

# ***Journey home after brain injury***



This booklet was developed by *The transition from hospital to home: a longitudinal study of Australian Aboriginal and Torres Strait Islander traumatic brain injury (TBI) project* (NHMRC Project Grant 1081947).



***The transition from hospital to home***  
A longitudinal study of Aboriginal and Torres Strait Islander traumatic brain injury



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**This booklet might help you and your family during your recovery after brain injury. It includes stories and art from other Aboriginal and Torres Strait Islander people who have had a brain injury.**

**Inside you will find information for you while you are in hospital. It also has tips to help you when return home.**



Disclaimer: This booklet has been prepared to provide general information only. If you are worried about your medical condition or unsure about what to do, you should speak to your treating doctor or attend your local community clinic.

# What is a traumatic brain injury?



Traumatic brain injury is an injury to the brain from being hit in the head. When this happens, the brain can move inside the skull.

The brain is soft, and floats inside the skull bone. When you get a knock to the head it can give your brain a bruise. Like bruises on the body, these injuries can take time to heal. It can also cause swelling, problems with the blood vessels, or bleeding between the brain and the skull. This bleeding usually stops on its own and the blood vessels heal like a cut you get on another part of your body.

The brain can heal itself, a little bit. This will be quickest in the first year after the injury.

The most common causes of traumatic brain injury for Aboriginal and Torres Strait Islander Australians are assault (being hit by another person) and falling down and hitting your head.

# Understanding my injury

## What happens in my brain after a traumatic brain injury

Traumatic brain injuries will be different for everybody. Some people say they did not feel like the same person as before.

Some people notice changes in the way they think and feel. Some people might behave in a different way to what they did before the injury.

Some people say they have trouble remembering things. They said that sometimes, they would be moody, and that they noticed changes in their feelings and behaviour.



*"Like with me sometimes I'm bit sensitive and they [my family] have to choose how they word certain things and spoke to me so I wouldn't get offended because I would get offended."*

*"I do get mood swings now still. But they're a bit more, a bit more stronger."*

*"I was just so shocked, it was crazy, I didn't know what was going on, I was like 'what's happening to me'. I felt like I was dumb. And I was like 'this is terrible'. Yeah I felt sad when I was in the hospital cause I didn't know what was happening to me."*



# Understanding the parts of the brain

**Front lobe: behaviour, intelligence, memory, movement**

Damage to the frontal lobe might cause changes in mood, personality and social skills.

**Parietal lobe: intelligence, language, reading, sensation**

Someone with damage the parietal lobe might not be able to feel sensations like touch.

**Occipital lobe: vision**

Someone with damage to the occipital lobe might have changes in how they see things.

spinal cord

**Temporal lobe: behaviour, hearing, memory, speech**

Damage to the temporal lobe might cause changes to personality, behaviour, trouble with hearing, memory and speech.

**Cerebellum: balance, coordination**

Damage to the cerebellum might give someone trouble with balance, speech, or co-ordination.

# Care in Hospital

## Tests you may need to have and why

In hospital, the team looking after you might do a range of different tests to help understand more about your injury. These tests might include:

- **CT scan** or **Computed tomography** provides a three dimensional view of the brain to detect abnormalities
- **MRI** or **Magnetic resonance imaging** use electromagnetic radio waves to produce either 3-D or 2-D images of the brain
- **X-rays** reveal damage to bones of the skull



## REHABILITATION?

### Why is it important?

After a traumatic brain injury, you may need rehabilitation to relearn some skills you could do before your injury. Rehabilitation is important.

Rehabilitation will be different for everyone. It will depend on what part of the brain was injured and how bad the injury was.

A good rehabilitation plan will be made just for you.

It is useful to write things down or take photos of what you achieve in rehab so you can see your progress.

*"Yeah, just rehab. It's the only thing that can help them get back on their feet. I wasn't, I knew someone that had an accident and they had the same problem as me in hospital when I was in there the last time and they couldn't walk. They had a brain injury. It was my own family, yeah. I was visiting him, helping him, pushing him down the stairs in a wheel chair, take him outside. Me and him were doing rehab at the same time."*

*"I had to relearn certain things... even from this day talking and finding the right words and saying the wrong things or choosing the right words to use is hard. Just getting used to things like noises, even like the sunlight and the light. Um. Just getting frustrated with myself sometimes because I can't do certain things or..."*

# Care in Hospital

## Emotional wellbeing

After a brain injury you might feel scared and confused, particularly if you do not have family with you.

If you are feeling confused or lonely, talk to someone you trust like the social worker, Indigenous liaison officer or another hospital staff member.

They may be able to help you:

- make contact with family and friends that might not be able to come to the hospital to visit over video or phone;
- with Centrelink or things to do with time off from work.

*"Yeah and, the social worker, social workers in...in like rehab like would help to send letters to Centrelink for me and to speak to them for me because I wouldn't know how to speak to them and what to say."*

*"I just didn't want to be there because I was, I had been there before with the ex when she had cancer and that feeling came back up and I just didn't want to be in hospital. [...] like being there, got flashbacks and all that."*

*"Hospital was lonely because I didn't have my family here. I wanted my kids and my missus."*



# Care in Hospital



## Before you leave hospital

After having a brain injury you might have trouble understanding and remembering medical information. Before you leave hospital, you can ask one of the nurses, doctors or an allied health worker to help you write down the answers to the questions below:

### Some things to ask your doctor or rehabilitation specialist:

- ☐ What day will I be discharged? \_\_\_\_\_
- ☐ Could you please explain my diagnosis? \_\_\_\_\_  
\_\_\_\_\_
- ☐ What should I expect as part of my recovery? \_\_\_\_\_
- ☐ Do I need to be referred to a Nurse Navigator? \_\_\_\_\_  
\_\_\_\_\_
- ☐ Are there side effects of the medication I have been prescribed? What are they?  
\_\_\_\_\_
- ☐ Who can I contact at the hospital if I have any questions about my ongoing care or if I'm having troubles when I get home? \_\_\_\_\_  
\_\_\_\_\_
- ☐ What are the details of the rehab staff that have been helping me? \_\_\_\_\_  
\_\_\_\_\_
- ☐ I will need a medical certificate for work or Centrelink. Can you please provide one?  
\_\_\_\_\_
- ☐ Are there things I should avoid doing when I get home? \_\_\_\_\_  
\_\_\_\_\_
- ☐ If I start feel unwell when I get home, who should I contact? \_\_\_\_\_  
\_\_\_\_\_
- ☐ What are the things I might need to come back to hospital for? \_\_\_\_\_
  - I should return to hospital if: \_\_\_\_\_
  - I should see a doctor if: \_\_\_\_\_
- ☐ Do I have any follow-up appointments? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# Care in Hospital

## Before you leave hospital

Some things to ask your doctor or rehabilitation specialist (continued):

☐ Will I need any more tests, and if so, when? \_\_\_\_\_

☐ Can you send a discharge summary to my doctor or local health clinic? Yes/No  
– can you provide a discharge summary to me so I can pass this on to my doctor?

☐ Have there been appointments made for me to continue with rehabilitation? \_\_\_\_\_  
(include date, time and place):

• Physio therapy

• Occupational therapy

• Speech therapy

• Other

☐ How long will rehabilitation continue?

☐ Who can I speak to about where I will be living to see if I will need to make any changes, or equipment to help me at home? \_\_\_\_\_

☐ I'm also worried about \_\_\_\_\_ who can I talk to about this?  
(if you are worried about money issues, legal issues, family violence or any other issues please raise them here) \_\_\_\_\_

☐ Other important information

*Tip: It might help if you record your conversations with doctors or rehabilitations specialists about your injury. This way you and your family can listen to it when you get back home.*

# When you get home

## When you get home

A brain injury can impact almost every part of your life. When you go home, it is important you look after yourself. Some tips for your recover include:

### Things to tell your doctor or clinic when you get home

- ✓ Let them know you have been in hospital with a traumatic brain injury
- ✓ Attend all outpatient appointments
- ✓ Ask for help to find out when you have medical appointments
- ✓ Talk to your doctor about how you have been feeling since you got home
- ✓ Speak to a doctor to get the ok before you return to driving
- ✓ Take a family member to your appointments, to learn of ways they can support you during your recovery
- ✗ **Don't miss your appointments**
- ✗ **Don't keep things bottled up inside**

*"I think being back here in my community is good to help my memory and re-learn new things."*

### Getting better



Eat well



Avoid alcohol



Rest often



Stay away from fights



Talk to someone



Avoid contact sport

### When you get home from, you might have troubles:

- Fixing problems when they come up
- Organising things
- Making plans
- Keeping your mind on one thing
- Remembering things
- Getting dizzy
- Having headaches



*Tip: If you are having troubles with accommodation, money or not knowing where to get rehabilitation and medical help you can reach out to your local clinic for help. They will be able to connect you with a doctor, social worker or support service within your community.*

# When you get home

## Fighting, stress and sadness



### Staying safe

- Another head injury can be really bad for your health.
- You can end up with permanent changes. This can make it hard for you to work, take care of yourself and your family.



### Fighting

- If fighting happens in your family, you might want to talk to someone you trust about it. There are ways to keep yourself safe like identifying safe places in your community.
- If you don't feel safe, let someone know.
- If you are worried or stressed you might want to talk to someone about it.



### Stress and sadness

- Your local clinic can help connect you with the right supports.
- Talking to someone might make you feel better and help you get better quicker.
- At home you might feel sad and no good because things have changed.
- Talking to someone might make you feel better and help you get better quicker.

#### Tip:

- Stay away from noisy places
- Do less because you might get tired more quickly
- Write things down
- Do things in the same order every day until your memory gets better
- Avoid alcohol and drugs
- Don't get hit in the head again



## Shared Journeys

Over the following pages you will see artwork and the story of other people's journeys following a traumatic brain injury.





# Disorientation – My Life's Journey



**Artist: Mr Douglas Smallwood**



# Disorientation – My Life's Journey is a painting of Doug's life.

As part of *The transition from hospital to home project*, participants were asked if they would like to share with others the story of their journey following a traumatic brain injury. This is Doug's story.

On the outer edge of the painting are twelve emu eggs, with each egg representing a story from Doug's life. Emu eggs are fragile even though they have these different layers of colours when carving into them.

If you carve too hard on them, they break. Doug sees this fragility in his life.

The emu is a native animal to Australia, with many stories of the emu in Aboriginal people's Dreaming.

First egg	This egg depicts the genesis of Doug's life, including his mother and father who created him.
Second egg	This egg represents his four brothers who are painted in orange and his three sisters painted in pink.
Third egg	This is where Doug lived as a young boy near Walsh's Pyramid. The Pyramid is about 30kms south of Cairns at Aloomba, near Gordonvale.
Fourth egg	This egg tells the story of Doug, his dad and brother Greg cane cutting by hand near Gordonvale.
Fifth egg	This egg contains the Aboriginal flag. Doug identifies as a proud Juru and Bindal Aboriginal man.
Sixth egg	This egg represents the bus Doug would catch to school daily to Aloomba Primary School, near Gordonvale.
Seventh egg	This egg represents Doug's achievements in his football career representing Townsville and winning three finals out of five years during his time in the senior rugby league.
Eighth egg	This egg tells the story of alcohol and how it has destroyed Doug's life and impacted on him and his family.
Ninth egg	This egg represents Doug's own family, including the mother of his children, who gave birth to his five children. Doug's four boys are depicted in orange and his only daughter is depicted in pink.
Tenth egg	This egg represents the damage Doug has caused to himself as well as the damage from others through binge drinking. Binge drinking has contributed to Doug's brain injuries through falling when he is intoxicated as well as fighting with his family. Doug calls the lines on the brain in this egg 'lines of confusion'.
Eleventh egg	This egg represents Doug's journey continuing with alcohol, with ambulances coming to his place when he has cut himself and being taken to hospital. It also represents head injuries that Doug has inflicted on himself as well as sustained from other people when he is binge drinking.
Twelfth egg	This depicts the Milky Way, where we go to heal as well as wait for rebirthing.

The middle part of the painting, depicted with vivid colours portrays the bright skies before occupation. This is Doug's dreaming where one day he hopes to return, allowing him to have a life again that is simple and without complexities. Returning back one day from the Milky Way, Doug desires to have learnt from his mistakes and make way for new life lessons to be learnt.



# Footsteps of my life





# Footsteps of my life is a painting of Doug's life.

As part of *The transition from hospital to home project*, Doug was invited to complete two pieces of art to share with others about his experiences following a traumatic brain injury. This is Doug's second artwork.

Doug has painted his family on the right hand side of the painting, acknowledging their importance before and after his transition home. Doug has five children (four boys and one girl) and six grandchildren.

On the left side, Doug has painted an outline of his head surrounded by his mother and father. The words inside and around his head relate to the emotions and issues Doug has experienced during his first year after head injury. Doug explains the meaning of these words:



- **Self-sabotaging**

After his head injury, Doug says he *"didn't care about nothing"*, sabotaging plans, just living day by day.

Doug says getting support from his family and services including the Men's Shed and Ozcare has helped him.

- **Despair**

Doug says he has felt lost since his head injury. He believes it is important to have family around when feeling loneliness and despair.

- **Love and family**

Doug says that he loves his children. Doug's eldest son experienced a head injury from playing sport. Doug says he doesn't want his other children to experience head injuries and wants to encourage them to look after their own health.

- **Anger, combativeness and aggravation**

For Doug, these things relate to what has happened to him in the past. Since his head injury, Doug has been thinking more about the past. He says these memories can make him angry at himself and others.

- **Courage**

Doug says *"stand up for who you are"* and *"you can solve a problem by the way you approach a situation"*. Doug says returning to painting after head injury was based on his courage and desire to understand himself.

- **Hope**

Doug says *"people can go a long way with hope when they use that to think about something they want to achieve"*. Doug hopes to change his life and to be a good person through sharing his art with other people.

- **Curious**

Doug says after head injury he was unsure of what his mind and body could do but felt curious about how far he could push himself to achieve different things. Doug said he recently got out of his comfort zone and started teaching children art.

- **Family violence and violence**

Doug says many of his head injuries relate to violence from family.

- **Alcoholism**

Alcoholism has been an issue for Doug both before and after his head injury. He says he wants to stop turning to drinking to cope.

- **Stubbornness**

Doug says his family tell him he should stop drinking. While he hates when people tell him what to do, Doug acknowledges he has to stop being stubborn and thinking the wrong way. He says he needs to start listening to family including his mum, sisters and son, Lawrence ('Toby').

- **Secretiveness**

Secrets lead to sickness and fights. Doug says *"secrets make life worse"*.

- **Self-destructiveness and self-mutilation**

Doug says he gets upset when there is fighting, arguing and stress around him. Doug says he often uses self-harm to cope with these situations. Doug acknowledges that he needs to find a better way to cope when there is stress around him.

- **Confusion**

Since his head injury Doug is more forgetful and confused. He says this can be frustrating and he sometimes needs help from family and services to remind him of appointments and important information.

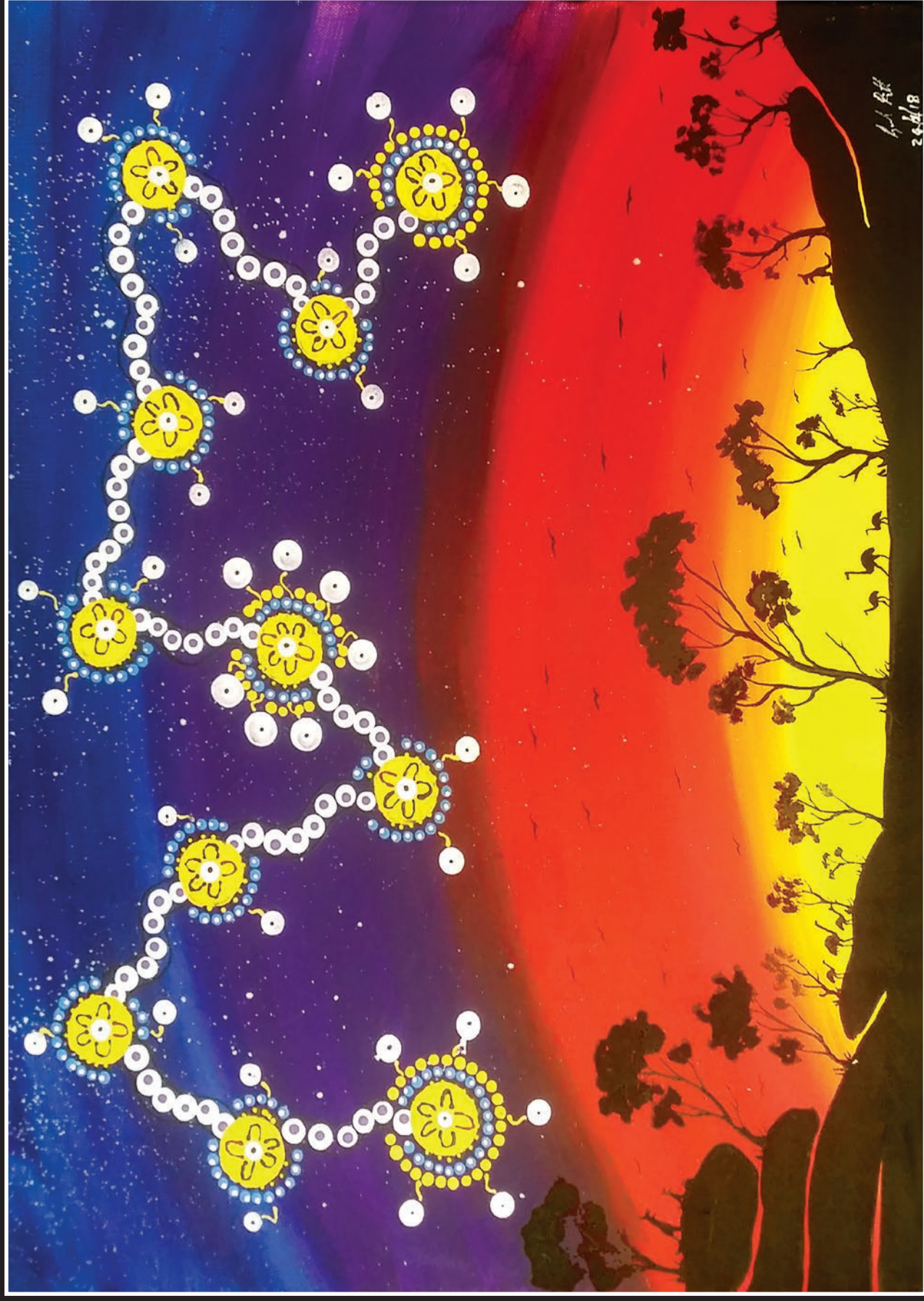
- **Identity and dispossession**

Doug says that since his head injury, he sees identity as changing your ideas of life. He says he feels stronger after doing this painting as it has made him think about the kind of person he is and where he wants to go in life.

- **Spirituality**

Doug says that he is a proud Aboriginal man and doesn't want to lose who he is. Doug says, in a way, his head injury has made him stronger. He now reminds himself to be proud and happy with who he is. Doug is going to keep his art going.

# Looking after family through country visits



24/18



As part of *The transition from hospital to home project*, Raymond was invited to complete a piece of art to share with others about his experiences supporting his brother who has had a traumatic brain injury.

Raymond said one of the biggest changes he noticed when his brother came home from hospital was that he was having trouble with community noise and people being around. It was making him angry and giving him headaches.

When he was struggling, Raymond would take his brother out of community and back to country. Raymond tells the story below:

***We like to go out camping, sit down, look at the sunset and tell a good story. When we go out, my brother remembers all the places he has been before, when we were kids spending time with our parents and grandparents from a long time ago. When we are on our country, we go looking for gemstones, we sing with all the family, we sit down with family and talk, catch up.***

***We set up camp, pick a spot near the creek and make a wind break. We make a fire, make a damper, cook kangaroo tail and sit around the campfire and talk. And if we have a guitar we sing. We go out and collect honey ants too.***

***What we end up doing, what he gets out of it, all our family come together and free our mind, just sit down and peaceful talk, from all the stress and troubles from around the community.***

***Other families come back into community and they're drunk, they're fighting and arguing and people with head injury struggle with it. We're not like that, that's why we get out of community and we go sit down and get away from that. We like going back to country.***

***Whatever happens there in community affects all of us. That's why we just go out and come back fresh.***

Raymond describes the painting as each yellow circle being a main camp with people sitting around the campfire. The camps with only the blue circles are the smaller communities, while the yellow and blue circles together are the large communities. Each campfire cares for an injured person. The injured people in the camps are represented in red. Each white dot leaving the main camps represents all the places people can travel to be on country.



Artist:  
Raymond Reiff

# Services who might be able to help:

<b>Cairns QLD</b>		
<b>Aboriginal and Torres Strait Islander Legal Service</b>	Can help with legal services for Aboriginal and Torres Strait Islander people.	<b>07 4046 6400</b>
<b>Apunipima</b>	Health and wellbeing service with a head office in Cairns and primary health and wellbeing services throughout Cape York.	<b>07 4037 7100</b>
<b>ATODS</b>	Can provide information including treatment and support services for alcohol consumption, smoking and drug use.	<b>07 4226 3900</b>
<b>Brain Injury Australia</b>	Can provide information and resources on brain injury.	<b>1800 272 461</b>
<b>Carers Queensland</b>	Can provides information, counselling and support services for carers.	<b>07 4031 0163</b>
<b>Disability and Community Care Queensland</b>	Can provide basic support services for eligible people who live at home and whose capacity for independent living is at risk.	<b>1800 600 300</b>
<b>Cairns Regional Domestic Violence Service</b>	Can help people who are living with domestic and family violence.	<b>07 4033 6100</b>
<b>DV Connect</b>	DVConnect Womensline telephone support if you or someone you know is experiencing domestic of family violence. DV Connect can provide counselling, intervention, transport and emergency accommodation for Queensland women and their children who are in danger from a violent partner or family member.	<b>1800 811 811</b>
	DVConnect Mensline provides professional, non-judgemental safety focused counselling and a referral service for men in Queensland.	<b>1800 600 636</b>
<b>Homeless Person Information Centre</b>	Can provide information about where you can find support, accommodation, meals or showers for people who are homeless or at risk of homelessness.	<b>1800 474 753</b>
<b>NDIS</b>	Can provide information referral and linkage for families and carers to be able to access supports in the community.	<b>1800 800 110</b>
<b>Patient travel subsidy</b>	Can provide financial assistance for eligible patients to access specialist medical services that are not available close by.	<b>13 43 25 84</b>
<b>Lifeline</b>	24/7 crisis support and suicide prevention services.	<b>131 114</b>
<b>Synapse</b>	Experienced brain injury coordinators can assist with engaging you with education and services for your individual needs after brain injury.	<b>1800 673 073</b>
<b>Cairns Hospital</b>	The hospital provides complex, high-level services across a wide range of specialties. You might have some outpatient appointments here after discharge.	<b>07 4226 0000</b>
<b>Cairns Hospital Nurse Navigator Service</b>	Can help co-ordinate your clinical care.	<b>07 4226 6354</b>
<b>Victims Assist</b>	Can help provide support if the injury was caused by violence.	<b>1300 546 587</b>
<b>Torres and Cape Nurse Navigator Service</b>	Can help co-ordinate your clinical care.	<b>07 4226 3005</b>
<b>Wuchopperan</b>	Health care service based in Cairns.	<b>07 4080 1000 (Manoora)</b> <b>07 4040 3100 (Edmonton)</b>