

Critical Care Follow-up Information

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Please remember:

This booklet is intended only as a guide; the hospital staff will give more specific advice - always be guided by them.

Introduction

Now that you are on a ward you may have physical and emotional problems that you do not understand. This booklet contains information about problems and concerns that some patient have. This does not mean that you will have all of these, but if you do, the booklet along with the visit from the outreach team may help. You should discuss any concerns with the healthcare team whether they are mentioned in the booklet or not.

Going to the ward

Transferring to the ward is a big step for you.

We base this decision on the fact that you are now getting better and no longer need such intensive care. In spite of this your recovery may have ups and downs, but this is normal. You may feel worried at this stage, because you are leaving a place you feel familiar with.

Having to meet new people on the ward may make you feel uncomfortable; this is also normal.

The staff on the ward understand these feelings and are used to looking after people who have been seriously ill. They will be more than happy to answer any questions, so feel free to ask them.

Critical Care Outreach Team

This is a nurse led team who all have a background in critical care.

The role of the outreach team is to provide support and advice during your recovery, this is to ensure that you have a smooth transfer and are settled onto the ward. A member of the team may visit you before you leave the ICU/HDU to introduce themselves and explain the purpose of the outreach service. They may give you a copy of this booklet at this time as well as answering any questions or anxieties you may have.

Following your transfer to the ward you will be visited regularly by the team until such time that you and the staff involved in your care feel that outreach input is no longer required.

The team will also be able to provide you and your family with information regarding your recovery and stay on the ICU/HDU. They are happy to answer any question that you or your family may have. So feel free to ask any member of the team or alternatively you can contact us on:

Huddersfield Royal Infirmary Tel No: 01484 342846

or

Calderdale Royal Hospital Tel No: 01422 224924

You will notice that there are fewer nurses for the number of patients on the ward than you have been used to before.

Even if you cannot see the nurse at all times there is always one nearby. You will have a call button to ask for nurse assistance, which will be answered as quickly as possible.

Remember you are taking a step nearer to going home

Follow-up care

As part of your care you may come across some or all of these members of the healthcare team:

- Dieticians
- Outreach team
- Physiotherapists
- Speech & language therapists
- Nursing/medical staff
- Pain management team
- Psychiatrists
- Occupational therapists
- Pharmacists
- Social workers

With time the emphasis of your treatment will change from full physical care to concentrate on your rehabilitation and preparation for home. (This may take several weeks).

The aim at all times is to move you from dependence to independence.

You may also see/contact other people who work in the hospital.

Hospital Chaplains

Citizens Advice Bureau

Patient Advisory Liaison Service (PALS)

Breathing

You may experience periods of breathlessness that you cannot relate to any kind of physical exertion. It may be related to something as simple as talking. If this continues and worries you, then discuss it with the nursing/medical staff or the physiotherapist involved in your care.

Tracheostomy

During your stay on intensive care you may have needed a tracheostomy to help you breathe. If it has been taken out before you go to the ward your voice and cough may still be weak but you can help this improve by holding onto the dressing when you talk or cough. This will also help the hole where the tracheostomy was to heal up. If you still have your tracheostomy in place you won't be able to talk, this is temporary until the tube is taken out. If whilst the tube is in you talk slowly and clearly people will be able to lip-read. The staff on the ward will work with the physio and outreach team to care for you whilst the tube is in and when you are ready the tube will be removed on the ward. The hole left by the tube will take approx 5-7 days to heal up completely until then a dressing will be left in place.

Smoking

If you smoked before your illness now is an ideal time to give up. If you stopped smoking in hospital, don't start again when you go home. Smoking kills 100,000 people a year; it causes heart disease, strokes, bronchitis, emphysema, cancer and duodenal ulcers.

There are lots of ways to reduce your cravings. You may already have been prescribed nicotine patches, if not, and you feel these would help please inform a member of staff. You can receive additional help by contacting your local NHS Smoking Cessation Group once you leave hospital.

Nicotine in cigarettes produces chemicals that make the heart work faster and raises your blood pressure.

Mobility/Muscle weakness

During your stay on intensive care you will probably have lost some weight, your muscles may be weak and your joints may be stiff from resting in bed. This may last for several weeks or months, but it will slowly improve as you increase your general levels of activity again.

You may have difficulty in doing small things i.e. writing, fastening buttons when dressing or holding objects and even opening an envelope may prove very difficult.

You may have generalised aches and discomfort, possibly more noticeable after rest. This is just your body readjusting itself and this may continue after discharge from hospital.

Remember how weak you felt last week compared to now

The physiotherapist will see you on the ward and decide on the best exercises to build up your strength. Then a treatment programme will be agreed upon.

Tiredness and exercise

It is normal to feel very tired at times after being ill. This will gradually improve with time. It is important not to spend a lot of time resting and sleeping, as this will make you less fit. If you gradually build up the amount of time you are active your strength will gradually improve. Take advice from the physiotherapists, it is better to do gradual, regular activity than over do it some days and 'collapse' the next.

Remember to listen to your body and aim for realistic, short-term goals.

Examples of short-term goals:

- To get out of bed into a chair unaided
- To walk independently
- To put on your own shoes

Eating and drinking

You may notice changes in your appetite that are affecting your ability to eat and drink. This is very common during illness, but it is very important to eat a diet that is as nourishing as possible especially if you are eating less.

You may be prescribed nutritional supplements by the dietician. These are high calorie and /or high protein drinks which come in a variety of flavours and can be fruit or milk based. If you do not like the taste or consistency please request to try an alternative.

These changes may include:

Feeding Tube

It will have been explained to you that we are giving you some nourishment via a tube in your nose that leads to your stomach. This may be because you are unable to eat anything orally for a medical reason or because you do not eat enough food to keep you well nourished.

Thirst

Unless you have been advised to restrict your fluid intake, it is important that you drink plenty. If you do not feel hungry or are only eating small amounts then try to have nourishing drinks between your meals

e.g. Horlicks, milky tea or coffee, glass of milk or a milkshake.

Altered taste

You may have noticed that food does not taste the same or that you no longer enjoy certain foods. These taste changes are only temporary, so concentrate on the foods that you like and leave those that you don't. However, retry these foods every few days. Using sharp tasting foods like fruit and sauces with your food may make it more palatable. If your mouth is dry then make sure you drink plenty and you may find that sucking boiled sweets can stimulate your saliva.

Appetite

It is very common not to feel hungry but because you may have lost weight it is extremely important to eat nourishing meals to help your recovery. Eating little and often will help, so aim for 3 small meals with snacks in between. If you are concerned then discuss it with the nursing staff or the dietician on the ward.

Dentures

Due to generalized weight loss you might find your dentures do not fit. This may be because your gums have shrunk, causing your dentures to rub causing irritation. As a result you may find eating food difficult. You could try a denture adhesive, until you are well enough to visit your dentist on leaving hospital. Soft foods may be better tolerated e.g. shepherd's pie/cottage pie or adding extra sauces/gravy may help moisten food.

If your mouth is sore then cold foods and drinks can be soothing but salty and spicy foods may sting.

Toilet habits

You may be experiencing anything from diarrhoea to constipation. This is quite common. Patients who have been seriously ill often experience these symptoms. Do not be embarrassed; let staff on the ward know. Advice about diet or medication may help.

Changes to your appearance

These changes may occur after being seriously ill but should be only temporary. However, if symptoms persist or you are concerned then please discuss these with your Doctor or a member of the Outreach Team.

Hearing

You may notice changes in your hearing. This may vary from slight hearing loss to your hearing becoming more sensitive. Also sometimes your sense of balance may be affected and you may experience dizzy periods.

Eyes

You may experience temporary changes in your vision especially when you are tired. It is important to rest your eyes as well as your body.

Hair

You may experience hair loss and changes in the quality of your hair as a result of being ill. It may take up to a year to recover. Tell your hairdresser if you are having this problem and they may be able to advise you on how to improve the condition of your hair.

Skin

The texture of your skin may change. It is quite common to find that your skin has become much drier than before, regular moisturizing will help. If your skin is itchy please ask staff for advice. You may also notice some scars that you feel are unsightly; eventually these should fade to your normal skin colour. After a serious illness you may have lost a lot of weight and notice your body image has changed. Try not to be concerned and dress for comfort. Exercise and a sensible diet will help restore your weight and shape in time.

Sleep

You may have difficulty sleeping e.g.

- Difficulty getting off to sleep or staying asleep
- Sleeping in the day but not at night

This is quite common after being seriously ill and most people find that as their daytime activity increases, sleep improves. Finally, the most important thing is **not to worry** about lack of sleep, whilst unsettling it is not harmful.

Nightmares

Some patients have nightmares when they first leave the intensive care unit or may have had them while in the unit. They may be very vivid and frightening. These usually go over a few days or weeks and again it is quite normal to experience this. Some patients experience hallucinations while they are on intensive care. Again these are common and are caused by a combination of being ill and the drugs that are given to keep you comfortable. If you have had, or are having similar problems please speak to a member of the healthcare team.

To help you sleep

- Milky drinks at bedtime will help you sleep, try to avoid stimulants such as tea and coffee.
- Use relaxation tapes or music of your choice.
- Use ear plugs.
- Use eye covers (to block disturbing lights).

To allow your normal sleep pattern to return it is advised that you get up each morning at a set time, gradually increase activity levels, avoid catnapping during the day and have a regular bedtime.

Medication

When you leave intensive care some of your medicines may have changed. This is nothing to worry about. If you are confused about your medicines or want to know more about them, ask the ward pharmacist or nursing/medical team to explain them to you.

Changes in mood

Many patients have mood swings, one day up the next feeling down. You may also feel very irritable and emotional. This is a normal reaction, and is part of the process of accepting that you have been seriously ill. You may find it helpful to share your thoughts and feeling with someone of your choice.

You may become frustrated with your progress, which seems far too slow, but remember you have been very ill and your body needs time to recover. Don't be frightened to ask your relatives or any member of the healthcare team about your time on intensive care as this may help you to understand the problems you are experiencing.

It is also quite common to feel anxious or become depressed.

Anxiety

If you experience overwhelming feelings of anxiety such as fear, edginess and an inability to relax or physical symptoms such as heart racing, breathlessness and tingling in your hands and feet, you may be suffering from an anxiety disorder. Help is available in the form of relaxation tapes, counselling and medication.

If you feel like this tell one of the healthcare team with whom you have contact.

Depression

If you experience persistent low mood, inability to enjoy yourself and poor sleep appetite, which last more than two weeks you may have developed a depressive illness. Although it may seem an understandable reaction to your circumstances, treatment in the form of counselling and/or medication is important. Research shows that treating psychological symptoms improves your ability to cope with your illness and affects how well you respond to treatment.

It is important to be realistic in what to expect during your recovery and make sure the goals you set in the short term are achievable. It will feel good to do something you planned.

Concentration

The inability to concentrate on even the smallest of tasks or make the simplest of decision may be frustrating. This should gradually become less of a problem over time. If it does not you may need to seek professional help and support.

Your family and relationships

Your family and friends will be delighted that you are getting better but they can be over-protective. Remember that they too have been through a very difficult time. This may lead to arguments and relationship problems. Try to talk about what's happened and tell each other how you've felt, this should help. Try to share your goals with your family, as they may be unrealistic.

Sexual Problems

Many patients and partners are frightened to resume a sexual relationship for fear of harming themselves or their partner. Talking to each other about this may help. It is common for illness to reduce your sex drive initially, but as you become stronger normal feeling should return. Sometimes agreeing not to have sexual intercourse for a period of time but making time for massage will help take the pressure off and let you get used to each other again.

Going Home

Once at home you may find the first few weeks euphoric but this may fade. Soon you will find that you are getting stronger week by week. As time goes on the rate at which you improve will slow down. It does not stop but it may be harder to see changes and improvement happening. You must realize that you may not achieve your previous level of fitness.

If you live alone and have worries and concerns about this please let ward staff know as soon as possible so that support can be arranged.

If you were a patient on the ICU or HDU for 5 or more days you will receive a letter approximately 6 months after your discharge from the unit inviting you to attend the ICU Follow-up Clinic. The aim of the clinic is to give you and your relatives the opportunity to meet with staff and discuss any issues or problems you may be experiencing relating to your stay on the ICU. The feedback you give will provide us with valuable information that we hope will enable us to constantly improve the service that we provide.

If you receive an appointment that is inconvenient please call the number on your letter to arrange a more suitable appointment.

If you are experiencing any problems at home in the meantime you can contact a member of the team using the phone numbers below.

Remember be patient, you are not alone.

For further information please contact

Outreach Team at Calderdale Royal Hospital

Telephone No: (01422) 224924 (direct line)

or

Huddersfield Royal Infirmary

Telephone No: (01484) 342846 (direct line)

If you have any comments about this leaflet or the service you have received you can contact :

Intensive Care Unit
Huddersfield Royal Infirmary
Telephone 01484 342452 or 01484 342453.

www.cht.nhs.uk

If you would like this information in another format or language contact the above.

Potřebujete-li tyto informace v jiném formátu nebo jazyce, obraťte se prosím na výše uvedené oddělení

Jeżeli są Państwo zainteresowani otrzymaniem tych informacji w innym formacie lub wersji językowej, prosimy skontaktować się z nami, korzystając z ww. danych kontaktowych

ਬ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਪ੍ਰਾਰੂਪ ਜਾਂ ਭਾਸ਼ਾ ਵਿੱਚ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਉਪਰੋਕਤ ਵਿਭਾਗ ਵਿੱਚ ਸਾਡੇ ਕਾਲ ਸੰਪਰਕ ਕਰੋ।

اگر آپ کو یہ معلومات کسی اور فارمیٹ کی زبان میں درکار ہوں، تو برائے مہربانی مندرجہ بالا شعبے میں ہم سے رابطہ کریں۔

"إذا احتجت الحصول على هذه المعلومة بشكل مغاير أو مترجمة إلى لغة مختلفة فيرجى منك الاتصال بالقسم المذكور أعلاه"