



A Carer's
Journey

If lost please return to -

Name:

Telephone Number:

**"May you find the strength
for tomorrow in the love that
surrounds you today."**

Anonymous

This journal is a Carers NSW initiative developed as part of the *wecare* Carer Mentoring Program and in consultation with the Carer Advisory Committee from *wecare* and Service Development Team from icare. We would like to acknowledge and thank icare NSW for its support and funding of the project.



Contacts Page

Family:

Friends:

Medical Specialists:

Lanie's Story

"This is my journey of how the diary came about for me and my family. It was New Year's Eve 2018. We decided to let my daughter out to a party with her friends. Tahlia was a responsible 17 year old girl. We later got police knocking on our door in the early hours of the morning, explaining that she was a passenger in the back seat of a car that was involved in a massive car crash.

Everything seemed like a blur. Like an out-of-body experience. Tahlia sustained a massive traumatic brain injury with multiple facial injuries. The next day my best friend came and I explained to her how overwhelmed I was with everything the doctors and nurses were telling me, and that I was confused and my brain just went blank. Looking back now it was my brain's coping mechanism. The following day my best friend bought me a diary so that I could document everything from who came to visit to what the doctor's confusing terminology was so I could google it when I had a chance. I was Tahlia's eyes and ears and I had to make life-changing decisions on her behalf.

Every night I would write down her time in the ICU (Intensive Care Unit) as I wanted her to read it one day and I felt like I had to fill in the blanks of her time in a coma. After a month in a coma, Tahlia finally started to wake-up- it's a condition that was gradual for her and it's referred to as storming. A week later we moved to the brain injury rehabilitation ward where Tahlia had to learn the basics of walking, talking and eating as she had a trachy (tracheostomy) which I'd never seen before. I felt so naive.

As time went on Tahlia improved. Each day I would document her appointments in the hospital as there were so many, even multiple, surgeries. We were able to bring our pet puppy into visit Tahlia which was so great for her morale.

I felt a sense of being in control as I could look back in the diary and reflect on how far she had come and on her ability to push herself. Family and friends' support has a massive impact on the recovery of loved ones. We were able to be discharged from hospital after three and a half months but our rehab still continues today. It's been five years. Tahlia now is a motivational speaker- she talks to young kids about the dangers of getting into cars and texting and driving.

We are currently dealing with our third party insurance company and looking back to my diary, I have been able to reflect on certain dates, times and appointments which has been a great tool for me to have."

**"Once you choose hope
anything is possible."**

Christopher Reeve

When Lanie's journal initiative was shared with other *wecare* family carers there was resounding enthusiasm for this initiative to be shared more widely.

Your Story...

This journal is for you and your loved one to keep.

We hope that writing down your thoughts and feelings will assist you with processing what has happened. You can express yourself and your feelings as creatively as you like through artwork, drawings or photographs, or in any way that is meaningful to you.

Research shows that Intensive Care Unit (ICU) diaries were introduced by nurses in Denmark in the 1980s, as a debriefing tool for the injured person after they had left the ICU. The use of ICU diaries helped reduce symptoms of anxiety, depression, and post-traumatic stress in both the person who had been injured and their carers. The diaries were also a tool for carers to provide their loved ones with a record of their ICU experience, express feelings and emotions, and document the presence, commitment, and supportive role of the staff and family.¹

"From my experience, love and support encourage recovery."

Stacy - Carer for her son Sashy

¹PLoS One 2014 October 16, Fiona Harris, Writing In and Reading ICU Diaries: Qualitative Study of Families' Experience in the ICU.

Tips from one carer to another

Throughout this journal you will find tips that other families in similar situations wanted to share with you.

Some behaviours and emotions may take you by surprise.

- You may feel frustrated with family and friends and the things they say and do but understand that they are just trying to comfort you. Some family or friends might pull away as they could find the whole situation too difficult to deal with.
- You may feel more comfortable talking to other people who are going through a similar situation or a professional counsellor to make sense of what has happened.
- You may experience brain fog such as not being able to make decisions about simple things like what to eat.
- You may feel a lot of guilt leaving your loved one but it's important to have a break.
- There may be massive changes in the relationships with your immediate family. Be patient and kind and make the commitment to look after each other. People deal with things differently.

Use this time to learn about your loved one's injury and the services and resources available.

This is the first step in coping with your grief.

Ask questions about anything you don't understand, even asking for any answers and explanations to be in easy to understand language.





























Tips from one carer to another

For the first few hours and days, your mind will be racing between thoughts about the present and worries about the future.

Communicating with family and friends

- **Choose a spokesperson:** This can be a trusted family member or friend who can inform relevant others of what is happening and any updates.
- **Social media:** Finding an easy way to keep everyone informed can save time and energy. For instance creating a Whatsapp group for different friendship groups. Before setting up any social media group be clear about your boundaries and discuss them with group members. For example, no sharing what is discussed in the group without your prior consent to protect the privacy and rights of everyone involved.

Communicating with medical staff

- Ask for the times of Doctor's rounds as you may need to request permission to access the ward if they are outside of visiting times or out of hours i.e. early morning.
- Request that reports and test results be emailed to the relevant team(s) with your GP and yourself copied in. This will help to ensure all relevant medical staff are kept in the loop.

Accepting help from family and friends can help alleviate the load while you are caring for your loved one. For example, provision of meals and assistance with household chores.































Carolyn's Story

"At 8.15am on 7th July 2018 our youngest child was on his way into town to meet the bus to go to a rugby game in Orange with his team. Only a few kilometres from home he rolled his car into a tree. He was flown by helicopter to Royal North Shore Hospital in Sydney and placed in the hands of a wonderful team of doctors, nurses and a surgeon we had never heard of who is now one of the greatest men in my son's life. We were so naive. It was very clearly evident that the spinal cord had snapped, what we later came to realise is called a 'complete' spinal injury.

Over the next weeks and months our little family of five received the most intensive education on spinal cord injury. In ICU, we were cocooned and supported in our time of grief as we passed from the old life into the new. The move to the spinal ward from ICU was so highly anticipated yet almost as traumatic as the accident itself, however it was paramount to our continuing education on navigating this strange, foreign new world. We long awaited a move to 'rehab' to get away from the trauma but that move wasn't at all as wonderful as we had hoped. There is nothing very easy about this spinal cord injury life. There was however, the most amazing transformation that took place in the whole family, instigated by Jarrod.

At 17 years of age Jarrod learnt, and he taught us, how to 'improvise, adapt and overcome'. Jarrod is a Complete T7 Paraplegic. He relearnt his daily routine with determination and focus, though for many, many weeks and months it was as hard as hell. Watching his frustration and disappointment knowing there was nothing I could do to fix him was the hardest time of my

life. Jarrod made sure he learnt to drive again before he left rehab. When he got home to our farm in Mudgee NSW he was there for a day before asking to go back to school to complete his HSC.

Jarrold is now studying a Bachelor of Business at University of Wollongong and also a Certificate IV in Fitness. It's been only four short years since his accident which I can confidently say has given him a love of life he never had before. He has had three full spinal surgeries since his accident due to broken bones below his original rods and then for a broken rod. He has had two further car accidents, but he continues to be independent. He has become an athlete, he plays Wheelchair Basketball for the AUSU23 Team and the Wollongong Rollerhawks. He has the most amazing mentors in life - this is the truest gift any parent could ask for.

The day we found out about the Spinal Cord Injury Australia (SCIA) mentors was the turning point. Along with the night I met another family in the hospital whose daughter also had a spinal injury. There are so many people that we have met in this incredible new life that have given us so much information, support and encouragement. In the darkest of days there was always someone who knew exactly what we were facing and who was able to stand beside us giving us help sometimes in most simple ways. This is a very rewarding and exciting life. We have all transformed, none more so than Jarrod. We are different people, but we are better people. Stronger, more resilient but also softer and more sensitive. As clichéd as it sounds, I would not turn back the clock for all the money in the world. We are who we are now because of our journey. Do not be afraid. For we are all with you."

**"Recovery is a process. It takes time. It takes patience.
It takes everything you've got."**

Anonymous





























Tips from one carer to another

Keeping accurate and concise records will mean information will be readily available for future reference.

You may find it beneficial to buy several small notebooks to help you keep track. Some suggested uses include:

- **Visitors Book and/or Photo Album**

Include photos of gifts, flowers, cards and messages. This can then be kept for you and your loved one and will help to fill in any gaps in memory.

- **Communication Book**

Staff can add therapy appointments, visitors that arrive unexpectedly and you have missed can add a message and you can let staff know that you have gone for a walk/coffee, etc and what time you expect to be back.

- **Financial Record**

You may be able to claim back some expenses from your insurance provider if you're eligible and so keep all receipts including for medication, travel expenses, parking, tolls, accommodation, food and beverages etc.

- **General Notebook**

Take notes during phone calls. It's easy to forget what you were told or when and how to follow up. Where possible prepare for meetings by writing any questions and concerns down beforehand.































Tips from one carer to another

Checking in with yourself and family is an important part of caring.

- In the early stages of your loved one's recovery, it's normal for you to worry more about them than yourself. But it's very important that you take care of yourself too.
- If you have children, explain what has happened. Try to keep life as normal as possible for them. Think about utilising supports such as a school counsellor/teacher/school chaplain.
- Telling your story can be traumatic so establishing boundaries with family and friends is a useful way of addressing this. Take the lead i.e. "I'm fine but I don't want to talk about it at the moment".

Are you feeling overwhelmed with the weight of everyone's emotions?

Find a quiet spot and place your hands on your belly.

Slowly breathe in and out feeling the change in pressure under your hands.

Repeat 7 times.































Tips from one carer to another

There are lots of little things you can do to support your loved one

- Let your loved one know that you are nearby by holding their hand and talking to them
- Record what has been happening each day in your journal
- Set up a code word with your loved one that indicates that they are tired and visitors need to leave
- Play their favourite music – The Hush Foundation seeks to reduce the stress and anxiety felt by patients and families in hospital with music designed to evoke a sense of calm and optimism <http://www.hush.org.au/>
- Some other suggestions are listed below but please check in with the nursing staff before you initiate any of the following: sprinkle lavender oil on their pillow case, give them a hand or foot massage using creams and essential oils, bring in some personal items from home i.e. a favourite blanket or photos, wash their hair or paint their nails, ask if there is a possibility of bringing the family pet onto the ward for a visit

**"All we could do was sit with her and wait.
I remember saying to her over and over that she was strong and
that she could get through this.
Years later a friend asked her how she recovered so well and her
reply was "because my mother told me I could". They always say
you should talk to them when they are in that state as you never
know what they may hear!"**

Suzanne - Carer for her daughter































Tips from one carer to another

You can help your loved one most by taking care of you

- Save your energy; rest when you can
- Maintain your wellbeing by eating regularly, taking short breaks in the fresh air and getting enough sleep
- Give yourself permission to leave the hospital. Your loved one is in the care of a well-trained medical team. If they need you urgently, they will call you
- Check in with yourself daily and seek assistance from your GP or a counselling service if you are feeling overwhelmed. Free counselling may be available through the hospital social worker. You can also contact the Carer Gateway on 1800 422 737

**Go for a walk and match your
pace to your mood or your need**

**Take a real coffee break.
Make it a mini retreat to
re-energise and re-focus**































Resources

Amputation	Amputees NSW Amputees NSW provides support to individuals and their families affected by amputation and limb difference. https://www.amputeesnsw.org.au/ 1800 810 969
Brain Injury	Brain Injury Australia (BIA) Brain Injury Australia (BIA) is the central clearinghouse of information and gateway to nationwide referral for optimising the social and economic participation of all Australians living with brain injury. https://www.braininjuryaustralia.org.au/ 1800 272 461
Burns	Synapse – Australia's Brain Injury Organisation Provides a range of specialist services and information for people who have a brain injury, carers and family members. https://synapse.org.au/ 1800 673 074
Burns	Australian and New Zealand Burn Association (ANZBA) https://anzba.org.au/ 07 3325 1030

Intensive Care

The Australian and New Zealand Intensive Care Foundation

Provides an overview of the ICU including what to expect when visiting, staff in the ICU, what the different machines do, what you can do to help your loved one, transitioning out of ICU and beginning rehabilitation.

Also includes inspiring stories and the latest research.

**<https://www.intensivecarefoundation.org.au/>
03 9340 3447**

Spinal Cord Injuries

Spinal Cord Injuries Australia (SCIA)

Working with people living with spinal cord injury and other neuro conditions to advance their rights, choices and entitlements, and to ensure that high quality, relevant services are readily available for people with spinal cord injury and other physical disabilities.

**<https://scia.org.au/>
1800 819 775**

Carer Resources and Support

Carers NSW	Improving the lives of all carers in NSW by providing information, education and training, resources and referrals to support carers. https://www.carersnsw.org.au/ 02 9280 4744
Carer Gateway	Provides practical advice and support including information on person-centred care and advocating for someone. Carers can access a wide range of help including counselling, peer support and respite care. https://www.carergateway.gov.au/ 1800 422 737
Beyond Blue	Beyond Blue provides information and support to help everyone achieve their best possible mental health. https://www.beyondblue.org.au 1300 224 636
Black Dog Institute	Free resources and support to manage burnout and maintain good mental health. https://www.blackdoginstitute.org.au/ 02 9382 4530

Lifeline	Lifeline provides all individuals experiencing a personal crisis with access to 24 hour crisis support. https://www.lifeline.org.au 13 11 14
Translating and Interpreting Service - TIS National	The Translating and Interpreting Service provides access to phone and on-site interpreting services in over 150 languages https://www.tisnational.gov.au/
Calm App	Calm is a popular app for sleep, meditation and relaxation. https://www.calm.com/
Insight Timer App	Free meditation app for guided meditations, sleep music and talks from mindfulness experts, neuroscientists and psychologists. https://insighttimer.com/meditation-app

Children and Young People Resources

Young Carer Program	<p>For children and young people, 25 years or under, who help to support a family member or friend living with a disability.</p> <p>https://www.carersnsw.org.au/services-and-support/programs-services/young-carers 02 9280 4744</p>
Association for the Wellbeing of Children in Healthcare (AWCH)	<p>Provides tools to help you through a hospital or healthcare experience which includes the effects of hospitalisation on children and young people and questions to ask health professionals.</p> <p>https://awch.org.au/ 02 9817 2439</p>
Headspace	<p>National Youth Mental Health Foundation which provides online, phone and in person support.</p> <p>https://headspace.org.au/ 03 9027 0100</p>
Kids Helpline	<p>24/7 online and telephone counselling for young people 5–25 years.</p> <p>https://kidshelpline.com.au/ 1800 55 1800</p>

Young Carers Network

An initiative of Carers Australia offering online information and resources to support and connect young carers.

<https://youngcarersnetwork.com.au/>

ReachOut

Online mental health service offering information and tools for young people and their families.

<https://au.reachout.com/>

Financial Resources and Supports

Being informed about what the options are can help with making financial decisions that affect you and your loved one. If your loved one is in hospital, request to speak to the Social Worker who can assist you to explore financial supports.

Centrelink	You may be eligible for government payments and services now that you are a carer. https://www.servicesaustralia.gov.au/individuals/centrelink
National Disability Insurance Scheme (NDIS)	Your loved one may be eligible for funding for services, care and equipment if they are under 65 years of age and as a result of their injury they have sustained one or more impairments that are likely to be permanent and will substantially impact their ability to do daily life activities. https://www.ndis.gov.au/ 1800 800 110
icare NSW	Motor vehicle accident injuries: If your loved one has been severely injured in a motor accident, they may be eligible for support under the Lifetime Care and Support Scheme. Lifetime Care pays for treatment, rehabilitation and care for people who've sustained severe injuries including brain injury, spinal cord injury, amputations (or equivalent impairment), burns and permanent blindness as a result of a motor vehicle accident in NSW. For enquiries, phone 1300 738 586 and request to speak to someone in Lifetime Care.

icare NSW

Compulsory Third Party Insurance (CTP):
For enquiries about CTP claims, phone CTP Assist
on 1300 656 919.

If injured at work, your loved one may be eligible for workers compensation:

Notify their employer as soon as possible and their employer can contact their insurer advising them of the incident.

Your loved one's employer may start the claims process or provide the insurers contact details so your loved one can lodge a claim. Even if the employer doesn't have workers insurance, a claim can still be made.

For assistance with lodging a claim, contact the customer support services on: 13 44 22

For more information on icare insurance schemes and services: www.icare.nsw.gov.au





