

Supporting your family member during their transition from hospital to home after traumatic 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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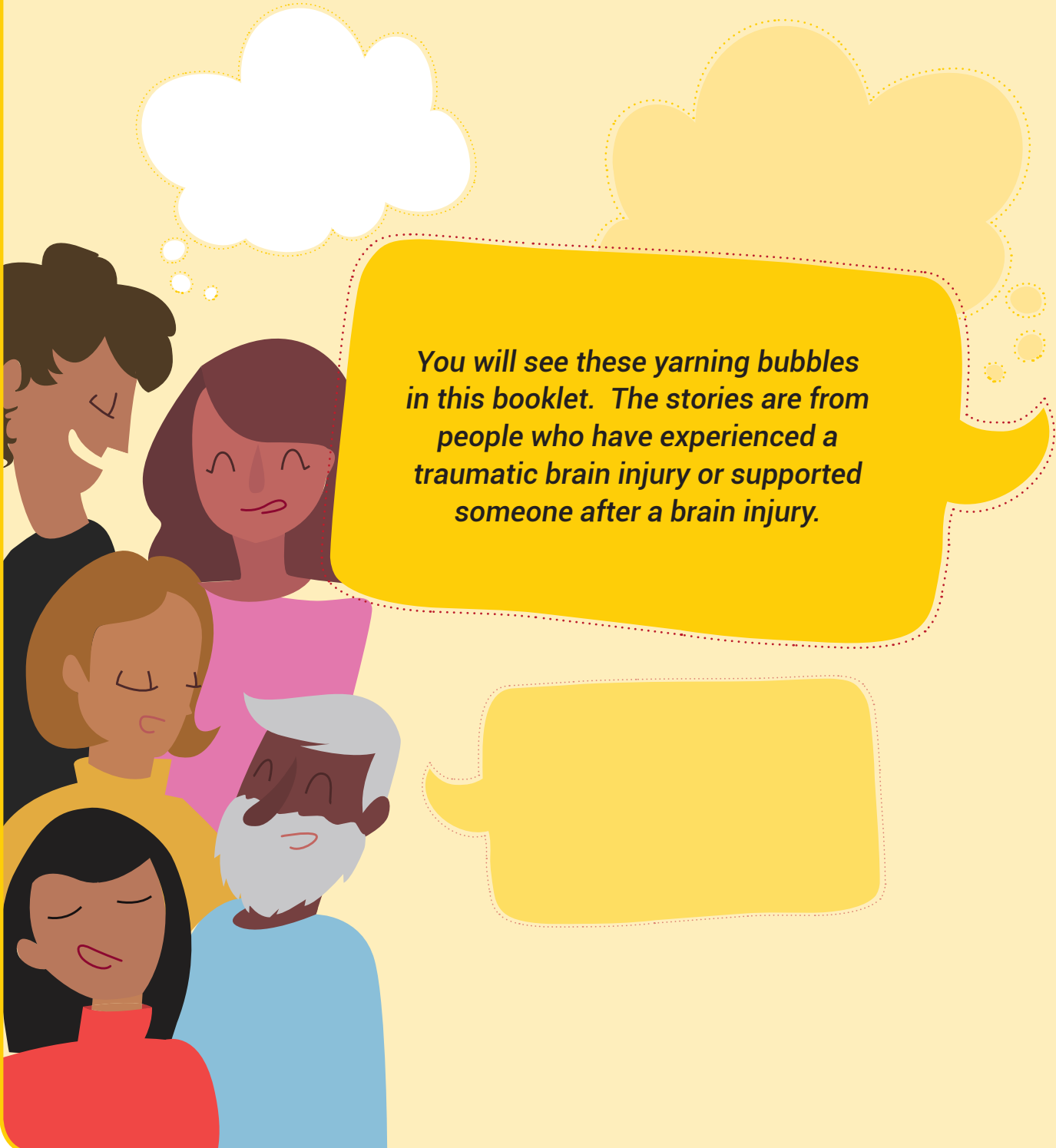
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**Someone close to you has had a brain injury.
This booklet might help make the journey from hospital to home easier.**



*You will see these yarning bubbles
in this booklet. The stories are from
people who have experienced a
traumatic brain injury or supported
someone after a brain injury.*

Disclaimer: This booklet has been prepared to provide general information only. If you are concerned about the medical condition of the person you are caring for or are 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 caused by being hit in the head. When a person is hit in the head, the brain can be damaged. Traumatic brain injuries are different for everybody.

There are lots of ways you can get a traumatic brain injury. For Aboriginal and Torres Strait Islander Australians, the most common cause is assault (being hit by someone) or accidentally falling.

Getting better will depend on what part of the brain was injured and how bad the injury is. The brain can heal itself a little bit, but the person will need your help.

"It looks like he is good on the outside so he must be good on the inside, but he is not on the inside... He looks okay, but inside things are not working the same as before."

"I don't know what is happening to his head, he is always getting really angry."

After a traumatic brain injury

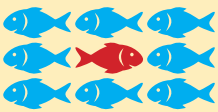
After a traumatic brain injury some people might:



- Not feel like the same person



- Notice changes in the way they think and feel



- Behave differently



- Be moody and emotional



- Have trouble remembering things



- Get tired very easily



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

In hospital

After a traumatic brain injury people can feel:

- Unsure of where they are or what is happening to them.
- Lonely or scared.
- Afraid to ask questions.
- Like they want to leave hospital before they are discharged.



You can help

When you have someone in hospital with a traumatic brain injury, you might be able to help them on their journey. It is a good idea to:

- Encourage them to stay in hospital.
- Speak to their doctors and nurses so you understand what is happening.
- Ask the hospital staff lots of questions.
- Help the person connect with other people at home that they might be missing.
- Go with them to their rehabilitation appointments.

*"He ran away.
But I also know
hospital help people."*

Rehabilitation

Rehabilitation is important. You could help by:

- Reminding them that rehabilitation will help them get back to how they used to be.
- Go to appointments with them if you can.
- Tell them to write things down or take pictures during their rehabilitation. This will help you both keep track of their progress.

*"I'd sort of sit there, I didn't
really participate, cos it
wasn't about me, it was just
about her and her doctor.
It was just for her to feel
comfortable."*

Care in Hospital

Hospital staff

Many hospital staff will be involved in helping with recovery. They might include:

Registrar

- A doctor who is in charge
- Helps make sure everything is being done to help the person with traumatic brain injury

Occupational therapist

- Helps the person recover so they can be independent and get back to activities of normal life
- Give complete cognitive and functional assessments

Physiotherapist

- Deals with the physical problems caused by the brain injury

Speech pathologist

- Helps with difficulties in speaking, listening, understanding language, reading, social skills, stuttering and using voice

Indigenous Liaison Officer

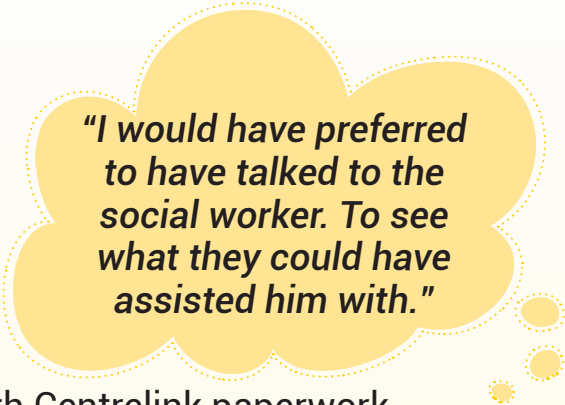
- Can help explain hospital services and procedures
- Helps communicate between you and hospital staff
- Can refer you to other services in the community

Social Worker

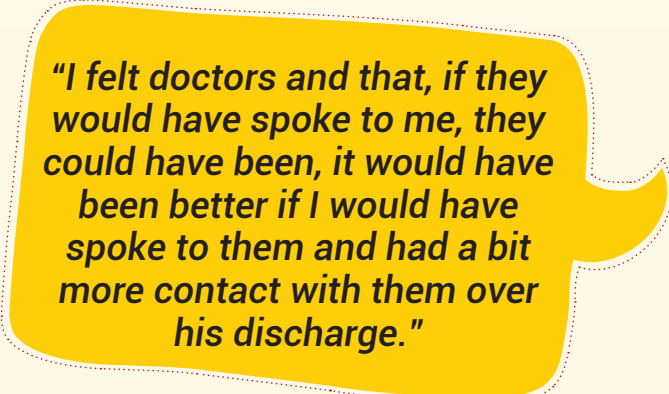
- Provides information and support including help with Centrelink paperwork counselling and clothes
- Can help with referral to drug and alcohol counselling

Nurse Navigator

- Can help support you and the person you are looking after by linking them with services in the community who can help
- Can also help with understanding the challenges that happen after a traumatic brain injury



"I would have preferred to have talked to the social worker. To see what they could have assisted him with."



"I felt doctors and that, if they would have spoke to me, they could have been, it would have been better if I would have spoke to them and had a bit more contact with them over his discharge."

Care in Hospital

Before leaving the hospital

Before going home, you might want to ask a hospital staff member to help answers the questions below. It's a good idea to write the answers down:



Some things to ask a hospital staff member:

- ☐ When is _____ being discharged? _____

- ☐ What is their diagnosis? _____

- ☐ Is there anything I need to watch for? _____

- ☐ Is there anything they won't be able to do? _____

- ☐ Are there any side effects of the medication they have been prescribed? _____

- ☐ What is the plan for their rehabilitation? _____

- ☐ Have there been rehabilitation appointments made, if so, when? _____

- ☐ How long will rehabilitation continue? _____

- ☐ Should _____ be referred to a Nurse Navigator before leaving hospital? _____

- ☐ Does _____ need any equipment before they go home? _____

- ☐ Is our home suitable for me to care for _____ or do we need to make some changes? Who can I speak to about this? _____

- ☐ Has _____ been given a medical certificate, they might need this for work/Centrelink? _____

Care in Hospital

Before leaving the hospital

Some things to ask a hospital staff member (continued):

- ☐ Do they have follow-up appointments? If so when? _____

- ☐ Will they need more tests? If so, when? _____

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

- ☐ 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 _____

Coming home

Coming home

It's exciting when the person you care for comes home from hospital. Everyone will want to get on with their life at home. It's important to remember there could be some troubles and things might not be the same as before:

A brain injury can be a long term injury

- Recovery will be different for everyone

Troubles for the person with the brain injury

- They might want to do things for themselves, but have trouble
- They might get angry more easily
- They might be lonely or sad
- They might get tired easily
- They might have headaches or body pains
- They might not know what's happening
- They might need your help to contact their doctor or local medical clinic

"During the first, the first, like at the start, when she came out, it was... we could see differences in here, like slight little differences in her personality. Like she had no tolerance for children or loud noises or anything, so we were sort of all walking on egg shells cos we were doing our best to accommodate her... we've had to change little things about ourselves so we wouldn't irritate her, to help her process it and get better."

Changes might make you feel worried, but remember:

- The person you are caring for might be more vulnerable
- They might need more help from other people
- Emotions are high for everyone

"He should stay away from the gunja. Alcohol. Not thinking properly. He thinking slowly, damage to his brain."

How you can help

- See a doctor in your community and let them know they have been in hospital for a traumatic brain injury
- Encourage them to eat well
- Have a quiet place so they can rest - they will need more rest than usual
- Encourage them to avoid alcohol
- Encourage them to avoid fighting and being hit
- Remind them when they have appointments
- Go to their appointments with them

"He's not all there sometimes. Sometimes I asked him where he left his wallet. He doesn't know. I have to do more of the shopping. I can't send him to the store because he will forget."

Coming home

After someone has had a traumatic brain injury, it can be hard for you as well. It might be a good idea to speak to someone about these things, they might be able to help. For you, this might be a family member, your doctor or a social worker.

Frustrations for you

- You might be frustrated with all the changes
- You might feel sadness about the changes in your life and the life of the person you are caring for
- You might have financial worries
- You might have fears and worries about the future
- You might have worries about the lack of understanding from people in the community



What can you do?

- Speak to someone about your worries
- Take care of yourself
- Don't be afraid to reach out for help

You need to take care of yourself so you can help the person you are caring for.

"I have been very stressed. I smashed my phone the other day. So I lost all my numbers. When we have argument I will just sit there and listen. I have tried to argue with [participant] when he is wrong with what he is saying, when he says no one cares. But that has made things worse. So now I just sit there and listen. "

"I can't say anything. I make it worse so I just listen. I tell other family about what my family deal with here. Sometimes I have to explain and remind them that she has brain injury and that we have to want for her to recover. She may never recover. That's what I tell other people in the community so no one punches here. She is still becoming easily annoyed. So we have to study her. That's what we do. We have to work out what sets her off and how to stop her when she is getting angry and yelling. I mainly just listen and then she calms down. "

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



Artist: Mr Douglas Smallwood

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 ways 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



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:

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