Worcestershire Acute Hospitals NHS Trust

Patient Diary Policy

This guidance does not override the individual responsibility of health professionals to make appropriate decision according to the circumstances of the individual patient in consultation with the patient and /or carer. Health care professionals must be prepared to justify any deviation from this guidance.

Introduction

Patient diaries can be used to help patients understand and come to terms with what has happened to them whilst they have been critically ill. Diaries provide a factual account of what has happened in Critical Care so filling in the gaps in memory. They provide a context for memories that exist and can help dispel inaccurate and delusional beliefs.

This guideline is for use by the following staff groups :
Intensive care staff at WRH and at the Alexandra Hospital

Lead Clinician Dr Andy Burtenshaw

Lead Author Dr Olivia Kelsall

Approved by the intensive care forum on: 12th November 2020

Review Date : 6th March 2025
This is the most current document and should be used until a revised version is in place

Key amendments to this guideline

Date	Amendment	Approved by:
September 24	Document extended for 6 months as per	Dr Kelsall

Patient Diary Policy

Introduction

Patient diaries

Patient diaries are a simple but valuable tool in helping patients come to terms with their critical illness experience.

1) During an admission to the intensive care unit, there are various cognitive, physical and emotional barriers to the formation of coherent and contextualised autobiographical memories including periods of amnesia, hallucinations, delusions, the impact of critical illnesses and treatment, pain and other forms of acute distress.
If delusional memories are persistent and pervasive, there is a higher risk of developing psychological consequences of critical care[1] and these factors should be addressed in order to tackle the psychological sequelae.

2) The content of diaries can help the development of a coherent narrative where there are underlying fragmented traumatic memories.[2] The Patient Diary helps the patient understand what has happened to them.

3) There is small-scale evidence from randomised controlled trials indicating reduced rates of psychological symptomatology in patient diary groups.[3,4,]
A recent meta-analysis has shown that diaries may reduce anxiety and depression while improving health-related quality of life[5] and this is supported by feedback from our own patient follow up clinics.

4) Additionally, many studies describe encouraging effects on patient experience, with patients specifically stating they were helpful for recovery.[6,7,8.] They may also be beneficial for family members, by lessening learned helplessness and providing individuals with a role,[9] and there is evidence suggesting they reduce PTSD among relatives.[5]

5) Photographs may be taken at points of change in the patient's condition, these are stored securely and offered to the patient with the diary on discharge from The Intensive Care Unit or at the Intensive Care Follow Up Clinic.

The Guideline

Starting a diary

1) The ICU patient diaries are backed by the trust legal department and by the trust Caldicott guardian
2) Diaries should be kept for all ventilated patients and those with delirium, or on CPAP and any patient whom a lengthy ITU stay is likely due to acquired muscle weakness.
3) Location of blank diaries including an information sheet for relatives, the camera, diary acceptance forms and diary register book are to be kept in a secure filing cabinet on each site.
4) A patient diary has a patient label attached on the outside of the diary
5) If a photo is taken the back should be marked with the patient's name, hospital number and the date it was taken. Relatives and staff may be photographed with the patient if they wish. The photographs will not be given to the family without the patient's consent.

6) The printed photographs will be stored in a sealed envelope marked with the patients name and hospital sticker and will be stored in a locked filing cabinet.
7) A space is left in the diary for the photograph to be mounted at a later date, label ‘‘photograph space’’, this space should be hatched out to avoid people writing in the space. If several photographs are taken during the patient’s stay they should be numbered.
8) Store the patient’s active diary in the drawer in the observation trolley in the patient’s bed space.
9) Give the patient’s family an information sheet about the diary and verbally encourage them to write in the diary.
10) Enter the patients name/patient sticker on the diary register book (to be kept in the filing cabinet)
11) Ensure the nursing care plan includes a line that the diary has been started

How to write in the diary

1) All entries should be dated, signed and marked with the writer’s job title
2) Avoid information of a sensitive nature, or that the patient may wish to keep confidential. Examples include malignancy, HIV status, sexuality or substance abuse.
3) Only write what you would be comfortable to disclose to a patient or a relative at the bedside.
4) Begin the diary with the story of how the patient came into hospital and then intensive care.
5) Entries should be made daily so there are no gaps when the patient reads through it later. Write any significant events such as extubation, tracheostomy, or sitting out of bed for the first time. If a patient is restless or agitated write about this as the patient may remember hallucinations from this time.
6) All members of staff are invited and are welcome to make diary entries. A diary with contributions from nurses, doctors, physiotherapists, occupational therapists and speech and language therapists and family is likely to hold more meaning than a diary filled in by one person only.
7) Avoid jargon and abbreviations and as far as possible use layman’s terminology.
8) Your writing style should always be professional and relevant.

Returning a diary to the patient

1) A healthcare professional should offer to go through the diary with the patient once they have agreed to keep it. The patient should then be given the opportunity to ask any questions. They should be talked through the photographs and the key things, such as central lines and ventilators pointed out and explained. If the patient wants to see the photographs they can be glued to the diary on the relevant pages.
2) A diary acceptance form must be signed by the Healthcare Professional and the patient. A copy should be kept by the patient and a copy should be placed in the Intensive Care notes.
3) The patient may want to receive the diary without the photographs. The photographs are to be destroyed in this instance.
4) Mark in the diary register that the patient has received the diary and the photographs.
5) The patient may not feel ready to discuss, receive or view the diary. They should be given a further opportunity to do this in The Rehabilitation Clinic and the diary should be stored in the filing cabinet until they are ready to receive it.

Diary and photograph storage once the patient has left intensive care

1) Once the patient has left the Intensive Care Unit, the diary, acceptance form and photographs are kept in the locked filing cabinet for a year
2) Record in the register that the diary has been stored
3) The diary can be kept for a period of a year, after this it can be destroyed by shredding.

Bereaved Relatives

1) Photographs that form the diary will be destroyed unless the patient has given consent for these to be returned to the relatives.
2) The written diary will be stored for a period of 3 months after death. The family will be written to after this time asking them if they would like to receive the diary.

Appendices

Patient Diary Acceptance Form

Relative Information Sheet – Patient Diaries Guidance for families

Appendix 1Patient Diary Acceptance Form

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 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:
……

Appendix 2 Patient Diaries Guidance for families

Many patients have very few memories of their time spent in the intensive care unit. This means they rely heavily on family and friends to explain how sick they have been, the treatment they receive and the equipment that was used to make them better. Some patients find this difficult to understand as they have little or no perception of how critical their situation was.
This lack of memory may hinder their recovery process as they have nothing to base their experiences of weakness, fatigue or memories of intensive care on.
We write diaries for our patients in order to help them understand how poorly they were and to give them a realistic description of their time on the intensive care unit. The diaries aim to promote understanding and allow them to come to terms with the recovery process.
We may take photographs of key steps in your relative's recovery and we will keep these securely. They will form part of the completed diary.
We will continue writing in the diary whilst they are on the intensive care unit and will keep the diary safe until they are ready to read it.
If your relative does not want their diary and photographs it will be destroyed and will not be returned to other family members.

Guidelines for family and suggestions

We suggest you write, or draw, or stick in cuttings about anything that you know interests your loved one—family, hobbies, sport or current affairs. This will help them to fill in the gaps once they are in the recovery stage.
Please be aware that relatives are not allowed to take photographs on the intensive care unit.
The intensive care staff will also be writing entries and will describe how serious the situation is. The aim is to help your relative come to terms with what has happened on intensive care.
Once your loved one has the diary themselves, it is their own choice to decide if anyone else can read it.
Please consider that at least one nurse will need to read the entries you make before returning the diary to the patient. This is because we need to ensure that there is nothing too distressing for your loved one to read and sometimes there is information that we need to discuss or explain.

Monitoring Tool

This should include realistic goals, timeframes and measurable outcomes.

How will monitoring be carried out?

Who will monitor compliance with the guideline?

Page/ Section of Key Document	Key control:	Checks to be carried out to confirm compliance with the policy:	How often the check will be carried out:	Responsible for carrying out the check:	Results of check reported to: *(Responsible for also ensuring actions are developed to address any areas of non-compliance)*	Frequency of reporting:
	WHAT?	**HOW?**	**WHEN?**	**WHO?**	**WHERE?**	**WHEN?**
	Monitor appropriate storage of diaries and photographs Ensure diaries are not part of medical notes Check completion of diary acceptance forms Check patients are receiving the diaries with appropriate healthcare support	Spot checks of diary and photograph storage Review of diary log and nursing documentation Review in follow up clinic of whether patient has received a diary	3 monthly review	Nurse in charge to verify correct procedure being followed	Matron Shelley Goodyear, Sister Donna Bagnell and Dr Olivia Kelsall	£ monthly after commencement

References

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2. Ehlers, A, Clark, D. A cognitive model of post-traumatic stress disorder. Behav Res Ther 2000; 38(4): 319–345

3. Knowles, R, Tarrier, N. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: A randomized controlled trial. Crit Care Med 2009; 37(1): 184–191.

4. Jones, C, Backman, C, Capuzzo, M, et al. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: A randomised, controlled trial. Crit Care 2010; 14(5): R168.

5. McIlroy, PA, King, RS, Garrouste-Orgeas, M, et al. The effect of ICU diaries on psychological outcomes and quality of life of survivors of critical illness and their relatives: A systematic review and meta-analysis. Crit Care Med 2019; 47: 273–279.

6. Bergbom, I, Svensson, C, Berggren, E, et al. Patients' and relatives' opinions and feelings about diaries kept by nurses in an intensive care unit: pilot study. Intensive Crit Care Nurs 1999; 15(4): 185–191

7. Bäckman, C, Walther, S. Use of a personal diary written on the ICU during critical illness. Intensive Care Med 2001; 27(2): 426–429.

8. Combe, D . The use of patient diaries in an intensive care unit. Nurs Crit Care 2005; 10(1): 31–34

9. Garrouste-Orgeas, M, Périer, A, Mouricou, P, et al. Writing in and reading ICU diaries: Qualitative study of families' experience in the ICU. PLoS One 2014; 9(10):

Contribution List

This key document has been circulated to the following individuals for consultation;

Designation
Sr. Samantha Armstrong, Sr. Donna Bagnall, Dr. Sian Bhardwaj, Sr.Andrea Carn, Dr. Caroline Davis, Dr. Stephen Digby, Dr. Nick Fitton, Matron Shelley-Ann Goodyear, Dr. Steven Haynes, Keith Hinton, Dr. Janos Mayer, Dr. Olivia Kelsall, Dr. Tracey Leach, Dr. Luke Simmonds, Dr. Shiju Mathew, Dr. Michael McClindon, Sr. Sally McNally, Victoria Muller, Dr. Nicholas Cowley, Dr Gareth Nichol, Dr. Phil Pemberton, Sr. Amanda Portman, Sr. Sally-Ann Rudge, Sarah Graham, Dr Gareth Sellors, Sr. Julie Share, Sr. Alison Spencer, Dr.Laura Tulloch, Dr. Stephen Graystone, Dr. Jeremy Thomas

This key document has been circulated to the chair(s) of the following committee's / groups for comments;

Committee
ICU Forum
Divisional Governance Meeting

Supporting Document 1 - Equality Impact Assessment Tool

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

		Yes/No	Comments
1.	**Does the policy/guidance affect one group less or more favourably than another on the basis of:**		
	• Race	n	
	• Ethnic origins (including gypsies and travellers)	n	
	• Nationality	n	
	• Gender	n	
	• Culture	n	
	• Religion or belief	n	
	• Sexual orientation including lesbian, gay and bisexual people	n	
	• Age	n	
2.	**Is there any evidence that some groups are affected differently?**	n	
3.	**If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?**	n	
4.	**Is the impact of the policy/guidance likely to be negative?**	n	
5.	**If so can the impact be avoided?**	n/a	
6.	**What alternatives are there to achieving the policy/guidance without the impact?**	n/a	
7.	**Can we reduce the impact by taking different action?**	n	

If you have identified a potential discriminatory impact of this key document, please refer it to Human Resources, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact Human Resources.

Supporting Document 2 – Financial Impact Assessment

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

	Title of document:	**Yes/No**
1.	Does the implementation of this document require any additional Capital resources	n
2.	Does the implementation of this document require additional revenue	Purchase of camera and provision of secure storage
3.	Does the implementation of this document require additional manpower	n
4.	Does the implementation of this document release any manpower costs through a change in practice	n
5.	Are there additional staff training costs associated with implementing this document which cannot be delivered through current training programmes or allocated training times for staff	n
	Other comments:	

If the response to any of the above is yes, please complete a business case and which is signed by your Finance Manager and Directorate Manager for consideration by the Accountable Director before progressing to the relevant committee for approval.