Patient Diary Guidelines -

For use in Critical Care

Collated by -Julie Platten, North of England Critical Care Network Manager

Version July 2018

Acknowledgments:

Mrs Coral Hulse & Dr Christina Jones, Cheshire and Mersey Critical Care Network**,**

Aileen Rooney and Susie Lawley, Rehabilitation Sisters, Gateshead Health Foundation Trust**.**

Julie Bruce and Linda Watson, City Hospitals Sunderland NHS Foundation Trust**.**

Dianne Miller, Outreach Sister, South Tyneside General Hospital

Dr Karen Connelly, Consultant Anaesthetist, Northumbria Healthcare NHS Foundation Trust.

NoECCN RaCI Working Group

Supported by:

North of England Critical Care Network

CONTENTS

Appendix

Patient and Relative Information Leaflets can be found on the website
www.noeccn.org.uk

Introduction

These guidelines have been compiled by the North of England Critical Care Network, the guidance is designed to be adopted and adapted by the units within the Network.

It must be recognised and acknowledged that a number of sources have contributed to the guidelines and that if adopted by other Trusts these sources should be acknowledged and referenced.

A word version is available by request and the text in red can be edited to adapt the guidelines to the individual Trusts

Background

Traditionally, intensive care treatment focussed solely on curing physical illness. Patients were often discharged from intensive care units with no psychological follow-up or counselling. Psychological problems often went undiagnosed and patients were left to cope at home without support. Research shows that patients who are sedated and ventilated on intensive care units can suffer memory loss and often experience psychological disturbances post discharge. Their memories are often chaotic mixture of dreams, hallucinations and amnesia. As expected the existence of false memories can have profound effects on recovery time and quality of life as patients struggle to understand what they have been through.

The use of patient diaries when patients are sedated and ventilated together with multidisciplinary follow-up clinics has proved to improve patient outcomes. Introducing patient diaries into intensive Care Units can provide comfort not only to patients but also to their families, especially when families are encouraged to participate in them. Diaries not only serve to fill the memory gap, but also provide a caring intervention, which can promote holistic nursing. (GPICS, 2015)

National Institute of Clinical Excellence (NICE) Clinical Guideline 83, Rehabilitation after Critical Illness (2009), states that rehabilitation should start as early as clinically possible, and to include an individualised, structured rehabilitation programme including measures to prevent avoidable physical and non-physical morbidity. Psychological symptoms can include delusional memories, anxiety, panic attacks, nightmares and depression. Backman and Walther (2001), Combe (2005), Jones (2009) and Knowles et al (2009) describe positive results from using detailed narratives in diary format for Critical Care patients. As well as filling in gaps in memory, they also seek to contextualise their illness of what has occurred and to provide a context for any inaccurate or delusional beliefs.

Equipping patients with a better understanding of what has happened to them in critical care may help to set more realistic goals for recovery and minimize the risk of adverse long term problems (Bergbom et al 1999). Patient diaries can be useful as a debriefing tool to assist in critical care follow-up to help put events in chronological order, and provide understanding of how ill they have been, and distinguish between real and hallucinatory experiences.

Legal and Ethical Considerations

Critically ill patients are a highly vulnerable group and it is often difficult to obtain informed consent. The legitimacy of next of kin is questionable under English law because no one is able to give consent for an adult who is unable to give consent for themselves, and however much they have their best interests at heart, there is evidence to suggest relatives do not make the same choice that the patients would make for themselves (Blackwood 2006). However, the Department of Health suggests it is good practice to involve next of kin or those closest to the patient to identify their wishes or values.

The use of photographs in the diary will help the patient understand visually what has happened to them in critical care and how ill they have been, therefore, becoming a useful tool to aid in the patients' recovery. The issue of photographs needs to be approached carefully because of litigation. It is important to remember that patient diaries are perceived as a "standard therapy" and not as clinical documentation. This is how it should be explained to the relative's and the patient where possible and assent/consent is not sought and the patient gives written retrospective consent once they are well enough to receive the diary.

A patient and relative information leaflet has been produced with questions and answers re content and storage of diaries

Inclusion & Exclusion Criteria

All critical care patients that are deemed high-risk / complex (as identified form the Short Clinical Assessment) should be considered for the commencement of a diary. It should be

recognised that some Level 2 patients who have an augmented stay in critical care may benefit from a diary.

No patients should be automatically excluded are but considered on a case by case basis. Consider discussing with the family as to the benefit of the diary for;

- Patients with senile dementia
- Patients where English is not their 1st language or patients who are illiterate. This is due to the legalities of interpreting.
- Patients who are seriously visually impaired.

Implementation

It is good practice to have a dedicated identified team who will be responsible for the implementation, management and storage of the diaries, and return of the diaries. Diary leads for the Units can be found on the website www.noeccn.org.uk/RaCI .

1: Materials

1.1 New diaries, in an A5 booklet with a wipeable cover, are kept in a central place location should be identified and stocks are maintained by identified designated people.

1.2 The Polaroid / digital camera is stored in a locked cupboard location identified, and consumable stock monitored by the Diary team or delegated member of staff.

2: Storage of Diaries

2.1 Diaries must not be taken outside of the Critical Care Department.

2.2 Whilst on Critical Care the diaries will be kept at the patients' bedside

2.3 When a diary is commenced for a patient on Critical Care the patients' details must be added to the diary register (Appendix 4). Where the list is to be located / held should be added. This allows the diary team to keep track of who has a diary and where the patient is.

2.4 When a patient is transferred to a ward or elsewhere from Critical Care then the diary must be held on the unit in a locked cupboard / draw location identified until the patient is well enough to receive the diary. A note must be made in the diary register as to where the patient has been transferred to.

2.5 Diaries can be stored for a period of 12 months. This time frame follows recommendations and is considered a reasonable amount of time for those patients who may not initially choose to keep their diaries to change their mind.

2.6 If after 12 months any patient should not wish to receive their diary then the original diary is destroyed by shredding.

2.7 Original copies of diaries of deceased patient's will be stored for a period of 12 months prior to shredding, **photographs will be destroyed immediately.**

3: Photographs

1.1 Photographs may be taken of patients but they must not be used without their consent. Therefore, photographs should be stored securely and must not be entered in to the diaries until the patient has seen those photographs and given their consent.

1.2 Photographs to be labelled with the patient's name, date of birth and unit number and also the date when the photograph was taken. This is for ease of identification and enabling the photographs to be mounted in the diaries chronologically.

1.3 Once taken the photographs must be stored immediately in a locked cupboard, location identified. Once printed the memory card is deleted. Photographs must not be saved on a computer, memory card or disc and thus the print will be the sole copy.

1.4 Photographs **must not** be given to family or friends.

1.5 An initial photograph is recommended when the patient is fully sedated and ventilated.

1.6 Photographs are intended to help the patients to understand visually what has been happening to them in Critical Care. Photographs may help to put progress and recovery onto perspective for patients.

1.7 Subsequent photos may be taken at "milestones" to show the patient awake or sitting in a chair, trip out of the unit or, for example on dialysis. Anything that staff feel would help a patient understand more about their critical care stay would benefit from being photographed.

1.8 Staff members may be photographed with the patient if they wish, verbal consent should be obtained.

1.9 Relatives may be photographed with the patient if they wish, verbal consent should be obtained.

1.10 A space should be left in the diary for the photograph to be mounted at a later date. The space should be labelled diagonally "photograph space" and the area surrounding it hatched out to avoid people writing in the space.

1.11 Photographs may only be removed from storage by diary team members.

1.12 Photographs will only be added to diaries after a member of the diary team has discussed and shown them to the patient and obtained written consent for their inclusion in the diary.

1.13 If the patient disapproves of their photographs for any reason the patient may choose for the photographs to be destroyed by shredding. The destroying of the photographs should be documented on the diary refusal / acceptance form (Appendix 4) and filed in the patients notes.

1.14 Photographs, like the diaries, may be stored for 12 months to allow the patient time to change their mind.

1.15 Photographs should not be transferred to a different with the diary but stored at the base hospital and information recorded in the diary and on the transfer sheet to the location of the photographs.

4: Diary Format and Writing Style

4.1 A diary should be considered in all patients that are identified at risk especially if they are expected to be ventilated for >48 hours. There is some evidence to suggest that for some long term Level 2 patients may also benefit from the use of a diary and consideration must be given to every patient. The decision to start a diary rests with the Diary team or the nurse in charge in their absence.

4.2 Do not write on the inside of the hard-backed covers of the diaries, as these pages will be difficult to shred if the diary needs to be destroyed.

4.3 The patients' name, date of birth, hospital number and date of admission should be written on the top of the first page for identification purposes. It is not recommended that addresses should be included, for security reasons.

4.4 All entries should be made in black ink, any errors crossed though and please do not remove any pages form the diary.

4.5 All entries should be dated and signed. The first entry should include a description of the reason for admission to Critical Care.

4.6 Avoid including information that could be of a sensitive nature, or that a patient may wish to be kept confidential. Examples include malignancy, HIV status, sexuality or substance abuse. A sensible approach is to write only what you would comfortable to disclose verbally to a patient or relative at the bedside.

4.7 Entries need not be made every shift although this will give a fuller picture of the patient's stay. However, entries should be made when there is a significant milestone to write about. Examples include extubation, a tracheostomy procedure, sitting for the first time. If progress is slow, still try to make regular entries.

4.8 Include the relatives. Encourage them to write to say they have been visiting. They may want to include what is happening at home or anything that the patient has a particular interest in.

4.9 A multi-disciplinary approach to the diaries is hoped for. All members of staff are invited and are welcome to make diary entries. A diary with contributions from nurses, doctors, physiotherapists, chaplains, speech and language and relatives is likely to hold more meaning than a diary filled by one person alone.

4.10 Avoid jargon and abbreviations. Use laymen's terms when describing clinical terminology in the diary. Try to relate what you write to how you would normally verbalise the information to a patient or relative. A glossary could be added to the back of the diary to help the patient interpret a few key words e.g. tracheostomy

4.11 Writing style should always be professional and relevant. As much care and consideration should be taken with diary entries as any other form of professional documentation.

4.12 If there are any concerns about how to describe an aspect of care or an event for entry into a diary, please consult a member of the RaCI/Diary team for advice or nurse in charge in their absence.

5: Handover of the diary to the patient

5.1 Diaries should be only passed to a patient by a member of the diary team.

5.2 Patients will be shown their diaries shortly after discharge from critical care as their condition allows.

5.3 A member of the diary team will have assessed the patient to see whether the patient is well enough to go through the diary with them.

5.4 The contents of the diary will be explained fully to the patient and the opportunity given to the patient to ask any questions

5.5 Patients will be given the opportunity to see their photographs at this meeting.

5.6 A diary consent form (Appendix 2) must be signed by the Dairy team member and the patient. The form denotes whether the patient has chosen to keep their diary and/or photographs or not.

5.7 If a relative (for deceased patient) accepts the diary complete the relevant form (Appendix 3) and file in the patients notes **(N.B. Photographs must not be given to relatives and must be destroyed.)**

5.8 If the patient chooses not to take the diary they will be informed of the option to change their mind for a period of 12 months.

5.9 One copy of the diary consent form will be given to the patient and one will be filed in the patient notes.

5.10 A record of the outcome will be kept in the diary register (Appendix 4). This allows for tracking of the diary within the 12 month storage period.

5.11 If the patient dies the family may accept the diary on their behalf. They should be informed that the diary is there and will be kept for 12 months if they would like to accept it. (Complete form in Appendix 3) The diary will be destroyed after 12 months and photographs destroyed immediately.

6: Transfer of Diaries

If a patient is transferred to a different hospital the diary should go with them (excluding the photographs that are to be stored at the base hospital).

If the patient is transferred to another Critical Care area:

- The diary should be handed to the accepting nurse along with the patients notes; this will allow the new area to continue with the diary.
- Acceptance form signed (Appendix 5). Form to be kept at the transferring hospital with the diary register for tracking purposes.

If the patient is transferred to a Level 1 ward area in a different hospital:

- Contact Diary Lead for receiving hospital and inform them of patient transfer
- Post Dairy to the Diary lead in the receiving hospital in a confidential envelope (same process as transferring patient notes)

7: Audit/ Evaluation of Diaries

7.1 Patients will be followed up during their recovery phase; the value of diaries will be assessed at this point.

7.2 Staff on Critical Care will be informed of progress with the diaries and the results of audits/evaluation.

References

Backman C, Walther S: ***Use of a personal diary written on the ICU during critical illness***. Intensive Care Med 2001: 27:426-429

Combe D: ***The use of patient diaries in an intensive care unit*****.** Nursing in Critical Care. 2005: 10:31-34

Faculty of Intensive Care Medicine / The Intensive Care Society**. *Guidelines for the Provision of Intensive Care Sevices.*** *(Edition 1) (GPICS)*,2015.

Jones C***, Introducing photo diaries for ICU patients***. Intensive Care Society. 2009: 10:183-185

Knowles et al: ***Evaluation of the effects of prospective patient diaries on emotional well-being intensive care unit survivors: A randomized controlled trial***. 2009: 37:184-191

Sussex Critical Care Network: ***Patient Diary Guidelines***. Cheshire and Mersey Critical Care Network. 2006

Bergbom I, Svensson C, Berggren E, Kamsula M (1999) ***Patients' and relatives' opinions and feelings about diaries kept by nurses in an intensive care unit; pilot study***. Intensive and Critical Care Nursing 15, 573-577.

NICE (National Institute for Health and Clinical Excellence) (***Rehabilitation after critical illness. NICE Clinical Guideline 83*** (2009)

Hospital Logo

Patient Diaries – Relatives' Assent Form

*Please initial **each** box*

I confirm that I been give information about the diaries. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I agree to a patient diary being written for:- …….. (Name of patient) …….. (Unit number) Whilst they are in Critical Care.	
I agree to photographs of: - …….. (Name of patient) to be taken whilst they are in Critical Care. I understand that these photographs will only be printed off when the person named above is able to give their consent for this. If they do not give their consent, the photographs will be destroyed. Once the photographs are printed, no digital of hard copies will be kept.	
I understand that my agreement is voluntary and I am free to withdraw at any time without giving a reason. If I withdraw my consent, the diary and any photographs will be destroyed.	

Please enter the date and sign below: -

_____ _____ _____

Name (PRINT) **Date** **Sign**

Relationship to patient: _____

_____ _____ _____

Name of person taking consent **Date** **Sign**

When completed: 1 copy (original) to be kept in patients notes
1 copy to the person giving consent

Trust Logo

Patient Consent Form Affix Patient Label

Or

NHS number: ……..

Hospital Number: ……

Surname: ……..

Forename: ……

Critical Care Diary (Patient)

I WISH TO KEEP MY DIARY: YES ☐ NO ☐

By agreeing to keep my diary I understand that its safekeeping is my responsibility. The Trust does not accept responsibility for the original copy of the diary once it has been handed over to the patient.

I understand that the diary contents have been photocopied and stored securely for reference purposes but will be shredded after 12 months.

I WISH TO KEEP MY DIARY PHOTOGRAPHS: YES ☐ NO ☐

By agreeing to keep my photographs I understand that their safekeeping is my responsibility. The Trust does not accept responsibility for photographs once handed over to the patient.

If I do not agree to this, the photographs will be stored securely for

12 months (to allow me to change my mind) and destroyed after this period.

I understand that the photographs are sole copy and original; copies are not available.

Patient's name: …… Date: ……

Patient's Signature: ……

Staff Members Name ……..

Signature of Staff member: ……

When completed: 1 copy (original) to be kept in patients notes
1 copy to the person giving consent

Trust Logo	Patient Consent Form Affix Patient Label Or NHS number: …….. Hospital Number: …… Surname: …….. Forename: ……

Critical Care Diary (Relative)

I WISH TO KEEP THE DIARY OF MY RELATIVE:

Name:……YES ☐ NO ☐

By agreeing to keep my diary I understand that its safekeeping is my responsibility. The Trust does not accept responsibility for the original copy of the diary once it has been handed over.

I understand that the diary contents have been photocopied and stored securely for reference purposes but will be shredded after 12 months.

Name: …… Date: ……

Relationship to the Patient: ……

Signature: ……

Signature of Staff member: ……

Designation: …… Date: ……..

Diary Register Critical Care

Appendix 4

Name / Hospital Number	Diary Started	Discharged from Critical Care	To Ward	Diary stored by	Outcome of diary

Diary Register Critical Care

Appendix 4

Trust Logo

Patient Consent Form Affix Patient Label

Or

NHS number: ……..

Hospital Number: ……

Surname: ……..

Forename: ……

Transfer of Diary

Name of patient:……

I have received the diary belonging to the above patient

Photographs are stored at ……

Receiving Hospital: ……

Staff Signature: ……..

Date: ……

Transferring Hospital: ……

Staff Signature: ……..

Date: ……

To be filed with Diary register of transferring hospital

Network Diary Leads

Information on diary leads for each unit can be found on the website.

https://www.noeccn.org.uk/RaCI

If there is a change of diary contact could you please inform the Sarah Gray sarah.gray@nth.nhs.uk so that the list can be updated.