

Critical Care Discharge Information



Information for patients and relatives during and immediately after discharge to the ward



Critical Care Discharge



Information for Patients

Information for Patients

care to a general ward. Everyone is different. This pack will help you to identify your own individual needs and get the information you require to support your recovery whilst on the ward. Name: Why was I in critical care? What happened to me? Completed by: (Print name and position) Date of discharge from critical care: Ward: Name of Ward sister/Charge Nurse:

This information has been designed to support you when you move from critical

Ward Tel no:

What else do I want to know?

Read through the following pages and write down any questions you have in the sections provided (or ask someone else to). Show this to the nurses, doctors, physiotherapists and other staff looking after you. They will be able to discuss these issues with you in more detail.

You can ask anything you want to know.

NO question is too trivial or too basic.

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Before discharge to the ward

Am I ready for discharge?

Being discharged from critical care is a positive step, but you can feel scared leaving the staff you have got to know and a place which is familiar. You may not feel ready and may still feel very unwell.

An experienced team of doctors, nurses and other health care staff will have made the decision that you no longer require such intensive monitoring and nursing. Ward nurses and doctors will be given a handover from the critical care team to enable them to continue your care.

If you feel concerned about the decision to move you to a general ward, you should tell this to the nurse or doctor who can discuss it with you further.

When will I go to the ward?

You might not be told which ward you are going to until a short time before and things can change quickly. Occasionally discharge to the ward can happen during the night, but this is avoided wherever possible. If there are delays in organising beds on the ward you may be taken off some of the monitoring as you will no longer need such high level observation.

Who will go with me?

A nurse from the critical care unit will help you pack your things, inform your family and will go with you. This is usually your bedside nurse. A porter will also usually come to help. Sometimes a nurse from the ward will also visit you on the unit before your discharge and may accompany you to the ward.

What ward am I going to?

This should be written on the front of this booklet. If you cannot find it please ask the nurse caring for you. Ask what type of ward it is.

What will it be like on the ward?



Many wards have information booklets explaining who the staff are, visiting times and how the ward works.

Ask for a copy when you get to the ward.

You could be in a bay with up to 8 other people of the same sex as you. The wards also have smaller bays and single bedded rooms. There will be less equipment than in critical care. Other patients may be able to talk to you, but the ward can be noisy and you may find this disturbing at first.

Each ward nurse will be looking after a group of people, assisted by a number of health care support workers. Even though you may not always be able to see a nurse you can contact them by pressing the call bell. Ask the nurse to leave it within your reach and press it if you want any help. You may have to wait for a short time if the nurses are busy with other patients. This can make you feel neglected or deserted. This isn't the case. You are being looked after. It is just that the level of care is different compared to critical care.

Staff on the ward will encourage you to become more independent. It can feel like they are asking too much of you, but it is an important part of your recovery.



The ward staff will be given a handover from the critical care team, but they may also ask you and your family some questions.

This is not because they do not know what is wrong with you, but because they need to get to know you as a person and plan your ongoing care.

Concerns about going to the ward

Use this section to write down any questions or worries you have about going to the ward and show it to your bedside nurse. Record any advice/information given. Ask your family or the nursing staff to help you complete it if you feel unable to do so alone.

Question/Concerns I have
Answers to my questions
/ I

On the Ward

Recovery is different for everyone. Information about some of the most common worries can be found on pages 12-18. You might find it useful to read through these. Most worries are temporary and will return to normal with time. **You may have some, all or none of these.** You may also have other worries.

What should I do if I am worried about anything?

The first thing you should do is tell the nurse looking after you and/or the nurse in charge of the ward. You can also tell the doctors or any other health care staff when they come to see you.

Write down any questions or concerns you have on pages 19-25 (or ask someone else to). Show these to your nurse, doctor, physiotherapist or other available health care staff. Ask them if there are some things you can do to help with your worries. Your family could also help with this. Together, you can work out what you can all do to make you feel better.

You can also talk to your relatives/friends if you are concerned about anything and ask them to speak to the nurse in charge and/or doctor on your behalf.

Your recovery from a critical illness

You have been very ill and you need to give your mind and body time to recover. The suggestions below may help your recovery. Do them as and when you feel ready for them.

What can I do to help my recovery on the ward?

Recognise the progress you have made

Some people find the following useful:

- Looking at any pictures of you that may have been taken in critical care. Ask the staff or your family if any were taken
- Reading and talking about what happened to you in critical care. Ask the staff or your family if a diary of your time in critical care was kept
- Keep a daily diary of your feelings whilst on the ward (page 23)

2. Set yourself short term, realistic goals

Achieving small things each day will help improve your confidence and morale.

Write down your goals on pages 17-18. Ask the staff what their goals for you are, and discuss with them how you are doing.

3. Listen to your body

Remember, you have been seriously ill and recovery will take time. Go at your own pace, guided by the health care staff. Do not judge yourself against how others are doing, as everyone is different and people are in hospital for lots of different reasons. Ask if you have any concerns.

4. Have a positive mental attitude

Each day try and think of one positive thing. If you cannot think of anything ask the staff or your family/friends to help.

5. Talk to family/friends and staff

Don't bottle things up. Share and discuss your feelings and concerns. Use the sections on pages 17-18 to help with this.

6. Exercises to aid recovery

You could try to do some of the exercises described on page 21. Do as much as you can and rest when you need to.

What common emotional worries might I have?

Feeling scared and anxious/ panic attacks/phobias/ loss of confidence

The first few days and weeks on a ward may not be easy and you may feel frightened, insecure, anxious and stressed (dry mouth, rapid breathing, fast heart beat, cold sweats, butterflies in the stomach).



You might be worried about getting ill again and might feel frightened if you have been told that you nearly died. You might also feel scared about being in an unfamiliar environment and being expected to do more for yourself.

You may have lost your confidence and might try to avoid things that make you feel scared. These are all normal feelings. For most patients, as time progresses your confidence will grow and return to normal.

Difficulty understanding what has happened

You are not alone. Many people are unable to remember all of their time in critical care. You have been seriously ill and may have been given strong drugs which made you sleepy. Coming to terms with what has happened can take time and you

may never remember everything. Everyone's experience is different and individual to them.



You may find that you cannot concentrate on anything for long and keep forgetting what you have been told. This should get better as you continue to recover.

Mood changes

It is normal for your mood to change often. One moment you may feel good and the next you may feel down or very tearful.

You may feel irritable for no specific reason, and you may feel depressed for some time. You might also feel restless, fidgety, unsatisfied, have racing thoughts or lose your sense of humour. These are normal reactions to being seriously ill. They are not permanent changes in you and will subside with time. You may also feel frustrated if it seems like you are not progressing, but remember you have been very ill and you need time to recover.

If you smoke or normally drink a lot of alcohol then you might also feel irritable due to nicotine or alcohol withdrawal.

Hallucinations/Flashbacks/Paranoia/Sleeping problems

You may have flashbacks and memories of disturbing or strange experiences. These are often 'unreal', but can be very vivid and frightening. You may also suffer from bad dreams or nightmares. These experiences are common and are related to your illness and the strong drugs you may have been given in critical care. They usually settle after a few days or weeks.

You might also find it difficult to fall asleep or you may wake frequently during the night. This might be because the ward is noisy, but your sleep pattern may also have been disrupted whilst you were in critical care. Being awake at night can be worrying and things easily seem to get out of proportion. Your sleep pattern will improve as you become more active during the daytime, but if you are concerned, talk to the ward staff.

What common physical problems might I have?

Changes in appearance, senses and voice



You may feel worried when you first look in the mirror as your appearance may have changed due to the effects of your illness.

You may look thinner and you may have lots of marks, bruises and scars on your body because of the various tubes, drips and injections used in critical care. The quality of your hair or nails may have changed and you may also experience some hair loss. You might also find that your skin feels itchy and drier than before.

You might also notice changes to your senses. For example, your hearing might be slightly worse or more acute, your vision might be affected and things that touch your skin can feel strange for a while. You might also experience dizzy spells due to an altered sense of balance.

Your throat may be sore if you have had a breathing tube in, and your voice may be weak and sound different. If you still have a tracheostomy tube, you may not be able to speak until it is removed.

These changes are usually temporary and most will disappear over time.

General weakness/Lack of energy/Poor mobility

You will probably have lost weight and your muscles may be weak and your joints stiff from being in bed. You may also have generalised aches and pains, feel exhausted and have no energy. The slightest activity may make you feel very tired. This is normal after a serious illness.



Your muscles have not been working for a while and will need time to build up their strength again.

You may experience difficulty in doing things which require fine movement such as fastening buttons, writing, holding cups etc. This means you are likely to still need some help with personal care such as eating, dressing, washing and walking. This should slowly improve.

Breathing problems

You may feel breathless at times, particularly when you are doing anything. Even talking can make you feel short of breath, and you might need some oxygen which will be given through a mask. You might also find it difficult to cough due to muscle weakness. These problems should improve over time, but may not completely resolve, depending on your condition.

Whilst in critical care you may have had a tube in your throat to help your breathing (a tracheostomy), and you may still have this on the ward. It will usually be

removed after a few days/weeks once you are able to breathe effectively on your own. The hole it leaves will gradually close. There will be a scar which will slowly fade and become less obvious.

Eating and drinking problems

You may be having food through a tube in your nose which goes down to your stomach, or by a drip straight into your vein. This is unlikely to be permanent and will be removed once things return to normal.



Food can taste very salty, sweet or have a metallic taste

You may be given nourishing yoghurts, drinks and food supplements to help build up your strength

When you first start eating and drinking again, food/drinks may taste different until your taste-buds readjust. You may not feel hungry, your mouth may be sore or it might hurt to swallow. These problems can be caused by the strong drugs you may have had. You might also develop a thrush infection (candida) in your mouth (a thick white coat over the roof of your mouth and tongue). This can make your mouth very sore. Your mouth can also feel very dry due to a lack of saliva. If you wear dentures, you may find that they no longer fit well, as your gums may have shrunk.

These problems are rarely permanent.

You may still have a tube in your bladder (a catheter) which drains urine from your body into a bag. This is so that staff can check your fluid levels. When the tube is taken out, your muscles may be weak for while so you may find it difficult to control your bladder. Sometimes, the medicines you are on can also change the colour of your urine.

You may develop a urine infection. Symptoms of this include not being able to pass urine, or passing very small amounts frequently. You might also have a burning pain whilst urinating and/or blood in your urine. Any such symptoms should be reported to the nurse or doctor caring for you.

Your bowels might also be upset for a while, but things should gradually return to normal.



You might have bloating, diarrhoea or feel constipated.

You might need some medicines to help you go to the toilet.

Concerns about my recovery

Use the following pages to record any questions or worries you have about your recovery, and any goals you have set or agreed with the staff. Ask your family or the nurses to help you complete it if you feel unable to do so alone.

Week 1 (Date)
Question/Concern I have
What I can do?

Week 2 (Date)
Question/Concern I have
What I can do?

Week 3 (Date)
Question/Concern I have
What I can do?

Week 4 (Date)
Question/Concern I have
What I can do?

What support will I get on the ward?

In addition to the ward nurses, health care assistants and doctors, many other health care professionals may contribute to your recovery. They include:

Critical care outreach team/Discharge liaison nurses

These are nurses from critical care whose role it is to check that recovery is going as planned. Sometimes, they are available to talk to patients about their critical care experience

Physiotherapists

Physiotherapists help with getting you moving again and increasing your strength. They can also assist with coughing and breathing

Speech and Language Therapists

They may see you if you have any speech or swallowing problems

Dieticians

Dieticians can give advice on diet and any necessary food supplements

Occupational Therapists

Occupational therapists help prepare people for going home. They can provide assistance with improving skills such as dressing, cooking etc

Chaplains

Support for different faiths is available. If you wish, they can talk to you and help support your religious/spiritual needs

Volunteer staff

Some areas have volunteers who are available to sit and talk with patients, provide reading materials, and help with simple tasks

Specialist support

As a result of your illness there may be temporary or permanent changes, which you have to adapt to, which can be difficult. Staff specialising in your condition can offer specific advice on rehabilitation. There may also be a charity for your specific illness or injury which can provide additional information and/or support.

Useful contacts

- Patient Advice and Liaison Service (PALS). They can offer general support and advice about being in hospital. Contact details can be obtained from the ward receptionist
- Chaplaincy: all hospitals have multi-faith support and ward staff can arrange for the appropriate person to be contacted

If you feel well enough, you could ask if there is any access to a computer on the ward or if your family can bring you a laptop. You can then look at some of these useful websites as and when you feel ready:

- ICUSteps website. A charity set up by former intensive care patients and their family members. Includes information such as 'Intensive Care: a guide for patients and relatives', plus experiences of former patients and family members, and links to support groups: www.icusteps.org
- DIPEx-Database of Individual Patient and Relative Experiences:
 www.healthtalkonline.org
- I-Canuk: A professional and independent national organisation which contains important publications and guidance documents, and links to patient experiences and information support: www.i-canuk.com.

There are also many charities set up for specific injuries and illnesses, which can provide support and information. Ask the nurses about those which might be relevant to you. You could also ask your relatives to look into relevant charities for you, either on the internet or at their local library.

Exercises

These exercises are designed to help you regain the strength that you may have lost during your illness.

- Take a deep breath through your nose and out through your mouth.
 Repeat 3 times
- Pull your toes up, down and round in a circle. Repeat 10 times
- Keeping your leg straight, pull your toes upwards, count to 5 then relax.
 Repeat on both legs 10 times
- Bend your knees and put both feet flat on the bed. Roll both knees together to the right keeping your shoulders still. Return your knees to the middle and repeat to the left. Repeat 10 times
- Place a rolled up towel under your left knee. Pull your toes upward and lift your lower leg off the bed. Hold for 5 seconds. Repeat 10 times on both legs.
- Stretch both arms out in front of you. Touch your nose with your outstretched hand, then straighten. Repeat 10 times on both arms
- Turn your head to look over your left shoulder, back to the middle, then turn to look over your right shoulder. Repeat 10 times
- Bend your head and try to touch your ear on your left shoulder, keeping your shoulders still. Repeat on the right. Repeat 10 times
- Take both arms out to the sides with your elbows straight. Circle your arms forward 10 times and backwards 10 times.

Do as much as you can. Rest when you need to

Acknowledgements

This information pack has been produced by Suzanne Bench of the Florence Nightingale School of Nursing and Midwifery, King's College, London.

It is based on research findings by Bench et al (2010, 2011), and was developed using feedback from health care staff and ex-critical care patients and relatives from across England, and a review of the content of the following publicly available documents:

- Intensive Care Society: Discharge from Intensive Care; information for patients and relatives
- Chelsea and Westminster Healthcare NHS Trust: Information for patients leaving the intensive care unit
- Salford Royal NHS Foundation Trust: Patient information; ICU patient discharge followup
- Southampton NHS University Hospitals Trust: After Intensive care; patients and relatives information booklet
- University Hospitals Birmingham NHS Foundation Trust: Critical care follow—up information
- Society of Critical Care Medicine: ICU issues and answers; What should I expect after leaving the ICU?
- ICUsteps: Intensive care; a guide for patients and relatives
- Mitchell and Courtney (2002) Transfer from ICU...for relatives. Griffith University,
 Australia
- Paul et al (2004) ICU discharge information booklet. Ninewells hospital, Dundee

References

- Bench S, Day T (2010) The user experience of critical care discharge; a meta-synthesis of qualitative research. International Journal of Nursing Studies 47: 487-499
- Bench S, Day T, Griffiths P (2011) Involving users in the development of effective critical care discharge information: a focus group study with patients, relatives and health care staff. American Journal of Critical Care (In press)

Reflective Diary

This diary can remain private to you or it can be shared with the nurses so they can help with any concerns. Write down how you feel each day. It might help to look back after a few days and see if things are improving.

Day/Date	How do I feel today?

Day/Date	How do I feel today?



Critical Care Discharge



Information for Relatives

Information for Relatives

Who is this booklet for?

This information is designed to support you during and after your relative leaves critical care to go to a ward. Everyone is different. This pack will help you to identify your own individual needs and get the information you require whilst your relative is on the ward.

We realise that close relationships come in many forms and that our closest relationships are not necessarily with someone traditionally classified as a 'relative'. For the sake of simplicity we use the term 'relative' throughout but realise that for many people terms like 'friend', 'partner', 'loved one' would be more appropriate.

What do I want to know?

Read through the following information:

Page 3-6: Before discharge

Page 7-11: Helping recovery on the ward

Page 12-18: Questions and concerns

Page 19-22: Looking after yourself

Page 25-29: Diary pages

Write down any questions, worries or concerns you have in the sections provided. Show this to the staff looking after your relative who will be able to discuss these issues with you in more detail.

You should also read the information pack given to your relative. You might like to read sections of it to your relative as they may be unable to read it themselves.

You can ask anything you want to know.

NO question is too trivial or too basic.

Before discharge

Is my relative ready for discharge?

Having a relative discharged from critical care is a positive step but it can make you feel scared leaving the staff you have got to know and a place where you feel your relative is safe. You may have developed close relationships with the nurses and doctors in critical care, and the technology and monitoring may have made you feel secure. You may not feel that they are ready to leave.

An experienced team of doctors, nurses and other health care staff will have made the decision that they no longer require such intensive monitoring and nursing, but if you feel concerned about the decision, you could speak to the nurse or doctor.

When/Where will my relative go?

Details of the ward your relative is going to can be found on the front of their information pack. We may not know this information until a short time before discharge, and things can change quickly. Sometimes there are delays in organising beds on the ward. This can mean that discharge sometimes happens during the evening or overnight, although this is avoided wherever possible.

The bedside nurse should keep you informed, but sometimes your relative may be discharged more quickly than planned. A full handover of care will always be provided to ward staff both day and night.

Will my relative be looked after on the ward?



There will be nurses and doctors on the ward, but they will be caring for other patients as well, and may not be visible at times.

You may feel neglected or worry how your relative will cope with this change. You should be reassured that your relative has been discharged to the ward because they are getting better and need less support.

Staff on the ward will encourage your relative to become more independent. This is an important part of their recovery plan, but may feel difficult at first.

The ward doctors will be given a handover from the critical care team, but they may also ask you some questions. This is not because they do not know what is wrong with your relative, but because they need to get to know them as a person and plan their ongoing care.

Visiting times in a general ward may not be as flexible as in critical care. Many wards have information booklets which explain who the staff are, visiting times and



how the ward works. Ask for a copy on the ward.

On the ward

What can I do to help my relative's recovery?

Read the information together

It may be helpful to read sections of the patient information pack to your relative. It is likely you will need to repeat the information at other times as they may not be able to remember it. Help them complete the sections detailing their worries, concerns and feelings.

People respond differently to a stay in critical care. Some people want a lot of information and some do not want to know anything. You will know your relative best and can help them to get the individual information that they need Your relative may not understand how ill they were. Talk to them about what happened, and how they are feeling. You may need to tell them about their injury/illness and treatments in stages or when they ask for more information.

They may be unable to remember the last few days/weeks. If they are ready to, help them fill in the gaps and piece together their time in critical care. You may have kept a diary of their stay, which you can discuss with them.

They may still feel very ill, feel they are not getting any better or not understand how ill they have been. Looking back will help them recognise the progress they have made.

Encourage independence

It is natural that you might feel over protective and want to help your relative as much as you can. However, it is important that they now start to regain their own

independence and you should, therefore, encourage them to do as much for themselves as they can.

Help them set realistic short term goals for recovery. Bring in personal items for them that will help them to regain their independence. For example, own clothes, toiletries, glasses, hearing aid, dentures.



A personal music player or laptop with headphones can also be useful and will help them to occupy their time.

Recovery for a critical care patient

Now your relative is in the general ward you may expect them to be happy and relieved that they are getting better and that they survived their illness or accident. However, they may act differently from what you expect.

They may be depressed, anxious, upset, irritable and/or unmotivated. They may still be very confused from all the strong medicines they have taken.

These are all normal reactions, but can be difficult for relatives to deal with.

Remember, your relative has been through a huge ordeal, and it can take a long time for them to recover physically and mentally.

You may also find it hard if they cannot understand what you have just experienced as a relative of someone in critical care, and what it was like for you to see them so ill.

Try not to expect too much. It may be useful for you to think back and see that they are making progress, even if it is very slow.

I have questions, where can I get answers?



You might feel like you want to go back to the critical care unit to speak to the nurses and doctors that were looking after your relative. This is natural, but they will not necessarily have an updated knowledge of your relative's condition after discharge as they will have handed care over to another team of doctors.

The first thing you should do is read through this information pack, and the information given to your relative. Talk to the nurse looking after your relative and/or the nurse in charge of the ward.

Although the ward nurses may be unable to give detailed ongoing explanations of each change in your relative's condition, they can arrange for you to speak to a doctor for an update if necessary. You can also ask to talk to the doctors or any other health care staff when they come to see your relative.

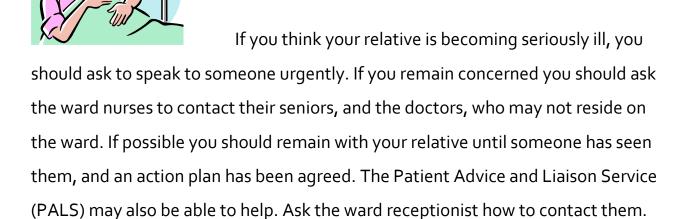


The ward can be busy.

It may not always be possible to speak to a doctor on the same

Write down your questions and concerns on pages 15-17 of this information pack. You can also record here any advice you are given.

What if I am really worried that their condition is getting worse?



Questions/concerns

Question/Concern I have	

Advice/What I can do	

Question/Concern I have	

Advice/What I can do	

Looking after yourself

Having a relative who has been critically ill is extremely stressful and you may feel both physically and emotionally exhausted. You may not have been eating or sleeping well, and you may also feel under pressure to support other family members and to maintain a normal life outside of the hospital. If you have young children, they might also be acting differently, and may need more attention than normal. Feelings of guilt, worry or depression are common at this time, particularly if you were afraid that your relative might die or feel that they are still too ill to be going to a ward.



You might also have money worries or concerns about your job

It is important that you share your feelings and devise strategies for coping. Try to ask friends and family to support you at this early stage of recovery—you may need as much or more help now even though your relative is out of critical care.

Use the diary on page 25 to record your thoughts and feelings. Discuss these with family and friends. You might also want to contact your own General Practitioner for further advice and support. Some of the organisations listed on pages 21-22 could also be of help.

Useful contacts

- Patient Advice and Liaison Service (PALS): contact details can be obtained from the ward receptionist
- Chaplaincy: all hospitals have multi-faith support and ward staff can arrange for the appropriate person to be contacted
- ICUSteps website. a charity set up by former intensive care patients and their family
 members. Includes information such as 'Intensive Care: a guide for patients and relatives',
 plus experiences of former patients and family members, and links to support groups:

 www.icusteps.org
- DIPEx: database of individual patient and relative experiences: www.healthtalkonline.org
- I-Canuk: a professional and independent national organisation which contains important publications and guidance documents, and links to patient experiences and information support: www.i-canuk.com.
- UK Debtline: call free on o8oo 731 7973. www.national-uk-debtline.co.uk
- Samaritans: provides confidential, unbiased emotional support, 24 hours a day, for people who feel distressed, desperate or suicidal. Helpline: 08457 909090.
 www.samaritans.org. Email: jo@samaritans.org
- British Association for Counselling and Psychotherapy: for details of counsellors and psychotherapists in your area call: 0870 443 5252. www.bacp.co.uk
- Princess Royal Trust for Carers: the largest provider of support services for carers in the UK: Tel; 0844 800 4361. www.carers.org

There are many different charities set up for specific injuries and illnesses which will be able to provide support and information. You could look for relevant charities on the internet or at your local library.

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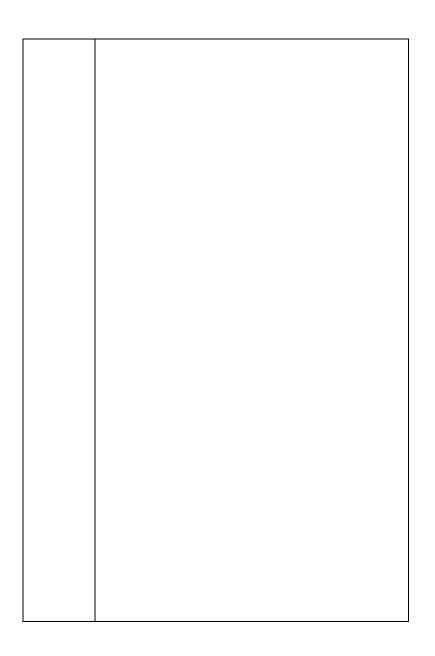
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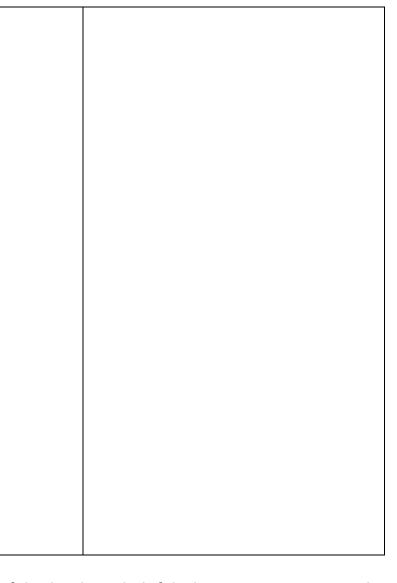
Reflective Diary

Write down how you feel each day. It might help to look back after a few days and see if things are improving.

Date	How do I feel today?
İ	

Date	How do I	fee	l today?	





If this has been helpful why not start your own diary or continue on the back pages of this pack

Day/Date	How do I feel today?

If this has been helpful, why not start your own diary or continue on the back pages of this information pack

Please add any additional hospital/department specific information here