily available, so raising funds will really help."

Stephen recalled those difficult days when his illness first took hold saying, "It started off as pneumonia, then progressed to swine flu in the end. I suffered from multiple organ failure, was in a coma for two weeks and hospital for 75 days."

Swine flu was the popular name for flu caused by a relatively new type of flu virus responsible for a global flu outbreak in 2009-10. It became known as swine flu because it is similar to flu viruses that affect pigs. It spread rapidly from country to country because it was a new type of flu virus that few young people were immune to.

The symptoms are the same as regular flu, they are usually mild and pass within a week or so. But as with all types of flu, some people - particularly those with underlying health problems - are at higher risk of serious illness.

Stephen explained his illness literally came 'out of the blue' saying, "I felt like I was getting the flu, then it progressed."

He recalled the fear he felt as his condition worsened. "It was the unknown, the not knowing what was

happening. I was getting progressively worse, then I was in the ICU for three weeks before I was diagnosed. Then I was placed in a coma to allow my body to rest."

Stephen said, "I was very anxious, there were all these alarms going off (in the intensive care ward) and I didn't know what was wrong with me, nobody seemed to have any answers and I was getting worse. So they sedated me to let my body rest in the hope that I would get better."

During this difficult time Stephen had little cause for his celebration when he turned 36 years old. "I was 30 when I was in ICU on January 21 and then I was placed into a coma on January 26. That is when they sedated me."

Following the sedation, Stephen faced a long road to recovery saying, "There was fear when I woke up. I had a tracheotomy in and I couldn't speak, everything was very confusing. Seeing my family so upset was quite hard - especially not being able to communicate, I couldn't speak, move or walk, everything just felt so dead."

He recalled the darkest days saying, "My parents were told at one point to expect the worst. They didn't know what way it was going to turn. They had hoped to transfer me to Leicester for oxygen therapy but on the day that was due to happen my lung

Stephen Wilson (centre) with his mum and dad, sister and niece looking through his memory book of the time he was seriously ill in the Ulster Hospital ICU. Stephen is holding a fundraising night at Bangor Football Club on Saturday evening to raise money for the hospital ICU. C17-20-07



collapsed."

Stephen paid tribute to the support he received from across the hospital's medical staff saying, "They kept your spirits up and were so attentive to everything. I'd like to thank Dr David Hendren, if it wasn't for him I probably wouldn't be here. He didn't give up, he was willing to try everything to make sure that I would survive."

He spoke of his mental state saying, "It was probably meeting one of the ex-patients - he told me he had spent 194 days in ICU and he really encouraged me."

"He said he had only been out of ICU for a few weeks and could walk and was driving again. I thought that I was going to be in a wheelchair and on an oxygen tank but he encouraged me that it does get better."

"Once I was in that mental state I just pushed on - two months after I got out of ICU I returned to work, just to

keep my mental focus."

As store manager of Bangor's TK Maxx branch he was delighted to return to work saying, "I had been working in Bangor and I was moved to Ards to be the manager of the new store, so I needed to make sure I was there for the opening."

Following his remarkable return to health, Stephen is now extending a warm invitation to his fundraising evening, "Anyone can come along. It is running from 8pm to 12am. Come along in your beach wear, shorts and T-shirts and be prepared to enjoy a really good fun night."

"It is a celebration of life, of still being here. I am delighted to be here."

To help Stephen reach his fundraising target make a donation by logging on to: [www.justgiving.com/crowdfunding/stephenwilson2/](http://www.justgiving.com/crowdfunding/stephenwilson2/)

# Next Step



## Photographs

- Input from Trust's Medical Photographer, Governance Officer, ICT manager
- Development of guidelines

## Obstacles

- Storage of photographs
- Returning photographs to patients

# References

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Perier, A et al (2013) Phenomenological analysis of healthcare worker perceptions of intensive care unit diaries. *Critical Care* 17:R13

Teece, A. & Baker, J. (2017) Thematic Analysis: How do patient diaries affect survivors' psychological recovery? *Intensive and Critical Care Nursing*. 41, 50-56

