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13 January 2016

Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to the follow-up of Critical Care patients.

Please could you send me any policies relating to intensive care/ critical care follow up of patients?

The Trust are aware of the need to implement a follow up service as per NICE guidelines 83 and the Guidelines for Provision of Intensive Care Services and are currently working towards these. There is a pilot nurse led follow up clinic at Tunbridge Wells Hospital and the Trust have put forward in the commissioning intentions to the CCG for 2016/17 to commence a follow up clinic for both sites, this is still in the planning stage. The Trust does not currently have a formal policy regarding follow up from Critical Care.

The Trust currently use patient diaries to inform patients about their ICU stay and try to fill in any gaps in memory as per the attached guideline and patient leaflet.

GUIDELINE FOR THE USE OF PATIENTS DIARIES IN INTENSIVE CARE

**Intensive Care Diary Group
Maidstone and Tunbridge Wells NHS Trust
February 2010. Reviewed and updated August 2015.**

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A Guideline for the use of diaries for patients in the Intensive Care Units at Maidstone and Tunbridge Wells NHS Trust.

1. Introduction

1:1. The Department of Health document “Comprehensive Critical Care” (2000) and Quality Critical Care (2005) recommended that all intensive care patients should have access to some kind of rehabilitation or follow-up. In their paper Rehabilitation after Critical Illness The National Institute for Clinical Excellence (NICE) acknowledge that diaries may be a useful part of the rehabilitation process as they can help patients understand their critical care stay. (National Institute for Clinical Evidence 2009).

1:2. In recent years it has become increasingly clear that ICU survivors suffer psychologically as well as physically describing nightmares and hallucinations, anxiety, depression, difficulty sleeping and post traumatic stress disorder (PTSD) involving panic attacks, fear, pain and flashbacks. More recently studies have demonstrated that relatives also express symptoms of PTSD. (Jones, et al. 2012)

1:3. Work on the psychological status of patients following intensive care treatment has shown that the incidence of post traumatic stress disorder, anxiety and depression is high. (Hopkins, et al. 2005. Jones, et al. 2007. Cuthbertson, et al. 2008).

1:4. Patients who experience delusional memories but no factual memory of ITU stay, previous psychological problems, deep sedation or physical restraint are most at risk of developing PTSD (Parker 2013)

1:5. Intensive care is acknowledged as expensive (Audit Commission 1999) but the outcomes have been shown to be improving (HSRU and ICNARC 2009) and therefore the expense is justified. Follow up is recommended by NICE (2009) to further improve outcomes.

1:6. Survival is now acknowledged as a poor measure of the success of intensive care treatment and the aim is to restore people as closely as possible to their previous level of health (Hall-Smith, et al. 1997).

1:7. Addressing this issue would comply with the “Code” (Nursing and Midwifery Council 2008) which states that “You must act as an advocate for those in your care, helping them to access relevant health and social care, information and support.” It also states that a registered nurse should “deliver care based on the best available evidence or best practice.”

1:8. The National Institute for Clinical Excellence (NICE 2009) have produced a guideline for critical illness rehabilitation. This is the gold standard for rehabilitation for critical care and advocates diaries as a method of helping patients and their families to understand their critical care stay. The giving

information and opportunity for discussion is seen as a method of explaining the time in a critical care unit and therefore reducing the symptoms of anxiety, depression and PTSD.

1:9. NICE guidelines (2009) state that rehabilitation should start as early as clinically possible and that information and support should be available during, throughout and after the intensive care admission. A number of observational studies have demonstrated that using diaries helped patients and relatives to understand their critical care stay, reducing anxiety depression and PTSD. (Knowles R E. 2010. Garrouste-Orgeas M, et al. 2012. Jones C, et al. 2012.)

2. Aims

Patient Diaries are used within both Intensive Care Units in Maidstone and Tunbridge Wells NHS trust.

It is acknowledged that a full follow up clinic with input from professionals qualified in psychological issues is the gold standard for patients following their intensive care admission in order to fully comply with NICE 2009 CG 83.

Diaries have been shown to be a useful tool for patients following an intensive care admission. Outcomes will be audited and research by others closely monitored.

The clinical aims of the use of diaries are:

2:1. to help avoid patients having unrealistic expectations for recovery by allowing them to appreciate how ill they have been and why they are so weak and dependant.

2:2. to fill gaps in memory during the time patients are sedated and to help explain delusional memories as advocated by NICE CG 83 to meet rehabilitation needs during and post critical care stay.

2:3. to try to reduce the incidence of psychological problems following an intensive care admission.

3. What is a patient diary?

Patient diaries will simply be a notebook kept by the patient's bed space to enable family friends and staff to make entries about progress or things of interest to the patient. It is designed to fill the memory gaps for patients who have been sedated or too unwell to remember or understand what has happened to them.

4. Benefits of patient diaries.

4:1. There is increasing evidence that patients are suffering from psychological problems such as post traumatic stress syndrome, anxiety and depression, following an intensive care admission. Parker A M, et al. (2013) strongly recommend diaries as a tool to reduce these symptoms by aiding recall, filling memory gaps and providing a way of explaining delusional memories. (Knowles R. E. 2012)

4:2. Roulin, et al (2007) Bergbom (2008) recommend diaries to avoid unrealistic expectations for recovery, helping patients to appreciate how ill they have been and why they are so dependant.

4:3. Jones C, et al. (2012) argues that relatives of Intensive Care patient's can experience symptoms of PTSD and diaries can help alleviate these symptoms

5. Evidence

5:1. A study by Garrouste-Orgeas M, et al (2012) showed 32.1% vs. 21% of patients (who received a diary vs. those who did not) saw a reduction in PTSD symptoms.

5:2. Jones C, et al (2010) evidenced that 5% vs 13% had new onset PTSD (diary group vs non diary).

5:3. Knowles RE, TARRIER N (2010) showed significantly reduced anxiety and depression in patients who received a diary.

5:4. A fourth study by Jones C, et al (2012) demonstrated that family members of patients with a diary experienced less PTSD symptoms.

6. Strategies for implementation.

6:1. When will diaries be commenced?

Diaries will be started on all ventilated patients admitted to the Intensive Care Unit, including non invasive ventilation. For non ventilated patients a diary will be commenced if they positively score (4 or more) on the Intensive Care Delirium Screening Checklist (ICDSC)

6:2. Who can write in the diaries?

All members of staff and relatives of the patient are invited and are welcome to make diary entries. A diary with contributions from nurses, doctors, physiotherapists, chaplains and relatives is likely to hold more meaning than a diary filled in by one person alone.

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6:3. What should/should not be written in them?

All entries should be in black ink, dated and marked with the writer's job title.

Avoid information that could be of a sensitive nature, or that a patient may wish to keep confidential. Examples include malignancy, HIV status, sexuality or substance abuse.

Write only what you would be comfortable to disclose verbally to a patient or relative at the bedside.

Entries should where possible, be made daily so there are no gaps when the patient reads through it later. Write about any significant events such as extubation, a tracheostomy, or sitting out of bed for the first time. If progress is slow, still try to at least write one line, for example *your condition has not changed, you are still needing help from the breathing machine and your blood pressure support from medication*. If a patient is restless or agitated write about this as they may remember hallucinations from this period.

Avoid complicated medical jargon. Please see Diary Glossary of Terms (Appendix 5) and ensure that a copy is fixed in the back of each diary. Try to relate what you write to how you would normally verbalise the information to a patient or relative.

The diary is not aiming to be a record of their medical progress but a commentary on their ICU experience. It does not need to be medically detailed.

Your writing style should always be professional and relevant. Try not to be over familiar or use colloquial phrases.

Open the diary with the story of becoming ill, then being admitted to ICU, follow with daily updates and finish with a closing statement about discharge to the ward or RIP. Please see following examples. A combination of the examples will often be required.

6:4. Storage of diaries

Once started the diary should be kept by the patient's bed space in a convenient place for those wishing to make an entry.

When moving to a ward the diary should be kept in a secure place (to be agreed on each unit) and kept safe until handed over to the patient. At this point a copy should be made and placed in the patient's notes. This should safeguard from entries being made at a later date.

6:5. Ownership of diaries

The diaries are the property of the patient as they are started to benefit the patient.

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6:6. Handing over of the diaries

Only ITU Nurses who have been trained by the diary group (including members of the outreach team), will hand over the diaries.

Once patients feel ready to receive the diary, they will be guided through the contents by the designated nurse. A second visit may be necessary, and should be evaluated on an individual basis.

Diaries will normally be handed over during normal shift hours, therefore, patients need to be aware that appointments may need to be re-scheduled due to workload of the ICU or outreach.

Diaries will be kept (in a locked cupboard) for one year and then if unclaimed will be stored in medical records

6:7. Diaries not handed over to patients

In the event that a patient is discharged before handover of their diary they will be sent a letter (see Appendix 3 part1) asking them to contact the unit to arrange a mutually convenient time to come to the unit and collect the diary. If the patient cannot return to the unit, the diary can be posted to them following an appropriately lengthy telephone conversation guiding the patient through their diary.

If there is no response from the letter and a follow up letter (Appendix 3 part 2) the diary will be kept for twelve months before being sent to medical records. Where a patient has died the same procedure will be followed with the next of kin, with wording as in Appendix 3 part 3.

6:8 Photographs should not be used in the diaries. This is due to financial and trust policy implications involved.

7. Psychological issues arising on handover of the diaries

7:1. Handover of the diaries may highlight some previously undiagnosed psychological problems. If staff handing over a diary, have concerns these should be discussed with the patient's team of doctors or they should be referred to consult their GP if they have been or are about to be discharged.

8. Ethical considerations.

8:1. Consent.

The patient will not normally be in a position to consent. The diary remains the property of the patient and when they are capable they can withdraw their consent. It will immediately be discontinued and stored for twelve months in case they change their mind. It will then be sent to medical records.

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8:2. Confidentiality

Diaries will be kept in the patient's bed space in a convenient place for those wishing to make an entry. Once the patient leaves the unit the diary will be kept locked away until the patient is ready to receive it.

9. Evaluation

9:1. A short questionnaire for the patient and relatives, or relative in the event of the death of a patient, (see Appendix 4) will be included with each diary.

This will allow feedback for staff and information to evaluate whether the diaries are useful.

Patient Leaflet**WHY START A DIARY?**

Patients in critical care rarely remember any of the treatment they have received whilst being so ill. This is due to the nature of their illness, together with the many sedative drugs that they receive to help them tolerate the drips and tubes they require.

Some patients may have a gap in their memory that is difficult to fill once they recover. This may leave them worried and anxious for some time. Having a diary completed for patients during their intensive care stay, has allowed some patients to read this once they have recovered and helped them to fill in the missing gaps.

WHEN SHOULD THE DIARY BE STARTED?

All patients who require a breathing machine or who are confused can have a diary. If you have any questions or concerns about this please discuss them with the nurse at the bedside.

WHO CAN WRITE A DIARY?

Any member of the intensive care team can write in the diary. Friends and family can all contribute.

Nurses will write down simple language about the care delivered and any progress or set backs. We actively encourage family and friends to write in the diary. You may write about your feelings and family events as well as your loved one's progress.

Diaries are intended to aid the wellbeing of the patient so should be realistic but positive.

WHAT ARE THE BENEFITS OF A DIARY?

Experience and evidence has shown that patients who have read their diary on the ward or at home have given very positive feedback. The diary has helped to fill in the gaps in time lost whilst ill. Patients are often frustrated by their progress after intensive care. The diary may help patients have a better understanding of how ill they were.

WHAT HAPPENS WHEN THE PATIENT IS DISCHARGED TO THE WARD FROM INTENSIVE CARE?

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The diary will stay in the intensive care unit until the patient is ready to receive it. It will then be handed over by a nurse linked to the unit, giving the patient an opportunity for discussion. A photocopy will remain in the patient's notes.

USEFUL TELEPHONE NUMBERS

Tunbridge Wells Hospital

Chaplain: 01892 634383

P.A.L.S: 01892 632953

Maidstone

Chaplain: 01622 224569

P.A.L.S: 01622 224960

Intensive Care Units Address and Contact

Intensive Care Unit
Tunbridge Wells Hospital
Tonbridge Road
Kent
TN2 4QJ
Tel: 01892635598

Intensive Care Unit
Maidstone Hospital
Hermitage Lane
Maidstone
Kent
ME16 9QQ
Tel: 01622 224401/224398

Appendix 2**Guideline for the Handing over of the Diaries.**

1. Please ensure that you have read the Policy for the 'Use of Patient Diaries in Intensive Care'.
2. When there is a diary to handover, liaise with both the ward and outreach to determine if the timing is appropriate for the individual patient.
3. Approximately 30mins should be allocated for the handover of the diary. The timing of the handover should be discussed with the nurse in charge in order to take account of the unit workload.
4. If circumstances change and time can not be given on that shift, contact the ward and patient as soon as possible to let them know of the change in arrangements, and rearrange an alternative time as soon as possible.
5. Communication with the ward staff is essential, prior to arriving on the ward to hand over the diaries.
6. Please remember that although this may be distressing for the patient it is not necessarily harmful to their recovery. Expressing emotions can be part of the healing process.
7. Should you feel that a patient needs more in depth support please contact the appropriate medical team and inform ward staff of your concerns and actions undertaken. (Letter to G.P will be sent anyway informing them of the patient's ITU admission).

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Appendix 3
Part 1

□

Intensive Care Unit
*****Add Hospital Address*****
Date.....

Dear

During your recent admission to the intensive care unit you may be aware that a diary was filled in for you in an effort to aid recovery. The diary is now being held on our unit for you.

If you would like to telephone us on ***** we can arrange a mutually convenient time to collect the diary.

An alternative meeting place can be arranged to hand over the diary if you are reluctant to return to the Intensive Care Unit.

Yours Sincerely

.....

Position held

.....

13
Appendix 3
Part2

□

Intensive Care Unit
*****Add Hospital Address*****

Date :

Dear

During your admission to the Intensive Care unit a diary was filled in for you in an effort to aid your recovery. We wrote to you to see if you wanted to collect the diary but up until now have not had a reply.

The diaries are started as they help fill in the gaps when you may have been to unwell to remember. This can help with on-going symptoms such as disturbed sleep, flashbacks or mood changes. If you feel that you would like your diary or more information about the diary, please contact us on *****. We understand that it was a difficult time for you and if you do not want to visit the Intensive Care Unit another meeting place can be arranged.

Alternatively, you may not want a reminder of your time on the Intensive Care Unit. If this is the case, please ignore this letter and we will file the diary after 4 weeks.

Yours Sincerely

.....

Position held

.....

14
Appendix 3
Part 3

□

Intensive Care Unit
*****Add Hospital Address*****

Date

Dear

We would like to express our condolences on the recent death of your
*****As you will be aware a diary was completed for***** during ***
his/her***** admission to the intensive care unit.

If you would like to collect the diary we can be contacted on ***** and a
mutually convenient time can be arranged.

We understand that this is a very difficult time for you and an alternative
meeting place can be arranged if you are reluctant to return to the Intensive
Care Unit.

Yours Sincerely

.....

Position Held

.....

15
Appendix 3
Part 4

□

Intensive Care Unit
***** Add Hospital Address*****

Date *****

Dear *****

Following your telephone call, I understand that you would like your diary to be

posted to you rather than collect it from the Intensive Care Unit (ITU). I have

enclosed the diary for you but would like to draw your attention to the first page on

the inside of the cover. This explains the purpose of the diary and common experiences after discharge from ITU.

If you have any queries or concerns when reading your diary please give me a call

on *****.

Yours Sincerely

.....

Position held

.....

Appendix 3
Part 5

□

Dear Doctor.....

I am writing in connection with your patient

Mr/Mrs..... D.O.B.

You may be aware that this patient has recently had an admission to the intensive care unit.

Evidence is now showing that an intensive care admission can have psychological effects on patients due to fragmented and gaps in memory.

To try to minimize this we have provided the above patient with a diary of the time they were in the intensive care unit which has been completed by the patient's relatives, friends and staff members.

It is still possible however that you may be approached by this patient because of ongoing psychological problems.

If you would like any further information on this subject please do not hesitate to contact me or any of the staff involved in the diaries on telephone number.....

Yours Sincerely

(name).....

(position).....

**Appendix 4
Part 1**

ICU Staff questionnaire re ICU patient diaries.

In order to help us evaluate the effectiveness and any problems encountered with the ICU patient diary project we would really value your thoughts and opinions. We would appreciate it if you could take the time to answer the following questions. Many thanks!

- 1) Was the time easily available to handover the diaries? If not, what problems were encountered?
- 2) Did any problems or concerns come up at the time of handover? If so, what were they and did you feel you were able to deal with them?
- 3) How did you feel about starting and writing in the diary?
- 4) Is there anything you would change about the way the diaries are used?
- 5) Did you feel you were effectively prepared to handover the diary? If not, in what way could we have prepared you better?
- 6) Any further comments? Please feel free to use the back of this questionnaire to tell us about anything which you feel will be helpful.

Thank you for your time.

Please return to:

Appendix 4
Part 2

ICU Patient Diaries – Patient Questionnaire.

Many patients have little memory of their stay on the intensive care unit, therefore the aim of your diary is to act as a record of your stay and help fill in any memory gaps.

Your relatives, friends and staff may all have contributed to your diary.

We are constantly trying to improve the service we provide therefore we would be very grateful if you could fill in this questionnaire and return it to the address below at your earliest convenience. All information will be confidential and anonymous.

1) Have you read your diary?

If not, why not?

2) Did you find the diary beneficial?

If yes, please tell us why.

If not, please tell us why not.

3) Did you find anything difficult or upsetting about the diary?

4) Do you feel that you received the diary at the right time during your recovery process?

5) Did you feel adequately supported through the diary process?

6) Do you feel the diary helped your recovery process?

7) Any further comments? Please feel free to use the back of this questionnaire to tell us about anything which you feel will be helpful.

Thank you for your time.

Please return to:

**Appendix 4
Part 3**

ICU Patient Diaries – Relatives Questionnaire.

During your relatives stay on the intensive care unit you may have contributed to their diary, we hope that this has been beneficial to you both. We are continuously trying to improve the service we provide, therefore, we would appreciate it if you could complete this questionnaire and return it to the address below. All information will be strictly confidential and anonymous.

1) Do you feel you had adequate explanation and understood the reasons for the diary?

2) Did you feel comfortable writing in the diary?
If no, which aspects did you find difficult?

3) Did staff support you with regards to writing in the diary?

4) Did you read the diary after your relative was discharged from the intensive care unit? If so, did the diary entries match up with your memories of what happened in the intensive care unit?

5) Do you feel the diary has been beneficial in your relative's recovery?

6) We realise that you may have found your relatives stay in the intensive care very stressful. Did you personally find the diary helpful whilst,
a) your relative was in the intensive care unit?
b) after they were discharged home?

7) Was the diary easy to understand?

8) Is there anything you would add or change to the diary to improve it?

9) Any other comments? Please feel free to use the back of the questionnaire to tell us about anything which you feel would be helpful.

Thank you for your time.

Please return to:

Patient Diary Glossary of Terms

Arterial Line – Most ICU patients have an arterial line, usually in the wrist or arm. Arterial lines are connected to the monitor to show the blood pressure and allow blood samples to be taken.

Bipap/Cpap Face Mask – A tightly fitting mask on the face, attached to a breathing machine to help open the airways and push air into the lungs when they are struggling.

Bronchoscope – This procedure is carried out using a fibre optic camera device. The bronchoscope is passed through the patients breathing tube into the air passages leading to the lungs allowing the doctor to see the airways of the lungs, washout secretions and sometimes take biopsies.

Central Line or Central Venous Line (CVP) – Most ICU patients will have one of these lines, they are usually put in the neck or groin. They have lots of ports going into a large vein, allowing drug administration. They can be connected to the monitor to provide observations. They are sometimes left in when a patient goes to the ward.

Catheter – A tube into your bladder that drains your urine.

Endotracheal Tube (ET Tube) - This is a tube which goes through a patients mouth and into the windpipe. It is attached to the ventilator or oxygen.

Extubation – The breathing tube is removed from the windpipe and the patients lungs work on their own.

Filter – A general term given to a machine that washes the blood when the kidneys are too unwell to do it. It is attached to a patient via a large line inserted into the vein in the neck or groin called a vascular catheter (vas cath).

Inotropes – Drugs used to help boost blood pressure when it is low, commonly named noradrenaline.

Nasogastric Tube (NG) – A tube that passes through the nose and down into the stomach. Most ICU patients have one of these. They are used to drain the stomach if necessary or where possible provide liquid food and drugs.

Nebuliser – This makes medicine into an aerosol which is breathed into the lungs and helps loosen thick phlegm and open the airways.

Optiflow – A way of giving lots of oxygen through small tubes that fit into the nostrils.

PiCCO – This is a special line which is put into an artery and is connected to the monitor which works out how well the heart is working and responding to drugs and fluids.

Tracheostomy – A tube is inserted into the windpipe through an incision made in the neck. It replaces an ET tube and is more comfortable when the sedation is turned off.

Ventilator – A breathing machine to do the work for the lungs.

Weaning – A term used to describe the phase when the work of the ventilator is decreased and the work of the patient's lungs is encouraged. The ventilator settings will often be changed to BIPAP or CPAP.

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Intensive Care Follow Up Service

Information for patients

The Tunbridge Wells Hospital Intensive Care follow up service is a service for patients who have been in the Intensive Care Unit (ICU) at some point in their hospital stay.

Being admitted to ICU can be a very distressing time and this service offers patients the opportunity to speak to an ICU nurse about their experience and ask questions about their stay, both on the phone and at a clinic appointment.

ICU phone number
635728

 01892

Why a follow up service is needed

During their ICU stay, many patients will experience confusion, anxiety, hallucinations and nightmares. These are caused by the severity of their illness and the drugs used to support them and aid their recovery.

For most people, these symptoms will fade as their condition improves, but it is not uncommon for patients who have spent time on intensive care to continue to experience disturbing side effects of their critical illness and their stay on ICU after they have been discharged home. These can include physical problems such as muscle weakness and fatigue and psychological problems such as anxiety, depression, memory problems and post traumatic stress disorder.

In order to help patients address some of these issues, Tunbridge Wells ICU have set up a follow up service for patients who have spent some time on Intensive Care.

What we offer

During your ICU stay, you may have had a diary written by the nursing staff and maybe your family and friends, documenting your stay in ICU and discussing what has been happening to you each day. This can sometimes help you to fill in the gaps in your memory of your ICU stay and put some of the events you do remember into perspective. This will be returned to you either after ICU when you are on the ward or can be collected from the unit by yourself or a relative after you have been discharged home.

The first couple of weeks after being discharged home can be quite difficult. If you have any immediate concerns, you can phone the number on this leaflet and speak to an ICU nurse. Someone may not be available immediately and if that is the case, then your details will be taken and we will phone you back when one of the ICU follow up team is on duty.

Approximately three months after your discharge home, you will be offered the opportunity to make an appointment to come back to speak to one of the ICU nurses. During this appointment, you will be able to talk through your diary with the nurse and ask any questions that you want.

You will also be able to discuss any aspects of your ICU stay and any problems that you are having since you have been discharged home.


We hope that this service will help to address some of your problems and enhance your recovery from critical illness.

Please use this space to write any notes or questions you may have.

Further information and advice can be obtained from:

- **ICUsteps:** a registered charity run by former intensive care patients and relatives aiming to improve the care and support available to patients recovering from critical illness during their long recovery. www.icusteps.org
- **NHS Choices pages on “intensive care”:** www.nhs.uk/conditions/intensive-care
- **I-canuk:** a project aiming to improve the longer term care of patients who have suffered critical illness by providing a forum for those involved or interested in ICU Follow-Up, producing educational and multimedia resources, promoting the role of ICU Follow-Up Services etc. www.i-canuk.com

NHS 111

 111

NHS Choices online

www.nhs.uk

MTW NHS Trust is committed to making its patient information accessible in a range of languages and formats. If you need this leaflet in another language or format please ask one of your clinical care team or the PALS Team. We will do our best to arrange this.


Patient Advice and Liaison Service (PALS)

If you would like to raise any concerns, make comments and suggestions or require information on Trust services, you can contact **PALS**. Office opening times are Monday to Friday 10.00am to 4.00pm. Both offices offer a 24 hour answering machine. Messages will be responded to within one working day, so please do leave a contact number.

PALS Maidstone Hospital

 01622 224960

PALS Tunbridge Wells Hospital

 01892 632953


PALS Email

mtwpals@nhs.net

PALS SMS

 07747 782317

PALS Maidstone Fax

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 01892 632954

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