

Healthier Communities,
Outstanding Care



Sherwood Forest Hospitals
NHS Foundation Trust

Booklet 3

Rehabilitation after critical illness

Non-physical (psychological) factors

Information for patients



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This is one of four booklets which aims to help you and your family with your critical illness rehabilitation. If there is anything you do not understand please ask a nurse on the ward or contact one of the critical care team. Contact details are at the back of this booklet.

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 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, for example “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 effect adrenalin 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.

While 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 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 adrenalin, 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 which 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, breathe in slowly through your nose saying in your head “one thousand, two thousand, three thousand in” and then without holding your breath, breathe 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 which services are available in your area.

Changes in mood

It is 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, discuss this with your GP. Most surgeries are now able to offer a variety of help for this type of common problem. This ranges 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 while in intensive care can affect 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 spent there. This, while 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 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 while in the intensive care unit. 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 of 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 are at the back of this booklet.

After discharge, your concentration may be poor and you may find 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 recover fully. It is important you do not expect too much of yourself too soon. By the same token, it is also important 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 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. The next goal would be 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 which 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 now you are getting better. 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 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 you are able to do more than they will let you. If this becomes a problem, you need to discuss your feelings with them and come to a compromise 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 which is particularly worrying, talk to your GP or with one of the critical care follow up team. Contact details are 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 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. It is important 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 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. 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, 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, 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 breathe - there may be scars 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 should return 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. 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 between meals 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.

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 between meals.

Have your tastes changed?

Concentrate on foods you like and leave those which 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 or eggs. Alternatively 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 as 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 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 the chemist.
- Keep a list of your medications with you.
- Don't stop taking any of them without first discussing with your doctor.
- Don't let anyone else take them, even if they seem to have a similar problem to yours.
- 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 these 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 pill boxes which have different compartments for different times and different days of the week. You can tell at a glance whether you have taken your tablets.

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

Sometimes the chemist will give you tablets which 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 easing, or is worsening, 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 patients 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.

Patients will normally have a considerable amount of spare lung capacity so they may not notice the damage. However, 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 Smokefree National Helpline is **0300 123 1044**.

Checklist

How many of the following things have you done to help yourself recover?

- Stopped smoking
- Reduced smoking
- Exercised more
- Eaten a balanced diet
- Reduced alcohol intake
- Followed a daily exercise plan
- Walked more
- Swimming or cycling
- Exercise classes or yoga
- Relaxation time
- New hobbies or interests
- Made time for family or friends
- Made time for enjoyment
- Made time for yourself
- Saying "no" sometimes
- Not trying to do everything
- Taken things slowly and steadily
- Balanced work with other interests
- Sorted out tensions at home
- Taken 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 you were admitted to the Adult Critical Care Unit (ACCU) until your discharge from hospital, we have assessed your needs and planned for your rehabilitation. Some patients may need to be followed up again 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, the first person to refer to is your GP.

Recently there have been major changes in what your GP can offer in the way of help for common psychological problems. A new service called IPAT (increasing access to psychological therapy) means most patients will be able to obtain self-help materials, guided self-help, advice or even brief psychological therapy close to home and with only a very short wait. Modern medications are also an option. Your GP will be able to discuss these various options with you.

Some patients find it can be helpful as part of their recovery to speak to staff involved with their care in ACCU and maybe ask questions which friends and family have been unable to answer.

Some may benefit from re-visiting the ACCU. If you'd like to discuss the possibility of doing either or both of these, please contact the critical care follow up team - see details below.

If you are worried about any of the problems identified in this booklet, please contact the **Complex Patient and Family Liaison Nurses** on **07584 331934** (call or text) between 8am and 4pm.

Please feel free to use the following pages to write anything down that you would like to ask the team.

Further information is at the end of this booklet.

Websites and links:

The Intensive Care Society website provides useful information.

The Intensive Care Society,
29B Montague Street
London
WC1B 5BW

Website: www.ics.ac.uk

Telephone: 0207 291 0690

I-CANUK – the Intensive Care Aftercare Network provides a forum for those interested or involved in critical care follow up.

Website: www.i-canuk.com

Everyturn - providing NHS talking therapies in Nottingham, Nottinghamshire, and Bassetlaw.

Website: <https://www.everyturn.org/talking-therapies/locations/nottingham/>

To self-refer: <https://notts-talk.co.uk/>

ICU online support for ex-patients and their families.

Website: <https://www.icusteps.org/support/online-community>

Mental Health Texting Support

Open: 24 hours a day, 7 days a week

Text: SHOUT to 85358

Self-help for COVID Survivors

Telephone: 0115 9111 332

Website: <https://www.selfhelp.org.uk/COVID-19survivorsgroupuk>.



Further sources of information

Diabetes UK: www.diabetes.org.uk

NHS Choices: www.nhs.uk/conditions

Our website: www.sfh-tr.nhs.uk

King's Mill Hospital:

01623 672222

Newark Hospital:

01636 685692

Email: sfh-tr.PET@nhs.net

Patient Experience Team (PET)

PET is available to help with any of your compliments, concerns or complaints, and will ensure a prompt and efficient service.

If you would like this information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call the Patient Experience Team on 01623 672222 or email sfh-tr.PET@nhs.net.

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