

# POST-TRAUMATIC AMNESIA (PTA)

## A GUIDE FOR FAMILY AND FRIENDS

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## What is a traumatic brain injury?



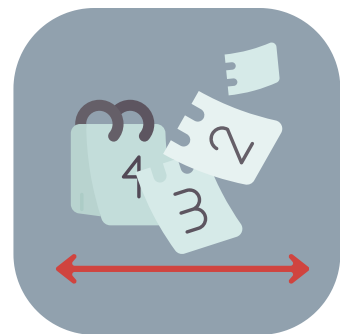
- A traumatic brain injury (TBI) is a brain injury caused by an outside force, such as a direct hit or jolt to the head.
- TBIs can occur during a motor vehicle crash, fall, sport, or an assault.

## What is post-traumatic amnesia?

- Post-traumatic amnesia (PTA) is a *temporary* and *expected* stage of recovery for most people after a TBI.
- PTA does not occur in other brain injuries (e.g., a stroke or tumour).
- During PTA, people are confused, unsure of the time and place, and have difficulty with their day-to-day memory.
- People in PTA may act differently to their usual self.
- **This is not their fault or a choice. It is caused by their brain injury.**

## How long does PTA last?

- PTA can last for hours to weeks.
- The time spent in PTA is different for each person.
- PTA will typically be longer in more severe injuries.
- There is no way to predict how long PTA will last.
- No treatment is proven to make PTA end sooner.
- We will talk to you about how the person in PTA is progressing.



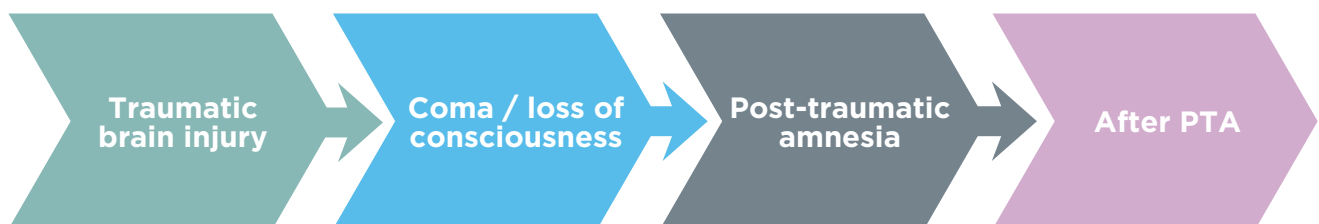
## How do you know when PTA is over?

- Each day, staff will ask the person with a TBI questions about their memory and orientation (e.g., to time) to check if they are in PTA.
- A sign that PTA has ended is when people can consistently remember new information.
- Staff need to correctly measure PTA to guide the person's care.
  - It is important not to help the person in PTA 'pass' these questions, such as writing the answers down for them.
  - Passing too early could mean they get rehabilitation or are discharged before they are ready.

## Stages of recovery

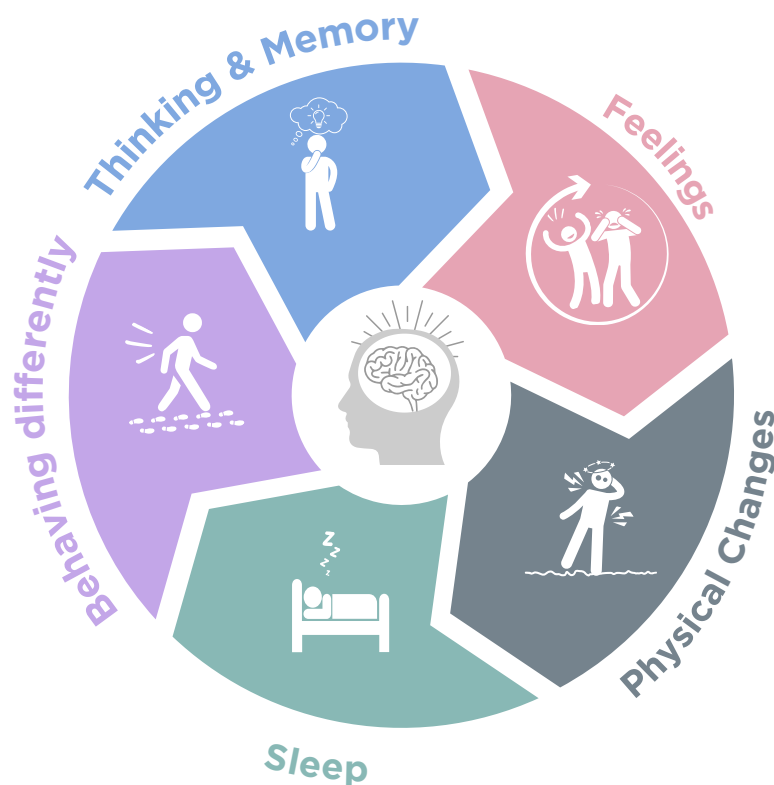
- During or after PTA, some people will be moved from an acute hospital to a rehabilitation hospital.
- People in PTA will often have rehabilitation/therapy while in hospital.
- Further assessment and rehabilitation is often needed after PTA has ended, and may continue after being discharged.
- **The team will talk to you about what your family member or friend needs. This will be different for each person.**

### Most people follow this path



## Symptoms during PTA

- People in PTA may have some or all of the following symptoms.
- **These are a result of the brain injury and being in PTA. They are not a choice.**
- Try not to take what the person in PTA says or does personally during this time.
- If you are confused or upset by any symptoms, or notice any major changes in your family member or friend (e.g., in their personality), please let the healthcare team know.
- The team will help you understand these symptoms, and how you can best support the person in PTA.
- Each person in PTA is different. Avoid comparing your family member or friend with others in PTA.
- Many challenging symptoms will improve once PTA has ended, however some may persist.



## 1. THINKING AND MEMORY

People in PTA often have changes to their thinking and memory.

**Confusion and Disorientation** - People in PTA may:

- Not know where they are, or the day, time or year.
- Not recognise people around them, including family.
- Not know or understand what happened to them, or why they are in hospital.
- See or hear things that are not there, or have false beliefs that seem real to them.
- Get upset when you leave, as you provide comfort.
- Have changing levels of confusion, which may be worse at night.



**Memory Difficulties** - People in PTA may:

- Have trouble making new memories and recalling daily events.
- Get stuck on one topic or thought and be hard to shift. They may repeat themselves, change topics quickly, and have trouble following a discussion.
- Forget things you have told them.
- Ask the same questions over and over, like:
  - Can I go home? Can I go outside?

**Reasoning and Decision Making** - People in PTA may:

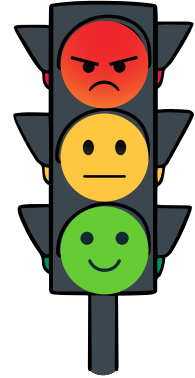
- Find it hard to focus, plan and carry out tasks.
- Try to convince others that they are 'well' and can go home.
- Not understand that the recommendations from the team are there to support them.
- Not understand why they need to be in hospital, and try to leave.

## 2. FEELINGS

People in PTA may have changes to their feelings and personality, such as being more:

- Cheerful or laughing more than expected.
- Sad, depressed, withdrawn or teary.
- Scared or anxious than usual.
- Irritable, aggressive or defensive than usual.

They may also have sudden changes in their mood.

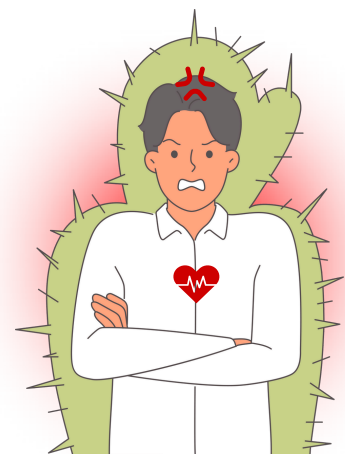


## 3. BEHAVING DIFFERENTLY

People in PTA may also have changes in how they behave such as:

- **Agitation** (e.g., becoming aggressive, angry or easily frustrated, or being restless, such as wandering, pacing, or constantly moving in bed).
- **Acting without thinking** (e.g., pulling bandages or lines out, using broken limbs, lunging for items, eating or drinking too fast, eating non-food items).
- **What they say** (e.g., swearing, making threats, acting or speaking in a sexual way that is not usual for them, being overly direct or impolite).
- **Confabulation** (e.g., storytelling, or saying things that are not true, but seem very real to them).
  - These things can worsen when tired or overstimulated.

People in PTA can be confused and have trouble expressing themselves. At times, what seems to be an “aggressive” behaviour may be the person trying to protect themselves from things they do not understand, or to communicate their needs.



## 4. PHYSICAL CHANGES

After a brain injury, physical symptoms can occur such as:

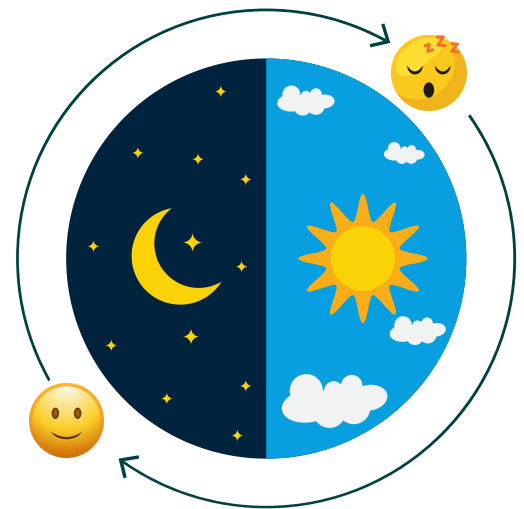
- Pacing, impulsive movement
- Poor balance and coordination
- Physical weakness and fatigue
- Sensitivity to light and noise
- Incontinence (loss of control of bladder or bowel function).



## 5. SLEEP

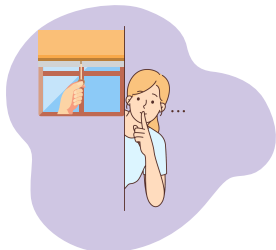
Sleep changes can occur during PTA. People in PTA may:

- Become tired easily
- Need to sleep more than usual.
- Have trouble getting to sleep or staying asleep.
- Sleep during the day, and have poor sleep at night time.



## What can be done to help during PTA?

### Environment



- Provide a quiet, safe and consistent setting. Limit noise and activity in the person's space to avoid overstimulation.
- Allow access to natural light, and adjust artificial light as needed.
- Limit technology for the person in PTA and visitors.
- Encourage rest. People in PTA often nap during the day. Talk to the team about when to wake them or let them sleep.
- For safety, people in PTA are usually not able to leave the ward.

### Supporting Orientation



- Remind the person in PTA of the time and place often.
- Bring a few familiar items from home (e.g., photos, a blanket).
- Some people may find their favourite music, talking about familiar topics, or doing simple familiar activities comforting.

### Communication



- Keep conversations simple and sentences short. Speak calmly.
- Speak one at a time. Give time to reply. Repeat yourself if needed.
- Ask yes/no questions if needed.
- If the person is agitated or confused, try not to argue. Agree with them, change the topic, or gently try to reassure them.
- Be conscious of what you discuss. Speak respectfully. Ask the team for advice (e.g., neutral topics, how to discuss the accident).

### Visitors



- Visiting hours may be flexible for immediate family if helpful.
- Keep track of how the person in PTA reacts to you being there.
  - If confusion or agitation increases, a break may be best.
  - The team will work with you to see what works best.
- Limit other visitors (e.g., extended family, friends) to 1 to 2 people at a time. Keep these visits short and spaced out during the day.
- Take regular breaks from the hospital. This gives you and the person in PTA time to rest.

## How to manage risk during PTA

While in PTA, some symptoms may cause a risk to the person or others. We need to ensure the safety of all patients, visitors and staff. These are some things the team may do to help manage risk in PTA. **The team will talk to you about what is relevant for your family member or friend in PTA.**

### Medication

- Medication may be needed if the person in PTA is:
  - Agitated and acting in a way that causes risk.
  - Having hallucinations or delusions that cause risk.
  - Having emotions that make them distressed.
  - Having poor sleep - this can make agitation or confusion worse.



### Staff

- At times, people in PTA may have a team member sit with them to support their needs closely (e.g., to stop them from getting out of bed, wandering, or harming themselves).

### Physical Restraints

- Restraints are things that can help keep the person (and others) safe, like mitts, straps, or a low, enclosed, or padded bed, to prevent falls or injury.
- Restraints are avoided, but may be needed at times.
- People in PTA may move without thinking, or act aggressively.

### Limiting Technology

- Due to their confusion and poor memory, people in PTA may misuse technology (e.g., calling someone over and over, posting things online, or mishandling their money).
- For their safety and recovery, personal devices (e.g., phones and computers) are usually removed or used sparingly.

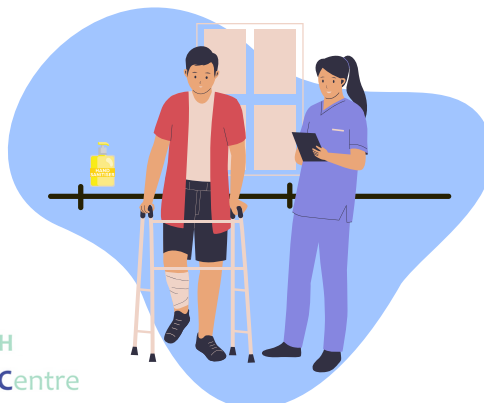


### Decision Making

- People in PTA are temporarily unable to make important lifestyle, financial or medical decisions. A 'next of kin' will help with this.

## Care and rehabilitation/therapy during PTA

- Many people play a role in the person's care in PTA.
- People in PTA may receive physiotherapy, occupational therapy, speech therapy and more.
- The type and amount of rehabilitation/therapy a person receives is based on their needs and abilities, and will change as they recover.
- Care and rehabilitation will be individualised as much as possible, including considering cultural needs.
- Therapy sessions will be short, with breaks throughout the day.
- Family or friends may be asked to join some sessions if it helps the person in PTA.
- **The team will work with you and the person in PTA to see what works best.**
- Knowing the person in PTA better can help us adapt and provide care that is respectful of their values.



## How can family and friends help during PTA?

Family and friends can play a key role during PTA. They may be involved in caring for the person in PTA in many ways.

### Comforter

- Some people in PTA may feel more at ease when their family or close friend is with them.
- A familiar face may help settle confusion, agitation and tricky feelings. It can help the person feel safe and reassured.

### Informant

- Family and friends can help the team learn about and build a connection with the person in PTA, which can help tailor care.

### Advocacy

- Family and friends can ask the team questions and speak up to make sure the person's needs are being met during PTA.
- They can help the team notice progress or changes in the person to help guide care.

### Support in Therapy

- Family and friends can suggest ways to adapt therapy to the person's interests, and give hands on support in sessions.

### Decision Making

- Family may be needed to help make decisions about the person's care while they are in PTA and cannot do this for themselves.

The role of family and friends is different for every person in PTA. It may change across recovery. The team will work with you to see how you can best be involved.



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## Impact on family and friends - looking after yourself

We know that PTA can be a hard time for everyone.

- Changes due to a brain injury can be upsetting and confusing to see.
- There can be a lot to deal with both practically and emotionally.
- You may feel lost, alone or overwhelmed.
- Ask the team about the supports that you can access.

### You may find some of these things helpful to have during PTA.

- **A diary or notebook** for questions and thoughts about the person in PTA. This can be shared with the team and visitors.
- **A roster for visits.** This can help you and others plan your time and share the load. It also gives everyone time away from the hospital.
- **A self-care routine.** It can be hard to take time away from your family member or friend, but:
  - Recovery can be a long process. Pace yourself.
  - It is okay and recommended that you take breaks.
  - Look after yourself by eating well, exercising and resting.
  - Outside life does not stop for a brain injury, and you will still have other needs (e.g., work, childcare, life admin).
  - Ask others for help with things like cooking, shopping or childcare.







This document was developed through a collaboration between:

- Researchers at the Monash Epworth Rehabilitation Research Centre (School of Psychological Sciences, Monash University),
- People with lived experience of PTA,
- Family members of people with a traumatic brain injury, and
- Healthcare professionals from the following organisations:

The Alfred Hospital, Bathurst Health Service, Epworth Healthcare, Finders Medical Centre, Grafton Base Hospital, Liverpool Hospital, Royal Darwin Hospital, Royal Hobart Hospital, Royal Melbourne Hospital, Sir Charles Gardiner Hospital, South Australia Brain Injury Rehabilitation Service, Tweed Valley Hospital, The University of Newcastle, The Brain Injury Rehabilitation Service, Westmead Hospital.

Further information on PTA can be found below:

Ponsford, J., Trevena-Peters, J., Janzen, S., Harnett, A., Marshall, S., Patsakos, E., Kua, A., McIntyre, A., Teasell, R., Wiseman-Hakes, C., Velikonja, D., Bayley, M. T., McKay, A., & INCOG Expert Panel (2023). INCOG 2.0 Guidelines for Cognitive Rehabilitation Following Traumatic Brain Injury, Part I: Posttraumatic Amnesia. *The Journal of head trauma rehabilitation*, 38(1), 24-37. <https://doi.org/10.1097/HTR.0000000000000840>



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# “ABOUT ME”

Every person is unique and deserves to be cared for in a way that supports who they are. Please fill out the below prompts to help us get to know the person in PTA. Add additional information to the blank box. You may also like to provide a photo of the person prior to their injury to the team.

## A bit about me

*For example: my preferred name, values and personality, the important people in my life, my jobs or roles are (e.g., work, study, parenting)...*

## My likes

*For example: my hobbies and interests, favourite things (e.g., sports, music, movies, shows, books, places), topics of interests/importance, things that are comforting...*

## My dislikes

*For example: things that make me uncomfortable, things I do not like to discuss, I prefer to be alone/with company...*

## Other

## The care team

During PTA, the following team members may be involved.

### **Doctors**

Look after the person's medical needs by treating medical issues, talking with other specialists, updating the family about the person's condition and overseeing the rehabilitation program.

### **Our Doctor**

### **Nurses**

Give 24-hour nursing care for the person's medical needs, help with daily tasks (e.g., dressing and feeding), therapy programs, and advocating for the wellbeing of the person in PTA.

### **Our Nurses**

### **Speech Pathologists**

Look after swallowing difficulties and thinking and communication challenges, and assist the person (and their family) to communicate.

### **Our Speech Pathologist**

### **Occupational Therapists**

Help the person do daily tasks (e.g., bathing and feeding), and work with other therapists to monitor and support the person's physical and thinking skills.

### **Our Occupational Therapist**

## ***Physiotherapists***

Help improve the person's movement, prevent stiff muscles and joints, and help organise aids for movement (e.g., wheelchairs or walking aids).

## ***Neuropsychologists***

Monitor the person's memory and thinking, and support challenges with memory, behaviour and mood.

## ***Dietitians***

Make sure the person's diet gives them the nutrition needed to help their recovery, and give advice on the use of feeding tubes, if needed.

## ***Social Workers***

Help families access funding and supports, and give information and education to families.

## ***Support Services***

This includes ward clerks, transport orderlies, pastoral care workers and the hospitality team, who also play an important role in your experience of the hospital.

## **Our Physiotherapist**

## **Our Neuropsychologist**

## **Our Dietitian**

## **Our Social Worker**

## **Names**