Liverpool University Hospitals
NHS Foundation Trust

Critical Care Rehabilitation Manual

An information booklet for patients and their relatives.

CG APPROVED ★

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This booklet is designed to help you and your family during your recovery on the ward after your stay in the Critical Care Department (CCD). If there is anything you are uncertain about, please do not hesitate to ask a member of staff.

The booklet is divided into two parts:
Part one will provide you with information about the CCD and some common problems that may occur. The booklet will answer some of your questions and give some simple suggestions to try and help you manage any difficulties you may encounter.

Part two contains general advice about exercise and how regular exercise should form part of your recovery.

Information provided is based on recommendations from the National Institute for Health and Clinical Excellence (NICE) and work by Dr Christina Jones from St Helens and Knowsley Teaching Hospitals NHS Trust. This booklet has been adapted from original information provided by Sherwood Forest Hospitals NHS Foundation Trust.

Contacts

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What is the Critical Care Department (CCD)?

On the CCD we care for patients who need closer monitoring and more intensive treatment than those patients cared for on the wards. Due to the specialist treatment and constant monitoring that patients require on critical care it has a higher level of staffing. Nurses on the CCD care for either one or two patients. We will endeavor to maintain the highest standards of care throughout your stay and all changes will be explained as they occur.

Critical Care Diaries

Patients who are requiring admission to the CCD for three days or more will have a diary started for them. It is common for patients who have been admitted to the CCD to remember little of their stay and not understand how ill they have been. This is common after the use of sedative medication or a serious illness.

It can be very stressful being a relative of someone on critical care. Diaries can help your relatives and close friends, by giving them something to focus on and give them an opportunity to express their feelings and collect their thoughts.

Your diary will tell a story of what has happened to you whilst you have been in critical care. You will receive your diary when you leave critical care. If you wish to discuss any of the content, or ask any questions, please inform the critical care staff. If you do not wish to keep your diary, it will be destroyed after one year.

Transfer to the ward

Some patients who have been on CCD for a few days will be invited to a follow up outpatient's clinic approximately two/three months after leaving the unit. This may be while you are still in hospital, in which case a member of the follow up team will visit you on the ward. This allows the family and patient an opportunity to discuss any issues, concerns or feelings they may have had during their stay on CCD. If you have completed a diary during your stay, this may provide a useful prompt for discussions at the clinic.

Occasionally a patient may be transferred to an Intensive Care Unit in another hospital. The nurse in charge of the CCD and a senior doctor will discuss this with you if such a transfer is being considered.

What will change when I go to a ward?

When you are well enough, you will be transferred to a ward. This can be quite stressful as you may have spent a long time on CCD, but moving to a ward is a positive step. The ward environment is different from the unit however and these changes may make you feel anxious or frightened.

While you were on CCD you and your relatives will have become familiar with the staff and the routine, so it is normal to feel unsettled about moving to a new place.

The critical care team will provide the staff on the ward with information that will help them to understand how ill you have been, what you are able to do for yourself and the treatment or assistance you still require. On the ward there will be less monitoring and you should have noticed this has become less as you started to improve on the CCD. This too can provoke anxiety, but it is a sign you are getting better. You will not have so much equipment around you on the ward and you may not have your observations (respiratory rate, pulse, blood pressure and temperature) recorded as often as before. Do not worry, this means you are getting better.

Who will look after me on the ward?

The nurses on the ward will introduce themselves to you and continue your care. You will notice there are less nurses on the ward than CCD. This is because there are more patients on the ward who are not as ill as those on CCD. The nurses are always nearby and you can get help by using the nurse call buzzer. There will also be more Health Care Support Workers to help with your needs.

When you leave CCD, a member of the Critical Care Outreach Team will visit you on the ward. They routinely ‘follow up’ everyone discharged from the CCD. The Outreach Nurse will ensure that your recovery and rehabilitation continues and will support the nurses on the wards with providing for your needs. The Outreach Nurse will provide you and your relatives with the opportunity to talk about your experience on CCD and answer any questions that you may have.

Other professionals will continue to provide your ongoing care once back on the ward such as the physiotherapist, dietician, pharmacist, speech and language therapist, occupational therapist, and other specialist nurses.

Introduction to Recovery

After a critical care admission it can take quite some time to get back to feeling your normal self, for some this can take up to one year. Recovery depends upon the individual and many other factors including type of illness, how long you were ventilated and weight loss.

Will I be able to eat and drink?

Depending on what has been wrong with you, the nurses on CCD and on the ward will know what type of diet you require and whether or not you can drink. Please ask if you are unsure. If you can eat, you may find that your appetite is slow to return to normal. This is because you may not have eaten much since you became ill. You may have been fed using a tube up your nose in to your stomach, or, via a drip into one of your veins. You may still need these now that you are on the ward. You might be referred to a dietician who will help you. Follow their advice, but try to eat a wide variety of food that is bitter, sour, savoury, warm and cold. This will help your taste buds to return to normal. To ensure that you have no swallowing problems you may also see the speech and language therapist, particularly if you had a tracheostomy on the CCD (a tube which allows you to breath through a hole in your neck rather than your nose). You may be given exercises to help with your speech and swallowing.

The ward nurse will observe what you are eating. You may be given fortified drinks or food such as nourishing puddings, porridge and whole milk. If you are worried a nurse will be available to discuss your eating and drinking and may refer you to a specialist. You may find that food does not taste the same, particularly if you have been on a ventilator (breathing machine) for a long time. Common changes include a metallic taste in the mouth or food may seem sweeter than normal or have no flavour at all. This will settle with time.

Depending on what treatment you have had, you may find that you have a change in your bowel habits. You may be constipated, have diarrhoea or loose stools. This is common in patients who have been on CCD. You have not been walking around or doing normal activities for a while and have been on drugs which may have slowed your digestive processes down during this time. It is important to remember that these are only temporary problems that should return to normal. The nurses can offer advice on any worries that you may have.

Can I expect any problems as I recover?

Sleep

CCD can be noisy and due to your illness your sleeping pattern may have changed. You may find it difficult to sleep or sleep for short periods only. Try to relax, have a hot milky drink, read or watch the television. If you are still finding it difficult to sleep tell the nurse, sometimes it may be possible to prescribe something to help you sleep. If you do not need close observation, moving to a cubicle or simply having the curtains closed round your bed may help you to sleep better.

Sometimes patients may experience nightmares or ‘flash back’ memories of their time in CCD. These may appear real, vivid and frightening. They could occur for a few days, until you settle on to the ward. If they continue, discuss them with the nurse or ask the ward staff to contact the Critical Care Outreach Team. It may be that some events are unclear and that you would benefit from talking about your experiences. If you were given a diary, written by staff and visitors while you where ill on CCD, it may help to read this. Ask your relatives to talk about what happened to you. A visit to CCD when you have improved sufficiently may help to put these thoughts to rest. If you wish to do this, please ask the nurse on the ward or ring the CCD unit to arrange it.

How can I be helped to get back to normal?

After critical illness, it is common to find it difficult to do things you usually take for granted. You may need help with washing, dressing, moving in bed or getting to the toilet. It may be that you cannot get out of bed yourself or walk very far without help, especially if you have been ill for a long time. The two main reasons for this are:

- You may feel weak, tired and stiff because you have not been able to use your muscles while you have been ill.
- Increased activity may cause you more discomfort or make you more short of breath.

Whilst on CCD, you have been seen by a physiotherapist. This will continue on the ward. The physiotherapist will ensure that your chest remains clear and will monitor your breathing. They will give you exercises to improve your muscle strength and help you get stronger.

You may need walking aids such as a frame or stick as you recover to help you walk. All the staff will be aware of what you can and cannot do and will assess how you progress. Other healthcare specialists may also be involved in your ward care to ensure you continue to recover well.

You may be referred to an Occupational Therapist who will help with the functional tasks such as, washing and dressing, and they will also be involved in ensuring you are safe to return home, when it is appropriate.

Family and friends may be tempted to try to do everything for you. They have seen how ill you were on CCD and may be frightened of you hurting yourself. It is much better for your muscles, joints, heart, lungs and your morale if you try to do things yourself, but if you are unsure please ask the nurse caring for you.

What if I feel breathless?

You may feel breathless, but this improves as the muscles you use for breathing become stronger. Gradually increasing the amount of activity that you do will help this. The physiotherapist will assess you and may give you exercises to do. The physiotherapist will give you breathing exercises to do, as it is important to take deep breaths and cough regularly. If you are unable to do this because you have pain or your sputum is thick, please inform the staff.

You may return to the ward with a tracheostomy in situ (a hole in your neck to help you breathe. The nurses on the ward, the physiotherapist, Critical Care Outreach and other specialist staff will care for the tracheostomy. Hopefully it will be removed once your breathing muscles have improved. During this time talking, eating and drinking may be difficult or you may be unable to do these things. This can be stressful, but with support and explanation we will help you and your family understand what we are doing and how we aim to remove this tube over a period of time. This may involve using different equipment, all of which will be fully explained to you before it is used. If required, we will give you aids to help you communicate with the healthcare professionals and your visitors.

To help with your breathing you can:

- Settle into a relaxed position, lean forward or relax when sitting.
- Sitting forward, leaning over a table may help.
- Sitting as upright in bed as possible will also help.
- Keep your upper chest and shoulders as relaxed as possible.
- Feel your stomach and your lower ribs expand as you breathe in.
- The more relaxed you are, the easier it will be to breathe out.
- Ensure you have sufficient pain medication. You must inform a member of staff if you are unable to do these exercises because of discomfort.

You must also try to move your legs and feet while in bed to prevent complications. This helps to move the blood around your body. These exercises should be done hourly and try to avoid crossing your legs. You may also be receiving ‘blood thinning’ injections and wearing stockings. These are all treatments to reduce the risk of clots forming in your leg veins. Please follow the advice from the nurses, doctors and other healthcare professionals

What about my family and friends?

Although you may not remember much about your illness, it has probably been a very difficult time for your family and friends. It common for patients to remember nothing about the CCD and this can be frustrating for you. You may find your progress slow and frustrating, but your friends and family will notice the improvements all the time. The move to the ward is a big step in your recovery.

While in CCD your relatives may have felt they could do nothing to help you. They may now appear over protective to you. This may be their way of showing how much they care; even though you may think you can do things on your own, your relatives have been through a difficult time too.

How will I feel?

You may notice that your appearance has changed during your illness. You may have some weight and hair loss, dry skin or a sore mouth. You may also notice new scars or wounds. The doctors and nurses will explain what these are. As you improve you will notice these problems fade.

Feeling ‘normal’ again can take a long time and be a slow process. Do not expect too much of yourself, take each day at a time. Aim for small achievable targets each day. This will help you see how you are getting better. Try to face it with a positive attitude. If you are depressed you may already be on a small dose of antidepressants, but if not, and you feel depressed or low in mood, this may be a possibility. Discuss these feelings with the nurses and doctors caring for you.

It is not uncommon for you to feel very different after a serious illness, both physically and emotionally. You may experience some ‘good’ and ‘bad’ days, having some ‘ups and downs’. Being irritable or tearful for no apparent reason is quite usual after being very ill.

Stress and Anxiety

Anxiety is a normal biological reaction to stressful situations. When our minds detect a potential threat to our safety our body produces adrenaline to help us to escape from or fight whatever the threat is. This is sometimes referred to as the ‘fight or flight’ reaction. You may have felt this in action if you’ve ever had to react quickly in a dangerous situation.

Unfortunately this reaction can be triggered when there is no actual threat to our safety, a kind of false alarm. This can happen when we have a frightening thought e.g. “I’m never going to get better”. There is nothing to fight or run away from so you may be very aware of the powerful physical affect adrenaline has on your body. The effects are numerous but may include:

- Increased heart rate, palpitations, sometimes chest pain
- Shaking; sweating; fast breathing
- A feeling of not being able to get air into your lungs
- Dry mouth; feeling sick; “butterflies in the stomach”
- Feeling out of control
- Irritability

Whilst these physical reactions are NOT dangerous they can be very frightening. In extreme cases they may turn into a full blown panic attack.

Panic Attacks

Anxiety can be considered to be on a sliding scale from feeling a bit nervous right up to full blown panic. What makes a panic attack different from normal anxiety is that, because the physical feelings are so strong, the individual believes that they are going to die or at least have a heart attack. This belief triggers the ‘fight or flight’ mechanism encouraging the body to produce even more adrenaline, which produces even stronger physical symptoms (palpitations or breathlessness), creating a vicious circle. Panic attacks are very frightening but they are NOT dangerous.

A normal way of dealing with this might be to take a gentle walk or get some fresh air. There is a simple breathing technique that it is helpful to learn. If you practice this regularly it can help to keep your anxiety at a manageable level.

A Breathing Exercise

Sitting quietly, breath in slowly through your nose saying in your head, “one thousand, two thousand, three thousand in” and then without holding your breath, breath out through your mouth slowly saying to yourself, “one thousand, two thousand, three thousand out”. Do this three times and then resume breathing normally.

It is helpful to practice this exercise regularly throughout your day. Some people find it easier to remember if they do it every time they put the kettle on, or every time they visit the toilet. It doesn’t matter how you remember it as long as you try to practice frequently.

Learning new techniques and strategies to help you manage stress and anxiety can have a positive effect on your general health as well as helping improve your quality of life. As well as this exercise you may like to try other ways of managing your stress and anxiety levels. Deep relaxation (sometimes called guided relaxation or just relaxation) can be a helpful and enjoyable way of doing this. There are many good relaxation CDs available or you might like to try a relaxation or yoga class locally. If you would like help managing anxiety or stress speak to your GP who will know what services are available in your area.

Changes in Mood

It is very common to feel very ‘up and down’ in the weeks following discharge as you adapt to what has happened. This should settle down as time passes. If your mood does not settle or if you feel you are becoming depressed then **discuss this with your GP**. Most surgeries are now able to offer a variety of help for this type of common problem ranging from lending helpful books, CDs and computer based resources to short psychological therapies. You can discuss both your difficulties and your preferred type of help with your GP.

Common signs and symptoms may include:

- Feeling down
- Not enjoying things that you used to
- Feeling tired all the time
- Disturbed sleep (possibly waking up early in the morning)
- Loss of self confidence or feeling worthless
- Feeling pessimistic or particularly worried about the future.
- Being irritable
- Loss of interest in sex
- Physical aches and pains.

Memory

The drugs given to make you comfortable whilst in intensive care can effect how your memory works for that period of time. This usually means that people have either no memory or only hazy memories of the time in intensive care. This, whilst not harmful, can be quite disturbing for some people.

It may be helpful to speak to your friends and relatives who may be able to fill in the gaps in your memory. You may have had a diary of your intensive care stay. If so, this will help you to make sense of what happened during the time for which you have limited or no memory.

Some people experience scary images coming into their mind, particularly when something reminds them of being ill or in hospital. These images can be intensely frightening and confusing and may have initially been experienced whilst in ICU. Sometimes they may be like nightmares and sometimes they may be more like hallucinations.

Although frightening this is quite a common psychological reaction and should lessen over time. Very occasionally these symptoms or intense anxiety may continue after physical recovery is complete. In such cases psychological help is advisable. If you are concerned speak to your GP or contact a member of the critical care follow-up team (details at the back of this booklet).

After discharge your concentration may be poor and you may find that you are forgetful. Both of these often improve as you gradually recover.

Continued Psychological Recovery

Being seriously ill is a major life event. Both physical and psychological recovery will take time. Sometimes it may feel as though things are not improving, as recovery is seldom a smooth path. There will be ups and downs along the way and it may take up to 18 months to fully recover. It is important that you do not expect too much of yourself too soon. By the same token, it is also important that you move on from thinking of yourself as ‘ill’ and see yourself in a recovery state.

Bite sized chunks – building up slowly

It is important that you are not tempted to overdo things during your recovery. You need to set yourself small achievable goals along the way. For example, if you used to go on ten mile walks, you might set yourself the first goal of walking to the end of your garden path with the next goal being to the first lamppost and so on. Alternatively you may set yourself a goal of some light dusting rather than cleaning the whole house. Accept that you will have temporary setbacks along the way and do not set yourself up to fail by setting too big a goal initially.

General recovery tips

- Try to focus on what you can do rather than what you can’t do.
- Make time to talk and socialise with friends and family, gradually at first.
- Do things that give you pleasure regularly.
- Try to ensure you get some fresh air and daylight most days.
- Eat well and be ‘kind’ to yourself.

Friends and family

Friends and family may treat you differently initially as they have been very worried about you. This is a period of adjustment for everybody. It is helpful, when you feel ready, to allow yourself and them the time and space to talk through the emotions that may be attached to the experience (even if you can’t remember it).

How will my illness have affected family?

This has been a worrying time for you and your relatives. Your friends and family may find it hard to understand how you feel because the illness seems now to be in the past. They may expect you to be as happy as they are that you are now getting better and they may feel just as frustrated as you that progress is sometimes slow.

Seeing someone you love in intensive care can be very upsetting because of the high-tech machines, strange noises and alarms. Friends and family often feel helpless and frightened. They may have been worried that you would not get better and this can take some people a long time to get over. Sometimes, as a result of this, they become very protective towards you and you may feel that you are able to do more than they will let you. If this becomes a problem for you then you need to discuss your feelings with them and come to a compromise that both of you can cope with.

Making Love

The old saying, ‘a bit of what you fancy does you good’ is particularly true for sex during your recovery. Your illness may have reduced your sex drive and your partner may be concerned that sex could be harmful for you and you may even feel that yourself. This is rarely the case, but as with other forms of exercise, you should do as much as feels comfortable. You will eventually be able to return to your normal relationship, but recognise that this may take some time and patience from both of you. If this is a problem that is particularly worrying, talk to your GP or with one of the critical care follow up team (contact details at the back of this booklet).

Lack of interest in sex or just feeling too tired to be bothered is very common after serious illness, but with time this will pass. The reduction in sex drive can continue for a number of months and may cause you some concern. Alternatively, you may find that you have not been affected in this way but your partner has. This is again a common problem. Your partner may have spent a considerable length of time worrying about you while you were ill in intensive care and it is difficult to switch off that anxiety. The important thing to do is to talk about the problem and plan together how to help each other.

Men's Issues

Physical difficulties usually refer to impotence and premature ejaculation, both of which are largely caused by anxiety and tension related to the sexual act. Impotence, the failure to achieve an erection, can also be caused by drugs used to treat depression and high blood pressure, alcohol, tiredness and certain medical conditions such as diabetes. The fear of impotence can create a vicious circle and often all that is needed is a sensitive and sympathetic response from the partner and sexual abstinence for a while. This usually allows the natural sex drive to return. If however you continue to have problems in this area have a chat with your GP.

Women's Issues

In older women painful intercourse, often related to lack of lubrication, can be a problem. For all women lack of sufficient foreplay can also cause this problem and you may need to be able to discuss this openly with your partner to give yourself more time to become aroused. Lubricants can be purchased from the chemist to overcome this problem. If the pain is deeply felt then it could be caused by an infection and in this case you should seek the advice of your doctor.

Living Alone

If you are worried about living alone on your return home there are a number of things you might do to support your recovery:

- Leave a key to your house with a trustworthy friend, neighbour or a relative who lives nearby.
- If you do not have a phone, consider having one fitted. If you have a medical condition then this will be done as a priority, so tell the company you have been seriously ill.
- Make sure you cook yourself proper meals to keep up your energy levels.

Try to stay motivated to keep up with the exercise programme you have been given.

Changes in Appearance

You may find that your appearance has changed as a result of being ill. Sometimes those who have been critically ill suffer hair loss or a change in the quality of their hair. Similarly, skin texture may change and it is quite common to find that skin is drier than before. These changes are almost always temporary.

You may also find that your fingernails have a ridge across them. This happens because the nails can stop growing when you are ill and then restart when you are recovering. The ridge will grow out in time.

If you had surgery or a tracheostomy (a tube in your neck to help you breath) there may be scars that you feel are unsightly, these will fade with time and, as your skin returns to normal, they won't seem as obvious.

You may have lost a lot of weight but with time, exercise and a sensible diet you will get back to normal. Coming to terms with what has happened to you does take time. It may help to talk about your experience.

Eating

It is important during this initial convalescent period to eat a healthy balanced diet with plenty of protein. But you may find that you do not have very much appetite or that your likes and dislikes have changed, this is not unusual. Although you may find eating difficult, it is still important to eat a well balanced diet. If your body is not well nourished

- You will be less able to fight off infection
- You will feel weak and tired
- You will lose weight as your body uses up its own food stores.

Have you lost your appetite?

- Eat small frequent meals. Have nourishing snacks or milky drinks in between and try to have something to eat every two or three hours.
- Take full advantage of times when you are hungry. Have your favourite foods as often as you like and keep snacks handy to nibble on.
- Avoid very heavy, fatty foods if you find these hard to digest.
- Take your time – eat meals slowly and relax for a while afterwards.
- If you feel full quickly, avoid liquids such as unfortified soups and fruit juices at meal times and have them later.
- High protein drinks such as Ensure Plus, Entera, Fortisip, Complan and Build Up make a good addition in between meals.

Has your taste changed?

- Concentrate on foods that you like and leave those that don't appeal. Try them in a few weeks when your taste may have returned to normal.
- If red meat tastes bitter, try more fish, poultry, eggs or try soaking red meat in fruit juice, wine, vinegar or sweet and sour sauce before cooking. This can improve the flavour.
- Cold meat may taste better with pickles or chutney.
- Use herbs and spices to enhance the flavour of food.
- Sharp tasting foods are refreshing and tend to leave a pleasant taste in the mouth. Try fresh fruit, fruit juices or boiled sweets.
- Fizzy drinks and lemon tea can be used an alternative to tea or coffee.
- Brush your teeth after each meal and try gently brushing your tongue to leave your mouth fresh tasting.

Are you feeling sick or nauseous?

This is usually temporary, but the following may be useful:

- Let someone else do the cooking if possible.
- If the smell of cooking makes you feel sick, try cold meats and sandwiches or food that you can just heat up quickly.
- Keep meals small and dry. Dry crackers, plain toast or biscuits can help relieve nausea.
- Sipping chilled fizzy drinks through a straw can help.
- Avoid greasy or fatty fried foods

Medications

You may not be on any medications when you come out of hospital but if you are, there are some simple rules to follow:

- Don’t mix them with other pills without checking with your doctor or chemist.
- Don’t take a lot of alcohol with them.
- Keep a list of your medications with you.
- Don’t stop taking any of them without discussing it with your doctor.
- Don’t let anyone else take them, even if they seem to have a similar problem to you.
- Never take more than the dose prescribed for you.

Many drugs have some side effects. If you think you are suffering from side effects, don’t stop taking your medicine, go to see your doctor to discuss it.

The doctor may be able to reduce the side effects for you by changing your medication.

How can I remember when to take my tablets?

Write out a list of which ones to take at which times. Alternatively you can buy pillboxes that have different compartments for different times and different days of the week. You can then tell at a glance whether you have taken your tablets.

My prescription has changed and the number of pills I have to take has changed.

Sometimes the chemist will give you tablets that are a different size, so you might need to take more or less tablets to get the right dose. If you think there has been a mistake, ask the chemist.

I was given painkillers by the hospital; do I need to carry on taking them?

You may need them when you first go home because of pain from a surgical wound or a broken bone, for example. Over a couple of weeks this will start to heal and you should only take the tablets when you really need them. Sometimes scars can feel strange when you touch them or can be a bit itchy. This is normal. If pain from the wound does not seem to be getting any better, or is getting worse, or if you are at all unsure, check with your doctor.

I don’t like taking so many tablets.

Your doctor may be able to reduce these so discuss it with him or her. Do not stop taking any medication without guidance from your doctor.

Smoking

If you smoked before your illness, now is an ideal time to give up. If you stopped smoking while you were in hospital, try to keep it going once you get home. For people who have been seriously ill in intensive care it is very important that they stop smoking. This is because the lungs are affected by the illness or being on a breathing machine, and may be damaged. People normally have a considerable amount of spare lung capacity so they do not notice the damage, but it is important that you do not continue to damage your lungs further after your illness by smoking. If you have started smoking again and would like to stop, but need some help the National Stop Smoking Helpline is **0300 123 1044.**

QUIZ

How many of the following things are you doing to help yourself recover?

- Stopped smoking
- Reduced smoking
- Exercising more
- Eating a balanced diet
- Reduced alcohol
- Following a daily exercise plan
- Walking more
- Swimming or cycling
- Exercise classes or yoga
- Relaxation time
- New hobbies or interests
- Making time for family or friends
- Making time for enjoyment
- Making time for self
- Saying no sometimes
- Dropping the superman complex
- Taking things slowly and steadily
- Balancing work with other interests
- Sorting out tensions at home
- Taking medication as prescribed

As you come to the end of your recovery programme, look back over what you have achieved. Doing a little bit more each week applies not only to exercise, but other things you like doing. Set yourself realistic targets to achieve over the next few weeks. If you liked gardening or baking before your illness, but have not had the energy to do it yet, set this as one of your targets and work up to it gradually.

Remember, many patients can take quite a long time to recover from critical illness. Sometimes it can be hard to see the progress you've made. Congratulations on the progress you have made so far.

From the time when you were admitted to the CCD, until your discharge from hospital we have assessed your needs and planned for your rehabilitation needs. Some patients may need to be followed up further once they return home and may be invited to a Critical Care Follow Up Clinic.

Further Sources of Help

If you have any concerns about your psychological recovery your GP is the first person to refer to. Your GP will be able to support you in accessing a variety of help for this type of common problem ranging from self-help leaflets, CDs and computer based resources to short psychological therapies. Medications are also an option. You can discuss both your difficulties and your preferred type of support with your GP.

Some people find that it can be helpful as part of their recovery to speak to staff involved with their care in ICU and maybe ask questions that friends and family have been unable to answer. Some may benefit from re-visiting the

ICU. If you'd like to discuss the possibility of doing either or both of these contact the Critical Care Follow Up team (see details below).

But if you are worried about any of the problems identified in this booklet please speak to the CCD secretary who will arrange for you to speak with the Critical Care Follow-up Clinic staff.

0151 529 3790

(0900-1400 hours Mon-Thurs)

What can I expect on discharge from hospital?

After your stay in CCD there may be some issues that you are concerned about. This could be related to memories of before, during or after your admission to the CCD, or worries about your health now. Members of the multi-professional team will discuss with you and your family what you may need at home to make it a little easier for you as you continue improve. Throughout your CCD stay and time on the wards the multi-professional team will have been assessing and planning for your rehabilitation needs and implementing a plan of care to help you achieve optimum activities of daily living. Some patients make a full recovery before they leave the hospital and do not require any further assistance, but some need support after they return home.

You may be invited to return to the CCD for a Critical Care Follow Up Clinic appointment. You can bring a friend or relative if you wish and, if transport is a problem, we may be able to arrange this. During the appointment you will have the chance to speak with specialist healthcare professionals from the CCD about your recovery, rehabilitation and time spent on the unit. They can offer further advice or help on getting back to ‘normal’ at home and discuss any physical or psychological problems you may be concerned about. Attendance at the clinic provides an opportunity for your relatives to discuss any concerns they may have too. Further Follow Up Clinic appointments may be required, but this will be discussed at your initial visit.

If you feel you are having problems or not coping well once you have left CCD, please do not hesitate to contact the Critical Care Outreach Nurses or Follow up Clinic Staff on **0151 529 3790** via the unit ward clerk**.** If you wish to visit CCD once you are feeling better or you have returned home and you wish to talk to someone, please ring the CCD. You may telephone the CCD at any time on **0151 529 3790**, to make any enquires or ask any questions.

If we cannot help with your concerns or enquiries then the Patient Advice and Complaints Team (PACT) situated by the Main Entrance of the hospital will be happy to discuss any concerns. Please contact them by visiting their office or telephoning **0151 529 3287.**

There are various websites providing support and information to patients and families affected by critical illness. Please see support services section.

Support Services

Patient **A**dvice and **C**omplaints **T**eam provide

- Advice and support for patients, their families and carers.
- Information on NHS services to help you make choices.
- Listening to your questions, suggestions, concerns and complaints.
- Help sort out problems quickly on your behalf.

You can contact them at University Hospital Aintree,

Monday to Friday 9am-5pm, telephone 0151 529 3287.

ICU Steps

Offers a website for patients and relatives affected by critical illness. It provides information, support groups and an online community. This can be found at www.icusteps.org

The Intensive Care Society (ICS)

This is the organization that represents medical healthcare professionals working in critical care. The website has a patients and relatives area, information regarding meetings, guidelines and links to related critical care sites. www.ics.ac.uk

BrakeCare

This organization helps those who have been affected by motor vehicle accidents. www.brake.org.uk

Talk Liverpool

An NHS service that offers psychological support to people suffering with depression, anxiety and stress. www.talkliverpool.nhs.uk/self-help/

Drugs

This site provides straightforward advice about drugs for young people.

Free phone 0300 123 6600 www.talktofrank.com

Turning Point

Turning point provides services to meet the needs of people with substance misuse or mental health problems and those with learning disabilities.

www.turning-point.co.uk

Al-Anon

Al-anon provides support to anyone whose life is, or has been affected by someone else's drinking.

www.al-anonuk.org.uk

Alcoholics Anonymous

Meeting at Emmanuel Church, Higher Lane, Fazakerley, Saturdays 19:30

www.alcoholics-anonymous.org.uk

Part 2

Exercise Plan

The information in this booklet is aimed to help you regain some of your strength and mobility you will have lost during your time spent in intensive care. You may have many physical side effects from the stay on intensive care including stiff joints, tiredness and weakness.

Your joints may feel stiff. When a joint has not been used for a while, it stiffens up, even in young people. The stiffness will go as the joint is used more.

You may feel easily tired at first, which is normal as your muscles have not had to do any work for a while and they need time to build their strength again. It may take some months until you feel that you are back to normal. Everyone is different and so it is impossible to give an exact timetable for how much exercise you should take and when.

This booklet aims to give you general advice about exercise and how regular exercise should form part of your recovery. It may be quite a shock when you realise how weak you have become whilst in hospital, especially if you cannot remember a lot of your time in the intensive care unit. It can be very distressing to suddenly wake up and be hardly able to move, especially if you were very active before you became ill. **Please make sure you read through the whole of this booklet before you begin any exercise.**

Why Exercise?

Exercise is important after being ill and will:

- Strengthen your heart.
- Help to rebuild lost muscle.
- Help to reduce stress.
- Help you to get good refreshing sleep.
- Improve movement in your joints.
- Can improve your confidence.

While you were ill your body took what it needed to survive from its stores in the muscle. This means that all your muscles will have got smaller and weaker and so you may find:

- You feel tired very quickly even when you are pottering about.
- You have difficulty climbing stairs or have to take a break part way.
- Your balance is not as good as it used to be.

The good news is you can rebuild your muscles back to what they were before and, in some cases, even better. But you will need to do some exercises, it will not happen by itself. It may take some months until you feel that you are back to normal. Everyone is different and so it’s impossible to give an exact timetable for how much exercise you should take and when.

Important points about exercise

- Do not try to do too much too soon, because this will just make you feel overtired and disheartened.
- If you have had a bad day, don't get upset about it. Everyone feels like that at some time. Ask yourself if you've been doing rather more than normal over the past few days. This may explain why you feel a bit tired.
- Always warm up and cool down before and after your exercise.
- Allow 2 hours after eating before you exercise, to allow food to be fully digested.
- If you feel unwell reduce your normal level of exercise until you feel well again.

When to stop exercising

You should stop exercising and rest if you experience any of the following:

- Severe chest pain
- Increase in chest tightness
- Dizziness or feeling faint
- Much more breathlessness than you experienced the last time you did this exercise
- Joint or muscle pain

If you have been discharged from hospital and are now at home and the symptoms persist, contact your GP immediately. If you are still in hospital, contact your ward physiotherapist or nurse for advice.

How hard should I be working?

The Borg Scale (see below) allows you to record how hard you are working during a particular activity. The scale is made up from numbers 6 to 20 and, as you can see, by some of the numbers there are words explaining what the level of exertion should feel like to you. When you are first able to do an activity you may find that it takes a lot of effort and this would be a score of 13 or above. Choose the number that best describes how difficult you are finding the activity. Ideally you want to be working around 12- 14.

It is very important that you do not suddenly start or stop your exercise, so always warm up before starting your exercises and cool down afterwards. During the warm up and cool down you should be aiming for 9 and 10 on the Borg scale. Your physiotherapist will give you advice on a suitable warm up and cool down.

Borg Scale of Perceived Exertion

6		
7	Very very light	
8		
9	Very light	Warm up/cool down
10		Warm up/cool down
11	Fairly light	
12		Exercise
13	Somewhat hard	Exercise
14		Exercise
15	Hard	
16		
17	Very hard	
18		
19	Very very hard	
20		

Whilst you are in hospital your ward physiotherapist will give you information regarding exercises and advise you how to progress your exercise.

When you do exercises at home try it out and rate it using the Borg exertion scale. When performing an exercise you want to be working between 12-14. If when you first try an exercise you score your exertion above 15 then this exercise is too difficult for you and you should either

- Do fewer repetitions.
- Do it for a shorter time.
- Choose an easier exercise to replace it.

If on the other hand when you first do an exercise you score below 9 then this is too easy for you and you need to either:

- Increase the number of repetitions.
- Increase the time you do it for.
- Choose a harder exercise.
- Add some weight i.e. hold a small bottle of water.

When you have completed your exercises don’t forget to record it in your exercise diary (page 38) and record your Borg score.

Common questions about exercise

“Am I too old to take up swimming or jogging?”

Whatever age you are it is possible to take exercise. Even if all you can manage is a few minutes of home exercise each day you will start to feel the benefits.

“I get breathless very quickly when I exercise - should I continue?”

As you build up your exercise you will find you will gradually be able to do more before you get breathless. As with all your other muscles, the muscles involved in breathing have got weaker and smaller. They will gradually get stronger as you exercise. This is also true for patients with chronic chest problems. To become fitter you need to be active enough to make you feel slightly breathless for ten to twenty minutes.

“I have a long-standing chest problem, is it safe for me to exercise?”

Yes, research has shown that people with long-standing chest conditions benefit from graded exercise because it makes their muscles able to use oxygen more efficiently. When completing these exercises follow the guidance from this booklet and from your Physiotherapist. Remember to complete the exercise diary (page 38) to monitor your progress.

EXERCISE DIARY	**DATE:**		**DATE:**		**DATE:**	
	REPS/TIME	**BORG**	**REPS/TIME**	**BORG**	**REPS/TIME**	**BORG**

EXERCISE DIARY	**DATE:**		**DATE:**		**DATE:**	
	REPS/TIME	**BORG**	**REPS/TIME**	**BORG**	**REPS/TIME**	**BORG**