



Life after a critical illness

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

ICUfollowup@nbt.nhs.uk

The ICU Follow Up service contact details are:

ICUFollowUp@nbt.nhs.uk

0117 4141400

This telephone number is to ICU Reception please request to leave a message for the follow up team and we will try and get back to you as soon as possible.

The ICU Follow Up Team are:

ICU Sister Mo Maddock

ICU Sister Jordan Sumner

ICU Sister Emma Milton

ICU Sister Rebecca Cash

ICU Consultant Dr Ben Walton

ICU Consultant Dr Andy Ray

ICU Physiotherapist Tom Maggs

Clinical Psychologist Nick Ambler

Clinical Psychologist Hannah Golden

Due to the nature of our work our time is predominantly spent working clinically however we endeavour to answer messages as soon as possible.

If you have an emergency please call 999, or if you require urgent advice contact your GP or utilise the NHS 111 service, over the phone or online.



Working well together



Putting the patient first



Recognising the person



Striving for excellence

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Introduction

This information booklet has been designed to assist patients and their relatives in their recovery following a period of critical illness. It aims to offer advice and provide understanding of some of the challenges and worries that patients may experience during recovery. In the first few days after leaving ICU you may find this booklet a little overwhelming and tiring to read, the information is also relevant to your relatives to allow them to gain a better understanding of what you are going through.

After critical illness it is common for it to take a significant period of time for you to feel like your normal self. This will be different for everyone and can be dependent on your length of stay in hospital, and what caused you to be admitted in the first place.

This booklet aims to explain some of the more common challenges experienced by patients after critical illness, such as changes to your sleep, energy levels, appetite, mood, and family relationships.

It is likely that you won't 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.

Please be reassured that there is every chance you will return to your previous state of health and your symptoms will pass with time.

ICU Follow Up Clinic

When you are discharged from hospital after being critically ill, there will be a period of physical, mental and emotional recovery that will likely take some time. We feel it is important to ensure you are not alone during this.

Our follow up clinic aims to provide somewhere for you and your family to be supported through this journey after hospital. All patients admitted to NBT ICU are entitled to attend our follow up clinic, however, as one of the largest ICUs in the country we treat on average 250 patients a month. As you can appreciate this creates a huge volume of potential visitors to our follow up clinic. In order for us to manage these numbers there are certain patient groups we will actively contact, based on their length of stay and condition. That doesn't mean we don't welcome everyone else, but instead ask that you contact us via our email address if you feel the need to discuss your time with us in ICU, we'd love to hear from you.

For those who we actively contact, we aim to get in touch approximately 8 weeks after being discharged from hospital. We ask you to complete a health questionnaire allowing us to gain more information about how you are getting on post discharge. Once completed and returned to the Follow up Clinic, a member of the team will contact you to discuss the questionnaire in more detail and establish whether you would benefit from more input. In this instance, you will be invited back to the hospital for a face-to-face or virtual meeting with the team, where we will aim to establish any current issues and attempt to assist you in dealing with these or signpost you to support available. You may also wish to look at the helplines listed in the back of this booklet.

Going to the ward

Going to the ward is a big step in your recovery from critical illness and gets you one step closer to going home. However, it is a big change in your care and therefore very normal to feel apprehensive. The ICU routine and staff may have become familiar to you and the thought of meeting new people and learning a new routine can make you feel anxious.

There are fewer nurses for each patient on the ward and this can sometimes feel as though you are waiting slightly longer for assistance. However, this also reflects the fact you are now able to do more for yourself, and you will continue to be closely monitored. The staff on wards have lots of experience in caring for patients recently discharged from ICU and will be able to assist you with any concerns you may have.

When first transferring to a ward some patients may still be experiencing episodes of delirium or acute confusion. This can be quite common and although very scary for both the patient and the relatives experiencing it, this should improve and settle with time. There is no magic treatment to stop this, however, as relatives you can support your family member by trying to reorientate them to the date, time of day, and where they are. Also helpful is acknowledging that it can be very scary for the patient not being able to understand or remember where they are or what is happening to them, and providing reassurance.

The ICU steps website has an information booklet on Delirium that may be of help, the website address can be found in the helplines section.

Exercise and Mobility

Immediately after your discharge from ICU you may find even the smallest amount of activity can leave you feeling extremely tired. You may have lost weight and therefore muscle strength during your stay, other patients report stiffness of their joints having been less mobile for a period of time, all of which will impact your ability to be active.

This tiredness is normal and will improve as you continue to recover. Rest is vitally important at this time, and you may find it useful to plan regular rest periods into your day.

There is no specific time frame for when this may improve, and it will vary between every patient. Your age, severity of illness, previous levels of fitness and the length of time you have been unwell will all impact this. Please do not be alarmed should this take weeks or months to fully recover.

Whilst you are on the ward you will continue to be seen by a physiotherapist who can assist you with exercises that are suitable for you.

Over the next few pages we have supplied some very generic exercises which you may find useful whilst developing your strength. You should only do what you feel your body is able to cope with, starting with the seated exercises and moving onto the standing exercises as you feel able.

However, these exercises do not take into account individual post-op orthopaedic or surgical instructions. If you have been given a different weight-bearing status or range of movement limitations by your consultant please follow the advice specific to you.

It is normal to feel a degree of breathlessness when you are exerting yourself after experiencing critical illness, as you may have lost some exercise tolerance. Things you may not have considered as exercise before, such as climbing stairs may feel harder. This is normal and will improve gradually.

You should stop exercising should you experience any of these symptoms:

- Severe chest pain
- Increased chest tightness
- Dizziness or feeling faint
- Extreme breathlessness

As you build your strength you may wish to participate in more vigorous exercise, swimming, walking and cycling are all useful in building limb strength without placing too much strain on your joints.

Seated Exercises

Ankle Pumps



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Whilst either in a seated position or lying down:

Pull your toes and foot up towards you

Point your foot down away from you

Continue to alternate this movement across both feet, 10 times per foot.

For a video of this movement YouTube search: 'Supine, active ankle plantarflexion/dorsiflexion Physiotec' or see link below.

Knee Extension

Sit up in a sturdy chair with your feet supported on the floor.

Bend your ankle and straighten your knee using your front thigh muscles in a controlled manner.

Return to the starting position

Repeat 10 times on each leg.

YouTube search: 'Sitting resisted knee extension Physiotec'



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Hip Flexion



©PhysioTools

Sitting in a sturdy chair with your feet supported.

Lift your leg up off of the seat, bringing your knee towards your body, keeping your knee bent.

Return to starting position.

Repeat 10 times on each leg

YouTube search: 'Seated hip flexion Physiotec'

Ankle Pumps: www.youtube.com/watch?v=2o4USvzLly8

Knee Extension www.youtube.com/watch?v=15HREbasCUU

Hip Flexion www.youtube.com/watch?v=KZ40yziHPmY

Standing Exercises

Mini Squats



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Stand tall with feet hip width apart. Take support if needed.

Squat down by bending at the hips and knees. Return to the starting position.

Keep hips, knees and toes aligned and chest up.

Repeat 10 times

YouTube search: 'Partial Squat with support Physiotec'

Sit to Stand

Using a chair.

With your feet slightly apart, lean forward so your shoulders are over your feet and stand up.

To sit back down push your hips backwards towards the chair whilst bending your knees.

Repeat 5—10 times.

YouTube search: 'STS: sit to stand Physiotec'



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Heel Raises



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Stand tall, with your weight distributed evenly on both feet.

Take support if needed.

Rise up onto your toes and in a controlled manner return to the starting position.

Repeat 10 times.

YouTube search: 'Heel raises Physiotec'

Mini Squats www.youtube.com/watch?v=2cfsUQynp8I

Sit to Stand www.youtube.com/watch?v=130tQPpU42g

Heel Raises www.youtube.com/watch?v=_Mhr00UyBI4

Eating normally again

Whilst being cared for on intensive care you may have been receiving food via a tube through your nose into your stomach, or sometimes directly via your blood circulation. As soon as you are able you will be encouraged to take your food normally by mouth.

It can feel hard to return to eating normally after being unwell. You may find your appetite is reduced, or your interest in eating is diminished due to feeling tired and weak. Food may taste different to what you remember, perhaps you have a dry mouth, or feel full quickly. These are all very common symptoms, which should improve with time. Eating and drinking a good amount of the right foods is very important to support your recovery, and help how your hair, skin and nails grow as well.

These are some tips from the ICU steps website where you can find other information leaflets that may be useful:

- Every mouthful counts, try and remain positive about what you are able to eat.
- Eat whenever you feel hungry.
- Try foods you don't usually eat.
- Keep snacks readily available.
- Avoid fizzy drinks.

Eating little and often can support you in building up your appetite again and ensuring you are getting enough calories throughout the day. You can also add 'extras' to food to boost their calorific or protein content. The ICU Steps Information leaflets on Nutrition can offer more detailed advice around this.

You may have already been taking nourishing supplements and drinks whilst in hospital to boost your calorie or protein intake. You may need to continue taking these when you return home at first, you will be advised by a Dietician if this is necessary. Some patients have issues around swallowing after their stay in ICU, if this is the case a Speech and Language Therapist (SALT) will have been involved in your care, they will be able to offer advice on certain diets to make swallowing easier and safer for you, your GP can refer you to the SALT team should you require more support.

Sleeping

A change in sleep pattern can be very common after critical illness, many patients report difficulty falling asleep or waking up frequently during the night. Often your daily activity levels can impact your sleep pattern, as you recover you are likely to become more active and this should help your sleep pattern to return to normal. Having a bedtime routine can support this pattern in returning to normal, some people find having a bath or shower before bed can help you to relax and make going to sleep easier. Going to bed at the same time each evening and waking up at the same time in the morning, even if you haven't had a good night sleep will help recover your normal routine. Reading before bed can also help you to relax and take your mind off any worries you may have before bed.

Being awake during the night can be worrying, and often worrying about being awake can make it even harder to get back to sleep. Reminding yourself that if you are in bed and resting your body is still experiencing the benefits of that rest. Trying to not force yourself to get back to sleep can prevent you from getting worked up, a lack of sleep will not do you any harm in the short term, and things will get back to normal as you recover. Reading or listening to the radio in the night may help you drift back off to sleep, or at least pass the time if you do not fall asleep.

Some patients can experience vivid dreams about their time in ICU, either whilst they are still on the unit, or shortly after they leave. This can be your mind's way of processing an intense and stressful event and is very normal, you are not going mad. These can be extremely realistic and frightening but they should subside over a number of days or weeks.

It can be helpful to discuss these experiences with friends and family. They may be able to reassure you of reality and this can support your mind to work out what is real and what isn't. However, speaking to people who have had similar experiences may also be beneficial for you, the ICU Steps website (see helplines) has access to an online community where patients can communicate with one another and share experiences to gain support. Similarly some patients have found returning to ICU to see the unit now they are more recovered can help make sense of what they experienced. This is something you can discuss with the follow up clinic, please feel free to get in touch via email should you feel this would be of benefit.

Changes in mood

Emotional changes after being critically ill are extremely common. Fluctuations in your mood, one day feeling up and the next very down, is a normal reaction to illness and should lessen with time. People can feel low in mood for a considerable period, and it may feel as though you will never get back to normal. Particularly if you feel as though your recovery progress is slow. The up and down struggle to recover your physical health can be discouraging so it is important to manage this accordingly.

Setting yourself reasonable targets that you can reach will help to boost your mood and build your confidence. It is important to ensure these targets are attainable, setting targets that are too difficult could potentially cause you to fail and this may be more difficult to cope with emotionally. Asking your nurses, doctors, and physiotherapists to guide you with what you can reasonably do may help keep your targets within reach. You may find it useful to record videos/pictures of yourself along the way, this will allow you to look back and see how far you have come, as it isn't always easy to acknowledge what you've achieved when you're still struggling. Having support from friends and family can also help, as they will be able to see how far you've come and remind you when you may forget.

If you feel your mood is so low and you don't know how to feel better it could be important to speak to your GP to get some support. The helplines in the back of this booklet may be able to signpost you to support if you require it.

Your family and relationships

It is likely that your family will have been through an extremely worrying time whilst you have been in hospital, and they may feel a little overprotective whilst you start to do more in your recovery. It is important to communicate how you are feeling to allow them to know when you might require assistance, and when you feel well enough to do things yourself. It can also be beneficial for all of you to share any worries you may have and work through them together.

Regarding sexual relationships, your illness may have reduced your sex drive, or it could be possible that you or your partner are worried that sex might hurt you. This is rarely the case, but it is important with any exercise to only do as much as feels comfortable and communicate with each other to ensure you are both on the same page. Your relationship may feel a little different for a while but with time, patience, and communication from both of you it will hopefully be able to return to normal.

Changes in appearance or voice

Being critically unwell can have an impact across all aspects of your physical appearance, usually these changes don't last long, however they can be difficult to cope with when you're first recovering. You may have lost a significant amount of weight, you may experience hair loss, or a change in the quality and texture of your hair, your skin texture may feel different and possibly a lot drier than it was previously. All these factors can play a huge part in how you feel about your appearance, but it is important to remember that with time, exercise, and a sensible diet these symptoms usually improve and return to normal.

Some patients find that their voice has changed since being unwell, this is likely caused from being on a ventilator, and should resolve itself. If this continues to be an issue, speak to your GP about a referral to a speech and language therapist who may be able to support you further.

Stress and Relaxation

Many of the symptoms discussed in this booklet can be worsened with stress so it is extremely important to try and manage your stress levels as much as possible whilst recovering. Everyone benefits from periods of relaxation, it can be anything you enjoy doing such as watching television, gardening, knitting, painting, walking in nature, if you are able. Planning relaxation periods into your day can be particularly useful, utilising free meditation or yoga sessions (particularly Yoga Nidra) using YouTube or free apps may give you some guidance in developing your relaxation skills.

Post Traumatic Symptoms

Some of our patients do experience symptoms of post-traumatic stress (vivid unwanted memories, troubling dreams, feeling on high alert) following their ICU stay. This is a relatively common reaction after a highly stressful event and in the majority of patients, this does get better on its own. We have found that early intervention managed through the follow up clinic is of great value. If you find this does not get better over time we can refer you to specialist services.

Energy Levels

Recovering from being critically ill will take up a lot of your resources, including your general energy levels. It is very common to experience fatigue following physical or mental exertion, and your threshold for what you find tiring will be much lower. It can be tempting to push yourself on a 'good' day, however people often find this then means a period of complete exhaustion for a longer period afterwards.

Setting yourself a manageable level of activity that you can maintain every day and then increase gradually when you are ready will help you recover more effectively in the long run. Activity can be anything that demands physical or mental energy, as well as things that bring you some enjoyment. Try and build this into a regular daily routine. This may mean being kind to yourself, taking frequent rest breaks and adjusting your expectations about what you may be able to do early on in your recuperation period. It may be helpful to remind yourself of long-term goals and think of your recovery over a number of months.

Patient Advice and Liaison (PALS)

PALS is a service for patients and their relatives that offers support and advice around non-clinical issues. They can assist in finding information needed to answer questions, answer general enquiries about health care services provided by the hospital and help to resolve problems or concerns you may have by identifying the correct people to talk to.

The PALS team is based at Gate 18, Brunel Building their opening hours are Monday—Friday 10:30—15:30, you can contact them via email: **PALS@nbt.nhs.uk** or telephone: **0117 414 4569**.

Helplines

This list of helplines aim to signpost you towards charity support services outside of the NHS. You will find Bristol/South West based charities as well as national charities, separated into an alphabetical list of common issues our patients may require support with. For any specific concerns please contact your GP who will be able to assess you and determine if you need referral to an NHS service or other support that they can offer.

AIDS/HIV

Terrence Higgins Trust www.tht.org.uk 0808 802 1221
info@tht.org.uk

Brigstowe www.brigstowe.org 0117 955 5038 info@brigstowe.org

Alcohol and Drug Abuse

Bristol ROADS www.dhi-online.org.uk 0117 440 0540 roads@dhi-services.org.uk

SMART recovery www.smartrecovery.org.uk 0330 053 6022

Drinkline National Alcohol Helpline 0300 123 1110

FRANK National Drugs Helpline www.talktofrank.com 0800 77 66 00

Amputation

The Limbless Association www.limbless-association.org 0800 644 0185

Douglas Bader Foundation www.douglasbaderfoundation.com

Steel Bones www.steelbone.co.uk 01223 734 000
hello@steelbone.co.uk

Amputation Foundation www.amputationfoundation.org

Aphasia/Dysphasia (difficulty with language)

Speak with IT www.speakwithit.org 01924 888608
info@ speakwithit.org

Stroke Association Helpline www.stroke.org.uk 0303 3033 100
helpline@stroke.org.uk

Asthma

Asthma UK www.asthma.org.uk 0300 222 5800 info@asthma.org.uk

Bereavement

Cruse Bereavement Support www.cruse.org.uk 0808 808 1677 /
0117 926 4045

The Harbour www.the-harbour.org.uk 0117 925 9348 info@the-
harbour.org.uk

SANDS (Stillbirth and Neonatal Death Society) www.sands.org.uk
0808 164 3332 helpline@sands.org.uk

Winston's Wish www.winstonswish.org 08088 020 021
ask@winstonswish.org

Survivors of Bereavement by Suicide www.uksobs.org 0300 111 5065
email. Support@uksobs.org

Cancer

Penny Brohn UK www.penybrohn.org.uk 0303 3000 118

Positive Action Cancer (Counselling for those affected by cancer)
www.positiveactioncancer.co.uk

Macmillan Support Line www.macmillan.org.uk 0808 808 00 00

Marie Curie www.mariecurie.org.uk 0800 090 2309

Citizens Advice Bureau

Bristol www.bristolcab.org.uk 0808 278 7957

National www.citizensadvice.org.uk 0800 144 8848

Crime Victims

Victim Support www.victimsupport.org.uk 0808 1689 111

Debt

Money Advisor Network www.adviser.moneyhelper.org.uk

National Debtline www.nationaldebtline.org 0808 808 4000

Step Change Debt Advice www.stepchange.org 0800 138 1111

Depression & Mental Health

Bristol Mental Health www.bristolmentalhealth.org

Avon & Wiltshire Mental Health Partnership www.awp.nhs.uk 0800
953 1919

Mind www.mind.org.uk 0300 123 3393 info@mind.org.uk

Off the Record (counselling in Bristol for 11-25 yr olds)
www.otrbristol.org.uk 0808 808 9120 hello@otrbristol.org.uk

Rethink www.rethink.org 0808 801 0525

Samaritans www.samaritans.org 116 123

Diabetes

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

Domestic Abuse and Violence

Bristol Against Violence and Abuse www.bava.org.uk
Next Link www.nextlinkhousing.co.uk 0800 4700 280
National Domestic Violence Helpline 0808 2000 247
ManKind www.mankind.org.uk 01823 334244

Elderly Care

Age UK www.ageuk.org.uk 0800 678 1602

Guillain-Barre

GAIN Charity www.gaincharity.org.uk 0800 374803

Epilepsy

Epilepsy Action www.epilepsy.org.uk 0808 800 5050
Epilepsy Society www.epilepsysociety.org.uk 01494 601 400

Head Injuries

Headway Bristol www.headwaybristol.org.uk 0117 414 3222
info@headwaybristol.org.uk
Headway National www.headway.org.uk 0808 800 2244

Heart Disease

British Heart Foundation www.bhf.org.uk 0300 330 3311

ICU Steps

ICU Steps www.icusteps.org Find support, and an online community on the website.

Legal Advice

Stewarts The Legal Service www.thelegalservice.org 020 7822 8000
info@thelegalservice.org OR contact ICU reception on 0117 414 1400
ICUAdminteam@nbt.nhs.uk to arrange an appointment

Meningitis

Meningitis Research Foundation www.meningitis.org 080 8800 3344

Miscarriage

The Willow Tree Centre Bristol www.thewillowtreecentre.org.uk 07760 830525
Miscarriage Association www.miscarriageassociation.org.uk 01924 200799
info@miscarriageassociation.org.uk
Sands www.sands.org.uk 0808 164 3332 helpline@sands.org.uk
Tommy's www.tommys.org 020 7398 3400

Pain

Pain Concern www.painconcern.org.uk 0300 123 0789
help@painconcern.org.uk
Fibromyalgia Action UK www.fibromyalgia-associationuk.org 0300 999 3333

Sexual Abuse

Somerset & Avon Rape & Sexual Abuse support www.sarsas.org.uk
0808 801 0456/0464 support@sarsas.org.uk

Shared Experiences

HealthTalk www.healthtalk.org

Smoking

SmokeFree www.nhs.uk/better-health/quit-smoking 0300 123 1044

Stoma

Colostomy UK www.colostomyuk.org 0800 328 4257
info@colostomyuk.org

Ileostomy & Internal Pouch Association www.iasupport.org 0800 0184
724

Information Leaflets

At your follow up clinic appointment information leaflets relevant to your recovery can be provided, please inform us if there are specifically any leaflets you would like.

Feedback

We really appreciate any feedback you may have regarding your stay in ICU and the information provided in this leaflet.

You will receive a Feedback questionnaire after discharge from ICU, please complete this and return it to us to allow us to improve our service.

You will also be asked to provide feedback on your experience of the ICU Follow up Clinic if you are involved.

All feedback positive or negative is valuable. Feedback received will be analysed, reported and actioned if possible as swiftly as we are able. All staff will have access to feedback, this allows us to learn and develop as a service, this feedback will always be anonymous.



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Southmead
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