NHS
Royal Berkshire
NHS Foundation Trust

Life after a critical illness

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

0118 322 7248

The Recovery after Critical Illness (RaCI) service contact details are:

0118 322 7248

rbb-tr.raci@nhs.net

The RaCI team is:

Specialist Nurse Practitioner Helen Kieras
Specialist Physio Practitioner Abbi Tolputt
Dr Lissy Otto – Highly Specialised Psychologist in ICU
Dr Petra Kagleder – Counselling Psychologist
Dr Will Orchard – Intensive Care Consultant
Dr Jodie Smythe – Intensive Care Consultant
Dr Liza Keating – Intensive Care Consultant
Dr Mike Raffles – Intensive Care Consultant
Dr Jon Hughes – Intensive Care Consultant
Dr James Hardwick – Intensive Care Consultant
Dr Kate Hames-Brown – Intensive Care Consultant
Dr Mike Peters – Intensive Care Consultant
Jackie Teague – Administration Assistant

Our role is to support patients and relatives, in the Intensive Care Unit (ICU), on the ward following discharge from ICU, in the RaCI clinic and at home/discharge destination. Due to the nature of our work, our time is spent predominantly where patient and their relatives' needs are. We are not office based however, if you do contact the team and we are not available please leave a message on our answerphone and we will endeavour to contact you as soon as possible.

If you need to speak with someone urgently, please contact the ICU on 0118 322 7257.

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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 may 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 service is available to support both the patient and their relatives throughout the recovery 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 describes some of the common issues you may experience during your recovery from critical illness. These issues may be physical, psychological and cognitive, known collectively as post-intensive care syndrome (PICS).

We want to emphasise that you will probably not experience all of the issues 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.

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 hopefully 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 physiological recovery, assisting where necessary.

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

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

Following your critical illness, you may find that day to day tasks which you previously completed without thinking, are now quite challenging and come with symptoms of extreme tiredness (fatigue). In this section the aim is to reassure you this is very normal and, with help from your physiotherapist, family and other members of the multidisciplinary team (MDT) we will support you with your rehabilitation journey and help you to achieve your goals.



Muscle weakness following a critical illness, is a result of prolonged bed rest or immobility due to being medically unwell, along with the damage which occurs to your muscles from the illness itself. This may all be recovered from but, please be assured that this can take time. It is difficult to put a specific time scale on recovery as everyone responds at different rates, but age, previous fitness levels and length of illness will all play a part. Your physiotherapist will have started rehabilitation as soon as safely possible on ICU, and this will be continued on the ward. If you would like some additional exercises to complete outside of your physio sessions and haven't been given any, please highlight this to your physio and they will be able to provide some to meet your needs.

Another key role of a physiotherapist is to support you in feeling confident with your mobility, and to help you return to your previous activity or exercise level. If you are managing to walk around the ward independently you may not have been signposted to the physiotherapy team. Perhaps you are not feeling as confident with your walking or would like to return to a higher level of activity or exercise.

If this is the case please let the ward staff or RaCI service know and we will be more than happy to make the appropriate referral.

Fatigue is also very common following a critical illness, and strategies need to be put in place to aid your recovery. It is common to have ‘good days’ and ‘bad days’ with fatigue, and our aim is to help you self-identify these days to prevent inactivity or over activity. We recommend writing an activity diary as this will allow you to identify activities which may be contributing to you to feeling fatigued. We also recommend following the 3 P’s; Pacing, Prioritisation and Planning, this will help you to prepare your exercise and activities in advance, allowing you to get the most out them without overdoing it. If you would like further information on this please see our ICU Fatigue management leaflet.

Simple exercises to aid recovery

Here are some gentle stretches you can complete if you find you are more sedentary than normal and want to help prevent stiffness and pain.

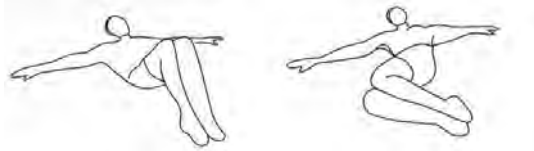
1) Ankle pumps: Gently move your foot forwards and backwards as far as you can. Repeat on both ankles.



2) Knee flexion: While laying or sitting in bed, slide your foot up the bed to bend your knee as far as you can, then with control, slowly straighten your knee again. Repeat on both legs.



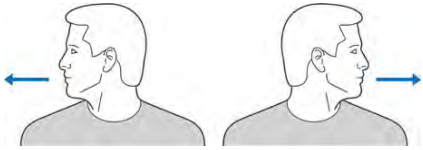
3) **Knee rolls:** While laying on your back, bend both your knees and roll them as far as you can from one side to the other. While you're doing this, aim to keep your back and shoulders flat on the bed.



4) **Shoulder flexion:** While lying or sitting, hold your hands together and lift your arms above your head. With control, slowly return to your starting position.



5) **Neck rotations:** Ideally while sitting, look as far over your left shoulder as you can. Slowly return to neutral, then complete looking over your right shoulder.



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 advice is available from the RaCI service.

As your strength returns, you may want to take more vigorous exercise, like swimming, fast walking or cycling. Done regularly, these will help strengthen your limbs.

Ask your GP or physiotherapist for specific advice if you want to take part in other sports activities.

Eating normally again



It is common after critical illness to feel differently about eating and drinking (your nutrition). You may find that your appetite has changed and food doesn't taste how you expect it to. You may also experience changes to your swallowing, please discuss with the speech and language therapist (SALT) and follow any advice they have given you about texture and fluids.

Your body is recovering and needs the right nutrition for you to heal, have more energy, fight infections, and rebuild your strength and muscles. The nutrition you need will change as your recovery continues, often problems get better as you get stronger.

To start with, here are some tips to help you eat:

- be positive about what you are able to eat – every extra mouthful helps
- eat whenever you feel hungry – like having cereal at midnight
- try different foods – you may find that you like things you don't usually eat
- keep snacks nearby where you are, such as on the bedside table or coffee table
- try not to drink just before meals as this may fill you up and spoil your appetite, unless you need to drink to help with swallowing
- although salads and vegetables are an important part of a healthy diet, don't eat too much with each meal if they are filling you up quickly
- avoid fizzy drinks as they can make you feel full up
- accept offers from friends and relatives for help with cooking and shopping

- convenience foods are a useful standby and can be just as nourishing
- when you are stronger and if you are able to cook for yourself, try to prepare food in advance when you feel like cooking and store it in the freezer (if you have one) for when you are not feeling so well
- a short walk before a meal or some fresh air may help you feel hungry.

(BDA Critical Care Specialist Group 2020)

There is lots more information that can help you if you have problems such as: changes to hair and nails, not feeling hungry, sickness, tummy problems and returning to healthy eating. This information can be found here: Tips to help with eating problems after critical illness | British Dietetic Association (BDA)

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.

Sleep is vital for your physical and psychological wellbeing. It allows the body time to recharge and your mind to process information. Practising sleep hygiene is an excellent way of regulating your sleep patterns.

- Have a good sleep routine. 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.

- Relax and unwind before it is time for bed. Avoid electronic devices including mobile phones, tablets and computers (all blue light devices) at least an hour before bed. Reading, listening to soft music or a podcast can help if you have trouble sleeping.
- Try mindfulness for sleep. Anxiety, worry and stress can affect how well we sleep. If it is possible chat to someone about your concerns or write a journal. You can also use mindfulness apps (see helplines and useful information) they can help you to reframe unhelpful thoughts and feelings.
- Create a restful bedroom environment such as keeping the room temperature at a comfortable level and keep it as dark and quiet as possible.
- Most importantly, do not force sleep. If you find yourself awake, get up and sit in a comfy place, read or listen to music and only return to bed when you feel sleepier.
- Lastly a good diet and exercise can help, avoid large meals close to bedtime as well as bedtime caffeine, alcohol and nicotine if you can. These are all stimulants which can make you feel more alert.

More information can be found on www.nhs.uk/every-mind-matters/mental-health-issues/sleep/

Being awake at night can be worrying. Things may feel like they are getting out proportion and it is common for a small problem to seem overwhelming in the early hours especially 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. 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.

Nightmares and hallucinations

Some patients will have experienced nightmares and hallucinations whilst in the ICU, and for some people, this may continue for some time after leaving the ICU. Critical illness does not only affect the

body, but will also impact on the way the brain responds to significant physical illness as well as the ICU environment and medication to support treatment. ICU associated nightmares and hallucinations are not a sign of mental illness, but the experience can be very distressing. For many people, nightmares will lessen and eventually stop following an ICU admission. However, for some people, they can persist and be accompanied by new experiences of anxiety and panic attacks, as well as hypervigilance. If this is the case, please do not hesitate to contact the RaCI service, as you may benefit from some therapeutic support post ICU.

It may also 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.

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 talk with one of our ICU patient volunteers. Should this be something you wish to discuss further please let us know.

Changes in mood

Many patients can experience changeable mood states following their critical illness. This is a common response to physical illness and will often improve as the body recovers. However, 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. Sometimes, a change in the ability to concentrate or a



change in memory can also impact on mood following an ICU admission.

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 small, 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. Some people will benefit from additional therapeutic support for their mood post ICU. If you would like to discuss this further, please contact the RaCI service.

Your family and relationships

After you have been critically ill, those who are close to you may seem a little bit different. They may be overprotective and may not let you do as much as you feel able to do. It is important to let them know how you are feeling, if you can, talk with them and let them know.

Your family and friends will be delighted that you are getting better but it has been a worrying time for them. Whilst you may not remember your time in hospital, they will, and it may be helpful to talk to them about what they remember, how they felt when you were ill and what they remember about what happened.

Sharing your worries will help you work together towards your recovery.

Intimacy

Having sex for the first time following your critical illness can be daunting. Your illness may have reduced your libido 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. Make sure that you continue to talk with your partner, it might feel difficult at first but try to relax and take things slowly. You will be able to return to your normal relationship, but this may take some time and patience from both of you. Should you feel that you need support with any intimacy issues, the RaCI service will be able to support you and provide referrals to our andrology and psychosexual health service.

Changes in appearance and 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 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 Recovery after Critical Illness 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 distress following their critical illness, with can include new onset of high levels of anxiety, panic attacks, hypervigilance, flashbacks, and nightmares. This is known as post-traumatic stress disorder (PTSD). For some people, PTSD symptoms can be very debilitating, and we have found that early intervention managed through the RaCI clinic is of great value. We may be able to offer support you through ICU Psychology or refer you to other specialist services.

Recovery after Critical Illness Service

Once you leave hospital you will be sent an 'PIFU' (Patient Initiated Follow Up) letter which will invite you to be followed up by the RaCI service; this will usually arrive a couple of weeks after your discharge. We know that recovery from critical illness can take time and we will be guided by you as to how long you need us for. We also understand the impact critical illness can have on family and friends and we welcome them to join you at your consultation should you wish them to. We recommend our service to all patients recovering from critical illness.

If you decide to activate PIFU, a clinic appointment will be scheduled to review your progress and recovery following your 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 and help to support your physical and psychological recovery.

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 service on telephone: 0118 322 7248 or email rbb-tr.raci@nhs.net

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)

Patient Advice and Liaison Service (PALS)

PALS 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 PALS 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 PALS 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 PALS Team on 0118 322 8338. You can also e-mail in any concerns or comments to PALS@royalberkshire.nhs.uk

Helplines and useful information

AIDS/HIV

- www.nhs.uk/conditions/hiv-and-aids/
- Terence Higgins Trust Helpline 0808 802 1221 www.tht.org.uk

Alcohol and drug abuse

- www.nhs.uk/live-well/addiction-support/
- Alcoholics Anonymous Helpline 0800 9177 650 www.alcoholics-anonymous.org.uk
- Frank (Drugs) Helpline Freephone 0300 1236600 www.talktofrank.com
- Narcotics Anonymous Helpline 0300 999 1212 www.ukna.org

Aphasia / Dysphasia (difficulty with language)

- The Stroke Association Helpline 0303 3033 100 www.stroke.org.uk

Asthma

- Asthma and Lung UK 0300 222 5800 www.asthmaandlung.org.uk

Bereavement

- Ataloss 0800 448 0800 www.ataloss.org
- National Bereavement Service 0800 0246 121 www.thenbs.org
- Cruse Bereavement Care 0808 808 1677 www.cruse.org.uk
- SAMM (support after murder and manslaughter) 0207 735 3838 www.samm.org.uk
- SOBS (survivors of bereavement by suicide) 0300 111 5065 www.uksobs.org

Birth loss

- The Mariposa Trust 0300 323 1350 www.mariposatrust.org
- The Miscarriage Association Helpline 01924 200799 www.miscarriageassociation.org.uk
- Antenatal Results and Choices (ARC) 0845 077 2290 Helpline (Monday to Friday 10.00am - 5.30pm).
- www.tommy.org

Cancer

- Macmillan Cancer Support 0808 808 0000 www.macmillan.org.uk

Carers

- Carers UK 0808 808 7777 9am – 6pm Monday – Friday www.carersuk.org/ or email advice@carersuk.org
- Age UK Berkshire (for all carers 19+) 0118 959 4242 or email: carers@ageukberkshire.org.uk
- Berkshire Youth (for carers age 18 and under) 0118 909 0927 or email: admin@berkshireyouth.co.uk
- Reading Mencap (adults with a Learning Disability) 0118 926 3600 or email: carers@readingmencap.org.uk
- Age UK Reading (caring for someone 50+ years in Reading) 07716 418 941 or email: carers@ageukreading.org.uk
- Age UK Berkshire (caring for someone 50+ years in West Berkshire) 0118 959 4242 or email: info@ageukberkshire.org.uk
- CommuniCare (all other carers in Reading & West Berkshire) 0118 926 3941 or email: office@communicare.org.uk

Citizens Advice Bureau and local services

- www.citizensadvice.org.uk
- **Reading** 0800 144 8848 www.citizensadvicereading.org Minister Street, Reading RG1 2JB
- **Newbury** 01635 516605 www.citizensadvicewestberkshire.org.uk 2nd Floor, Broadway House, Northbrook Street, Newbury RG14 1BA
- **Bracknell** 0808 278 7914 www.caeb.org The Colombia Centre, Market Street, Bracknell RG12 1JG

Debt

- National Debtline 0808 808 4000 www.nationaldebtline.org
- www.gov.uk/debt-advice

Depression

- Mind 0300 123 3393 www.mind.org.uk
- Sane 0300 304 7000 www.sane.org.uk
- Togetherall www.togetherall.com

Diabetes

- Diabetes UK 0345 123 2399 www.diabetes.org.uk

Disabilities

- Disability Rights UK 0330 995 0400 www.disabilityrightsuk.org
- Limbless Association 0800 644 0185 www.limbless-association.org

Domestic violence

- BWA 0808 801 0882 www.berkshirewomensaid.org.uk
- Refuge 0808 2000247 www.refuge.org.uk

Elderly care

- Age UK Advice line 0800 678 1602 www.ageuk.org.uk

Epilepsy

- Epilepsy Action helpline 0808 800 5050 www.epilepsy.org.uk
- National Society for Epilepsy Helpline 01494 601400 www.epilepsynse.org.uk

Guillain-Barré Syndrome

- www.inflammatoryneuropathies.uk

Head injuries

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

Healthtalk

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

Heart Disease

- British Heart Foundation 0808 802 1234 www.bhf.org.uk

Intensive Care Society

- Assisting in raising awareness of critical care. www.ics.ac.uk Patient resources available

ICU Patient and Relative Support Reading

- www.readingicusupport.co.uk/

Meningitis

- Meningitis Research Foundation 0808 800 3344 www.meningitis.org
- Meningitis now 0808 801 0388 www.meningitisnow.org

Mental Health Support

- Talking Therapies 0300 365 2000 www.talkingtherapies.berkshirehealthcare.nhs.uk/
- Mind 0300 123 3393 www.mind.org.uk
- Samaritans 116 123 (24-hours) www.samaritans.org
- Time to talk Confidential counselling for young people aged 11-25 www.t2twb.org
- Sane 0300 304 7000 www.sane.org.uk

Mindfulness

Apps

- Headspace – mindfulness
- Calm – mindfulness

Apps recommended by NHS

- Pzizz – to help you sleep
- BlueIce – helps young people to manage their emotions and reduce urges to self-harm
- Catch it – learn to manage negative thoughts and look at problems differently
- Chill panda – Breathing techniques to help you relax, worry less and feel better

Pain

- Action on Pain 0345 603 1593 www.action-on-pain.co.uk
- Pain Concern 0300 123 0789 www.painconcern.org.uk
- Pain UK www.painuk.org

Smoking

- Smokefreelife Berkshire 0800 622 6360 www.smokefreelifeberkshire.com

Stoma

- Colostomy UK 0800 328 4257 www.colostomyuk.org
- Ileostomy and Internal Pouch Association 0800 0184 724 www.iasupport.org

Stress

- Mind 0300 123 3393 www.mind.org.uk
- Every mind matters www.nhs.uk/every-mind-matters
- Talking Therapies 0300 365 2000 www.talkingtherapies.berkshirehealthcare.nhs.uk

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

- Patient Advice & Liaison Service (PALS)
- Information for carers and Carer Passport
- How we use your personal information
- Sepsis
- Call 4 Concern© Supporting Martha's Rule: Detecting Deterioration
- Coping with traumatic experiences

These leaflets are available to download from the Trust website www.royalberkshire.nhs.uk

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. To any health care professional during or after the critical illness episode.
2. Through the Recovery after Critical Illness process - clinic and 1:1 visits or by email rbb-tr.raci@nhs.net
3. Via the contact form on the ICU support Reading website readingicusupport.co.uk/contact-us/

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.

Notes

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

Notes

Notes

If you have any questions about your Critical Care admission or about the Recovery after Critical Illness service, please do not hesitate to contact us on:

0118 322 7248

rbb-tr.raci@nhs.net

We also have a website that you may find helpful – either scan our QR code or use the link below.

www.readingicusupport.co.uk

ICU SUPPORT READING

University of Reading

Royal Berkshire NHS Foundation Trust
London Road
Reading RG1 5AN
0118 322 5111 (Switchboard)

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT ICU, September 2005
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