



RETURNING HOME

AFTER ACQUIRED BRAIN INJURY

Working in partnership with:



01482 620229
www.paulforbrainrecovery.co.uk

Working in partnership with NHS Hull CCG and CHCP

P.A.U.L For Brain Recovery is commissioned by NHS Hull CCG to provide community support for individuals and families affected by acquired brain injury (ABI).

Our free service is the next step after leaving hospital to support brain injury recovery, helping to minimise the long-term effects and manage the different stages.

We are a charity that understands brain injury and the impact it can have. We provide a safe space to support and guide those affected beyond hospital, aiming to make life easier during recovery.

Read this guide for some helpful ways to adapt to life at home.



CHANGES YOU MAY EXPERIENCE WHEN RETURNING HOME

After ABI, leaving hospital is a positive step forward. However, some people may feel apprehensive and unsure of what to expect during recovery.

Brain injury recovery is experienced differently by everybody.

Returning home can be a stressful time. For some, it can be hard to deal with the initial change. ABI can result in physical, emotional, behavioural, and cognitive impairments, which may be temporary or permanent. This can present difficulties that can affect many aspects of life. Some of the common difficulties are listed below.

- **Emotional changes may occur.** You may feel emotions either much bigger or rawer, or much less and a bit flatter than they were before.
- **Memory** both short and long term memory can be affected.
- **Changes in or loss of identity** may occur due to feeling and behaving like a different person.
- **Dividing attention and concentrating** may be difficult and cause frustration.
- **Confusion and understanding** of “normal” life may be altered or different to before. Having conversations with others could be overwhelming and making decisions might be difficult.
- **Neuro-fatigue** or extreme tiredness is common and can affect completing even simply everyday tasks.
- **Sensory overload** can sometimes occur where there is noise, bright lights or in busy environments. This can lead to a feeling of confusion, panic or you may become tired.



HELPFUL GUIDANCE FOR PATIENTS WHEN RETURNING HOME

- Take it easy whilst settling back into home life. Brain recovery can be a long journey and, in many cases, good days as well as more challenging days can be common.
- Communicate with your family to help them understand how you are feeling.
- Don't expect too much of yourself. Take regular breaks and quiet time to help your brain recovery.
- Although seeing friends may be helpful, being social might be unexpectedly overwhelming for you, especially in the first few weeks after leaving hospital.
- If you are able, gentle exercise and fresh air can be beneficial.
- Follow a good sleep routine. You may also need to take short naps during the day.
- Try to eat a balanced diet, eating meals at regular times. Keep hydrated, and don't eat too late at night.
- Ask a family member or a person you trust to help you with everyday tasks if you need support.



**BE KIND TO YOURSELF – FEELING STRESSED AND DOING TOO MUCH
CAN SET YOUR RECOVERY BACK.**

GUIDANCE FOR FAMILIES

How to support your loved one

As with any injury, ensuring your loved one is comfortable, and they feel supported plays an important role when they return home after being in hospital. As well as being aware of the guidance in the first section of this booklet, here are some ways that could help make life easier for your loved one, yourself, and everyone within the household:

- Try to reduce stress and pressure. Help to make decisions when you feel it might be helpful.
- After brain injury, understanding how to complete everyday tasks may be a challenge. Altered thinking and feeling may make it difficult for your loved one to keep track of conversations and process information. Try not to overload your loved one with unnecessary information and don't expect them to contribute to conversations as much as they would have done pre-brain injury. Using a slower pace during conversations may help.
- Keep visitors to a minimum. If people do come to visit, try to ensure your loved one has had a rest beforehand to avoid overstimulation.
- Make adaptations to your home to help with poor memory. Using sticky-note reminders to label drawers could help your loved one with tasks like getting dressed or making food. A wall chart might be helpful so that your loved one knows what day it is, and what to expect during the day or the days ahead.
- Support your loved one by breaking any tasks down into manageable chunks. If tasks become too overwhelming, then suggest that you complete the task together.
- Reduce the amount of visual and audible stimulation. Your loved one may be sensitive to light and noise. Too much can cause stress, confusion, and sensory overload.
- Liaise with the hospital, GP and other relevant services like P.A.U.L For Brain Recovery to take the burden away from your loved one.



- Be patient, understanding and try to offer support even if changing emotions occur.
- Varying difficulties may be more debilitating on some days, more so than other days. Avoid placing expectation on your loved one as setbacks are common and pressure can hinder recovery.
- Support a routine which incorporates plenty of time for rest. Set times for meals, exercise, medication, sleep, visitors, etc. can avoid your loved one suffering the effects of neuro-fatigue and becoming overwhelmed.
- Encourage a balanced diet and ensure your injured loved one drinks plenty of water. Smoking, alcohol, caffeine and excess sugar should be avoided.
- Help to ensure medication is taken on time. Using a pill box and setting an alarm on your phone could help.
- Although it may be difficult for your loved one to identify and communicate how they are feeling, regularly take the time to talk away from distractions. In some cases, a brain injured person cannot always understand or make sense of their injury.
- Keep a diary of mood, improvements and setbacks, and any medication problems. A diary can help to track progress and may be useful when talking to medical professionals.



Dealing with changes as a family

The consequences of brain injury can affect the whole family unit. Personality, behavioural, physical, and emotional changes can affect routines, family roles and responsibilities. This can impact upon relationships within the family, which can be especially difficult for children to understand.

Since the family's role can be critical, it's important that the family come together. Support can help to optimise recovery and minimise the long-term effects.



Ways to support one another within the household:

Communicate possible impacts with the family - Talking to family members within your household about possible changes, common effects of brain injury and consequences could be helpful.

Regularly check-in with family members - Talking to one another could help to understand how everyone is feeling. It is very common to feel high levels of guilt, anxiety, hope, despair, frustration, or even resentment. Talking about this may be useful to identify and offer specific support or find positive solutions that could be helpful for everyone.

Make alternative arrangements - Asking extended family or friends for extra support, especially during early recovery could ensure that everyone is feeling supported and help avoid problems building up over time.

Ensure sufficient rest – Supporting an injured loved one often requires patience and attention which is harder when tiredness occurs. Sharing responsibilities to allow rest-breaks may be necessary. Practicing self-care can be helpful to better support yourself and loved one.

P.A.U.L For Brain Recovery offer families support, guidance, and education to help manage the difficulties that can occur as a consequence of brain injury. This could help your family cope, and help you better support your loved one during recovery.

HEROES WORDS OF WISDOM

At the charity, some of our inspirational service users are part of a Heroes group that gives them the opportunity to be the voice for brain injury survivors. From their lived experience, here are some of their thoughts of early recovery, along with some advice on what you could expect and helpful tips on what was useful to them.



" You may not know what all your challenges are until you try to return to living life 'normally' at home. "

" Feeling overwhelmed and vulnerable when returning home can be normal. "

" It can be a lonely battle but it does get better with time. "

" Looking back, my family would have benefited from basic brain injury understanding. "

At the P.A.U.L For Brain Recovery charity, we can offer your family an opportunity to learn about brain injury and the common consequences that can occur. Family members can benefit from talking to a member of our experienced team, at any stage of recovery. Guidance can be helpful towards managing difficulties at home and learning how best to support your loved one.

“Energy levels may fluctuate from day-to-day.”

“Neuro-fatigue was one of the most debilitating things during recovery, but it did get better with time.”

“I found stress and pressure hard to deal with.”

CHANGING THE SUBJECT DURING A CONVERSATION WAS CONFUSING AND OVERWHELMING FOR ME.

REMEMBER: Everyone's experience of recovery and the impact is different. The charity can offer support and guidance, and help you access the relevant services that you're entitled to.

“Seek advice about returning to work. Returning too early could set your recovery back.”

A desire or need to return to work soon after brain injury can be common. It may be helpful to look at different options to ensure this does not negatively impact recovery. At the P.A.U.L For Brain Recovery, we can help to ensure you are fully informed so that you can make choices based on your wider health and wellbeing needs.

EARLY RECOVERY AND WHY COMMUNITY SUPPORT IS IMPORTANT

Recovering from a brain injury relies on the brain's plasticity - the ability for undamaged areas of the brain to take over functions of the damaged areas. This means that the brain may be able to re-learn and compensate for lost abilities, due to the injury.

Recovery can be a long and challenging journey. Some things will get better over time, but some things may not change much at all. It is normal to see bigger improvements in the early weeks and months but the speed of improvements often slow down as time progresses.

P.A.U.L For Brain Recovery can:

Help you understand and manage the different stages of recovery. We offer support, guidance and education to help you understand ABI and help all affected to manage the difficulties and consequences often faced.

Assist you with accessing other services to help take the burden away during a difficult time. We can help with referrals and signposting to ensure you are accessing all relevant support services, including such things as Carers Support and benefits advice.

Help to minimise some of the common consequences of brain injury and improve quality of life. Tailored support plans can combine any of our free sessions and activities that are designed to optimise recovery. These include, weekly social meet-ups, day trips, yoga, gym, time at our allotment, walking groups and peer support. We also hold one-to-one and family support sessions.

Help you learn to accept difficulties and feel hope of a brighter future. Being social within a supportive community of others that are going through a similar experience may offer reassurance that you are not alone in how you are feeling. It could help you to accept and manage your difficulties and help you to make new friends.



Joining the P.A.U.L For Brain Recovery community could help you to take positive steps forward towards reaching your new potential after brain injury.

“ It was amazing to meet people who understand me and who have been through similar experiences ”

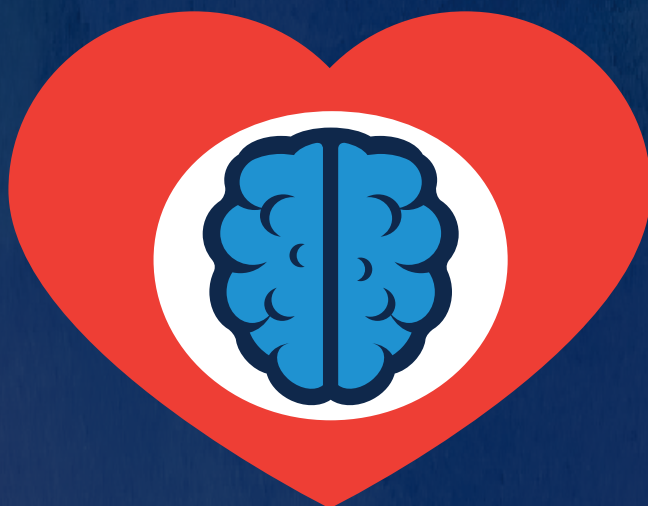
- Service user feedback



**You are not alone.
Our friendly team have the experience to help make life
easier after brain injury.**

Find out more at www.paulforbrainrecovery.co.uk

Please get in touch if the charity can help you further with your recovery journey



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@P.A.U.L For Brain Recovery

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