West Yorkshire
Critical Care & Major Trauma
Operational Delivery Networks

Patient Diary Guidelines

For use in Critical Care

Contents

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Acknowledgements	Harrogate and District NHS Foundation Trust. CTU Diary Protocol North of England Critical Care Network. Guidelines for Patient Diaries (2016) Nuffield Health Hospital. The Use of Patient Diaries in Critical Care. (2020) South East Coast Operational Delivery Networks. Patient Diaries Standards and guidance for the use of patient diaries in Critical Care (2015)

Introduction

Critical care patients have an increased risk of developing post-traumatic stress disorder (PTSD), anxiety and depression, and the provision of a patient diary has been shown to reduce the incidence[7]. Staff and relatives should be encouraged to write in the diary. GPICS (2019)

In addition, 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.

Purpose & Scope

These guidelines have been compiled to offer guidance to Critical Care Units within the West Yorkshire Critical Care Operational Delivery Network on the use of patient diaries during the process of rehabilitation following critical illness. They provide guidance on standards to be achieved in terms of writing, storage and handover of diaries and in the use of photographs.

Many Critical Care Units have established polices governing the use of patient diaries and it is the purpose of these guidelines to supplement but not supplant those. Similarly, there are a number of formats for patient diaries and it is not the purpose of this document to determine the exact format and content. Specific arrangements for the management and use of diaries should be determined by local policy. All Critical Care Units are encouraged to develop a comprehensive local policy to govern the use of patient diaries in Critical Care.

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.

Agreement from the patient that a diary be completed for them should be obtained from the patient whenever possible. For planned level 3 patients verbal consent should be gained from the patient at the pre-operative visit carried out by the critical care nursing staff. The patient needs to be informed of the purpose and potential benefits.

A diary must not be commenced when agreement has been refused.

A diary may be commenced without patient agreement when in the best interest of the patient. The potential benefit to the patient permits the writing of a diary when a patient is unable able to express their agreement. For example, an unplanned admission to critical care where the patients is sedated and ventilated on admission.

Agreement from the patient for continuation of a diary must be sought at the earliest opportunity and the detail of this agreement recorded.

Inclusion 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.

Caution should be taken in writing a diary for someone for whom English is not their first language where there is the potential for misinterpretation.

Implementation

Units may find it helpful to have a designated Patient Diary Lead and Diary Team to help with their implementation (GPICS 2019).

1. Materials

1.1 New diaries are kept in a central place location should be identified and stocks are maintained by identified designated people. The format for the diary can vary from pre-printed booklets to a loose sheaf of paper bound together on completion.

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 Whilst the patient is on the Critical Care Unit the diary should be kept at the patient's bedside for both staff and relatives to complete.

2.2 When a diary is commenced for a patient on Critical Care the patients' details must be added to the diary register (Appendix 1). 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.

2.3 When a patient is transferred to a ward or elsewhere (within the same Trust) 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.

2.4 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.

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

2.6 Original copies of diaries and photographs of deceased patient' will be stored for a period of 12 months prior to shredding.

3. Photographs

Photographs are a powerful means of helping patients understand what has happened to them and can enable patients to put their experience and ongoing recovery into perspective.

3.1 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.

3.2 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.

3.3 Once taken, the photographs must be stored immediately in an identified locked cupboard. 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.

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

3.5 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

3.6 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 feels would help a patient understand more about their critical care stay would benefit from being photographed.

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

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

3.9 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.

3.10 Photographs may only be removed from storage by diary team members

3.11 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.

3.12 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 2) and filed in the patients notes.

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

3.14 Photographs should not be transferred to a different hospital 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.

3.15 If a patient dies their photographs must not be given to family or friends. Photographs are not offered to bereaved relatives due to the lack of patient consent.

4. Diary Format & 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 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.

4.3 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.

4.4 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.

4.5 All entries should be made in black ink

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

4.7 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.

4.8 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.

4.9 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.

4.10 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 Diary team for advice or nurse in charge in their absence.

5. Handover of the diary to the patient

The diary should be given to the patient at a time of their choosing. This could be shortly after discharge from critical care or at a critical care follow up appointment. The content of the diary has the potential to be distressing in the short term and patients need to be supported throughout.

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

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

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

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

5.5 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.

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

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

5.8 If a patient dies, the patient's family may request to keep the diary without photographs. The relative should be offered support through this process. Photographs are not offered to bereaved relatives due to the lack of patient consent.

5.9 If a relative (for deceased patient) accepts the diary complete the relevant form (Appendix 3) and file in the patients notes. They should be informed that the diary is there and will be kept for 12 months if they would like to accept it.

5.10 A record of the outcome will be kept in the diary register (Appendix 1). This allows for tracking of the diary within the 12 month storage period.

6. Transfer of the Diary

6.1 If a patient is transferred to a critical care unit in a different or the same hospital the diary should go with them (excluding the photographs that are to be stored at the base unit).

- The diary should be handed to the receiving personnel along with the patients notes; this will allow the new critical care unit to continue with the diary.
- Transfer of Diary form (Appendix 4) should be signed by receiving and transferring personnel. A copy of the form to be kept by the accepting and transferring unit with the patient notes and the diary register updated for tracking purposes.
- When the patient is ready to receive the photographs, the unit holding the photographs should be contacted and arrange for these to be handed to the patient.
- If the patient does not wish to receive the photographs they will be stored securely for 12 months (to allow them to change my mind) and destroyed after this period.

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

- If the patient is ready to receive the diary and photographs prior to transfer this should be arranged.
- If the patient is not ready to receive the diary at this stage, the dairy and photographs should remain at the transferring hospital in secure storage until the patient is invited back to critical care follow up clinic where they should be given the option to receive their diary and photographs.

6.3 Update the diary register. This allows for tracking of the diary within the 12 month storage period.

7. Audit / Evaluation

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.

7.3 The use of patient diaries will be benchmarked annually in line with the West Yorkshire Critical Care Operational Delivery Network's Benchmarking audit calendar.

References

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Appendix 1 - Patient Diary Register Template

Name / Hospital Number	Date Diary Started	Date Discharged from Critical Care	Ward discharged to	Diary Stored by (name)	Diary Outcome (Handed to patient/refused but retained for 12mth storage/handed to relative)

Appendix 2: Patient Consent

Critical Care Diary (Patient Consent) to keep the Diary & Photographs.

Name of patient:……

DOB:……

NHS Number:……

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.

If I do not agree to this, the diary will be stored securely for 12 months (to allow me to change my mind) and destroyed after this period.

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 diary and photographs are sole copy and original; copies are not available.

Patient's name: ……

Patient's Signature: ……

Staff Members Name ……

Signature of Staff member: ……

Date: ……

Appendix 3: Next of Kin Consent

Critical Care Diary (Next of kin Consent) to keep the Critical Care Diary & Photographs.

Name of patient:……

DOB:……

NHS Number:……

I WISH TO KEEP THE DIARY OF MY RELATIVE: YES □ NO □

By agreeing to keep the 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 Next of Kin.

If I do not agree to this, the diary will be stored securely for 12 months (to allow me to change my mind) and destroyed after this period.

I UNDERSTAND THAT IT IS NOT POSSIBLE FOR ME TO KEEP ANY PHOTOGRAPHS TAKEN FOR THE PURPOSE OF THE DIARY DUE TO LACK OF CONSENT

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

NOK's name: ……

NOK's Signature: ……

Staff Members Name ……..

Signature of Staff member: ……

Date: ……

Appendix 4: Transfer of a Critical Care Patient Diary

Transfer of Critical Care Patient Diary

Use this form when transferring a critical care diary to another critical care unit or ward in another organisation

Name of patient:……

DOB:……

NHS Number:……

I have received the diary belonging to the above patient

Photographs are stored at (Hospital / Ward) ……

Receiving Hospital: ……..

Staff Member Name:…….

Staff Member Signature:……

Transferring Hospital: ……..

Staff Member Name (please print): ……

Staff Member Signature: ……

Date: ……