What you should know after
leaving an intensive care unit (ICU)

RECOVERY AFTER
CRITICAL ILLNESS

FONDATION LAUREN ALEXANDER FOUNDATION

INTRODUCTION

Your experience of Critical Care may continue to affect you physically and emotionally after you go home. It doesn't matter how old you are, how unwell you were or how healthy or active you were prior to your illness. You have been very ill and it may take some time for you to recover.

THIS IS FOR YOU, YOUR FAMILY AND YOUR FRIENDS

People are often shocked and upset by what someone in Intensive Care has gone through. Most people who know you might not have seen quite how ill you were, so it's easy to understand why they might expect you to feel better very soon.

Your family, friends and wider support network will be pleased you are back home, but they may not understand what you went through or why you feel like you do.

You will need their support as you recover. During the recovery process, although you may look well, you may not feel well. Your family, friends and wider support network need to understand this, so it's important to share information on how you're getting on with those that are close to you.

HOW LONG WILL IT TAKE TO RECOVER

Recovery will commonly involve your whole body. Many people encounter new physical, cognitive, psychological and emotional problems during their recovery. It is normal to go through a period of recovery and most people will eventually make a full recovery.

- Recovery time varies for each person. Generally, it can take a few weeks to a few months, but for some people it can take longer. Some people have very few or no problems following critical illness.
- There are contributing factors that can influence recovery such as age, medical history and length of hospital stay.
- For those people who have suffered significant organ damage, recovery will take time and be complex, often involving ongoing treatment. If you have suffered organ damage and/or had an amputation, specific information will be given to you by your healthcare team.
- The recovery period following CoViD-19 is quite variable, but is likely to have similarities to the recovery from other type of severe infections.

WHAT IS CRITICAL ILLNESS

Critical Illness is the medical condition in which a patient, because of a major surgery or severe illness, requires immediate intensive medical support of vital organ functions in order to survive. This care involves treatment to support one or more organs which were beginning to fail. This could be the lungs (breathing), heart and circulation (blood pressure or heart rate) or kidneys (not passing urine).

You may be reading this because you, a relative or friend have recently received Critical Care in a High Dependency Unit (HDU) or Intensive Care Unit (ICU). These units are sometimes combined and during times of high demand on hospital resources, such as was the case during the COVID- 19 pandemic, you may even have received Critical Care support elsewhere in the hospital.

WHY DID YOU NEED CRITICAL CARE?

The Intensive Care Unit (ICU) is where the most unwell patients in a hospital are treated. In ICU:

- you are carefully watched and monitored, including checking your pulse; blood pressure; breathing rate; oxygen levels; how much liquid you take in and how much you urinate. These checks are all very important because staff can quickly identify any deterioration in your condition and change your treatment as needed.

- you receive different treatments including support for your major organs, like your heart, kidneys and lungs.

- you are supported by highly trained doctors, nurses, respiratory therapists, physiotherapists, occupational therapists, pharmacists and nutritionists. Because of your critical illness your nurse may have been assigned to only your care, or to you and one other patient. The team also support your family by informing and explaining what is happening to you.

THE HELP YOU MAY HAVE RECEIVED IN CRITICAL CARE

A team of doctors, nurses, physiotherapists and other health professionals will have treated you, looked after you and tried to make you as comfortable as possible.

The nurses will have spent the most time with you and with other team members they will have done things like:

- Checking how you were responding to treatment through watching your blood pressure, oxygen levels etc.
- Giving you the drugs that you needed.
- Washing you and changing your bed sheets.
- Turning you often so that you didn't get bedsores and moving your legs and arms so that you didn't get too stiff.
- Putting a catheter in. This tube would have been put into your bladder to allow urine to be collected.
- Sometimes, during periods of confusion and agitation (a common occurrence known as delirium) it is necessary to restrict your movements so as to prevent injury to you from inadvertent disconnection of important equipment used to support you. The team may have used limb restraints or padded gloves at times, and you may remember this as unpleasant.
- Removing phlegm from the lungs if you had a breathing tube or a tracheostomy, as you wouldn't have been able to cough strongly. This would have been done by using a suction tube which was put down the breathing tube. It might have made you cough and retch while it was being done, which you may remember.

EQUIPMENT & TREATMENT

There is a range of equipment used in Critical Care that's different from the rest of the hospital. Here are descriptions of some of the equipment and treatments used in ICU:

Alarms

The ICU is noisier than a general hospital ward because of the sounds of equipment and alarms. If you heard an alarm it didn't necessarily mean something was wrong, there may have just been something the staff needed to be aware of — for example a drug infusion which was nearing empty and needed to be changed.

Breathing tubes

Many patients in ICU need support with their breathing. In the most severely ill, this involves passing a plastic breathing tube (endotracheal tube) into the mouth and down the windpipe. Most patients will need sedation to keep them comfortable while this breathing tube is in place, though the staff will try to use as little sedation as possible to help the patient's recovery — the aim is to keep patients as relaxed and calm as possible.

Ventilator or breathing machine

The ventilator is also sometimes called a breathing machine. This helps the patient to breathe while they are very ill, or too sleepy or weak to breathe by themselves. It is connected to the patient via a tubing system and a breathing tube (endotracheal tube) that is inserted into the patient's mouth and windpipe. The tubing allows the ventilator to push air and oxygen (under varying amounts of pressure) into the patient's lungs. Sometimes a tracheostomy or `trach' tube is required. This is connected to the ventilator via a tube that is inserted through the neck and into the windpipe.

Blood pressure monitoring

Blood pressure is measured in ICU using either a blood pressure cuff (like the one at your family doctor's office) or using a cannula inserted directly into an artery, usually in the wrist or groin. This is called an arterial line.

An arterial line can measure blood pressure accurately and continuously, helping to identify problems quickly. It can also be used to take blood samples which show how much oxygen and carbon dioxide is in the blood. This helps make sure that the patient is getting the right support from the ventilator.

Intravenous Catheters

Intravenous catheters (IV lines) are plastic tubings placed into veins. In the ICU, special large IV lines are often required in order to deliver some of the medications required to stabilize blood pressure, monitor your heart function, and administer nutrition and basic essential elements and fluids. These large IV lines are called Central Lines, and they are placed in large veins, either in the neck (jugular veins) or just below the collar bones (subclavian lines). You may notice marks on your neck or chest from these lines. Over time, these marks should fade, but they may always be noticeable to you.

Feeding in the ICU

It's very important for patients in ICU to maintain adequate nutrition and a good calorie intake in order to fight infection and enhance recovery, so while patients are unable to eat normally, feeding tubes are commonly used. A nasogastric tube (NG tube) is the most common type of feeding tube used. These are long thin tubes, placed by a nurse or the doctor, which goes into the nose or mouth, down the oesophagus (food pipe) until it reaches the stomach.

Some patients whose symptoms are severe may be unable to absorb food through their gut. In this case, the nutrition team will support the doctors in designing intravenous nutrition, otherwise known as TPN.

Dialysis machine or ‘filter’

A dialysis machine or ‘filter’ is a form of kidney support. This is a machine that can temporarily take over the work of the kidneys when they are struggling to work normally. Health professionals can monitor how well the patient’s kidneys are working by recording the amount of urine they pass and by doing simple blood tests.

WHAT YOU MAY HAVE EXPERIENCED IN CRITICAL CARE

You may have no recollection of your time in ICU, or you may have very confused memories of what happened to you there. This is common, as your body and mind will have been affected by your critical Illness, your treatment plan and the drugs used to make you better

You may have:

- felt slightly aware but didn't know where you were or what was happening

- had nightmares or thought things were happening which were not real — and these can be very frightening. You may not have realized you were in hospital and your mind may have tried to make sense of what was happening, by making you think things like you had been kidnapped or were being held captive. Experiencing this confusion and hallucinations is called delirium and is very common.

- been unable to talk or let people know what you were feeling

- have found it very difficult to sleep, or experienced strange dreams when you did

- not known what time of day it was, or how long you had been in hospital

Not remembering what happened to you is extremely common. Memories can often be hazy or 'jumbled'. It can be difficult to piece together what happened before being admitted, and what took place while you were there. Some people remember the end of their admission, whilst others remember almost nothing.

Some people are happy not to remember very much, but for others, this can be upsetting. It may be that you are only ready to find out more in the weeks, months and sometimes years after getting home. It may be that you just want to put it behind you. It's completely up to you whether or not you'd like to find out more about what took place.

HOW YOU MAY BE FEELING

Here are some common physical and cognitive problems you may experience during recovery

- Fatigue
- Problems sleeping
- Brittle hair and hair loss
- Joint pains and muscle weakness
- Nausea
- Breathlessness
- Poor appetite
- Change in vision and hearing
- Reduced kidney function
- Short term memory loss
- Judgement and decision-making
- Speech, for example finding the right words
- Loss of concentration
- Difficulty performing tasks that were previously simple

WHAT YOU MAY BE THINKING

Here are some of the most common psychological and emotional problems experienced during recovery:

- Low mood and/or mood swings
- Lack of interest in things that you previously enjoyed, and possibly your personal appearance
- Anxiety about becoming unwell again
- Loss of confidence
- Wondering ‘what if I hadn’t survived?’, as well as feeling guilty that you did survive.
- Feeling guilty about what you have put your friends and family through
- Flashbacks and nightmares
- Frustrated that nobody understands
- Strain on personal relationships

During your recovery you may experience some or all of the problems listed, while looking relatively well to the outside world. Be reassured that it is normal and common to experience physical, cognitive and psychological problems after any critical illness. Give it time and seek support as you need it — you are not alone in your recovery. It is important to take your time getting back to work, study or other activities. It may be advisable to discuss a phased return to work with your family doctor or Occupational Health team at work to assist with the recovery process. If you are currently in higher education, you may find it useful to talk to a Student Wellbeing Officer or academic advisor.

WHAT TO DO TO HELP YOUR RECOVERY

There are a number of ways to help yourself during your recovery period. These include:

Time

Allow yourself time to recover - there is no standard pattern for this and recovery times vary greatly.

Pacing

It can take time to recover physically, so try to pace your activity and do not rush yourself. Remember to work on things you enjoy, as well as things you know you ought to do. Try to take time for the things that you would have enjoyed before, even if you don’t feel like doing much. Your strength should slowly return as you become more active, but this may take longer than you expect it to. Try to think of your energy a bit like your household budget: don’t spend it all on day one - spread it out over the days.

Space to talk

The more often you have the opportunity to share your thoughts and feelings about what happened in a way that feels comforting to you, the better your recovery. The professional staff from the Critical Illness Recovery Centre (CIRC)can provide you with information, support and advice about what has happened and what to expect.

Self-care

Look after yourself. Try to eat healthy, nutritious food including fresh fruit and vegetables and drink plenty of water. Preparing meals can be tiring, especially when living on your own. If you have little appetite when you leave hospital, try eating little but more often if you struggle with bigger meals. In the early recovery phase, it is normal to find yourself eating more and craving things like protein. Listen to your body- it needs these vital ingredients to rebuild itself.

Sleep

You need regular sleep to keep your body healthy. It can take time to get back into a normal sleep routine. You may find it harder to fall asleep, or you may wake more frequently during the night. Sleep should eventually improve but, if it doesn't, look to the further resources page or contact your family doctor for advice about sleep hygiene.

Managing stress and anxiety

As you get better and start doing more, you may face new challenges. One common challenge is accepting that you were ill, understanding that illness and focusing on how to get better. This can make you feel scared but, with guidance and support, this should become more manageable.

Diary

Keeping a daily diary documenting your physical symptoms and feelings, sleep and activity can be both therapeutic and useful. A diary can chart your progress and can help you to monitor any symptoms that you may want to discuss with your family doctor. It is important to celebrate your achievements, regardless of how small you feel they may be.

Light Exercise

It is important to keep mobile if possible, but you may not have energy to do the same amount of exercise that you were doing before you were ill and may have lost muscle tone. Speak to your doctor or physical therapist — they can suggest some gentle exercises to get you started for improving strength, balance, and flexibility.

WHERE TO GET HELP AND SUPPORT

Family and friends

Loved ones can help with daily chores like laundry and shopping. They are also there to listen to what you have been through and will need to understand that it may take some time for you to feel better again.

Family doctor

It is important to update your family doctor with your progress, especially if you have had a long ICU stay. Your family doctor can also review your medicines and may be able to offer you treatment or refer you to other health care professionals to help you through your recovery.

Critical Care follow up

The MUHC Critical Illness Recovery Centre is a structured followup program dedicated to helping you better understand what you went through in ICU, and to support and promote your recovery during your journey after the ICU. You will very likely be offered to participate, with a family member, in this program where you will have a chance to meet with ICU professionals as well as other persons who have been through Critical Illness. You can also reach out to the Program to participate during your recovery. You can reach the Critical Illness Recovery Centre either by phone or email at the coordinates below:

MUHC — Critical Illness Recovery Centret
1650 Cedar Avenue suite B2-118
(514) 934-1934 ext. 44185
icurecovery@muhc.mcgill.ca

WHEN TO SEEK EXPERT HELP

Most symptoms will improve with time as you make adjustments. You will get aches and pains, just like any other person. This is normal and does not necessarily mean anything bad.

Speak to your family doctor if you are still experiencing the following problems more than a month after discharge from hospital:

- Frequent anxiety or worries that interfere with your ability to face day-to-day life
- Low mood or depression, impacting on motivation, your opinion of yourself, or your thoughts about the future
- Continued poor sleep, ongoing nightmares or flashbacks
- Change in behaviour
- Difficulty doing previously ‘normal’ tasks, or looking after the home and family
- Using drugs (prescription/ non-prescription/ recreational) or drinking a lot of alcohol

Adapted with permission from The UK Sepsis Trust publication
"Recovery After Critical Illness"

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