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Royal Berkshire NHS Foundation Trust
London Road
Reading RG1 5AN
Telephone 0118 322 5111
www.royalberkshire.nhs.uk

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Life after a critical illness

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

0118 322 7248 / 7249

The Rehabilitation after Critical Illness (RaCI) service
contact number is:

0118 322 7248 / 7249

The RaCI team is:

Dr Carl Waldmann

Sister Melanie Gager

Senior Staff Nurse Sara Evans

Staff Nurse Helen Kieras

Due to the nature of our work, our time is spent predominantly
where patients' needs are, e.g. on the ward, in the Intensive Care
Unit (ICU) and in the clinic, so we are not office based.

However, we do endeavour to answer messages as soon as
possible.

If you have an emergency, please contact
the ICU on 0118 322 7257.

[Notes](#)

Notes

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

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Introduction

This information booklet is largely aimed at assisting the patient in recovery following a period of critical illness. However, from experience, it is evident that the relatives need to read this first. During the first few days after leaving the ICU, the patient may be unable to concentrate, understand and apply the information to themselves. By reading this booklet the relatives will hopefully gain an understanding of what the patient is going through and this helps them to be actively involved in the patient's recovery and rehabilitation.

The RaCI 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.

Message for the patient

As you have been ill, it may take 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 and suggests simple ways to try to solve them.

We want to emphasise that you will probably not experience all of the problems described here, but if you do suffer from any of them, we hope that 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.

Your views

We value the feedback we receive from our critically ill patients, their families and friends as it is a measure of the quality of our service.

Ways to feedback include:

1. Suggestions / Comments box in the Critical Care Waiting Area.
2. To any health care professional during or after the critical illness episode.
3. Through the Rehabilitation after Critical Illness process - at both clinic and 1:1 visits.
4. Through the Critical Care Bereavement team.
5. Through the ICU Support Network – email: icu.support@aol.com
6. By posting a review/rating on NHS Choices www.nhs.uk/comment

The way we use your feedback:

1. At the time – if it is pertinent and safe to action the feedback immediately, we will do so.
2. Through the Clinical Governance process – all feedback is thematically analysed, reported and actioned.
3. Through clinical practice – communication of feedback is essential to be timely and current. If a particular theme emerges our practice is to invite service users (patients, family and friends) to work with staff to resolve the problem.

Stress

Stress, Anxiety and Depression Confidential Helpline 01622 717656

www.stresshelp.tripod.com

Acknowledgements

It has been a real privilege for the RaCI team to produce this information leaflet with the involvement of both patients and relatives.

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](#).

List of Trust leaflets and where to get them

- Talk to us
- I am a carer
- The Department of Spiritual Healthcare (Chaplaincy)
- Your healthcare information
- Sepsis/Severe Sepsis
- Call 4 Concern[®]
- Coping with traumatic experiences

Most of these leaflets should be available on wards or you can download them from the Trust website www.royalberkshire.nhs.uk or contact the Patient Information Manager on 0118 322 8706 to get copies.

Going to the ward

Going to the ward is a big step on the way to getting better and going home, and 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 but 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, as 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 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. You will have a call bell to use if you need any help, which 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-hrs after your move from the ICU. They will work with the ward staff to monitor your physical recovery, assisting where necessary.

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

If you feel concerned that the healthcare team has not recognised your or your loved one's change in condition you can contact Call 4 Concern[®]. This is a patient safety service for patients and families. 0777 475 1352.

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: your age, your previous level of fitness, how ill you have been, how long you have been ill. However, do not be alarmed if it takes you weeks or even months to get fully back to normal.

During your stay in the ICU you will probably have lost some weight and muscle strength, and 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 and 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 and will work out an exercise programme that is suitable for you.

Your family are very welcome to attend exercise sessions, so that 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, and building

ICU Support Network Reading

icu.support@aol.co.uk

www.readingicusupport.co.uk/

Meningitis

Meningitis Trust 0845 6000 800 www.meningitis-trust.org

Mental Health

Mind 08450 7660163 www.mind.org.uk

Saneline 0845 767 8000 www.sane.org.uk

Miscarriage

The Miscarriage Association Helpline 01924 200799

www.miscarriageassociation.org.uk

National Childbirth Trust 0870 444 8707 www.nct.org.uk

Tommy's 0870 777 30 60 www.tommys-campaign.org

Pain

Pain Concern 01620 822572 www.painconcern.org.uk

Pain Support www.painsupport.co.uk

Samaritans

116 123 www.samaritans.org

Smoking

Smokefreelife Berkshire www.smokefreelifeberkshire.com

0800 622 6360

Stoma

British Colostomy Association Helpline 0800 328 4257

www.bcass.org.uk

Domestic violence

Refuge Freephone 0808 2000247 www.refuge.org.uk

Elderly care

Age UK Advice line 0800 169 6565 www.ageuk.org.uk

Epilepsy

Epilepsy Action Freephone 0808 800 5050 www.epilepsy.org

National Society for Epilepsy Helpline 01494 601400

www.epilepsynse.org.uk

Guillain-Barré Syndrome

Guillain-Barré Syndrome Support Group Freephone 0800 374 803

www.gbs.org.uk

Head injuries

Headway Freephone 0808 800 2244 www.headway.org.uk

Healthtalk

Personal experiences of health and illness www.healthtalk.org and youthhealthtalk.org

Heart Disease

British Heart Foundation 08450 70 80 70 www.bhf.org.uk

Heartbeats (West Berkshire) www.heartbeats.btinternet.co.uk

Intensive Care Society

Assisting in raising awareness of critical care.

www.ics.ac.uk Has patient/relatives area.

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 and do not overdo these exercises in the early stages. As a rough guide you should not feel your heart racing during the exercise and 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 and then roll them to the left. This counts as one exercise and should be repeated 5-10 times.
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, then straighten your arm down. Repeat 5-10 times and then change arms.
3. Lie on your side. Starting with your top leg straight, bend your knee to take your heel to your buttock and then straighten your leg again. Repeat 5-10 times and then turn over to exercise the other leg.
4. Lie on your side with your bottom leg bent and your top leg straight. Lift your top leg up about 12 inches, keeping your toes pointing forward, and then lower slowly. Repeat 5-10 times and then turn over to exercise the other side.
5. Lie on your side with your bottom leg bent and top leg straight. Take your top leg backwards, keeping your body still. Repeat 5-10 times and then turn over and repeat with the other leg.
6. Sit up, place your hands on your lower ribs and then take a deep breath in through your nose and then sigh out through your mouth. Repeat 3 times.

7. Sit up, turn your head slowly to look over your left shoulder, and then turn slowly to look over your right shoulder. Repeat 5-10 times.
8. Sit up, stick your arms out to the side and with your elbows straight, circle your arms in large circles. Do 5-10 circles forward and then 5-10 circles backwards.

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

1. Stand, holding a small weight, such as a tin of baked beans, in your hand. Lean forwards, swing your arm backwards, forwards and round in a big circle (let the weight help your arm to swing). Repeat 5-10 times on each arm.
2. Stand, holding a towel in both hands as if you were drying your back. Move the towel up and down 5-10 times with your right arm above your head. Repeat with your left arm.
3. Sit up and bend your arms with your elbows tucked into the side of your waist. Keeping your elbows at the side, bring your palms of your hands together and then move them apart as far as they will go. Repeat 5-10 times.

If you experience problems that do not ease after a few days of exercising, you should go and see your GP, who can refer you to the physiotherapy department for treatment. Alternatively, rehabilitation manuals are available from the RaCI team.

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

Carers

Carers UK 020 7378 4999 www.carersuk.org/
 Reading & West Berkshire Carers Hub 0118 324 7333
www.berkshirecarershub.org

Citizens Advice Bureau

Minister Street, Reading RG1 2JB 0118 959 8059
 16 Bartholomew St, Newbury RG14 5LL 01635 521903
 Wellington House, Wellington Rd, 0118 989 0389
 Wokingham RG40 2AG
www.adviceguide.org.uk

Crime victims

Victim Support Helpline 0845 3030 900 www.victimsupport.org

Debt

National Debtline Freephone 0808 808 4000
www.nationaldebtline.co.uk
 Direct Debt Line 01323 481111 www.directdebtline.com

Depression

Depression Alliance 0845 123 23 20 www.depressionalliance.org

Diabetes

Diabetes UK 020 7424 1000 www.diabetes.org.uk

Disabilities

Disability Alliance www.disabilityalliance.org
 Limbless Association 0208 788 1777 www.limbless-association.org
 RADAR Disability Network 020 7250 3222 www.radar.org.uk

Frank (Drugs) Helpline Freephone 0800 77 66 00

www.talktofrank.com

Narcotics Anonymous Helpline 020 7730 0009 www.ukna.org

Aphasia/Dysphasia (difficulty with language)

Speakability Helpline 0808 808 9572 www.speakability.org.uk

The Stroke Association Helpline 0845 303 3100 www.stroke.org.uk

Asthma

National Asthma Campaign Advice line 0845 7010203

www.asthma.org.uk

British Lung Foundation Helpline 0845 8 50 50 20 www.lunguk.org

Bereavement

National Bereavement Helpline 0845 226 7227

Cruse Bereavement Care 0870 167 1677 (National)

0142 056 1456 (Basingstoke)

0118 958 8133 (Reading)

Sudden Death Association 0118 988 9797

SAMM 0207 735 3838

A self-help group for those bereaved by homicide.

SOBS 01235 863060

Helpline for survivors of bereavement by suicide.

Stillbirth & Neonatal Death Society 0207 436 5881

Cancer

Macmillan Cancer Support Freephone 0808 808 0000

www.macmillan.org.uk

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 and should return to normal within a few weeks.

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 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 and 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 but you will be advised if this is necessary. If you are having problems with eating, then ask your GP 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 you should find your sleep pattern returns to normal.

Go to bed at the same time each evening and 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.

You may find 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 is helpful, but you should avoid tea, coffee and large amounts of alcohol. Reading just before going to sleep is also 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. Finally, the most important thing is not to worry about the lack of sleep as it will not do you any harm, and as you recover, things will get back to normal.



Relations Team can liaise with staff and managers to sort out issues quickly, can help you get information about NHS services and can refer you to specialist agencies for further help. The Patient Relations office is on Level 2 behind the main reception desk and is open Monday to Friday between 9.00am and 4.30pm, or you can ring them on 0118 322 8338 or get a member of staff to contact them to come and visit you on the ICU or ward.

Single sex accommodation

The Royal Berkshire 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 or the ICU manager in the first instance or the matron for the area.

Alternatively, you can contact the Patient Relations team on 0118 322 8338. You can also e-mail in any concerns or comments to talktous@royalberkshire.nhs.uk

Helplines

AIDS/HIV

National Aids Helpline (24-hr) Freephone 0800 567123
Terence Higgins Trust Helpline 0845 12 21 200 www.tht.org.uk

Alcohol and drug abuse

Alcoholics Anonymous Helpline 0845 769 7555
www.alcoholics-anonymous.org.uk

Post Traumatic Stress Disorder

Some of our patients do experience severe symptoms of stress following their critical illness. This is known as post-traumatic stress disorder. This does get better over time and we have found that early intervention managed through the RaCI clinic is of great value. If necessary we can refer you to specialist services.

Rehabilitation after Critical Illness Service

A clinic is held regularly to review the progress and recovery of patients following their critical illness. It provides an opportunity for you to discuss any issues that you or your family may have. We are able to give advice, or if necessary, we will refer you for further specialist treatment. We are also able to provide a counselling service that you are welcome to use.

Many patients and relatives have found the RaCI 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.

You can contact the clinic through the office of Dr Carl Waldmann, Consultant Intensivist, telephone: 0118 322 7248 / 7249.

ICU Support Network Reading

Support group for ICU patients and their relatives/carers www.readingicusupport.co.uk.

For more information telephone:

0118 322 7248 (answerphone) or email icu.support@aol.com



Patient Relations

Patient Relations is an impartial confidential Trust service that can provide patients, relatives and carers using the Royal Berkshire Hospital with 'on the spot' help, support and information. The Patient

Nightmares and hallucinations

Some of our patients have experienced nightmares and hallucinations whilst in the ICU, or have been bothered by them when they first leave the ICU. This is the way the mind processes a significant event and is nature's way of healing. This is quite common and you are not going mad. Although they may be very vivid and frightening, they usually settle over a few days or weeks and again it is quite normal to experience this.

It may be helpful to discuss your nightmares and hallucinations with your family and friends (who may have featured in them) as it can help to explain their meaning and may help your own state of mind. These usually get better with time however if you are concerned please do not hesitate to tell someone or contact the RaCI team.

In our experience we have found that sharing your experience with someone who has been through the same thing can be therapeutic. In order to assist with this we can arrange for you to watch a DVD or meet with one of our ICU patient volunteers. Should this be something you wish to discuss further please let us know.

Visit www.royalberkshire.nhs.uk/in_the_press/trust_films.aspx to watch a film called ICU – Insight and Aftercare.

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, and try to be patient when you have setbacks. When you are at home, it is also important to involve family and friends in setting the targets or goals, because 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, but 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, so 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 and it is possible that either you or your partner is 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 as 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 being ill, but these changes are usually temporary. You may suffer hair loss or a change in the quality of your hair, or find that the texture of your skin has changed and has become much drier than before. You may also have lost a lot of weight, but 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, and 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 having a 'breathing tube' or of having a tracheostomy. This should return to normal over time.

Stress

The period of recovery after a critical illness can be stressful. The degree of stress, and how long it lasts varies. 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 there 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 Rehab after Critical Illness service, your GP or one of the self-help groups listed in the back of this booklet.

