

RECOVERING FROM A BRAIN INJURY

A practical guide for patients, families and carers



DEFINING BRAIN INJURY

We use the term brain injury to refer to any type of brain disorder or neurological disruption which is acquired rather than developmental.

Generally, brain injury is defined as damage that occurs after birth. Fetal Alcohol Spectrum Disorder (FASD) is often classified as a developmental disorder because it is present at birth, however as it relates to impairments caused by exposure to alcohol or drugs in utero, we view it as a brain injury.

Primary Causes of Brain Injury

Stroke/Aneurysm

Blocked blood vessels; bleeding in the brain

Degenerative Diseases

Dementia; Alzheimer's; Parkinson's; Multiple Sclerosis

Trauma

Traumatic Brain Injury (TBI) is caused by external force and/or acceleration/deceleration injuries, e.g. car accidents; falls; sporting accidents; repeated knocks to the head or concussions; assaults; domestic violence

Hypoxic/Anoxic Injuries

Lack of oxygen to the brain from stroke, near drowning, heart attack, drug overdose, strangulation, severe asthma, accidents involving anaesthesia, carbon monoxide inhalation and poisoning

Infections & Diseases

Meningitis; Encephalitis; brain tumours; brain cancer

FASD

An umbrella term for a range of impairments acquired in utero through alcohol and/or drug use during pregnancy

Epilepsy

Epilepsy can cause neural damage and is a risk factor for a traumatic brain injury through a fall or violent convulsion.

Epilepsy can also result from a brain injury.

Alcohol and/or Drug Misuse

People who misuse alcohol and drugs are at risk of brain injury due to their intake as well as high-risk behaviours. Long term abuse of alcohol, drugs and other substances can result in brain injury, often affecting cognition, memory and perception. Damage can be temporary or permanent.

Brain injury is not

A Developmental Disorder

Intellectual disability, Autism and Down Syndrome present at birth and affect global functioning.

A Mental Health Disorder

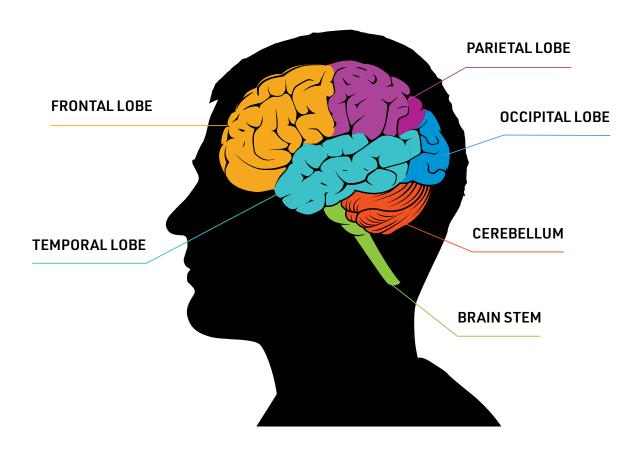
May have similar effects and is often present with a brain injury.

THE EFFECTS OF A BRAIN INJURY

The long-term effects of a brain injury can vary greatly depending on the person and the type of injury sustained. Brain injury can effect a person's ability to think (cognition), their ability to control movement (physical), or a combination of both.

Below are the different areas of the brain and the effects caused by injury.

Functional Areas of the Brain



FRONTAL LOBE

- Self-awareness / insight
- Motivation & initiation
- Attention & concentration
- Planning & organising
- Decision making & problem solving
- Impulse control
- Working memory
- Speech Control (Broca's Area)

PARIETAL LOBE

- Sensation
- Perception of touch
- Mathematics

TEMPORAL LOBE

- Laying down new memories
- Auditory processing
- Language reception & understanding
- Sequencing skills (logical order)

OCCIPITAL LOBE

- Processing visual information
- Reading
- Writing
- Visuospatial processing
- Depth perception

CEREBELLUM

- Muscle actions
- Fine motor skills
- Coordinating movements
- Balance
- Posture

BRAIN STEM

- Swallowing
- Speech
- Eye Movements
- Sleep/wake regulation
- Pain
- Temperature
- Regulation of: cardiac function, respiratory function, central nervous system

THE STAGES OF RECOVERY FROM A BRAIN INJURY

Recovery at a glance

TESTS AND DIAGNOSTICS

- Once stabilised in hospital, a range of assessments will be conducted to determine the extent and the nature of the damage to the brain
- These tests are extremely important to help guide the rehabilitation and intervention options
- Tests may include: MRI, CT, MRA, PET Scan, SPECT Scan, Electroencephalogram, evoked potentials and x-rays





SURGERY AND ICU

- Around 50% of patients with a severe brain injury will require surgery to remove or repair hematomas, contusions or tumours
- After surgery, the patient will be transferred to recover in ICU

RECOVERY

• The recovery process can be an uncertain time as it is difficult to predict the long-term effects of the brain injury on an individual

There are three broad stages of recovery following a brain injury



ACUTE

- The acute medical stage of the recovery process occurs in hospital
- It involves intensive medical treatment that may be needed for survival and to prevent further complications
- At first, improvements can occur rapidly as swelling and bruising subsides
- Improvements can continue as damaged cells heal, but this process can slow and appear to plateau



REHABILITATION

- The rehabilitation stage involves intensive therapy aimed at helping the natural process of recovery and reducing the likelihood of long-term disability
- Emphasis is placed on the patient regaining previous skills and learning strategies to overcome or compensate for some of the effects of the brain injury
- For more information on rehabilitation in the hospital, refer to page 7



RETURNING HOME

- The returning home stage focuses on everyday living and returning to previous community activities such as work, study and leisure
- Synapse is here to help you navigate this stage through our range of services
- Talk to Synapse about how we can help put services and support in place to make things easier when your loved one returns home
- For more information on returning home, refer to page 10

ACUTE

What is the acute hospital phase?

The acute medical stage of the recovery process occurs in hospital and involves intensive medical treatment that may be needed for survival and to prevent further complications. During this stage improvements can occur rapidly at first as swelling and bruising subsides. Improvements can continue as damaged cells heal, but this process can slow and appear to plateau.

Adjusting to the experience

For family members and close friends, this may be one of the most stressful and emotional times in their life. People must look after their own emotional and physical health if they are to care for the patient and other family members. Support groups may be available at the hospital.

Understanding medical information

Understanding medical terminology can be difficult, especially during times of stress. However, it is better to ask questions than not understand what is happening. If hospital staff use words you don't understand, ask them to explain it in a simpler way.

Some hospitals hold meetings with family members where you can ask questions. Write these down and record the answers.

Examples include:

- What are your treatment goals?
- What is being done to achieve these goals?
- Do you have any idea of how much recovery can be expected?
- What ongoing effects from the brain injury are expected?
- How can the family help at this point in time?
- Should we be doing anything now to prepare for discharge?

Waiting for the prognosis - predicting the future

Predicting the level of recovery after a brain injury is difficult. Doctors are usually cautious about early prognosis. Family members and other visitors have the right to ask questions, express a point of view, and receive clear and timely information. Sometimes the answer may be "we don't know" and this may be the only honest answer available. Patience and persistence are required in the search for information.

Why are predictions difficult?

Predictions of recovery are difficult in the months following a brain injury, with the person and their family often frustrated by lack of knowledge about the future.

This uncertainty is common along the spectrum of brain injury, and the long-term effects of the injury may not be evident for some time. With a severe injury, doctors can make their best estimates, yet these are only ever a guide, and the degree of recovery may not be known for months or even years after the injury.

Why aren't there accurate predictions?

Physical injuries do not give an accurate picture of the degree of brain injury sustained. The victim of a serious car accident may have numerous fractures, yet there can be less brain trauma than someone who fell over in the bath tub.

The CT and MRI scans used to detect brain injury are good at detecting bleeding in the brain, yet fail to accurately show trauma at the microscopic level. Brain trauma can sever the connections between brain neurons over areas of the brain yet this will not show in many tests.



Emotional reactions for the family

It is very stressful for families when a loved one acquires traumatic brain injury, stroke or similar brain disorder. A period of shock or disbelief is common at first. Many report a sense of unreality and being on "automatic" so it is hard to take information in. It can help to write everything down.

Everyone reacts differently – you may feel despair and blame yourself while another family member may be very angry and looking to blame others. Try to be supportive of each other despite the different ways everyone will cope.

Coping strategies

This is a very stressful and emotional time for family members. Look after your own emotional and physical health so that you can provide support for the patient and each other in the weeks ahead. A common reaction is the family feeling they should be at the hospital as much as possible but remember to go home regularly and recharge your batteries for the long haul.

Support in hospital

In the Intensive Care Unit (ICU), a registered nurse is always available and assigned to patients. Most hospitals should have a social worker available who can assist with information and coping with the hospital system.

Advocacy

Families are entitled to ensure that their family member's best interests are being served. Most hospitals provide support for families to obtain information and make decisions about a patient's care. The person providing this support is often a social worker, who will advocate for the patient on the family's behalf.

Informing the patient

The focus of family members at this time is typically the wellbeing of their loved one, and they may be reluctant to convey potentially upsetting information to the injured person. Conversations about the person's condition, or another person's death require sensitivity, and may be distressing for families.

It is advisable to discuss any concerns with the appropriate hospital staff who will provide guidance in this matter. It is usually preferable to tell patients any traumatic news (although they may forget) and at times, their reaction may be different to what is expected as a result of the brain injury.

REHABILITATION

What is rehabilitation?

Rehabilitation usually commences in the hospital and often continues for up to two years after the injury has occurred. It involves a variety of tailored therapies that aim to help the patient regain lost cognitive or physical functions, adapt to the injury and set goals for the future.

Why is it important?

A tailored rehabilitation program is vital to optimise recovery following a brain injury and restore as much ability and quality of life as possible. The brain has a limited ability to heal itself, but the biggest improvements are usually seen in the first year. Rehabilitation aims to make the most of this healing period.

Rehabilitation also relies on neural plasticity - the brain's ability to 'rewire' itself to a certain extent and start using other parts of the brain to bypass the damaged area. Rehabilitation helps optimise this rewiring ability. Using and stimulating the brain regularly will aid recovery, and staying active and engaged in activities will boost motivation and help to reduce any social, cognitive or behavioural issues.

Who is involved in rehabilitation?

Because the effects of a brain injury can be so wide-ranging, a number of allied health professionals may be involved in creating and managing a rehabilitation plan. To help you understand each professional's role, here is an overview of who you could expect to encounter in the hospital:

Neuropsychologist

- Determines the impact of the injury to the brain, any resulting impairments and how severe those impairments are
- This assessment will help inform the rehabilitation plan and help you to understand the impact of the injury

Neuropsychiatrist

- Specialises in how the brain works and how it affects behaviour, memory, learning and personality
- Diagnoses and treats any behavioural or cognitive disorders that may have been caused by the brain injury
- May be involved in creating a rehabilitation or treatment plan and may also prescribe medications

Physiotherapist

- Assesses a patient's mobility and physical functions
- Creates a rehabilitation plan aimed at improving the patient's functioning and quality of life
- This may include specific exercises to help with mobility, and advice on equipment, pain relief and how to prevent falls
- The plan and exercises will be reassessed and adjusted as the patient's recovery progresses

Dietitian

- Provides tailored advice on nutrition and diet to assist in the patient's recovery
- May also provide advice on additional nutritional supplements

Social Worker

- Focuses on creating a supportive environment for the patient and their family by providing emotional and practical advice
- Keeps the family informed of the patient's treatment, provides counselling for the patient or family members, and connections to relevant support groups

Speech Pathologist

- Assesses the patient's speech, and ability to read, write and swallow
- This assessment will inform the rehabilitation plan specifically regarding non-verbal communication aids, such as cards with pictures or words, and individual or group therapy that will help the patient practice how to say certain words or sounds, and how to swallow or chew

Occupational Therapist

- Assesses the patient's ability to function independently in their daily life
- Trains the patient in domestic activities and uses various therapies to help with recovery
- Identifies any assistive technology that may help the patient, such as a wheelchair
- Conducts an assessment of their home environment to identify any modifications that may be required to help with daily living and recovery, such as ramps for wheelchair access

The role of friends and family in rehabilitation

A brain injury can cause a range of heightened emotions in both the patient and their loved ones. In the days and weeks following the injury, it is normal to experience feelings of shock, denial, anger and hopelessness or a sense of being overwhelmed.

While these feelings are normal, it's important to remember how vital your role is in the rehabilitation process. Encouraging and supporting your loved one in a positive way and being involved with your rehabilitation team will help enhance their recovery process.

Practical ways you can help during the formal rehabilitation process in hospital

- Be as involved as you can in any therapy appointments
- Stay positive, patient and supportive
- Remind your loved one of their recovery achievements and celebrate them no matter how small they may seem
- Record as much as possible in writing, such as results of tests or assessments, conversations with the medical team, and physical or cognitive recovery milestones so that you have all details documented.

What family and friends can do while in hospital

Don't forget to look after yourself, too

It is natural to put yourself last while your loved one is in hospital, but it's important to also think about your own needs at this challenging time.

- Accept or ask for offers of help, such as looking after children or with daily household tasks
- Take some time out for yourself to recharge and keep your strength up
- Ensure that you are eating well and getting enough sleep
- Organise a rotating schedule for visits by family members
- Reduce other sources of stress in your life
- Be aware that others may deal with the situation very differently from you



THE SAAVEDRA FAMILY'S STORY



The Saavedra family has been touched by brain injury twice. Despite the significant challenges they've faced, their story is one of true hope and perseverance. It's also one of just how powerful the love and support of family can be.

Shortly after resettling in Australia from Columbia, Libardo suffered the first of multiple strokes that would leave him with reduced mobility. With the strong support of his wife, Dora, Libardo successfully adjusted to the impact of his brain injury.

A few years later, their son Julian graduated from high school. Fluent in English, Spanish, Russian and French, he was looking forward to studying linguistics at university.

But on a night out celebrating with friends, Julian walked onto a road and was hit head-on by a car. He was rushed to hospital with a severe traumatic brain injury where he remained in a coma for 20 days and critical for four weeks. Julian spent a total of six months in hospital undergoing rehabilitation, but gradually regained his speech and movement.

When he returned home with his family, Julian faced a difficult time.

"I was in a really bad place. Before the accident, I had an independent life. But when I came home from hospital, I had to face the fact that things were different. I had nothing to do and I became frustrated and depressed. I was lost."

His mother, Dora, knew he needed something to put his energy into. She decided to try and refocus him on his love of languages. Offering him constant support and encouragement, she helped him set a goal of translating a book into Spanish.

"Julian needed to be busy and I wanted to help him do what he loved. He needed to have a purpose and we had to find a way to help him use his strengths," said Dora.

The book they chose was Surviving Acquired Brain Injury, a Synapse publication.

Over four months, Julian translated more than 300 pages of English text into Spanish, with his mother and father proofreading. According to Julian, the discipline of this task and the support of his family were key to him overcoming the ongoing impacts of the injury.

But that was just the start of Julian's post-brain injury achievements. He now works part-time at Synapse translating a range of publications and helping other young people who have sustained a brain injury. He is also adding to his language portfolio, studying Japanese at university and AUSLAN (sign language) at Deaf Services Queensland. His aim is to become an interpreter in Spanish and AUSLAN.

His Mum, Dora, couldn't be more proud of him. And Julian couldn't be more grateful for the love and support of his family.

"My family gave me discipline, structure, patience, and most importantly, love. Without their love, I could not have achieved what I have. It took a lot of hard work but I love my life now."

RETURNING HOME

Preparing for the return home

While you are still in hospital, there are some practical things you can do to make the return home a little less stressful.

Use the information in this booklet to find out how to access support options and information, and what details you can record in the Daily Activity Journal for future reference (contact Synapse for a copy of the Daily Activity Journal).

Leaving hospital and returning home can seem daunting, but Synapse is here to help you make this transition as smooth as possible. The family may have to make a range of changes to their normal routine to care for the patient and assist ongoing rehabilitation.

In some cases, the patient can start to display challenging behavioural or personality changes when they return home, such as impulsiveness, emotional outbursts, depression or anxiety. The patient may be completely unaware that their behaviour has changed and this can make it more difficult to manage.

It's important to identify any behavioural issues as early as possible, and you can access a range of fact sheets about challenging behaviour on our website or ask Synapse for more information.

Continuing rehabilitation

Once the formal inpatient rehabilitation has finished in hospital and the patient has returned home, rehabilitation usually continues as an outpatient service. The family's support in this stage is still very important.

If your loved one requires intensive ongoing therapy, it can unfortunately be difficult to access and expensive. However, your physiotherapist or other members of your allied health team may be able to provide you with a continuing rehabilitation program to do at home with the support of family members and appropriate community services.

For more information about how to do this, see our fact sheet called Family Guide To A Low Cost Rehabilitation Program on our website, and talk to Synapse to find out what options are available in your area.



SELF-CARE FOR CARERS

Caring for a person with a disability is one of the most difficult challenges a family can face. The constant demands of a carer's role can leave little time to pursue personal interests and a social life. The person caring for a partner often has to take on a much larger everyday workload, taking on the management of all the household's domestic and financial duties. In addition, carers can often feel they have lost their own identity.

Common reactions for carers

All carers respond to the demands of caring for their loved one in their own way, and it's very important to remember that there are no right or wrong feelings. Most carers experience feelings of being overwhelmed and confused which are normal, natural reactions to such a change of circumstances. Other common feelings include:

GUILT

Carers may feel responsible for the brain injury occurring, or may feel guilty for not wanting to be a carer, losing their temper, or being embarrassed by the person they're caring for. Carers may particularly feel guilty about taking a break from caring or placing the person in respite care.

ANGER AND FRUSTRATION

Feelings of anger can arise when someone is either the sole carer or the family member who feels they do the lion's share of the caring duties. This person can become frustrated when faced with regular challenging behaviours, irrational outbursts, self-centeredness or many of the other issues that can arise after a brain injury.

RESENTMENT

Carers can often develop feelings of resentment if they think they aren't receiving enough help from support services or if contact from friends begins to wane over time. They can also feel resentment when everyone's focus is always on the person with the brain injury.

Take care of you

If you are a carer, it's essential that you prioritise your own health and wellbeing as much as possible. You need to be healthy, well-rested and mentally strong enough to be able to support your loved one.

Some of the most important tips for carers include:

- Ask for help when you need it
- Take time for yourself (e.g. respite services)
- Exercise, eat healthily and sleep well
- Relax regularly
- Keep up your social contacts
- Attend a carers group for support
- Access all available services and funding
- Acknowledge and deal with your feelings

FEAR AND ANXIETY

It's very normal for carers to have varying degrees of anxiety about what the future might hold. They may become frightened about how much their loved one will recover and how the family will cope.

GRIEF

Many families experience grief. If their loved one has undergone significant personality changes, it can feel like the family has lost their loved one without being able to say a proper goodbye. Caring duties can also be so overwhelming and consuming that people can feel a strong sense of loss about their former lifestyle.

STRESS

Along with the stress of coping with caring duties it can also be stressful dealing with legal issues, such as a compensation claim. Over time, stress can cause a range of physical symptoms, such as headaches, sleeping difficulties, illness and fatigue. Carers may also find themselves feeling out of touch with reality, forgetful and prone to tears, and they may not eat or look after themselves properly.

Support groups

A carer's support group is a great way to meet others in a similar position and find information and support. Sharing experiences, ideas and feelings with people who know what your situation is like can help you feel less isolated.

You can access fact sheets about self-care tips for carers and family members, accessing respite care, or joining our online brain injury forum via our website at **synapse.org.au**.

THE EFFECTS OF A **BRAIN INJURY ON A CHILD**

One of the most important differences between children and adults who acquire a brain injury is that a child's brain is still developing.

After a brain injury in an adult, rehabilitation primarily focuses on helping them relearn lost skills. If a child sustains a brain injury before they have learned particular skills, they will require extra support to ensure their development occurs as normally as possible. Predicting brain injury recovery can be difficult, but especially with children. This is because specific problems may only become apparent at certain stages of a child's development.

It is generally regarded that the younger a child is when a brain injury occurs, the more impact it will have on their development. Recovery appears to be an easier process when basic functional skills have already been developed. However, a child's age only has a limited impact on recovery.

The key factors that impact recovery are:

- The severity and type of brain injury
- The supportiveness of the family
- Rehabilitation
- The ongoing support they receive at school in key learning and developmental areas

Effects on cognitive abilities

A brain injury may lead to a general decline in a number of a child's intellectual abilities. Like adults, however, a child may still be within the normal range on measures of intellectual functioning and yet display significant problems in specific areas of attention, memory, language, and visuospatial and executive functioning.

Effects on sensory and motor skills

A child may either lose some previously acquired skills or have difficulty learning new skills, such as holding a pen, drawing, using a keyboard, constructing and manipulating objects, using cutlery, getting dressed, recognising objects, and a variety of other eye-hand coordination activities. They may also experience swallowing and speech difficulties or problems with balance and coordination. Professionals such as physiotherapists, occupational therapists and speech pathologists will play an important role in assessing sensory and motor disorders, and creating a rehabilitation program.

Effects on language and communication

Many children experience receptive problems that involve difficulty processing different parts of spoken or written information. Comprehension problems occur when a child cannot understand what he or she is reading or what another person is saying. Spoken or written language expression may be affected in terms of pronunciation, fluency, grammar, intelligibility, or the meaning and retrieval of words.



Effects on social skills, behaviour and emotions

A child may experience difficulties relating to peers and siblings or joining in group activities. Some children can demand a lot of attention from parents or teachers, and may find it difficult to follow rules and instructions. Behavioural and emotional problems can include depression, anxiety, mood swings, hyperactivity, distractibility, impulsiveness and aggression. Other issues can include poor judgment, reduced control of anger and frustration, sleep disturbance and poor motivation. There are various rehabilitation strategies to assist with these issues and early intervention can improve outcomes.

Brain injury and a child's development

While a brain injury can disrupt a child's normal development, many can still make good progress even if it is limited to some extent. Tailored support and assistance is critical in ensuring a child with a brain injury develops to their optimal ability. This is especially true at school, where the degree of support needed is often underestimated within the education system.

For more comprehensive information on brain injury in children, visit the Family and Carers section of our online information hub Understanding Brain Injury at www.synapse. org.au/understanding-brain-injury. You can also access our publication Acquired Brain Injury: The Facts on our website or speak to the Synapse team to obtain a physical copy.

KATE'S STORY



66

Our daughter, Kate, is a beautiful, articulate, happy and healthy teenager.

She is intelligent, attends high school full time and loves playing netball. She also has a brain injury.

Kate has experienced two episodes of Acute Necrotizing Encephalopathy (ANE) - an extremely rare and often fatal disease.

The first one occurred when she was just 11 months old. Initially admitted to hospital with uncontrollable temperatures and lethargy, she then developed seizures, a rash and cold extremities. The diagnosis wasn't clear but after three days, she started recovering and returned home. Apart from having to relearn to crawl, within a month there were no signs that she had been ill at all.

Then, when she was 13, Kate experienced her second and much more severe ANE episode. Her initial flu-like symptoms worsened and became so unusual that she was admitted to hospital where she presented with confusion, Bell's palsy, slurred speech and unsteadiness. She was having minor seizures, vomiting and one pupil was much larger than the other. An MRI showed she had lesions all over her brain. The Neurologist diagnosed it as ANE.

Kate was unable to use her hands and needed support to walk. She spoke like she was intoxicated, was hallucinating and her emotions, including inhibitions, were haywire. Understandably, this was an extremely scary and overwhelming time for the family.

"Our time in hospital was a blur. There were so many specialists coming in and out of her room and we didn't understand the medical terms or who we needed to speak to about what. There was so much paperwork and so much information to take in. We were in shock," her mother, Kim, recounts.

After intensive therapy with the brain rehabilitation team, Kate recovered enough to return home. But the disease has left its mark. Kate suffers chronic headaches, has some cognitive and fine motor control issues, and certain social situations overwhelm her.

"We are eternally grateful that Kate pulled through. We received amazing support from our rehab team that supported us practically and emotionally through the hospital experience and the return home. Kate's psychologist, speech therapist, occupational therapist and social worker have been fantastic. Kate was determined to return to school. This was inspiring but it also brought challenges because her teachers weren't aware of the effects of a brain injury. We've had to learn many new strategies to help her deal with learning and the school environment, fatigue and memory difficulties."

Displaying amazing tenacity, Kate has learned to accept her brain injury. She now openly shares her story with her school peers and teachers to help raise awareness of the many different types and outcomes of brain injury.

People meeting Kate today would never know that she has a brain injury. Her family has connected with 100 families all over the world who have been dealing with ANE and have found the shared support of this online community invaluable.

WHAT TO ASK BEFORE LEAVING HOSPITAL

To help you gather the important information you'll need to access, here are some questions to ask before you leave hospital.

When is the discharge date?

Will a discharge summary be sent to our doctor or can you provide us with a discharge summary so we can pass it on to our doctor?

Is there a social worker that we can speak to?

Do we need any equipment before we leave hospital, such as a wheelchair or a shower commode?

Do we need to make any modifications in our home before leaving hospital, like installing grab rails or a wheelchair ramp? If so, who can help me do this?

Do we need to book in for any follow-up appointments or tests? (You can use the Appointment Schedule in the Daily Activity Journal to record your appointments.)

What is the rehabilitation plan?

Who is involved in the rehabilitation plan?

Are the rehabilitation appointments already made, or do I have to make them?

How long will the rehabilitation last? What can I do to help the rehabilitation process?

What medication is prescribed, and what is the dose and timing of the medication?

Does the medication have any side effects?

Is there anything that the patient should avoid doing or won't be able to do?

Who should we contact in an emergency?

Write down any other questions you have here:



FOLLOW US









Freecall: 1800 673 074

Email: info@synapse.org.au

synapse.org.au

