

Returning Home After a Critical Illness

Information for patients & whānau
after a stay in the ICU



Te Rui Atawhai
Wellington Intensive Care Unit

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This book belongs to:

Who was in the ICU:

to

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Introduction

A stay in the Intensive Care Unit (ICU) can often be a life-changing event for you and your whānau. Being critically ill can be distressing, painful, surreal and confusing. However people also describe their ICU experience as an opportunity to focus on and prioritise what's most important in life.

This book will share information that may be helpful in your recovery after a long stay in the ICU. It will go back through what you may remember of your ICU experience and what to expect once home. The advice and suggestions in this book has been created by content experts including a speech and language therapist, Dietitian, Clinical Psychologist, Senior Nurses and an ICU consumer.

Even though everyone's ICU experience is different and your recovery journey is your own, know that you are not alone.

About this book

This book has been designed to give you some very general information about what life might be like for you during your recovery at home. It has been written by experienced ICU clinicians with an understanding of how the ICU experience can be for patients who have spent a long time in the ICU. It is about acknowledging the journey that you have been through and letting you know what may lie ahead as you recover at home.

It will not give any specific instructions or information related to any surgery or treatments you have received. Please continue to follow any instructions that you have been given by the healthcare teams who cared for you.

Who should read this book?

This book has been designed for those who had an extended stay in the ICU. Sometimes a "long stay" can be hard to define but we use 5-7 days and beyond. We know that patients who have had a long stay, or had delirium, or have been very complicated and "sick" can have a long and challenging recovery. This book is intended for patients who have been on a breathing machine, had delirium and/or had an extended stay in ICU beyond 5-7 days.

When should I read this book?

There are no rules around when to read this book. However, the information is probably going to be most helpful if you feel a need to make sense of what you have been through or need information about what life will be like during your recovery.

- Consider reading it together with your whānau or loved ones. Having the support of each other can make this process easier for everyone.
- If you are accessing mental health support, talk with your provider about sharing this information with them.
- If you are a relative reading this booklet, be aware that your loved one may not want to read this until they feel ready. Keep the book somewhere safe until the right time.
- There is a section for family members at the end of the book in recognition that the journey can be as challenging for whānau.

When to get urgent help –

i.e. call an ambulance/get to the Emergency Department (ED)

Seek emergency medical care if you experience:

- Sudden or worsening breathlessness
- Chest pain
- New or worsening confusion
- Unable to eat or drink, or keep fluids down
- Any new face drooping, arm weakness, speech difficulty
- Thoughts of self-harm or feeling unsafe
- Choking or swallowing problems.

Or any situation in which you or your whanau have immediate concerns for your safety, well being or health status.

Transitioning from hospital to home

Leaving hospital is a major milestone in your recovery. While it may take some time to get back to a normal life, leaving hospital remains a very positive step. It can be both a stressful and exciting time for you and your family.

The health care teams involved in your care will do their best to ensure you have all the information you need to leave hospital and return home:

- Your healthcare team should discuss and organise any referrals that need to be completed prior to leaving hospital.
- Ask about any equipment you could take home such as raised toilet seats and mobility aids (walkers etc). Often someone will have organised this, please ask a nurse to organise an assessment with the Occupational Therapists (OT) a couple of days before intended discharge if you are having issues walking/mobilising etc.
- The team you were “under” in hospital, should provide information around your condition or surgery, with instructions on any appointments and ongoing care before you leave.
- Instructions, plans or activities for beyond hospital should be written down prior to your discharge so that you have a record of the next steps once you are back at home. If your hospital health care team hasn’t done this, please insist that they do – it is common for people to struggle to remember these sorts of details after a critical illness.
- Ask that appointments be sent to you in the way that you can manage (either by telephone, or text or email for example).
- If something happens at home that worries you, make an appointment to see your GP who can ensure you are seen by the right people.

Memories of the ICU

In the early stages of being so sick, you may have only very hazy memories or you may remember nothing at all. Both are common and normal. Memories are different for everyone.

You may remember machines and monitors that made noise and alarms around you. These sounds were all very normal and allowed the nurses to respond and manage any changes to your progress and treatments.

You may also remember lots of tubes and lines in your body to support breathing, food, give medications and fluids. All these things are very common for patients in the ICU and are a normal part of being critically ill.

At the stage where you were getting better, you would have been “woken up” from your sedation (what the ICU staff would have called “de-sedation”). As the sedatives and pain killers wore off, your awareness of everything around you would have gradually returned. This is where you **may** have started to have memories again.

You may recall or be unsure about other aspects of the environment: your moving mattress that reduces the chance of pressure injuries; noises coming from the bedspace next to you; or groups of people attending the medical rounds. There are countless confusing and unique aspects to the ICU environment.



Delirium

Delirium is a change in awareness that affects a lot of patients in the ICU. It is seen from the outside as a change in a person's thinking or behavior – being agitated, paranoid, confused, tearful, or quiet and drowsy. The patients' experience of delirium is different from person to person and unique to their life story.

If you had delirium you may remember seeing, hearing or feeling things that were unusual – a distortion fragmented memory, or something happening around you on the unit.

Sometimes people experience frank hallucinations – seeing, hearing or feeling things that are not real. Thoughts that you were being held captive, trapped, or that staff were trying to hurt you are also common. Disturbing dreams or nightmares are also often described by patients as being a reason they don't want to go back to sleep.

Memories of these experiences can be confusing. Sometimes it can be hard to understand what was real and what was not. Delirium is common for someone who has been critically ill and is caused by the illness or the medicines used to treat it. It stops once people start to feel better. You may have memories of being not well behaved, or acting completely out of character and in some cases lashing out or shouting. Please don't feel guilty – all ICU staff understand this is not you – this is delirium and the result of being sick. There is no judgement.

Patients describe how helpful it is to talk about this aspect of their experience. Find someone you trust and share this information with them. At the end of this book, there is a section with information specifically on delirium for you.

What were the machines around my bed?

In the early stages of your critical illness, you may have needed to be on a breathing machine (ventilator). You may have needed a breathing tube that was attached to the ventilator to help you breathe. At the point where you were getting better, you would have had your sedatives stopped and if you have been sick, it may have taken time to come round. Often patients remember waking up to feel the sensation of the tube in the throat and this can be distressing until the breathing tube was removed. For a couple of days you may have needed some oxygen either by a tight fitting face mask over your face or some small oxygen tubes inside your nose.

In some cases, you may have needed to return to the ventilator for some extra support with breathing. At this point it may have been necessary to have a tracheostomy placed so that you were more comfortable on the breathing machine. The tracheostomy is a small curved plastic tube placed in your neck that attaches to the ventilator and also helps you breathe. If you had one of these, you will have a scar on your neck where the tube was inserted. The scar will gradually fade and become less obvious and often heals very quickly.

You may remember the sensation of weaning was difficult and scary or struggling to breath. Often the weaning from the ventilator is a key memory for patients but was a necessary step to getting better. Sometimes patients remember “trachy weaning” as one of the hardest things they had to do.

BREATHING TUBE (mouth)



FEEDING TUBE IN THE NOSE



In order to give you food, you will have had a long plastic tube inserted through your nose and into your stomach (known as an “NG tube”). This may have been there for most of your admission. Some people find the tube very irritating, others

not so much. The nurses would have given “liquid food” (called NG feed) through a small purple pump at the head of your bed.

BREATHING MACHINE (ventilator)



DIALYSIS (kidney machine)



If you were very sick, sometimes your kidneys do not work well. This means that they are not able to clear (filter) your blood of some of the medications properly, or the acids and electrolytes that they normally would. When acids and electrolytes build up this can cause serious illness. One of the machines that helps to filter your blood is called the dialysis machine. This would have involved a very large

plastic tube with two ends inserted into your neck where blood was taken out, and then cleaned and returned to your body. This is a very common therapy in the ICU and even though it sounds very strange, it is life-saving.

OXYGEN THROUGH THE NOSE (high flow nasal prongs)



MONITOR (heart, oxygen and blood pressure)



You would have been closely observed in the ICU via monitoring attached to you. The big screen that looked like a TV would have had all the information about your heart rate, blood pressure, and oxygen levels which the nurses

would write down every hour. The blood pressure would have been monitored continuously by a “drip” (called an arterial line) in your arm or hand. When you were better, this would have been removed and the nurses would have placed a normal blood pressure cuff around your arm.

TRACHEOSTOMY (breathing tube in the neck)



BLOOD PRESSURE MONITORING
(cuff and arterial line)



INTRAVENOUS LINE
in the hand



CENTRAL LINE
in the neck



OXYGEN MONITOR
("sats probe")



The blood oxygen levels would have been monitored continuously by a small plaster wrapped around your finger.

MACHINES THAT GIVE FLUID AND MEDICATIONS VIA THE DRIP IN YOUR HAND, ARM OR NECK ("pump")



FLUID AND MEDICATIONS

Most ICU patients need either a drip into their veins (usually in the hand or arm) or a drip into the neck (central line). This is because you needed fluids and lots of strong medications that could only be given this way. There are special pumps that gave you this fluid and medications.

Other memories, emotions and experiences

You may have other memories of the ICU such as being in pain or having procedures which were uncomfortable. Sometimes people describe sadness, shame or frustration with the loss of independence that comes with an ICU stay. Fear, worry and feeling tense or "on guard" is another understandable response. Anger and frustration with the ups and downs of recovery are also common difficulties and sometimes you may feel like you are on an "emotional roller coaster". If this starts to get you down or you feel like you need help and support, make an appointment with your GP.



A visit back to ICU

Some patients find it helpful to return to the Unit to see where they were and piece together memories of their experience. Some never want to return – that is okay too. If you are curious or think it may help to visit, please phone the hospital on (04) 385 5999 during business hours and ask to be put through to the ICU reception who will pass your call on to the appropriate person.

How a critical illness may affect you once home

What is Post Intensive Care Syndrome?

It is likely that you will continue to have some health problems which need time to recover from. We know from research that many patients return home with issues and ongoing difficulties after ICU as a direct result of being so sick. These difficulties can affect how patients feel and function physically, mentally, and emotionally.

These problems can involve your body by affecting your physical function and mobility because the muscles are weak. There can also be problems with how you remember things, making you feel confused or unable to concentrate on things that otherwise you would find easy (doing a crossword, reading the newspaper, using the computer). You may also have feelings of anxiety or low mood and feel “washed out” or tired all the time. You may experience some or all of these things. These issues are known as the Post Intensive Care Syndrome (PICS).

PICS is a result of bed rest whilst you were on a breathing machine and being given lifesaving treatments. We estimate it can take months (sometimes over a year) for these things to get better and this can be really frustrating. This may also affect getting back to work and driving.

For some patients, thinking about memories of ICU may bring up feelings of dread, or anxiety. These feelings are a normal part of realising just how sick you have been. However for others, more serious issues may be apparent when memories may start to intrude on daily life, creating anxiety and a feeling of not being able to cope. If you are experiencing any of these, please go and see your GP or mental health professional.

Physical issues with your body

Breathing

In the ICU you may have been on a breathing machine (ventilator) with a tracheostomy. Whilst the breathing machine was a necessary part of your treatment, the effects of feeling short of breath can last for weeks, or sometimes months afterwards. This is especially if you had pneumonia or a very serious respiratory illness. Do only what you can manage each day, stop regularly if you become short of breath. If the shortness of breath does not improve over time or gets worse, see your GP.

Problems with your muscles

ICU-acquired weakness is muscle weakness that occurs as a result of being very sick on a breathing machine, and being bed bound. When this happens most muscles in your body would have become weak. The muscles that are affected are most likely your arms and legs but can also be muscles involved in breathing, coughing and swallowing.

In the early stages of your recovery, you may find that even walking a few metres may make you feel weak and short of breath, needing to stop frequently for a rest. If you have had severe weakness that has affected your arms and hands, you may find holding things in your hands, writing, feeding and grooming problematic.

- The key to getting back your strength is regular exercise, good nutrition, sleep and rest periods.
- You will need to slowly increase your activity to build up your strength, but make sure that you rest when you need to.
- If your physiotherapist gave your exercises on discharge, follow these.
- Set realistic short term achievable goals each week and keep a progress diary with your whānau so you can see your progress each week. Physical recovery will be measured in months rather than weeks and it may take up to 18 months for you to feel fully better.
- At times when you feel low or frustrated with your recovery, read your progress diary so you can see how much progress you are making.

With time this will get better but may require ongoing rehabilitation. If you have been seeing a physiotherapist in hospital they will make the necessary referrals for physiotherapy after you return home. If you return home and find you are having issues and were not seeing a physiotherapist, please make an appointment with your GP who will refer you back to the hospital for further assessment.

Voice changes

If you've had help with your breathing, your voice may have changed. At first your throat may be sore so don't strain your voice. Try to relax as much as you can when you speak, and drink plenty of water. You may also have a dry mouth caused by a lack of saliva. Later during your recovery if you notice a hoarse or gravelly voice, this might be something called dysphonia and is also a result of being on a breathing machine. Approach your GP about this problem as this may require an appointment with a speech and language therapist (SLT) or an Ear, nose and throat (ENT) Doctor.

Managing fatigue

You may find it frustrating because recovery is not as fast as you had hoped, or not being able to return to your life like it was before your illness. It is a careful balance between trying to do a little more each day, and not pushing so hard that you experience a set-back. Paced activity is key to steady recovery.

When you have been critically ill, you will probably feel very tired even in the day. Fatigue will gradually get better as you build yourself up and start to eat and sleep better. It may take months to get back to full strength. You may find you have good days and not so good days, but hopefully, as you go through recovery, the good days will become more common.

Strategies to manage fatigue in the first few weeks/months involve regular rest periods and spacing out activities through the day. As you go on, you may find that those activities that require concentration or more effort are best done in the morning when you are more awake. It is best to see what works for you. Keeping a progress diary to manage your daily regime may also help.

Here are some general tips also that may help:

- Set yourself achievable targets to help you get back to normal, and keep doing the exercises your physiotherapist gave you.
- Do not overdo your exercise as this can set your recovery back. You will know if you have overdone it because you may find you are more tired afterwards or the next day. If you have pushed yourself, take some time out the next day to recuperate.
- If you have had an operation, you must follow your surgeon's advice.
- If you feel unwell, have an increase in pain or get out of breath, stop what you are doing and rest. If that feeling persists even with rest, you may need to see your GP.
- Try setting small goals in your daily routine as this can help you recover and show you that you are improving. A small goal could be something as simple as making a drink for yourself, or walking a few steps further without needing to rest. It will all depend on how you are at the time of discharge.
- Longer term goals such as going for a day out, or returning to study/work should be realistic but achievable.

Appetite and nutrition

Leaving hospital after critical illness is a big step forward in your recovery. Your body has been through a lot and eating and drinking well is important to help with your recovery. Eating well can help you to:

- Rebuild strength and muscle
- Fight infections and have a strong immune system
- Have more energy and feel less tired
- Avoid losing any more weight.

It is common to have a low appetite, to quickly feel full after eating or drinking small amounts, for food to not taste 'normal' or to feel easily exhausted after eating or preparing a meal. These things can make it difficult to eat and drink enough. The amount of food that our bodies need varies from person to person, but to help with your recovery your body will probably need more than usual to build up muscle strength again.

You may have been given special advice around food and drink by a dietitian when you were on the ward. If so, follow this advice as it has been developed especially for you.

If you weren't given specific advice by a dietitian, some tips that can help are:

- Eat small meals and snacks regularly through the day, even if you don't have much of an appetite. This helps to build up your appetite and get your taste buds working properly again.
- Try not to drink large amounts just before meals, as this can fill you up and reduce your appetite.
- Have a protein food at each meal. Foods high in protein include meat, chicken, fish, eggs, legumes/lentils, baked beans, nuts and dairy products.
- Keep snacks on hand so that when you do feel hungry you can get something quick and easy to eat. Some snack ideas include crackers with cheese, hummus or peanut butter, yoghurt, muesli or nut bars, a small bowl of cereal, rice pudding or fruit with yoghurt or custard.
- Nourishing drinks can be a good snack option. This might be a milky Milo®, milky coffee, a milkshake or smoothie that is made with milk, flavoured milk, Up&Go® or a special nutrition drink like Fortisip®, Ensure® or Complan®.
- Consider having some meals in the freezer so that if you don't feel like cooking you can easily reheat a meal.
- If you get out of breath when eating, try having meals that contain more moisture and need less chewing – add sauces and gravies, try mince-based meals or casseroles rather than grilled or fried meats, choose foods that you can easily break with the side of a fork.

If you have ongoing problems with eating and drinking, keep losing weight, or are unable to put on weight once you're home, talk about this with your GP. They may be able to refer you to a dietitian at your local hospital for some more specific advice.

Swallowing difficulties

Swallowing difficulties may have prevented you from swallowing your saliva effectively, or from being able to eat food and drink normally. This can happen for a few different reasons: a particular illness can have a direct impact on your swallowing; a breathing tube can affect patients' swallow; or people have weak swallowing muscles if they have been very sick and on bed rest for a long time.

Swallowing problems can sometimes lead to food, drink or saliva going down the wrong way, which can be dangerous. If you had problems with this during your ICU stay you may have been nil by mouth, or the Speech and Language Therapist (SLT) may have modified the texture of your food and drink. They may have given you strategies or exercises to improve the effectiveness and safety of your swallowing.

If you haven't been seen by a SLT and you are having swallowing problems once home, inform your GP/medical professional to organise a referral for an assessment of your swallowing. Signs include:

- Difficulties moving or clearing food/drink in your mouth
- Coughing/choking/or gurgly voice when eating or drinking
- Multiple swallows to get food or drink down

Tips for safe eating and drinking include:

- Always eat and drink in an upright position, out in a chair if possible
- Minimise distractions when eating and drinking
- Avoid eating too quickly
- Avoid putting too much in your mouth when eating and drinking

Weight, taste and smell

You may have found that during your hospital stay your weight fluctuated greatly. While in ICU, weight tends to increase not because you are given too much food, but as a result of the body holding on to salt and fluid. As your health improved, you may have been given medications to make you urinate more, to get rid of this fluid.

You may now notice that your muscles are smaller than before and that you also lost fat/weight. This may be as a result of not being able to take in enough nutrition to support your body during illness and because you were not using your muscles whilst on bed rest. As you begin to recover and build your muscles up gradually, your weight should increase.

Your taste and sense of smell may have changed, which can be upsetting. Some types of medications that you received can leave a metallic taste in your mouth. You may remember a tube that was placed in your nose and into your stomach which was giving you a special liquid food. When you begin to eat and drink normally again, food may taste stronger or just different. Your sense of smell may also be affected because it is closely linked to your sense of taste. All of this should improve as you recover.

Hearing and sight

You may have sore, dry eyes because you were asleep for a long time, or your eyes may be puffy and swollen because of the fluids you were given to keep you hydrated. You may feel very sensitive to different things touching you and to bright light or loud sounds. These changes are usually temporary and should disappear over time. Sometimes the medicines that are given to treat infections (antibiotics) can also cause some hearing loss. Also, because you weren't able to use your mouth to eat, this can cause ear wax build up in your ears which can also affect your hearing. If you are having trouble with your hearing, please go and see your GP who can have a look inside and if needed, refer you to an audiology clinic.

Your skin and hair

Your skin may be dry or itchy after your illness. Moisturising it regularly can help stop this. You may notice changes to your hair and some of it may fall out. This is not unusual and can even happen months after you leave hospital. It usually grows back but it may be more curly, straight or thin, or a different colour from how it was before.

Bruising

If you were on a drip or had other tubes in you, you may have bruises and scars. These are usually on your hands, arms, wrists, neck, groin or sides of your chest. You may also have bruises on your stomach because of injections to stop your blood from getting clots.

Problems going to the toilet:

When you were in the ICU, a doctor may have put a tube in your bladder. This is called a urinary catheter. It drains urine from your bladder and allows the staff to check your fluid levels. When the tube is taken out, your muscles may be weaker so you may find it difficult to control your bladder. Don't worry, this usually returns to normal, but you can ask your medical team for exercises that may help in the meantime. If you have problems urinating, you may have an infection, so see your doctor or a nurse as soon as possible. Symptoms include:

- Not being able to pass urine for several hours
- Having a burning pain while urinating, and
- Blood in your urine.

Sometimes medication can change the amount and colour of your urine. It may even affect how often you go to the toilet. The medication may also affect your bowel movements. If you're worried about any of these things, talk to your doctor about them.

Issues with your memory or thinking

Some patients may have difficulty with remembering, paying attention, solving problems and working on complex tasks. To you this may feel like “brain fog” or just not being able to understand certain things.

After leaving the ICU, 30% to 80% of patients may have these kinds of problems. In the ICU we call this “cognitive dysfunction”. Some people improve during the first year after discharge from the hospital; other people may never fully recover.

Cognitive dysfunction may affect whether you can return to work, the ability to manage finances, or concentrate on thinking activities. Driving may not be safe.

- If you are struggling to make decisions, or remember things, make an appointment with your GP. They may want to ask questions around this to assess the level of thinking and concentration
- The key to recovery is to take things slow, try to get good nutrition, rest and sleep
- If things like reading, writing, or working on the PC give you headaches – stop and take a break
- Try to space activities out during the day so you are not overloading yourself too much
- Do not attempt to drive a car until your GP thinks you are safe to do so
- If lists help, consider a diary or a whiteboard to remember important dates.

Sleep difficulties

You may have remembered in the ICU not having a lot of sleep, or feeling sleep deprived. This is a very common problem for ICU patients and can be very stressful at the time. You may find that you have some ongoing sleep disruption at home. It is important that you try to keep to a day-night routine as much as you can and maintain regular rest periods during the day to manage fatigue and tiredness. The fatigue that happens during the day may feel like “jet lag” and may stay for some time.

- If you can, accept help with household chores and daily activities and build up your daytime routine slowly, with regular rests in between.

Issues with mood & wellbeing

Post ICU trauma and anxiety

Having been through a long illness and a stay in the ICU may have left you feeling glad to be alive and thankful that you made it through. However, with this there can be other emotions and thoughts that linger and they may not always be the happy and positive emotions. This is normal.

Reminders of your illness may produce intense feelings or strong, clear images in your mind. You may also feel depressed or anxious and may have symptoms of ongoing stress. These include having nightmares and unwanted memories, feeling anxious and wanting to avoid thinking or talking about your stay in the ICU.

If you are having any of these issues, please make an appointment with your GP early. Do not wait to see if they go away, go and seek help.

At the end of this booklet there are some helpful links and telephone numbers if you want to talk through some of those emotions. However the key to managing this, is to talk about it early and get help and treatment. Open up to your whānau and loved ones if you feel able.

Patient diaries

If your whānau kept a diary while you were in the ICU, it can be helpful to look at this together. They would have been writing in it each day with your progress and what was happening to you whilst you were asleep. The diary can be really beneficial to go through when you are struggling to piece together memories and events. You may not feel ready to go through your diary straight away, but at the time when is right for you, we would suggest sitting with your whānau and going through it together. Take it slowly if you are finding it an emotional process. If you are accessing mental health support, share your diary and this book with your service provider.

Be guided by your mental health professional, your own feelings and your whānau.



Delirium

ICU Patient Information – Intensive Care Unit

Delirium is a severe state of confusion that can happen as a result of being very sick. It is a very common condition for patients in hospital and in the ICU. If you have experienced delirium you may have some memories of being very confused, or not able to recognise where you were or what was happening to you.

This is an information pamphlet to help you understand what delirium is and what you may have experienced. We realise this time may have been very distressing for you.

If you have questions please do not hesitate to ask the nurses or your medical team in hospital or if you are at home, make an appointment with your GP to talk about your concerns.

There are some very informative websites that have been made especially for patients who have had delirium. Please see the end of this pamphlet for the website addresses.

What is delirium?

Delirium often develops quickly, lasts for a couple of days and then settles as you recover from your severe illness. In some patients it may last longer and (usually) this happens with patients who have been very unwell and who have been given medications (sedatives) to keep asleep whilst on a breathing machine.

There are two main types of delirium. The first type of delirium often makes patients appear very frightened or distressed. They also may be very fearful of the doctors and nurses around them (and may suffer from some paranoia). This type of delirium often results in confusion and agitation, and patients may try to get out of bed and pull at tubes and drips.

The second type of delirium appears slightly differently in that the patient may appear calm, or just very sleepy and not wanting to talk or interact. However, often patients may feel very muddled and unable to think clearly or concentrate on simple tasks. This type of delirium is very common.

Causes of Delirium

There are many causes of delirium and many different illnesses can cause it. It is often thought of as a result of the “brain being sick” as a reaction to illness.

The following illnesses in particular have been found to make people much more likely to develop delirium:

- A severe acute illness, such as a urine infection or chest infection
- A blood infection called “sepsis” from a severe infection
- A stroke or a direct blow to the brain
- Undergoing withdrawal from stopping daily alcohol use or smoking cigarettes
- Severe, uncontrolled pain
- A broken hip
- Heart surgery
- A known diagnosis of dementia.

What might you have experienced?

You may have some memories or experiences of things that did not make sense when you were very ill. You also may have a hard time telling what was real or not when you look back at your time in ICU.

Some of these memories and experiences may have been very frightening and you may have felt that your brain and thoughts were not quite working properly. Be assured this is a common experience for many patients who are going through severe illness and it should settle over time.

It is important to realise that delirium is NOT dementia. Although patients who have been diagnosed with dementia may be more prone to delirium, delirium will not lead to dementia.

Some of the other things you may have experienced are:

- Emotional changes, feeling vulnerable, scared, anxious or paranoid
- Unable to think clearly / clouded, foggy brain
- Trouble paying attention and concentrating
- Seeing or hearing things that are not there (hallucinations). These things at the time would have seemed very real
- Agitation and restlessness
- Not knowing if it was day or night.

What happens now?

Some patients are very worried about how delirium changes their ability to think clearly and how fast they can get back to normal life after recovery from illness.

The time frame is different for everyone and there may be some effects that last for weeks to months. Some of these may be:

- Difficulty with concentration
- Finding the right words
- Making your thoughts clear
- Being able to process information.

There may also be some anxiety or depression following your stay in ICU. These are very normal reactions to being so unwell.

Please take time to see and talk with your medical team or GP about any of these feelings as they will be able to help with this.

What other things can you do?

- Once home, maintain friend and family support networks and return to your hobbies as you are able
- Take the time to recover, eat and sleep well. Talk to your dietitian/medical team/GP about what kind of foods you should eat during recovery to enable your body to regenerate
- Schedule rest periods during the day and try not to do too much
- If your family completed a “patient diary” in ICU, sometimes reading this can help to “fill in the gaps”. Ask your family if they can help you remember things from your stay in ICU
- Talk to those around you if you feel lonely or sad
- Ask for help from your GP if you are having anxiety, depression or trouble sleeping
- Keep your home or room quiet and comfortable. Surround yourself with familiar objects such as pictures of your family and friends or memorabilia of favourite hobbies or events
- Keep a calendar and clock nearby to remind you of the date and time if you are having problems with short-term memory.

Additional information that may help:

The following websites may help in giving you more information:

Critical Illness, Brain Dysfunction and Survivorship (CIBS) Center

An American website with very good information on delirium.

<http://www.icudelirium.org/patients.html>



Patient

<https://patient.info/doctor/mental-health/delirium-pro>

Social, financial & relationship issues

After you've been critically ill, you and the people around you may seem to change. Your family may make a fuss and might not understand why you seem different, or why you aren't keen on the hobbies and interests you used to enjoy. Your family and friends were afraid you might die, so they may want to do everything for you when you get home. If this annoys you, talk to them calmly about how you feel. Don't bottle things up and get angry.

Social life and hobbies

When you have been seriously ill, returning to the things you used to do may not seem quite as enjoyable. You may struggle with big groups of people or find social events exhausting:

- Start by seeing one or two friends at a time for short periods
- If socialising was something you really enjoyed before your illness, build this into your longer term goals as something to achieve. It is important to take this slowly
- Limit use of alcohol and recreational drugs as your body is healing
- Slowly build hobbies into your daily routine, starting with the easier things first.

Relationships and family

Your whānau would have been around you in the ICU at the point you were the sickest. They would have seen things which you do not remember, maybe struggling to come to terms with seeing you so sick or recovering themselves from the emotional rollercoaster of your ICU stay.

Families respond to the ICU journey in many different ways and the experience may have impacted on relationships across and within families and yourself.

Talk to them calmly about how you feel now. You may not remember your time in hospital clearly and it may help to talk to your family about what they remember and how they felt when you were ill.

It may be that your whānau would benefit from talking to someone to help them deal with their own experience of you being so sick – this is also common for ICU families.

Sexual relationships following critical illness

It is normal to be worried about when it is safe to start having sex again. Your partner is likely to be thinking about this too. There is no right or wrong time to re-engage, it is dependent on when you and your partner feel ready. If you are worried about your strength, compare the energy needed for sex with the energy you need for your exercises. Take things slowly and see what happens. Sometimes medical problems can impact on feeling a desire for sex or getting and keeping an erection. Medications can also affect your sex life. Talk to your GP if you have concerns.

If you have children

If you have children it is likely they will have seen you very ill in the ICU or early in your recovery. It is normal for them to be curious about why you were sick and also to worry that you will get sick again. Skylight Trust offers some helpful advice on managing difficult conversations with children and young people so that you can explain what has happened to you and alleviate some of their worries.

The following tips are taken from Skylight trust information pamphlet.

When you are ill – ways to help your children

What children need

- Safety and security, to be included in family life
- Continuity in daily activities and normal routine
- Not to be burdened with too much information, unedited emotions, or too many new responsibilities
- Truthful and honest information that is age appropriate. Encourage questions and curiosity. This is because even very young children know something is going on. Sometimes fear of the unknown and imagination are often worse than reality. Lying or withholding information can lead to a betrayal of trust.

Help yourself first then help your children

Most of us lack experience in talking with adults or children about illness or death. Carefully consider the age and stage of your child and keep your message to a few main points. Do your best and be compassionate with yourself and your children:

- Listen carefully to your children; observe them. Listen to those who know your children best, including yourself
- Talk with other ill parents, with a spouse or partner, with a professional, or someone you trust and respect
- Explore age-appropriate books and websites
- Keep the lines of communication open
- Expect to revisit the same questions, as well as to address new concerns, through the immediate crisis and even years later
- Expect your children to respond with anger, fear, disappointment, and suffering. Hold this with them as you can, without blame and judgement directed at them, yourself, or others. You will find surprising strength in yourself, and so can they in themselves
- Stay alert for signs that your children may need extra help.

For more information on Skylight Trust see page ???

General things that may help you recover once home

Finances & social support

Lots of people worry about coming home from hospital and returning to work after a critical illness. If you used to work, you may not be well enough to return full-time straight away. This can be a very stressful time for you especially if there are financial worries. Depending on your job, you may be able to do a few hours a day at first and alter the tasks you complete to suit your needs. If there is an occupational health team at your workplace they will be able to help with planning your return to work. If your income has reduced as a result of your illness and you have been unable to return to work, you may be able to receive some support through ACC or Work and Income (WINZ).

ACC can support people who have had an accident. An ACC claim would have been lodged when you were first admitted to hospital and it is likely that someone in your whānau was set up to have authority to act on your behalf for the ACC claim when you were unable to. If you were working before the accident and are eligible, weekly income compensation will most likely be being paid into your bank account. Speak with someone at ACC for further information – your claim number will be on your hospital discharge summary and you may have a recovery partner assigned. More information about ACC is available on their [website](#). Seek support from your whānau or those supporting you if needed.

WINZ can provide financial assistance for people whilst they are looking for work or have reduced hours/ unable to work due to a health condition, whether this is temporarily or long-term. Someone in your whānau may have applied to be able to act on your behalf in relation to WINZ when you were unable to and may applied for a benefit for you. Speak with your whānau or phone WINZ to check. Update WINZ once you are home to ensure you are receiving what you are entitled to. You can check your eligibility for financial assistance from WINZ and submit an application [online](#). If this is not accessible, phone WINZ instead. Again seek support from your whānau or those supporting you if needed.

If you were receiving a WINZ benefit prior to your hospital admission contact WINZ to update them on your situation and check that you are receiving what you are eligible for. This may have changed since your hospital admission.

WINZ can provide assistance to support people back into work. Speak with someone at WINZ if this is something you are considering.

Also think about whether you have any health/ life insurance policies you can make a claim on due to your admission, whether you can apply for a mortgage holiday or request withdrawal of your Kiwisaver if needed. Your specialist or GP will be able to assist with any medical reports required for these.

There may be community social services in your area that can assist with meeting basic needs if you are struggling financially, such as food parcels, clothing or providing budgeting advice. Contact your local Citizens Advice Bureau (CAB) who should be able to advise you on services in your area.

If you have concerns about the wellbeing of yourself and/or your whānau speak with your GP about a referral to a Te Whatu Ora Social Worker who can assess your strengths/needs, consider your support network, assist with accessing appropriate services and provide advocacy if required. A Social Worker may also be available through community social services, check with the individual service.

Te Waa is the time needed for wellness and healing on all levels – emotionally, spiritually, physically and mentally. Healing is a personal journey and very individual. Community based activities that are run by the church or marae can be fun and therapeutic and may help you to reconnect with your community. Consider easing into the big group based activities slowly, but if it is comforting and healing, go for it.

See the directory at the back of this booklet for contact details for ACC, WINZ and Citizens Advice Bureau.

Connection with whānau & taha wairua

Recovering from a serious illness is not just about the body. For Māori, healing is about restoring balance between tinana (body), hinengaro (mind), wairua (spirit), and whānau (family). All of these matter in your recovery.

What you might be feeling

After ICU, it is common to experience:

- Tiredness and weakness
- Poor memory or concentration
- Anxiety, low mood, or distressing memories
- Feeling disconnected from yourself, your whānau, or your wairua.

These are part of Post-ICU Syndrome. You are not alone, and recovery takes time.

Ways to support your healing

1. Care for your wairua (spirit)

- Spend time in places that feel meaningful (home, marae, whenua)
- Use karakia or quiet reflection if that feels right for you
- Stay connected to your beliefs and values.

2. Stay close to whānau

- Let whānau support you—healing is not something you have to do alone
- Share how you are feeling, even if it's difficult
- Involve whānau in appointments and recovery decisions.

3. Look after your hinengaro (mind)

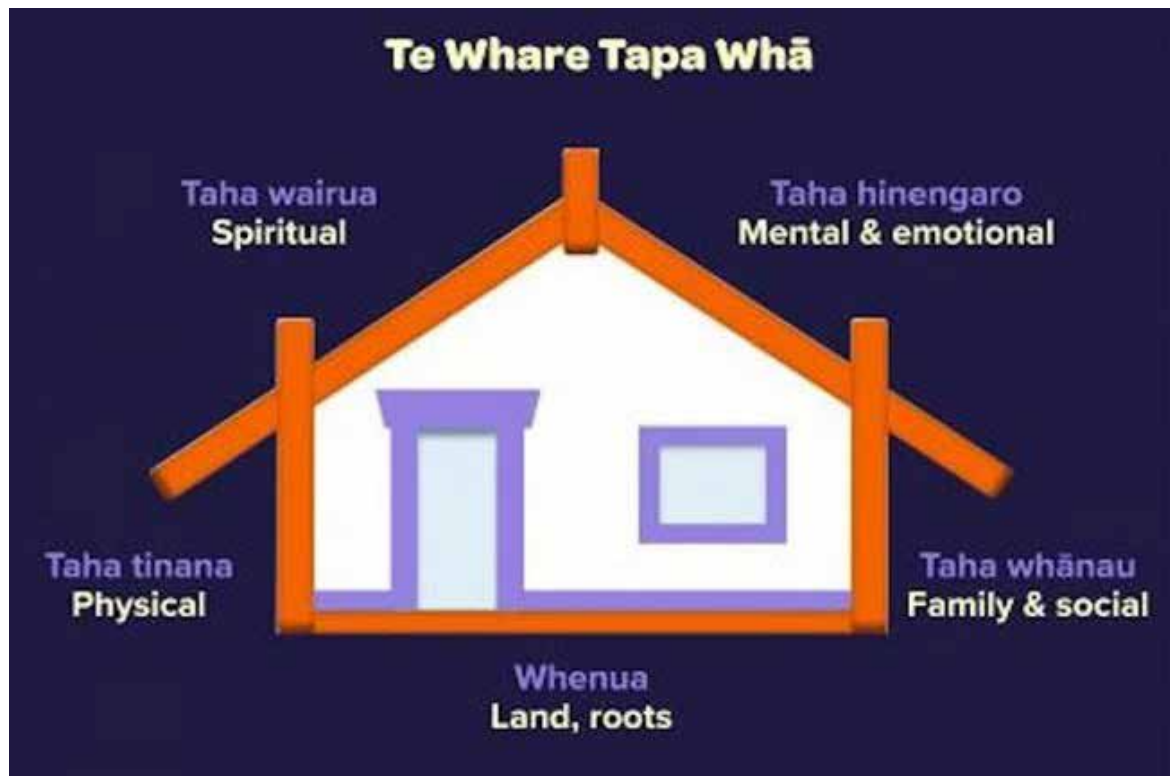
- Talk about your ICU experience with someone you trust
- Ask for help if you feel anxious, low, or overwhelmed
- Take things slowly—your mind needs time to recover too.

4. Rebuild your tinana (body)

- Start small and build up your strength slowly
- Gentle movement, walking, or culturally meaningful activities can help
- Rest is just as important as activity.

5. Reconnect with who you are

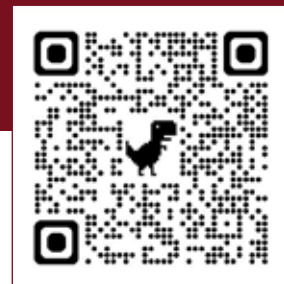
- Spend time with your culture, language, and identity
- Connect with whakapapa and the things that give your life meaning
- Take pride in each step forward—recovery is a journey
- For whānau: How You Can Help
- Be present—your support makes a real difference
- Learn about Post-ICU recovery so you know what to expect
- Encourage, but don't rush—healing takes time
- Look after your own wellbeing too.



Rongoā Māori

If you are Māori you may also wish to involve Rongoā Māori healing into your ongoing care. There are several Ministry of health funded Rongoā Māori providers in New Zealand. The following website lists them:

<https://www.health.govt.nz/our-work/populations/maori-health/rongoa-maori-traditional-maori-healing>



The experience of whānau

The experience for relatives and whānau who have been through this journey of critical illness is also really hard. This section of this book is for family and whānau members who have been affected by this journey.

As whānau, you may not have realised how affected you have been until you are all home. However, this is the time when you may realise just how much you have also been through and this can be very emotive and painful. On one hand you will be so thankful to have your loved one home and safe with you. On the other it will also have been a tremendously hard emotional roller coaster.



Post Intensive Care Syndrome (PICS) is recognised as a common experience to patients and their close family members that have been part of the ICU stay. When this happens this is called PICS-family (or PICS-F). There may be the same emotional, psychological and mental health issues that affect you and your loved one.

We want to acknowledge the incredible journey you have been on. Your support and care of your loved one whilst they were in hospital and ICU would have been a big pressure on you and very stressful. This stress may or may not still be there now you are home. Please try and be kind to yourselves during recovery at home. Here are some very general tips to help you manage all of these thoughts and emotions.

- Accept offers of help around the house, cooking, child care and chores when it is offered.
- Make an early appointment for you to see your GP. Even if this is all but a chat about what you have been through and how you are feeling now, this is a good step.
- If you are dealing with some intense emotions such as feeling low, or anxiety and depression, definitely make an appointment to see your GP. They will make the appropriate referrals.
- At the back of this book are also some useful numbers/websites in which to get support and more information on.

- Try to do the basics of eating a balanced diet, getting exercise and maintaining a regular sleep pattern. Avoid use of alcohol and recreational drugs.
- Continue to hold hope - it may not always be this hard.
- Reconnect with the things that bring you joy; whānau, hobbies, a walk in the sunshine.

Positive aspects of going through a critical illness

Are there any positives which I may experience as part of my recovery once home?

This book focuses on providing support and information for those with issues following an ICU stay. It is important to allow time to re-adjust and to grieve for the life you once had.

However, there is plenty of evidence from patients who recover with positivity, who learn lots about themselves through this experience, and sometimes gain a new lease of life. Experiences such as these can often bring families closer and highlight meaning and purpose in life.

Even those who have been critically ill for months, or those who do not make a full recovery, describe adjusting to a new normal and living life with a different outlook. Access the support that will help you re-establish your new life and plan to reach new goals.



Post-ICU recovery strategies (summary)

Daily activities at home

- Start with basic tasks like washing, dressing, and preparing meals
- Break tasks into smaller steps
- Sit instead of standing where possible
- Plan rest before and after activities
- Accept help from others.

Managing fatigue (pacing)

- Do a small amount of activity, then rest
- Stop before you feel exhausted
- Increase activity gradually
- Avoid overdoing it on good days.

Managing breathlessness

- Stop and rest
- Sit leaning forward or supported
- Breathe out slowly (longer out than in)
- Wait until breathing settles before continuing.

Confusion and brain fog

- If confusion starts or gets worse after going home, seek urgent medical care (ED)
- If brain fog is a problem, write down daily jobs and appointments on a whiteboard or note book
- Using the reminders app on your cell phone can be helpful.
- Use the morning to schedule jobs that require a clear head and thinking
- Take regular breaks from the computer, or screentime.

Emotional wellbeing

- Feeling anxious, low, or overwhelmed is common
- Talk to someone you trust
- Seek help if symptoms are not improving or worsening.

For whānau

- Attend appointments where possible
- Help monitor recovery
- Encourage rest and pacing
- Watch for warning signs
- Look after your own wellbeing.

First week at home checklist

- ✓ Take medications as prescribed.
- ✓ Ensure you have received mobility aids (if you needed them) from the occupational therapy team.
- ✓ Eat small regular meals.
- ✓ Drink enough fluids.
- ✓ Move a little each day.
Get outside in the sunshine (remember SPF).
- ✓ Rest often.
- ✓ Stay connected with whānau.
- ✓ Make an appointment with your GP if you have any concerns during your recovery.

Further Information & resources

Critical Care & Delirium



My life after ICU

My life after ICU is an Australian and New Zealand website dedicated to information after a critical illness for patients and their whānau.



Online videos

The Society of Critical Care Medicine has developed several videos featuring interviews with caregivers and ICU survivors. These videos also are available at:

<https://youtube.com/playlist?list=PLsb8sp1zaJWoeZ2qY2Lymyinp671HS8&si=3Jj7iDtT9wOPvBcP>

ICU Steps

The ICU steps initiative was the first resource developed for patients and relatives in the United Kingdom and is a thorough and detailed resource.

<https://icusteps.org/home/patients>



Primary Solutions Wellington – Nga Pu hera Atawhai/ To Be Heard Wairarapa

Primary Solutions/To Be Heard Programmes provide a range of support services that are available to patients enrolled in Compass Health practices, who have a mild to moderate mental health issue*, **and** meet one of the following criteria:

Primary Solutions Wellington

All young people aged 12 to 25 years

Community Services Card holders
aged 12 years and over

Māori 12 years and above

Pacific Island people 12 years and above

To Be Heard Wairarapa

All young people aged 10 to 24 years

Community Services Card holders
aged 10 years and over

Māori 10 years and above

Pacific Island people 10 years and above

**A mild to moderate mental health issue may mean a variety of things. In primary care, depression and anxiety are quite common, but what is important to consider is how stress impacts a person's functioning. The severity of your difficulties is based on what you report, what can be observed and what can be measured. Everyone experiences stress, but for some individuals it is more difficult to manage.*



Primary Solutions/ To Be Heard Programme are:

- Free of charge
- Confidential and privacy is maintained
- Respectful of different cultural and spiritual values
- Considerate of the differing needs across the lifespan.

How can I be referred to these services?

- By your Doctor/GP
- Self-referral
- Or by direct referral within those primary practices where there are primary mental health practitioners based on a weekly basis.

Who can ask for support and information?

- Referrals from GPs and other health professionals
- Social and community agencies
- And who lives in the area from Tawa to Waikanae.

The service is:

- Free of charge
- Confidential
- Acknowledges and respects different cultural and spiritual values
- Recognises the differing needs.

What happens after I am referred?

A Primary Mental Health Practitioner will contact you to assess the factors impacting on your wellbeing and to identify the supports you require. Primary Mental Health Practitioners follow a Stepped Care approach to service provision by matching the level of intervention to the level of need. Services offered by the Primary Mental Health Coordinator may include:

- Face-to-face needs assessment and discussion that explores the different areas in your life where you might be struggling as well as focussing on your strengths, preferences and resources, occasionally this may be via telephone
- Assessments will be held either in your primary practice or the Compass Health counselling rooms which are based in Wellington, Porirua, Kapiti and the Wairarapa
- Information and links about support services available in your community and how to access these services, including making referrals to other agencies
- Actively monitoring your progress should you undertake a self-management or e-therapy programme to work through your difficulties
- Brief intervention, therapy to help you manage issues that are affecting you
- Working with you to plan a flexible package of care to meet your individual needs, which might include:
 - Assessment and short term therapy with the mental health practitioner
 - Seeing your GP or practice nurse for follow up appointments which can be funded
 - Access to external providers for those with more complex mental health issues.

Tū Ora Compass Health, Primary Solutions

04 801 7808

<https://tuora.org.nz/services/sub-services/7>

Skylight

Building resilient children young people, whānau and communities.



Who we support

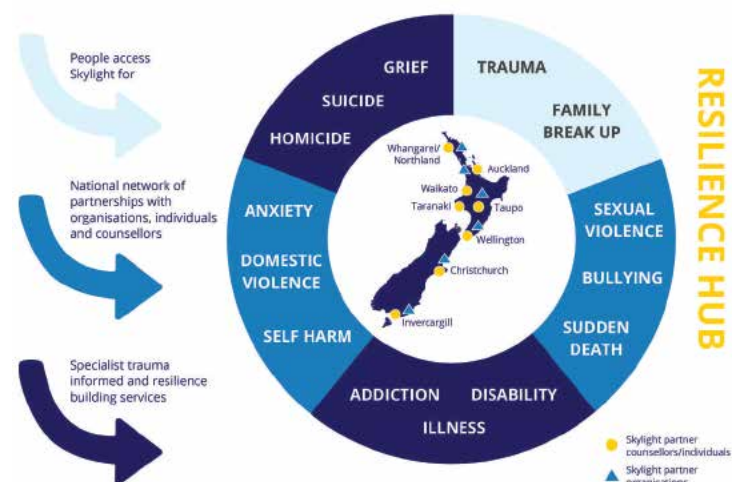
Supporting children, young people and their whanau to navigate through tough times by building RESILIENT INDIVIDUALS and COMMUNITIES.

What we deliver

- Resilience programmes
- School programmes
- Suicide prevention programmes
- Post suicide support
- Support groups
- Professional development
- Counselling
- Training
- Games/DVD/Library
- Specialist support information
- Research
- Children's programmes
- Advocacy and support
- Suicide services
- Webinars
- Web-series.

How we deliver

- High quality one stop shop through the Resilience Hub
- Increased accessibility to diverse communities
- Innovative, flexible and forward thinking
- Digital products and resources
- Growing community through partnering and networks
- Building community knowledge and capability
- National Network of specialist facilitators and trainers.



The right help at the right time in the right way.

Skylight

<https://www.skylight.org.nz/>

Mental Health Foundation mauri tu, mauri ora



An excellent resource to find a variety of numbers and a directory of helplines and local mental health service contact details.

Frequently Asked Questions:

Answers to common questions about mental health or accessing services.

Helplines and Support:

Helplines for you or someone important to you.

Accessing Mental Health Services:

If you need urgent mental health support, call your local mental health crisis team or a helpline...

Mental Health Conditions:

A handy list of mental health conditions.

I Need Help Now:

Help for you or someone important to you.

Community Support Groups:

Find free mental health support in your area. See listings of support groups by region and type of support.

Mental Health Foundation of New Zealand

<https://mentalhealth.org.nz/>

Email: resource@mentalhealth.org.nz

Phone: 09 623 4819

Lifeline Aotearoa (NZ)



Lifeline aims to reduce personal stress through readily available counselling and provides 24 hour, 7 days a week free telephone counselling; Face-to-face counselling and other services.

Lifeline Aotearoa (NZ)

<https://www.lifeline.org.nz/>

Phone: 0800 LIFELINE – 0800 54 33 54

Directory:

Tu Ora

An extensive list of counselling and support services in the Hutt Valley and Wellington.

www.teawakairangihealth.org.nz or <https://tuora.org.nz/>

Primary Mental Health, Compass Health Wellington

04 801 7808

Skylight

<https://www.skylight.org.nz/>

Mental Health Foundation of New Zealand

<https://mentalhealth.org.nz/>

09 623 4819

Email: resource@mentalhealth.org.nz

Lifeline Aotearoa (NZ)

0800 LIFELINE

<https://www.lifeline.org.nz/>

0800 54 33 54

Depression.org.nz

Home and Family Counselling (NZ) – All our counselling is provided by qualified and experienced professionals and is strictly confidential. As a community-based agency we don't set a fee for our services instead we ask clients to make a donation, which they can afford, towards their counselling time.

<https://www.depression.org.nz/>

Kidsline (NZ)

Kidsline is New Zealand's original telephone support line for kids. You can call free from anywhere in New Zealand or on your mobile phone between 4 – 6pm weekdays.

0800 KIDSLINE – 0800 543 754

New Zealand Association of Counsellors

Use our directory of Counsellors to search for practitioners.

<https://www.nzac.org.nz/site/counsel/find?nav=sidebar>

ACC

<https://www.acc.co.nz/>

0800 101 996

WINZ – Work and Income New Zealand

<https://www.workandincome.govt.nz/>

0800 559 009

CAB – Citizens Advice Bureau

<https://www.cab.org.nz/>

0800 367 222



Te Rui Atawhai
Wellington Intensive Care Unit

ICU: Level 3

HDU: Level 5

Wellington Regional Hospital
Riddiford Street, Newtown, Wellington
wellingtonicu.com