

## Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or [patient.information@addenbrookes.nhs.uk](mailto:patient.information@addenbrookes.nhs.uk)



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

# Life after a critical illness

## Patient Information

### Farman Intensive Care Unit

Useful information for patients who have been in the John Farman Intensive Care Unit and their relatives

#### Document history

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To contact the 'follow-up team' please ring: 01223 217258. Please leave a message if you reach the answer phone. The staff are often busy on ICU working with patients. We will get back to you as soon as possible.

**Due to the nature of our work, most of our time is spent working with patients on the ICU, so we are not office based. However, we do endeavour to answer messages as soon as possible.**

Alternatively you can contact us by email: [jvficufollowup@addenbrookes.nhs.uk](mailto:jvficufollowup@addenbrookes.nhs.uk).

If you have an emergency, please contact the ICU on 01223 217474.

## **Introduction**

This information booklet is aimed at helping patients in their recovery following a period of critical illness.

The follow-up team are available to support both the patient and the relatives throughout the rehabilitation process - the contact number for the team is on the cover and page 2 of this booklet.

## **Important information for patients**

As you have been ill, it will probably take you a while to get back to feeling your normal self. Exactly how long this will take depends on things like the length of time you have been ill, whether you have lost a lot of weight and whether your illness means that you will have to change some aspects of your lifestyle.

This booklet sets out to describe some of the common problems that can occur. It suggests simple ways to try to solve them.

We want to emphasise that you will probably not experience **all** of the problems described here. If you do suffer from any of them hopefully you will find the relevant advice helpful.

**We want to stress that there is every chance you will return to the state of health you enjoyed before you became ill, and your present symptoms will pass with time.**

During the first few days after leaving the ICU, a patient may be unable to concentrate, understand and apply the information to themselves. By reading this booklet relatives will hopefully gain an understanding of what a patient is going through. This helps them to be actively involved in the patient's recovery.

## Going to the ward

Going to the ward is a big step forward to getting better and going home. It is quite normal to feel apprehensive. You will have become familiar with the staff on the ICU and the routine there. The thought of meeting new people can be worrying at any time. It may seem harder when you have been ill and the new people are those looking after you. The staff on the wards understand this. They are used to looking after people who have been seriously ill, so feel free to ask them about anything that concerns you.



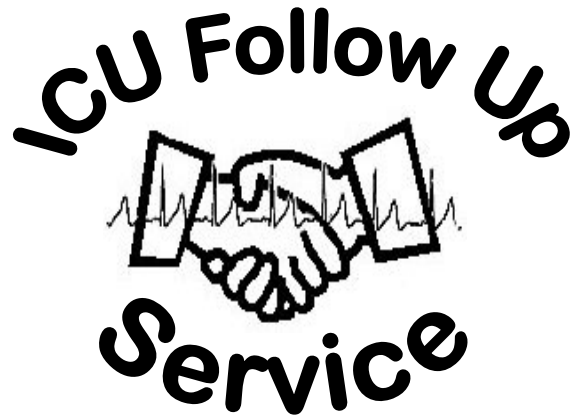
You will notice that on the ward there are fewer nurses caring for each patient compared to the ICU. This reflects the fact that you are now able to do more for yourself. Even if you cannot see the nurses all the time, they are still nearby.

## Notes

Please use these three pages to make notes or write down questions as you remember them.

## List of other Trust leaflets

A range of leaflets should be available in wards or departments. All are available from the Information Zone on Level 1 near the main reception. Alternatively, they are available to download from the Trust website [www.cuh.org.uk/addenbrookes](http://www.cuh.org.uk/addenbrookes) or contact the Patient Information Manager on 0118 322 8706 to get copies.



You will have a call bell to use if you need any help. The nurses will answer as quickly as they can. Going home is now in sight so you will need to work with the staff to be ready for discharge.

The Critical Care Outreach Team will visit you on the ward within the first 24 hours after your move from the ICU. They will work with the ward staff to monitor your physical recovery assisting where necessary.

The follow-up team will visit several days later to discuss any issues you and your family may have regarding your physical and psychological rehabilitation.

## Exercise and mobility

When you first read this you will probably find that the slightest activity takes tremendous effort and leaves you feeling very tired. This tiredness is normal and will improve with time. Unfortunately, it is difficult to place a time scale on your recovery as everyone responds at a different rate. It also depends on a number of

factors, such as: age, previous level of fitness, how ill you have been, and how long you have been ill. Do not be alarmed if it takes weeks or possibly even months to get fully back to normal.



During your stay in the ICU you will probably have lost some weight and muscle strength. Your joints may be stiff as you have been immobile for some time. After a prolonged stay in the ICU, you may not be able to grip small items such as a pen or pencil. You may not be able to write. This will pass in time and you will recover these abilities.

The ward physiotherapist will make an assessment of your problems. They will work out an exercise programme that is suitable for you. Your family are very welcome to attend exercise sessions. They can give you help and encouragement during your recovery. The exercises on the following pages are designed to improve your general mobility and strength.

## **Simple exercises to aid recovery**

These exercises can loosen stiff joints and build up strength during your recovery when you get home. The regime should be practised once a day starting with 5 repetitions of each exercise building up to 10 repetitions. Do not exercise if you have recently eaten or you feel ill. Expect a certain amount of stiffness when you first start a new exercise. If this does not ease within a few days, you should seek advice from your GP.

Do not overdo these exercises in the early stages. As a rough guide you should not feel your heart racing during the exercise. Although exercise may make you a little breathless, you should not be so breathless that you cannot talk.

1. Lie on your back on a firm bed or floor with both feet flat and knees bent up. Roll both knees to the right keeping your shoulders still on the bed. Return your knees to the centre. Roll them to the left. This counts as one exercise. Repeat 5-10 times.

## **Smoking**

NHS Smoking Helpline, Freephone 0800 1690 169  
[www.givingupsmoking.co.uk](http://www.givingupsmoking.co.uk)

## **Stoma**

British Colostomy Association Helpline 0800 328 4257  
[www.bcass.org.uk](http://www.bcass.org.uk)

Ileostomy and Internal Pouch Support Group 0800 0184 724  
[www.the-ia.org.uk](http://www.the-ia.org.uk)

## **Stress**

Stress, Anxiety and Depression Confidential Helpline  
01622 717656

[www.stresshelp.tripod.com](http://www.stresshelp.tripod.com)

Crisis Aid, 01223 237459

[www.crisisaid.co.uk](http://www.crisisaid.co.uk)

## **Acknowledgements**

This booklet is reproduced with thanks to the Follow-up team at the Royal Berkshire Hospital. They were one of the first ICUs in the country to recognise the needs of patients and their families after discharge from intensive care.

This advice it contains is from those who have experienced critical care and who recognise the impact it has on family dynamics. They are people who experience the recovery process on a daily basis.

Our heartfelt thanks go to them, as this reflection on recovering from a critical illness is credible, useful and true. - Thank you -.

## Medical equipment loan

The Red Cross has a large selection of aids available for loan for a small donation.

Cambridge branch: 511 Coldhams lane, Cambridge. CB1 3JS.

01223 868696 or look up your local centre at:

[www.redcross.org.uk](http://www.redcross.org.uk)

## Meningitis

Meningitis Trust 0845 6000 800

[www.meningitis-trust.org](http://www.meningitis-trust.org)

## Mental Health

Mind [www.mind.org.uk](http://www.mind.org.uk) 08450 7660163

Saneline [www.sane.org.uk](http://www.sane.org.uk) 0845 767 8000

Cambridge Mental Health Resource 01223 359561

Centre [www.mentalhealthandwork.co.uk/cmhrcentre.htm](http://www.mentalhealthandwork.co.uk/cmhrcentre.htm)

## Miscarriage

The Miscarriage Association Helpline 01924 200799

[www.miscarriageassociation.org.uk](http://www.miscarriageassociation.org.uk)

National Childbirth Trust 0870 444 8707

[www.nct.org.uk](http://www.nct.org.uk)

Tommy's 0870 777 30 60

[www.tommys-campaign.org](http://www.tommys-campaign.org)

## Pain

Pain Concern 01620 822572

[www.painconcern.org.uk](http://www.painconcern.org.uk)

Pain Support

[www.painsupport.co.uk](http://www.painsupport.co.uk)

**Samaritans** 08457 90 90 90

[www.samaritans.org](http://www.samaritans.org)

2. Stand with a small weight (such as a tin of baked beans) in one hand. Starting with your arm down by your side, bend your elbow so that your hand touches your shoulder. Straighten your arm down. Repeat 5-10 times. Change arms.
3. Lie on your side. Starting with your top leg straight, bend your knee to take your heel to your buttock. Straighten your leg again. Repeat 5-10 times. Turn over to exercise the other leg.
4. Lie on your side with your lower leg bent and your upper leg straight. Lift your upper leg up about 12 inches, keeping your toes pointing forward. Lower slowly. Repeat 5-10 times. Turn over to exercise the other side.
5. Lie on your side with your lower leg bent and upper leg straight. Take your upper leg backwards keeping your body still. Repeat 5-10 times. Turn over and repeat with the other leg.
6. Sit up. Place your hands on your lower ribs. Take a deep breath in through your nose. Sigh out through your mouth. Repeat three times.
7. Sit up. Turn your head slowly to look over your left shoulder. Turn slowly to look over your right shoulder. Repeat 5 to 10 times.
8. Sit up. Stick your arms out to the side. With your elbows straight circle your arms in large circles. Do 5-10 circles forward. Do 5 to 10 circles backwards.

If you have problems with your shoulders, such as stiffness or weakness, try the following exercises:

1. Standing. Hold a small weight (such as a tin of baked beans) in one hand. Lean forwards. Swing your arm backwards, forwards and round in a big circle (let the weight help your arm to swing). Repeat 5 to 10 times on each arm.

2. Standing. Hold a towel behind your back in both hands as if you were drying your back. Move the towel up and down 5 to 10 times with your right arm above your head. Repeat with your left arm.
3. Sitting up. Bend your arms with your elbows tucked into the side of your waist. Keeping your elbows at the side, bring the palms of your hands together. Move them apart as far as they will go. Repeat 5 to 10 times.

If you experience problems that do not ease after a few days of exercising you should go and see your GP. They can refer you to the Physiotherapy Department for treatment. Alternatively, rehabilitation manuals are available from the follow-up team.

As your strength returns, you may want to take more vigorous exercise, such as swimming, fast walking or cycling. These activities will help strengthen your limbs if you do them regularly. Ask the doctor or Physiotherapist for more specific advice if you want to take part in other sports activities.

## Eating normally again

Since being ill, you may find that you have lost your appetite or that your sense of taste has changed. It is common for food to taste saltier and sweeter than normal, or to have an unusual metallic taste. Many people find that sharp foods such as fresh fruit, fruit juices and boiled sweets are refreshing and leave a pleasant taste in the mouth. These taste changes are only temporary. They should return to normal within a few weeks.



## Epilepsy

Epilepsy Action Freephone 0808 800 5050

[www.epilepsy.org](http://www.epilepsy.org)

National Society for Epilepsy Helpline 01494 601400

[www.epilepsynse.org.uk](http://www.epilepsynse.org.uk)

## Guillain-Barré Syndrome

Guillain-Barré Syndrome Support Group

Freephone 0800 374 803

[www.gbs.org.uk](http://www.gbs.org.uk)

## Head injuries

Headway Freephone 0808 800 2244

[www.headway.org.uk](http://www.headway.org.uk)

Headway Cambridgeshire 01223 576550

[www.headway-cambs.org.uk](http://www.headway-cambs.org.uk)

## Heart Disease

British Heart Foundation 08450 70 80 70

[www.bhf.org.uk](http://www.bhf.org.uk)

## I-Canuk

Improving the care for patients following critical illness.

[www.i-canuk.com](http://www.i-canuk.com)

## Intensive Care Society

Assisting in raising awareness of critical care

[www.ics.ac.uk](http://www.ics.ac.uk) Has patient/relatives area.

## **DIPEX**

Personal experiences of health and illness

[www.dipex.org](http://www.dipex.org)

## **Disabilities**

Disability Cambridgeshire 01480 839192

[www.disability-cambridgeshire.org.uk](http://www.disability-cambridgeshire.org.uk)

Disability Huntingdonshire 01480 830833

[www.dish.org.uk](http://www.dish.org.uk)

Disability Alliance

[www.disabilityalliance.org](http://www.disabilityalliance.org)

Limbless Association 0208 788 1777

[www.limbless-association.org](http://www.limbless-association.org)

RADAR Disability Network 020 7250 3222

[www.radar.org.uk](http://www.radar.org.uk)

## **Domestic violence**

Refuge Freephone 0808 2000247

[www.refuge.org.uk](http://www.refuge.org.uk)

Cambridge and South Cambridgeshire Domestic Violence Taskgroup

[www.safeathome.org.uk](http://www.safeathome.org.uk)

## **Elderly care**

Age Concern 020 8765 7200

[www.ageconcern.org.uk](http://www.ageconcern.org.uk)

Help the Aged

[www.helptheaged.org.uk](http://www.helptheaged.org.uk)

Age UK Cambridgeshire 01354 696650

[www.accambs.org](http://www.accambs.org)

Age Concern Peterborough 01733 564185

[www.acpeterborough.org.uk](http://www.acpeterborough.org.uk)

If your appetite is poor then small meals with nourishing snacks in between are often easier to manage. Eating will be more enjoyable if you take your time, avoid heavy fatty foods and relax for a while afterwards. Provided that your doctor has not advised you to avoid alcohol, you may find that a small drink such as a glass of wine or beer before your meal, or with your meal, will help to stimulate your appetite.

In hospital you may be given a high protein diet with some of the foods fortified for extra nourishment. We can arrange nourishing drinks that you can take between meals. There are also glucose syrups and tasteless glucose powders available that can be taken as drinks or added to food to increase your energy intake. When you go home you may need to continue to take some of these nourishing supplements for a while. You will be advised if this is necessary. If you are having problems with eating, ask your doctor to refer you to the dietician for more specific advice on a nourishing diet at home.

## **Sleeping**

You may find that your sleep pattern has changed. It may be more difficult to fall asleep or you may wake frequently during the night. When your body is not active it does not need as much sleep as normal. As you recover and become more active your sleep pattern should return to normal.



Go to bed at the same time each evening. Most importantly get up at the same time each morning, even if you have not slept well during the night. This will help you to recover your normal routine and sleep pattern.

Taking a bath or a shower shortly before going to bed will help you feel more relaxed, making it easier to fall asleep. Many people find that a bedtime drink such as milk or hot chocolate is helpful. You should avoid tea, coffee and large amounts of alcohol. Reading just before going to sleep is a good way of relaxing.

Being awake at night can be worrying. Things easily seem to get out of proportion. It is common for a small problem to seem overwhelming in the early hours when you are the only person awake. This is quite normal but when you have been ill it is often harder to cope with things like this. If you are awake at night then you may find it helpful to read or listen to the radio. Even if you do not fall asleep this will at least help to pass the time.

## **Nightmares and hallucinations**

Some of our patients have experienced nightmares or hallucinations whilst in the ICU or have been bothered by them when they first leave the ICU. Although they may be very vivid and frightening at the time, they usually settle over a few days or weeks. It is quite normal to experience this.

It may be helpful to discuss your dreams or nightmares with your family and friends (who may have featured in them). This can help to explain their meaning and may help your own state of mind.

## **Crime victims**

Victim Support Helpline 0845 3030 900

[www.victimsupport.org](http://www.victimsupport.org)

## **CritPal**

Intensive Care Society Patient Liaison Committee

[www.ics.ac.uk](http://www.ics.ac.uk) (Search on "CritPal")

## **Debt**

National Debtline Freephone 0808 808 4000

[www.nationaldebtline.co.uk](http://www.nationaldebtline.co.uk)

Direct Debt Line 01323 481111

[www.directdebtline.com](http://www.directdebtline.com)

## **Depression**

Depression Alliance 0845 123 23 20

[www.depressionalliance.org](http://www.depressionalliance.org)

Cambridge MDF BiPolar Self-Help 0845 434 9780

Group [www.mdfcambridge.org.uk](http://www.mdfcambridge.org.uk)

## **Diabetes**

Diabetes UK 020 7424 1000

[www.diabetes.org.uk](http://www.diabetes.org.uk)

## **Cancer**

Cancer BACUP Freephone 0808 8001234

[www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)

Macmillan Cancer Relief Freephone 0808 808 2020

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Cambridge Cancer Help Centre 01223 840105

[www.cambridgecancerhelp.org](http://www.cambridgecancerhelp.org)

Wallace Cancer Care 01223 249220

[www.wallacecancercare.org.uk](http://www.wallacecancercare.org.uk)

## Carers

Carers UK 0207 490 8818

[www.carersonline.org.uk](http://www.carersonline.org.uk)

Crossroads Care 01223 415600

[www.crossroads-cambridge.org.uk](http://www.crossroads-cambridge.org.uk)

## Citizens Advice Bureau

[www.adviceguide.org.uk](http://www.adviceguide.org.uk)

66 Devonshire Road, Cambridge  
CB1 2BL Tel: 0844 848 7979

Foley Gate, Wellington Street,  
Newmarket CB8 0HY Tel: 01638 665999

Town Hall, Royston SG8 7DA Tel: 08444 111444

70 Market Street, Ely CB7 4LS Tel: 0845 130 6442

Lower Downs Slade, Haverhill CB9 9HB  
Tel: 01440 704012

6 All Saints Passage, Huntingdon  
PE29 3LE  
Tel: 01480 388900

28 New Street, St Neots PE19 1AJ Tel: 01480 388905

Willow House, 40 St Andrews Street,  
Mildenhall, Bury St Edmunds IP28 7HB  
Tel: 01638 712094

Finally, the most important thing is not to worry about the lack of sleep. It will not do you any harm and as you recover things will get back to normal.

## Changes in mood

Many patients complain of fluctuating moods - one day up the next feeling very down. This is a normal reaction to illness and will lessen with time. If you have been very seriously ill, or ill for a long time, you may find that you are quite low in mood for a while. Sometimes, it may seem that you will never get back to normal and that any progress you make is unbearably slow. The up and down struggle to recover your physical strength in itself can be discouraging.

It is important for you to be realistic about what you will be able to do for yourself. Gradually take on the activities that you did before you became ill. Set yourself attainable targets to help you to build up your confidence. Do not set yourself targets that are too difficult to reach as you

may feel as though you have failed. Ask the nurses, doctors and physiotherapists to tell you what you can reasonably expect to be able to do. Try to be patient when you have setbacks. When you are at home, it is important to involve family and friends in setting the targets or goals. They will often be the people who are best able to monitor your progress and encourage you.



## Your family and relationships

Your family and friends are obviously delighted that you are getting better. They may be overprotective and not let you do as much as you feel you are able to do. It has been a worrying time for them too. Talking over what has happened and sharing your worries will help you to work together towards your recovery.

The old adage 'a little of what you fancy does you good' is particularly true for sex during your recovery from illness. Your illness may have reduced your sex drive. It is possible that either you or your partner are concerned that sex could be harmful for you.

This is rarely the case, but as with other forms of exercise, you should do as much feels comfortable. You will be able to return to your normal relationship but recognise this may take some time and patience from both of you.

## Changes in appearance or voice

Your appearance may have changed as a result of you being ill. These changes are usually temporary. You may suffer hair loss or a change in the quality of your hair. The texture of your skin may have changed and become much drier than before. You may have lost a lot of weight. Time, exercise and a sensible diet will get you back to normal. You may also have some scars that you feel are unsightly. These will fade in time. As your skin returns to normal they will not seem as obvious.

You may find that your voice has changed. It may have become husky or may be so weak that you are unable to raise your voice or shout. This is probably the result of being intubated or of having a tracheostomy. This should return to normal over time.

The Bridge Project 01223 214614  
(Drug Advice Centre)

### **Aphasia/Dysphasia** (difficulty with language)

Speakability Helpline 0808 808 9572

[www.speakability.org.uk](http://www.speakability.org.uk)

The Stroke Association Helpline 0845 303 3100

[www.stroke.org.uk](http://www.stroke.org.uk)

Connect Head Office 020 7367 0840

[www.ukconnect.org](http://www.ukconnect.org)

### **Asthma**

National Asthma Campaign Advice line 0845 7010203

[www.asthma.org.uk](http://www.asthma.org.uk)

British Lung Foundation Helpline 0845 8 50 50 20

[www.lunguk.org](http://www.lunguk.org)

### **Bereavement**

National Bereavement Helpline 0845 226 7227

Cruse Bereavement Care 0870 167 1677 (National)  
01223 302662 (Cambridge)  
01707 278389 (Hertfordshire)  
01480 414511 (Huntingdon)  
01733 348439 (Peterboro)

Sudden Death Association 0118 988 9797

### **SAMM Tel: 0207 735 3838**

A self-help group for those bereaved by homicide.

### **SOBS Tel: 01235 863060**

Helpline for survivors of bereavement by suicide.

Stillbirth & Neonatal Death Society Tel: 0207 436 5881

## Research

Advances in medical knowledge and treatment have been brought about through research, and the practice of medicine today is based on evidence of what works.

There are always a number of research trials being undertaken in intensive care units throughout the country into different aspects of medical care. All of these research trials are approved by an independent ethics committee of outside experts to make sure patients' best interests are protected.

Patients are often too ill to give their own consent to enter a study. It is therefore very common for a close family member to be asked to act on the patient's behalf and help decide if the patient would wish to take part in the research. Taking part is entirely voluntary and no one is under any obligation to consent. Even after giving consent, withdrawal can take place at any time. The full details of any trial will be explained by the staff in the unit who are co-ordinating it.

## Helplines

### AIDS/HIV

National Aids Helpline (24-hr) Freephone 0800 567123  
Terrence Higgins Trust Helpline 0845 12 21 200 [www.tht.org.uk](http://www.tht.org.uk)

### Alcohol and drug abuse

Alcoholics Anonymous Helpline 0845 769 7555  
[www.alcoholics-anonymous.org.uk](http://www.alcoholics-anonymous.org.uk)  
Frank (Drugs) Helpline Freephone 0800 77 66 00  
[www.talktofrank.com](http://www.talktofrank.com)  
Narcotics Anonymous Helpline 020 7730 0009  
[www.ukna.org](http://www.ukna.org)

## Stress

The period of recovery after a critical illness can be stressful. The degree of stress, and how long it lasts can vary. Previous sections discuss some of the symptoms that may be related to stress, such as disturbed sleep, loss of appetite, change of mood, and problems with family relationships. You may find following the advice offered in these sections helpful.

Recovering from a stressful event takes time. If at the end of each week you can look back and say that overall things were better than the previous week, then you are making good progress. However, if you feel that you are making no progress, you may wish to make use of the advice offered through the ICU Follow-up service, your GP or one of the self-help groups listed in the back of this booklet.



## Post traumatic stress disorder

Some of our patients do experience severe symptoms of stress following their ICU treatment. This is known as post-traumatic stress disorder. This does get better over time. We have found that counselling is of great value. We can ask your GP to refer you to a counselling service.

## ICU follow-up service

A follow-up clinic is held regularly to review the progress and recovery of patients after they leave hospital. It provides an opportunity for you to discuss any issues that you or your family may have. If your stay on the ICU is more than three days, we will send you a letter inviting you to attend the clinic. We can give advice or if necessary refer you for further specialist treatment.

Many patients and relatives have found the follow-up service a great comfort as, even after discharge from hospital, there is someone who cares and is willing to discuss any problems that affect your recovery from critical illness.

If you do not receive an invitation to attend the clinic or would like to make one, contact the clinic via Dr Kevin Gunning - ICU Consultant, telephone: 01223 217433 or the JVF ICU voicemail on 01223 217258.

## Patient Advice and Liaison Service (PALS)

can:

- **help** answer any questions about your care in hospital,
- **advise and support** you and your family – we understand that being in hospital can be an anxious time and you might need someone else to act on your behalf,
- **listen to your suggestions** for improving our service for patients and visitors,
- **respond to your concerns** if you are unhappy with any aspect of your care,
- **pass on your compliments** to staff if you are pleased with any aspect of your care,
- **provide an information centre** for advice and support on health, care and benefit issues.

## Single sex accommodation

The Cambridge University Hospitals NHS Foundation Trust is committed to ensuring that all patients are treated with respect and that their dignity and privacy are maintained at all times.

Although, ideally, patients should be cared for in single sex wards or bays, in specialist areas such as ICU, mixing men and women may be unavoidable.

If you have any concerns about privacy and dignity, please speak to your named nurse, the ICU manager or the matron for the area.

Alternatively, you can contact PALS (the Patient Advice and Liaison Service) or the Patient Relations team on 01223 256170. You can also e-mail any concerns or comments to [pals@addenbrookes.nhs.uk](mailto:pals@addenbrookes.nhs.uk).

## Religious support

All hospitals have multi-faith support. The staff will be happy to arrange for the appropriate person to be contacted should the patient, relative or friend want to discuss any issues.

## Patient diaries

During your stay on Intensive Care the nurses may have kept a patient diary for you. This we hope will fill in any gaps that you may have in your memory of what happened to you during your stay in ICU. The diary will be given to you at your clinic visit approx two to three months after discharge home.