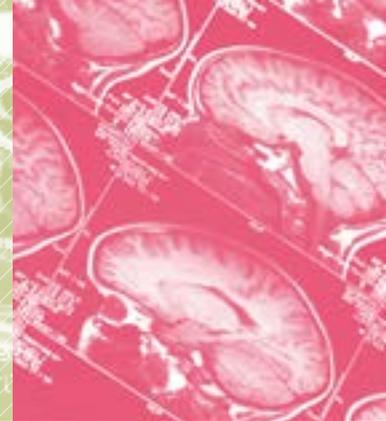




TRAUMATIC BRAIN INJURY  
**GUIDE**  
TO CARE OPTIONS

**CARE OPTIONS GUIDE FOR INDIVIDUALS WHO HAVE  
EXPERIENCED A TRAUMATIC BRAIN INJURY**

# TRAUMATIC BRAIN INJURY **GUIDE** TO CARE OPTIONS



TLW Solicitors have a local heritage, providing specialist legal services to people for over 15 years in the North East of England and beyond.

With extensive specialist training and an external accreditation from Headway (The Brain Injury Association), our serious injury solicitors work alongside experienced care and rehabilitation specialists to ensure our clients receive the very best professional advice and are able to access the support they require.

Care options for individuals who have experienced a traumatic brain injury may seem wide-ranging and complex.

As the period following any serious injury can be very difficult for the individual in question, as well as their family and friends, accessing the right care services to ensure the best brain injury treatment that one is entitled to can be a challenging time.

**For more information or to book a consultation with one of our team call us today on 0800 169 5925.**

## **SERIOUS INJURY IN THE NORTH-EAST**

Our 8 part care options guide details personal injury treatment and options available for individuals and their families who have experienced a traumatic brain injury.

### **CONTENTS**

#### **04: PART 1**

Emergency & Hospital Traumatic Brain Injury Treatment

#### **08: PART 2**

Post-Hospital Traumatic Brain Injury Rehab & Funding for Care

#### **14: PART 3**

Brain Injury Support in the Community

#### **19: PART 4**

Returning to Work After a Traumatic Brain Injury

#### **22: PART 5**

The Importance of Sleep After a Brain Injury

#### **27: PART 6**

Brain Injury Support and Financial Assistance

#### **31: PART 7**

Long Term Effects of a Brain Injury

#### **36: PART 8**

Assistive Technology for a Traumatic Brain Injury



# PART 1

## EMERGENCY & HOSPITAL TRAUMATIC BRAIN INJURY TREATMENT



### **ACUTE/EMERGENCY TRAUMATIC BRAIN INJURY TREATMENT**

Initial traumatic brain injury treatment can vary widely depending upon a person's injury and their location at the time the injury occurred.

A paramedic may be needed to stabilise the person, checking their breathing, stopping any bleeding, ensuring they are safe to be moved and making the person as comfortable as possible.

If a traumatic brain injury is of a certain severity the person will be taken to the closest major trauma centre. There are two major trauma centres in the North East, The Royal Victoria Infirmary in Newcastle and James Cook University Hospital in Middlesbrough. Both hospitals have facilities for a helicopter to bring patients into the hospitals.

When all the various checks have been made a person will be moved to hospital for further observation. Once stable a computer tomography (CT) scan may be carried out to detect the level of serious injury sustained. The extent of a brain injury may be assessed using the Glasgow Coma Scale, which is numbered from 3 to 15, the latter being the most severe.

Depending on what is found by the CT scan, a person may require surgery on their head and/or brain.

## INTENSIVE CARE & HIGH DEPENDENCY UNITS

Following surgery, an individual may need to spend some time in an intensive care unit (ICU) or high-dependency unit (HDU) as the next step in traumatic brain injury treatment.

The HDU is a bridge between an ICU and general ward, for patients who require more than regular observation but not as much as in an ICU. Timescales in each unit, and then on a general ward, can vary widely depending on a person's individual circumstances.

An occupational therapist (OT) will usually monitor a person daily from the moment a person regains consciousness. As people often display signs of post-traumatic amnesia (PTA) following a brain injury, an OT may monitor a person until they show signs of recovery for several days in a row.

PTA is an individual thing, but can include memory loss, confusion, restlessness and uncharacteristic behaviour. Signs of recovery may include them displaying an ability to learn new things and be able to discuss recent events without memory lapses.

Once an individual has been assessed as stable, rehabilitation sessions may be introduced, which an OT may continue to be involved in.

The type of rehab involved will be patient-specific, and may include speech and language therapy, neuro psychology and physiotherapy, alongside work with doctors and nurses. A person may also benefit from a consultation from a social worker and/or a dietician.

## STEP DOWN CARE UNITS

The time that hospital brain injury treatment may take is patient specific, and may last days, weeks, a number of months or even years.

Once hospital rehabilitation is complete, a person may be transferred to a Step Down Unit in order to continue with their recovery.

A Step Down is a bridge between hospital and home, with a long-term aim to equip an individual to be able to live in the wider community again.

**For more information, please see our section on Post-Hospital Head Injury Rehab & Funding in Part 2**

# PART 2

## POST-HOSPITAL TRAUMATIC BRAIN INJURY REHAB & FUNDING FOR CARE



### POST-ACUTE TRAUMATIC BRAIN INJURY REHABILITATION

After time spent in hospital, individuals will often require further traumatic brain injury rehab, specific according to their needs. This will usually take place in an acute trauma rehabilitation centre, and might include physical, occupational and speech brain injury rehabilitation, dependent on the service an individual requires.

The extent of a person's serious injury and also how they react to any rehabilitation will often determine the amount of time a person spends in a dedicated centre.

A post-acute brain injury rehabilitation centre should ultimately assist individuals to be well enough to return to their home and the wider community. Post-acute rehabilitation can take place in NHS or private sector facilities.

## NURSING/RESIDENTIAL CARE

If a person has spent time in a trauma rehabilitation centre but is unable to return to their home, nursing or residential care may be required. Ongoing brain injury rehab would need to be in a nursing or residential home specialising in specific traumatic injury, such as a brain or spinal injury.

Nursing and residential care not only provides the specialist care required according to the needs of an individual, but can continue the brain injury rehabilitation process, helping people to become more independent. Depending on the needs of the person the stay in a nursing or residential home may be temporary or permanent.

## SPECIALIST COMMUNITY CARE

Also known as home care or community care, specialist community care is an alternative to residential care. People are cared for in the familiar setting of their own home for the next part of their head injury rehab, by specialist healthcare professionals.

In order to provide specialist community care, a person's home may need to be adapted, and/or a person may require specialist equipment.

In addition to support with personal care and activities of daily living, specialist community Healthcare providers may assist with accessing services in the community and other activities to people are able to maintain active social lives.

## CARE PACKAGE/CARE PLAN

The exact nature of the specialist brain injury rehab/care delivered to a person with a severe or traumatic brain injury will usually be decided on by an assessment. The assessment is carried out by a healthcare professional, social worker or a multi-disciplinary team.

## DOMICILIARY CARE

Domiciliary Care is care in the home where an individual requires less-specialist care following their traumatic head injury. This may involve assistance with personal hygiene, support with cleaning or assistance when taking part in social activities. Domiciliary Care may be for several hours every day or just a short time, depending on what an individual needs.



## FUNDING FOR CARE AND REGULATIONS

The issue of funding for care can be complex following a traumatic brain injury. Certain services are provided through local council authorities, which are responsible for care services that fall outside the remit of the National Health Service (NHS).

**NHS Continuing Healthcare can be accessed if a person has significant care needs and meets the criteria. A funding for care assessment would consider the following:**

- » Behaviour
- » Cognition (understanding)
- » Communication
- » Psychological/emotional needs
- » Mobility
- » Nutrition (food and drink) continence
- » Skin (including wounds and ulcers)
- » Breathing
- » Symptom control through drug therapies and medication
- » Altered states of consciousness
- » Other significant needs
- » These needs are then given a weighting marked “priority”, “severe”, “high”, “moderate”, “low” or “no needs”.

**The multi-disciplinary team doing the assessment will then consider:**

- » What help is needed
- » How complex these needs are
- » How intense or severe these needs can be
- » How unpredictable they are,
- including any risks to the person’s health if the right care isn’t provided at the right time

Funding for care services that fall outside of the NHS begins with an assessment of an individual’s needs.

Depending on a person’s savings, they may be asked to pay or contribute to a service that is recommended to them. An assessment of a person’s financial status is then carried out every year.

## DECIDING ON A CARE PROVIDER

### CARE QUALITY COMMISSION (CQC) REPORTS

The CQC is an independent regulator of England’s social and healthcare services. Working with people who have accessed health and social care services as well as industry organisations and charities, the CQC inspects centres across the country, monitoring standards, publishing their findings and working with centres to help them improve. CQC reports are an excellent way of finding the quality-level of care that a particular service may offer.

### HEADWAY-APPROVED CARE

Headway (the brain injury association), has compiled a list of Approved Providers, and is able to offer an accreditation to residential care services for brain injury care if a particular service opts to be assessed by the association. Headway has compiled an expert list of standards that must be met by a service before it can be accepted onto the list. As with reports from the CQC, Headway’s Approved Providers scheme gives individuals who have experienced a traumatic brain injury a real insight into the quality of care they are likely to receive before accessing a particular service.

[www.headway.org.uk](http://www.headway.org.uk)

# PART 3

## BRAIN INJURY SUPPORT IN THE COMMUNITY



### **BRAIN INJURY SUPPORT: POST-REHAB**

It is important to be aware that serious injury rehabilitation does not have to stop once a person has left an official rehabilitation centre, and may continue in a number of forms by accessing brain injury support groups. Returning to the community can be a challenging process for people who have experienced a traumatic brain injury.

Whilst any barriers and issues faced are very much person-specific, an individual may still be adjusting to physical and/or cognitive changes that their brain injury may have caused. These changes may prevent a person from returning to work or hobbies they may previously have enjoyed.

In addition, home and family-life may be affected, with a person unable to take part in the kind of tasks and activities they participated in prior to their serious injury.



Furthermore, there is the issue of access. Some buildings, events, forms of transport and workplaces may not be equipped to allow access for individuals whose mobility may be impaired. Brain injury support can take on a number of different forms, and is always geared to the needs of an individual and their personal circumstances.

## BRAIN INJURY SUPPORT GROUPS

There are various types of brain injury support groups in the voluntary sector, available for people who have experienced a brain injury, as well as for their families, friends and carers.

**The following are some leading brain injury support groups in the voluntary sector, offering a host of information and help on a local basis.**

### HEADWAY

Headway, the brain injury association, have over 100 local support groups in the UK and can offer services including community outreach and rehabilitation programmes. They also work as an information hub, have a helpline and in some cases can provide grants for those in financial difficulty following a brain injury.

There are Headway groups and branches across the North East including:

- » Newcastle and North Tyneside
- » Central Northumberland
- » Gateshead and South Tyneside
- » North Northumberland
- » Wearside, County Durham
- » Tynedale
- » Hartlepool
- » Teesside
- » Darlington & District
- » Forces Support Group in Catterick

## MATRIX NEUROLOGICAL

Based in Middlesbrough, Matrix is a charity aimed at supporting young people and their families who have experienced a brain injury. Matrix Neurological offer support and expertise to young people and families, helping them to access the services they need as part of their ongoing rehabilitation.

## MOVING ON TOGETHER

The Moving on Together Initiative combines the work of three not-for-profit organisations – Momentum Skills, Brainbox and the Stroke Association – to offer a more integrated service for people and their families who have experienced a brain injury or other neurological condition. The initiative aims to support both adults and young people in becoming more independent and should also serve to increase awareness in the community, as well as ensuring better partnerships between different organisations that work in the field of head and brain injury. On the next page there is some more information about the groups involved.



## MOMENTUM SKILLS

Momentum is a not-for-profit organisation, providing care services and rehabilitation. Momentum Skills is the section of the group that focuses on training and employment. This includes their North East Access to Work service, based in Newcastle upon Tyne, for people who have experienced a head or brain injury or other neurological condition. This may involve working with a person's employer to ensure there are no barriers to them returning to work, cognitive retraining and support in finding new work placements and new employment.

## BRAINBOX

Brainbox runs a 24/7 help and support service for young people and their families who have experienced a head or brain injury. The organisation is based in Gosforth, Newcastle upon Tyne, and also has a face-to-face Counselling and Listening Service. Brainbox can also offer long-term counselling support.

## THE STROKE ASSOCIATION

A UK-wide charity focussing on researching and combating stroke and its effects, the Stroke Association's North-East centre is based in Gateshead. From increasing awareness to working in partnership with a wide range of health professionals, local and national government officials, plus other not-for-profit organisations, the Stroke Association is a hugely important resource for anyone who has experienced stroke.

# PART 4

## RETURNING TO WORK AFTER A TRAUMATIC BRAIN INJURY





## RETURNING TO WORK AFTER A TRAUMATIC BRAIN INJURY

Returning to work after brain injury is very much dependent on an individual's personal circumstances. Momentum Skills is the work-related sector of Momentum, a not-for-profit organisation providing care and rehabilitation for those affected by a brain injury.

### The organisation can provide:

- » Support to people and their employer, including awareness training and overcoming barriers to returning to work after brain injury.
- » Work-related skills training.
- » Personal development programmes.
- » Access to courses to improve job potential.

The local Headway branch can also assist an individual in making the right decision when moving forward, and talking to an occupational therapist may also help. In order to make returning to work after brain injury as positive an experience as can be, it is important to seek as much help and assistance as possible. TLW's care navigators offer expertise in helping individuals make the right decision and access all the support and services they may need when returning to work following a serious injury.

## RETURNING TO EDUCATION AFTER A TRAUMATIC BRAIN INJURY

As with returning to work after a traumatic brain injury, returning to or starting education is very much dependent on an individual's personal circumstances. Momentum Skills can assist in helping people learn new skills and access new courses. It is also worth meeting with a learning support adviser from the school, college or university that a person wishes to attend.

Although everyone is different, many people find it more difficult to retain information following a brain injury, or may tire quicker. A learning support adviser can help to establish what procedures need to be in place for an individual to ensure they have all the support they require.

TLW's care navigators can assist individuals in making decisions related to a return or start in education, and ensure the correct support is in place.

# PART 5

## THE IMPORTANCE OF SLEEP AFTER A BRAIN INJURY



### **DISTURBED SLEEP AFTER A BRAIN INJURY**

People are far more likely to develop disturbed sleep after brain injury, for many different reasons:

- » A brain injury can affect the part of the brain which sends us to sleep. A gland in the brain releases a hormone called melatonin, and if this gland is affected, the lack of hormone can result in a person staying awake.
- » Sleep after brain injury may be disturbed due to medications that have been prescribed and are helpful for another symptom, but cause insomnia as a side-effect. If a person's breathing has been affected, this too can have an impact. Irregular breathing can result in too little oxygen going into a person's bloodstream, which can cause a person to wake up.
- » Many of the symptoms that are commonly experienced by people who have had a brain injury can also contribute to insomnia. These include headaches, depression, confusion and disorientation.

## BRAIN INJURY INSOMNIA

An overactive mind can keep an individual awake, with worry preventing sleep. As a result of brain injury insomnia, some people may be able to get to sleep, but may wake up after a short space of time. This only serves to increase worry, hence starting the individual on a vicious, negative circle. Brain injury insomnia can result in a person needing to sleep during the day, and mixed sleep patterns can also exacerbate problems sleeping at night. Physical symptoms can also be present, such as Periodic Limb Movement Disorder (PLMD). In simple terms, this is an involuntary twitching of legs or arms. Even if a person manages to sleep after brain injury, physical symptoms such as these can result in a person waking up exhausted.

## WHY IS SLEEP AFTER BRAIN INJURY IMPORTANT?

Sleeping after a brain injury is especially important as it promotes healing in the body's cells and muscles. When a person falls asleep, every part of the body relaxes. Something as minor as a pulled muscle will start to heal itself through sleep, and can get better through good sleep alone. But poor sleep can stop muscles relaxing and healing themselves, meaning a minor ailment can last for months. The same is true of cells in the brain, and more serious ailments that don't get the opportunity to heal can thus have a huge impact on a person's day-to-day happiness. Brain injury insomnia can result in a host of problems. The obvious

outcome of tiredness can impair judgement and slow reaction time, meaning everyday tasks can become more difficult and prolonged.

If a person is relearning everyday tasks, the problem can become even more difficult. Negative emotions such as worrying and being more prone to anger commonly come more to the fore when a person is feeling tired. Mood swings are more likely and if an individual has any specific conditions such as depression, tiredness can act as a trigger factor. Such symptoms of lack of sleep are often common in individuals who have experienced a traumatic brain injury, even when they have had sufficient sleep. Therefore, insufficient sleep will tend to exaggerate these symptoms even further.

## HOW TO DEAL WITH BRAIN INJURY INSOMNIA

Everyone is different, and will have individual symptoms following a serious injury, so what works for one person may not work for another. For example, if worry is the main cause of keeping a person awake, counselling may be the answer. If the problem is more down to PLMD, counselling is unlikely to help.

Changing habits and setting in place a new pattern for sleep can help reduce symptoms of brain injury insomnia. A big part of recovering from a traumatic brain injury involves retraining the brain. Setting a specific sleep and wake time can contribute to this retraining. The first few days may prove difficult, but the brain



often begins to pick up ‘habits’ over time. Taking exercise everyday can help if physical exercise is possible – exercise not only tires the body and mind but releases the ‘happy’ hormone serotonin, which can help reduce symptoms such as worry. Avoiding stimulants such as caffeine can aid better sleep, as well as avoiding any ‘blue’ light – this is light from electrical sources such as mobile phones, laptops, and televisions. Ensuring your bedroom is free from clutter and distractions is important, as is lighting – blackout blinds can make all the difference.

If problems persist, it is well worth speaking to a healthcare professional. Medication may be prescribed to help sleep in the short-term. However, medication is unlikely to solve the problem in the long-term and may interfere with any existing medications. But a healthcare professional may be able to create an individual plan, tailored to an individual and their own specific needs. The sooner a problem is recognised, the easier it can be to deal with, and it is certainly possible that problems with sleeping after a brain injury can improve over time.

# PART 6

## BRAIN INJURY SUPPORT AND FINANCIAL ASSISTANCE





Brain injury support can take many forms, from initial medical help to advice and financial assistance.

The period following a brain injury can be extremely challenging on many counts, including from a monetary perspective.

Many people who have experienced a brain injury may not receive full-time pay from their occupation whilst they are in recovery. Others may be unable to work in the same capacity, or not at all. If a person is waiting for serious injury compensation payments following an accident, this can also take time, leaving a period where a person is in financial limbo.

There are several organisations that can be contacted for brain injury support and financial assistance at any time following an accident, with some included on the following pages.

## TURN2US

Turn2us is a not-for-profit organisation, working on a national scale, and can help individuals, their carers and families to access the right level of brain injury support services and benefits. The Turn2us website is full of useful online tools, including a grant search facility to find out what brain injury support you're entitled to in your local area, and a budget calculator for you to input your details and see what credits and benefits you can receive.

## HEADWAY EMERGENCY FUND

Headway, the Brain Injury Association, offers grants of up to £500 to provide support for individuals and their families in the aftermath of a brain injury. The Headway Emergency Fund is available to all families with savings of less than £1000, and can go towards a wide range of expenses including travel costs and hospital car parking fees.

## DISABILITY LIVING ALLOWANCE AND PERSONAL INDEPENDENCE PAYMENT

The Disability Living Allowance can assist with a person's costs if they have been registered disabled. Costs may include living needs and carer costs, for example. Disability Living Allowance was replaced in June 2016 by the Personal Independence Payment, for anyone aged 16 to 64. If you are aged 65 or over, you may be entitled to Attendance Allowance.



## SELF-DIRECTED SUPPORT

If a person is entitled to care and brain injury support, they have the option of managing their own budget to pay for the care they receive

Formerly, everything will have been done through local social services, who can still arrange a person's support if they prefer. Self-Directed Support involves a person being given a set budget to arrange and pay their own care and support services.

This would involve either a person, their carer or family member advertising for the brain injury support, interviewing carers/support workers and paying their wages directly.

## SERIOUS INJURY SOLICITOR

A specialist serious injury solicitor will look into securing any compensation that a person deserves, should a brain injury be the result of an accident that was not their fault. Compensation will take into account the kind of care a person will require and for how long. In addition, a specialist serious injury solicitor can act as a go-between on a person's behalf, contacting all the financial services a person is connected to, from a mortgage provider to utility bill providers.

Knowing the legalities of a situation inside out can help to make a complicated time as straightforward as can be and help a person stay financially 'above water' until serious injury compensation comes through.

# PART 7

## LONG TERM EFFECTS OF A BRAIN INJURY





People who have experienced a brain injury can be affected in a number of ways in the longer term, with behavioural changes often apparent.

Even when a person has made an excellent recovery, the long term effects of brain injury may mean they act differently in certain circumstances to how they may previously have acted.

This can prove a very challenging time for the person affected by the serious injury, as well as their friends and relatives, who may no longer recognise the person they once knew.

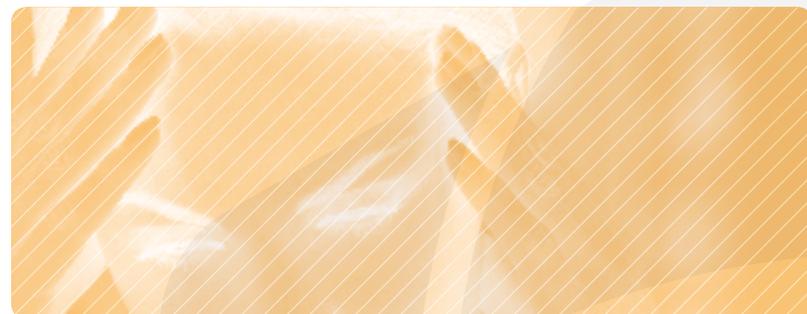
## EMOTIONAL PROBLEMS AFTER TRAUMATIC BRAIN INJURY

Emotional problems after traumatic brain injury can be wide-ranging. They may include a 'shutting down' of emotions, such as an inability to cry or to laugh at things that are sad or funny. A brain injury can also cause the opposite to happen, with a tendency to cry or laugh at moments that might be deemed 'inappropriate'. Although very difficult, it is important for the friends and family of a person affected to not be overly critical, and to recognise any changes as some of the long term effects of brain injury.

Improvements are possible through retraining of the brain and reminding a person of what is appropriate behaviour may help with this process.

## BRAIN INJURY AND DEPRESSION

Depression after brain injury can be very common, and may be a direct result of specific parts of the brain being affected, those parts which regulate and control mood. Depression after brain injury can also occur when a person comes to realise the situation they have been left with. A person affected by a brain injury may be unable to return to previous facets of their life that once brought them happiness, such as a job or particular hobby. They may find themselves cut off from friends or family members as they are unable to contribute to those relationships in the way they did previously.



## AGGRESSION AFTER A BRAIN INJURY

Aggression after a brain injury is also a common long term effect. This may manifest itself through people displaying a lack of patience, or getting angry at things that would previously not have affected them. Some people who have had a brain injury may swear more in the long term, even if they have rarely sworn prior to their serious injury.

## CHANGES IN SEXUAL BEHAVIOUR

A person's interest in sexual activity may be decreased or heightened following a brain injury. This may vary from a complete disinterest, to using sexually-inappropriate language in public spaces, to being more 'forward' with strangers than might be deemed acceptable. Although this may be difficult to understand, it often comes down to a part of the brain affected that controls impulse.

All of us receive thousands of fleeting thoughts

on a daily basis, and our brain controls which ones we act on. We may meet a stranger in public whom we find attractive for instance, but our impulse control would prevent us from raising this point aloud. If impulse control is affected, then a person is unable to filter what is appropriate or inappropriate to say.

## SUPPORT FOR THE LONG TERM EFFECTS OF A BRAIN INJURY

For anyone living or working with a person who has had a brain injury and is showing changes in their behaviour, Headway's booklets on *Managing Anger* and *Psychological Effects* are an excellent guide to helping a person deal with any changes in their personality.

Alongside this it is important to seek the advice of as many people in the healthcare sector as possible. The advice of a carer, occupational therapist or doctor may provide new ideas and suggestions on managing behaviour more effectively in future. Your local Headway branch will be able to advise and suggest other support groups which can help with behaviour management.

If not already carried out whilst in hospital, a person who has had a traumatic brain injury may benefit from a neuropsychological assessment, which can happen following a referral from a GP. An assessment may help to categorise the long term effects of brain injury for an individual and help with the identification of triggers that may result in inappropriate or negative behaviour patterns.

# PART 8

## ASSISTIVE TECHNOLOGY FOR TRAUMATIC BRAIN INJURY



Assistive technology for traumatic brain injury is geared to helping individuals gain more independence and control over their life.

As the consequences of a brain injury can differ so widely, assistive technologies are designed to be adaptable for an individual's own needs and requirements, and can include everything from a simple memory-jogger to equipment that allows a person to operate machinery without assistance.

### **BRAIN IN HAND**

Brain in Hand was set up to assist anyone with any condition that affects their brain's functionality, including those with traumatic brain injury. Brain in Hand is a mobile phone app aimed at giving those living with ABI or any other brain-related condition more independence. The app can be set up to match an individual's needs and can make up an important part of traumatic brain injury treatment. For example, it can provide alerts to help those whose memory has been impaired. It can also be set up to track anxiety levels and direct support. The cloud-based system is in continual development but has already helped a great number of people towards greater independence.

Traumatic brain injury assistive technology also includes a range of other apps, including:

- » **Yes/No:** Developed with a Speech Language Pathologist, Yes/No allows those unable to communicate verbally to answer yes/no questions via their mobile phone.
- » **Breathe2Relax:** Dedicated to anxiety management, Breathe2Relax is a portable way of controlling stress, with an emphasis on breathing exercises.
- » **MakeChange:** An app dedicated to relearning the everyday life skill of counting money, one of many cognitive procedures which can be lost following an ABI.

## SIP-AND-PUFF ASSISTIVE TECHNOLOGY FOR TRAUMATIC BRAIN INJURY

For anyone with communication and/or physical disabilities following a traumatic brain injury, sip-and-puff assistive technology allows an individual to communicate with a device using their own breath. A device can be programmed to recognise an individual's particular 'sip and puff'. This assistive technology can be used in some motorised wheelchairs, to enable the user to operate the device completely independently. It is also seen in computers, such as regarding mouse movement.

## ABILITYNET

The charity AbilityNet is dedicated to helping people who need support to use digital technology, whether at home, in an educational setting and at work. AbilityNet has put together an excellent guide called 'My Computer, My Way'. The guide details all the ways an individual can make their computer easier to use in accordance with their needs, from altering the screen resolution, to making websites easier to read.





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