



Headway
SOMERSET

Improving life after brain injury



Family and Supporters' Guide to Acquired Brain Injury - Somerset

In this guide:

- Advice for leaving hospital
- Information on support services available
- Information and tips for dealing with the effects of brain injury
- Practical suggestions

In the UK every year more than 1 million people attend an Emergency Department following an Acquired Brain Injury. In Somerset more than 3000 people are admitted to hospital every year with an Acquired Brain Injury. We refer to Acquired Brain Injury throughout this booklet as ABI.

For further information about Headway Somerset or to speak to someone for information, signposting or support please contact:

Main office 01823 618519

info@headwaysomerset.org.uk

Headway Somerset is an independent charity affiliated to Headway UK and was set up in 1990 by family members who wanted to establish services for people with ABI following discharge.

We would like to thank:

- Headway Somerset Shaping Our Lives Group
- Placement Student Nina Davies
- Headway Ireland for permission to use the format of their Family Guide to Brain Injury

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I would safely say that if this had been given to us as a family before D came out of hospital, we would have been a lot more prepared for what was awaiting us and we would have felt better able to challenge some of the decisions that were made around his care.

(Alyson, Family member)

”

“

Wow, felt quite emotional reading this.
So comprehensive and considered.
I wish I had this guide when H had his ABI,
it would have answered so many questions
and alleviated a lot of time and stress
trying to find services.

(Tina, Partner)

”

Introduction

How to use this guide

You may find it most helpful to read a section as you need it rather than reading through the whole guide at once. There is an index at the back so you can find information quickly. We have left space throughout the guide for you to make your own notes and record information which is important for you.

If you feel you don't need the guide yet, please keep it so you can use it when the time is right. This guide may also be useful for other family members and friends. They can obtain a copy from Headway Somerset or by downloading it from our website: **www.headwaysomerset.org.uk**

At various points in the guide we have included tips and suggestions that you may wish to use if they make sense to you. Use the spaces provided to record what works and what doesn't. This can be a useful record to discuss with the professionals supporting you and your loved one.

Not all sections of this guide will be relevant to you, your family members or the individual with ABI.

Practical help in the early days of hospital admission

Headway UK have a small emergency bursary fund which you can apply for to cover travel and accommodation costs to stay near a hospital. You can apply for the Headway Emergency Fund online at www.headway.org.uk/supporting-you/headway-emergency-fund/ or google 'Headway UK Emergency Fund'

You can also email emergencyfund@headway.org.uk or call **07585 102987** if you have any questions about the Emergency Fund or how to complete the form. Many hospitals can provide a parking pass for relatives who need to visit Intensive Care Units. Please ask staff on the Unit or Ward.

Headway Somerset Hospital Liaison staff visit Musgrove Park Hospital and Yeovil District Hospital each week as well as the Somerset Neurological Rehabilitation Centre (SNRC) based at Dene Barton Community Hospital. Hospital Liaison staff can be contacted on 07514 753384 or 07561 032329. You can also email info@headwaysomerset.org.uk or leave a message on our main number **01823 618519**.

There is also information on the Headway UK website: www.headway.org.uk (see page 35)

ABI

An acquired brain injury (ABI) is an injury caused to the brain after birth. There are many possible causes including road traffic accidents, falls, assaults, tumours and strokes.

The range and severity of problems resulting from a brain injury will differ from person to person because each person's brain injury varies in the extent and location of damage.

A brain injury can lead to a wide range of effects. They fall into three broad categories which are physical, cognitive (affecting the part of the brain responsible for understanding and speech) and emotional/behavioural. We break these down and look at the effects in more detail starting on page 17.

Planning for Leaving Hospital

Hospital staff should work with you as a key family member or supporter. You have a valuable role to play in the recovery and rehabilitation process.

When the person you support is ready to leave hospital, things may happen quickly. Make sure you have met with the team to plan the next steps and to get their support to apply for any services and help you may need at home as the person you support will need to continue with their recovery and rehabilitation. This planning will usually be led by the Ward Therapy Team – Occupational Therapists (OTs) and Physiotherapists (Physios).

It's a good idea to make an appointment to see staff to discuss this rather than just catch them on the ward.

Don't be afraid to ask as many questions as you need to. Take your time and if you don't understand what you are being told ask staff to explain it again.

Write down your questions before the meeting so you don't forget anything important.

Take a family member or friend with you to the meeting so they can take notes and give you support.

Hospital staff should give you all the information you need. There is a checklist on pages 9 and 10.

The professionals – who is who?

A **Neurologist** is a specialist doctor who treats diseases or injuries of the brain, spinal cord and nervous system.

Occupational Therapists (OTs) work to improve a patient's ability to do everyday tasks and assess any equipment needed.

Neuro Rehabilitation Specialist a doctor with particular expertise in rehabilitation following ABI

Physiotherapists help people to regain the use of their muscles and joints after injury and help with balance, movement and respiratory problems.

Speech and Language Therapists (SALT) help people to improve their communication skills.

A **Psychiatrist** is a doctor specialising in mental health.

A **Neuropsychiatrist** treats patients with psychiatric or behavioural disorders that occur in patients with neurological conditions.

A **Clinical Neuropsychologist** is a psychologist who specialises in the assessment and treatment of behaviour, emotional and cognitive problems following brain injury.

A **Clinical Psychologist** is trained in a range of mental health issues. They provide rehabilitation, talking therapy and assessments.

Counsellors and Psychotherapists work with people to explore their emotional problems and mental illnesses.

Social Workers provide practical advice on issues such as benefits, housing, transport and assistance at home and conduct needs assessments, both for people with ABI and their primary carer.

Hospital Liaison Workers are employed by Headway Somerset and visit hospitals in Somerset to offer support, information and advice whilst your family member is in hospital.

Checklist for Leaving Hospital

Check that the hospital team have:

- Answered any questions you have before you go home.
You may like to write down the answers and any key contacts
- Given you all the help required with any forms for DWP (Dept of Work & Pensions), Adult Social Care (Somerset County Council) or employer (including a fit note if required).
- Provided all medication required for the first days at home, along with a full list of all the medication prescribed.
- Given you the contact details and direct line for hospital staff so that you or the person you support can be in touch with any questions once they are home.
- Provided a time and date for a follow-up appointment and the name and medical speciality of who the appointment will be with.
- Given you a copy of the discharge letter (which will also be sent to the GP). This will contain details of all the treatment provided in hospital, the diagnosis and details of any follow-up services they have referred to.
- Provided the name and contact details of any Social Worker who has been in contact
- Given you the name and contact details of Headway Somerset Hospital Liaison
- Referred to Somerset Direct (the front-door for services from Somerset County Council) either by a member of the hospital team or by a family member or the individual themselves
- Given you the details of any other relevant community organisations including Somerset Carers Support Service (see index for contact details)
- Given advice about driving
- Given advice about returning to work

You may find it useful to:

- Order copies of Headway UK booklets through the Headway helpline by calling 0808 800 2244
- Make sure you have the number of Headway Somerset Hospital Liaison in your phone
- Make a list of all the things that need to be done at home. Family and friends will often ask what they can do – it helps if you have a list
- Make sure you write down all the important phone numbers, email addresses and names and add them to your phone.
- Keep all the important letters and medical information in a file so you can find them easily
- Invest in a wall chart or a whiteboard at home so everyone can see when medical appointments and important dates are.
- Use a paper or online diary to record all upcoming appointments or put a reminder in your phone.
- Investigate eligibility for free NHS prescriptions or pre-payment card. If the person you support takes lots of medication ask the pharmacy to put them into a daily or weekly dose packs. This service is free of charge.
- Arrange something for yourself, a meet-up with a friend, short trip out, appointment at the hairdresser – something that is just for you.

Notes

Options on leaving hospital

Further Rehabilitation

Sometimes, a period of rehabilitation in a specialist unit is recommended after an acute hospital stay. This is to help your loved one recover some of the functions they might have lost as a result of their ABI and to teach them strategies to manage their condition. The in-County facility in Somerset is the Somerset Neurological Rehabilitation Centre at Dene Barton, Cotford St Luke. Occasionally, the Brain Injury Rehabilitation Unit (BIRU) in Bristol is used. Both have a range of specialist inputs available, including Occupational Therapy, Physiotherapy, Speech & Language Therapy, Neuropsychology, Neurology and Nursing. (see page 4)

Nursing/Residential Homes

Sometimes a nursing or residential home may be an option. This applies, particularly when recovery has been good, but where the person needs a bit more time to regain their physical strength back before more intense rehabilitation or where there are no family supporters available or able to provide the support needed at home. This may be a short-term placement, or longer term.

The Somerset County Council (SCC) website has further information about nursing and residential care homes and Extra Care housing.

www.somerset.gov.uk/social-care-and-health/care-homes-and-housing/

Headway UK has developed the Approved Provider scheme, an accreditation scheme for residential care settings. The list includes NHS and independent hospitals, neurological rehabilitation units, residential and nursing homes and respite facilities specialising in acquired brain injury.

www.headway.org.uk/supporting-you/in-your-area/approved-care-providers/

Back at Home

Being back home can be a much anticipated event. It can be a huge relief to no longer need to visit the hospital every day but it can also be a time of great disruption and confusion. Things which might have seemed easy in the accessible and adapted space of a large hospital can feel very difficult in the restricted space of most family homes. It may help to think of this as not being an end-goal but the beginning of a new phase.

The person you support now needs:

Rest – they may become tired very easily so should be supported to pace themselves and rest when they feel tired.

Routine – establishing a routine especially after a long period in hospital is essential. Start with small steps e.g. getting up at the same time, having a shower/bath, getting dressed and progress from there.

Reduced Stress - a calm and stress free environment will make it easier to adjust to being at home and to concentrate on recovery.

“

*Go with the flow. Stay in the moment.
Don't look too far into the future.*

”

Looking after yourself at home

In many cases, it is the family who have the greatest responsibility for someone once they get home. It is important to take care of yourself during this time. Accept that you need to look after your own needs as well as the person you support.

- Don't be afraid to ask for help or to accept offers of help from friends, family and neighbours. Don't be afraid to direct them to what is most helpful to you.
- Do make applications to receive services as there may be a long waiting list and you can always change your mind later if you don't need/want the service.
- Don't sweat the small stuff! Try not to let small, everyday things bother you. Focus on what's most important.
- Encourage the person you support to be as independent as possible – if you do too much for them it will take longer for them to regain maximum independence.
- Be organised – buy a wall planner, a whiteboard, a diary. Set a time each week to review these and update them.
- Keep a diary – jot down a few lines about what has happened each day, who has visited, information you have been given, how your relative is. Sometimes progress can be hard to see when you are in the thick of it day in day out.
- Accept that although your loved one may outwardly look the same they may react differently to things in the short term.

“

*You can't physically do everything.
Every day is a new day. Start afresh.*

”

How to get services and support

You may find that you need support with caring for your loved one at home. There are a number of services that can help you with this.

Somerset Carers provide free support and information for anyone over 18 that looks after someone in an unpaid caring capacity.

Somerset Agents Service are Somerset based individuals with a wide knowledge base of local services and information. They are able to offer personal guidance and support.

You may want to have a Carers Assessment to assess your needs as a carer and ensure you are getting the right levels of support.

You can ask for a Carers Assessment by phoning **Somerset Direct 0300 123 2224**.

Headway Somerset Services

Headway Somerset aims to provide a comprehensive service to support people living with ABI, their families and those who support them. We currently provide:

Rehabilitation Service - centre based.

This is a supportive environment where individuals with ABI can re-learn skills that may have been affected by their injury or illness. People have the opportunity to develop person-centred outcomes through a wide range of rehabilitation activities with the support of trained staff and volunteers. Cognitive rehabilitation activity includes: developing memory, attention, executive skills, awareness skills, strategy development and implementation. Independent living skills include: computer based skills, cooking skills, money management, managing personal affairs, support towards volunteering and accessing other services. Psychological wellbeing is supported through peer support, reduced social isolation, improving social skills, arts and craft, music, gardening, Flexercise (seated exercise) Boccia (Paralympic Bowls) and guided relaxation.

Rehabilitation takes place in community settings across Somerset. See website www.headwaysomerset.org.uk for more details.

Somerset Adult Social Care funds clients to attend this service – contact Somerset Direct to arrange a Needs Assessment 0300 123 2224 We also have clients who are funded through direct payments or pay privately. Contact Headway Somerset on 01823 618519 to discuss.

Rehabilitation Outreach One to One Support

In situations where attending a Centre may not be the best solution, we can also offer one to one rehabilitation activities in the home to support independence, managing finances, managing tenancies etc and in the community for things such as re-learning to engage in the local community, support to volunteer or return to work. Adult Social Care fund some people to receive this service contact **Somerset Direct for a Needs Assessment 0300 123 2224**. We also have clients who are funded through direct payments or pay privately. Contact **Headway Somerset on 01823 618519** to discuss.

Stand-alone Assessment

At times it can be helpful to have a one-off bespoke cognitive/functional assessment undertaken over a time period agreed with the person needing support to assess how they can best be helped to achieve their goals. The assessment will cover memory, executive skills and awareness and will provide suggestions to help identify and implement strategies and identify long-term rehabilitation goals. Contact **Headway Somerset on 01823 618519** to discuss this service and costs.

Talking Headway

This is a free telephone information and support line open to anyone who has experienced ABI, is a relative, friend or colleague of someone with an ABI or is a professional who would like to know more about ABI, Headway Somerset services, for signposting or support. Available Tuesdays, Wednesdays and Thursdays 1pm – 3pm **01823 215014**

Hospital Liaison

This is a small team who work across wards at Musgrove Park Hospital, Yeovil District Hospital and Somerset Neuro-rehabilitation Centre (SNRC) – because we know that the earlier you can get help, support and information the better. The Headway Somerset Hospital Liaison team provides support for people with a new ABI and their families. Our workers can be contacted via our main office

01823 618519. Patient education groups are also run at SNRC.

Relatives Support

We provide free information and support to individual families, support groups by Zoom as well as running regular series of ‘Understanding Brain Injury’ workshops by Zoom. For details of the programme see either **www.headwaysomerset.org.uk** or call **01823 618519**

Making Headway – Buddying Project

Matching well-trained and supported volunteers with people with an ABI to build self-confidence, engage or reconnect with interests, hobbies, groups, sports...the list is endless. This is social and fun and not a substitute for rehabilitation. Contact our Volunteer Coordinator for volunteering opportunities and also to refer someone to the project. **info@headwaysomerset.org.uk** or **07927644128**

Effects of Brain Injury

A brain injury can have a wide range of effects and may bring a lot of difficult changes. It can be helpful to focus on what your loved one can do and try to help them use these strengths to develop new ways of managing.

Changes in cognitive skills

The cognitive effects of a brain injury affect the way a person thinks, learns and remembers.

Things your loved one may experience:

- Reduced attention and concentration - they may find completing tasks a problem
- Issues with planning and organisation - your loved one may struggle with thinking ahead and carrying out the sequence of steps needed to complete a task
- Language loss – your loved one may have difficulty making sense of what is said or they may have difficulty finding the right words to say
- Memory problems – your loved one may be able to remember things that happened ten years ago but may not be able to remember what happened that morning

> **Communication problems**

If your loved one suffers injury to the language centres of the brain this may lead to a condition called aphasia. This may lead to problems with reading, such as being unable to recognise letters or words, or they may be unable to understand simple written sentences. Damage to the language centres of the brain may cause what is known as expressive aphasia, your family member may have impaired ability to use and express language. Their language may lack fluency and they are likely to use short, simple sentences.

Tips for dealing with communication problems:

- Understand that you will be primarily responsible for guiding the conversation and don't expect immediate responses
- Encourage the person to use non-verbal skills to convey their message such as gestures, pointing or pictures
- Do not pretend to understand when you do not
- Feedback parts of the message that you have understood so that the person knows what they need to repeat

> Memory problems

Memory problems are one of the most common difficulties that people experience after brain injury. Old memories are stored differently in the brain from new memories so it may be that your family member can remember things from 10 years ago but struggle to remember what they did the previous day. Alternatively, your family member may forget information from before their injury but they can remember things after their injury without any issue.

Strategies for coping with memory problems:

- Use external aids – using diaries, notebooks, lists, alarms clocks, wall charts and calendars can help to remind your loved one to complete specific tasks or remember events.
- Get into a routine – having a daily and weekly routine means your loved one can get used to what to expect.
- Simplify information – concentrate on the relevant material that they need to remember.
- Ensure the information has been understood by having your loved one repeat it back to you in their own words.

“

*Try not to worry about what others think.
Prioritise your own needs. You have to be sustainable.*

”

Physical and sensory problems

Mobility can be affected following brain injury. Your loved one's movement may become slow and their balance may be affected.

Weakness or paralysis is also common after brain injury. This usually affects one side of the body more than the other.

Changes in sight, hearing, touch, temperature regulation, appetite and sense of taste or smell may also be affected.

Tips for dealing with physical and sensory problems:

- Choose clothes without fastenings such as t-shirts, polo shirts and trousers with elasticated waistbands. Dress the affected side first and undress it last.
- If there are sensory problems, such as inability to feel heat or cold, take care to ensure the affected area does not get too hot or cold or come into contact with things that could burn, scald or cause other injury.
- Practising weight adjustment can be helpful for balance problems. Get your loved one to practice shifting balance over their feet without moving their feet.

> Fatigue (Tiredness)

Fatigue is very common after brain injury and the type of fatigue experienced after brain injury may not improve with rest. It is likely to have a significant impact on your loved one being able to do the activities they want to do.

Tips for dealing with fatigue:

- Pace yourself – help plan your loved one's day so that it includes regular rest breaks and prioritise where they want to use their energy
- Have a regular sleep routine – this helps the body prepare for going to sleep by winding down and helps your loved one to feel more alert on waking

Personality, behaviour and mood changes

Your loved one may experience changes in their personality after brain injury. It may be that their 'filter' which controls their behaviour or emotions has been damaged. This may mean that your loved one says inappropriate things or becomes angry despite not being like this before the injury.

Common changes include:

- Rapidly changing mood swings
- Frustration and anger
- Becoming withdrawn
- Doing or saying inappropriate or hurtful things
- Disinterest in activities they previously enjoyed

> Anger, irritation and mood swings

Anger is one of the many emotions that someone is likely to feel after brain injury. Many brain injury survivors are frustrated over the changes that they experience after their injury.

Things that may trigger anger or frustration:

- People not understanding their brain injury
- Busy, distracting environments
- Consuming alcohol
- Situations that require waiting
- Information 'overload'
- Feeling angry about the accident or injury
- Worries about the future

Tips for dealing with anger:

- Try and become aware of the physical signs of anger building. If you can learn to recognise the changes in your loved one, you may be able to calm them down before the anger becomes aggression
- Recommend to your loved one that they avoid drinking alcohol. Alcohol can affect a survivor more than it did before the injury.
- During an anger episode, try using calming techniques such as focusing on breathing or listening to music

Taking care of yourself:

- Remember that even if the anger is being directed at you, this is most likely not personal. Rather, it is a common effect of brain injury
- Remove yourself from the area if the anger is being directed at you. Explain to your loved one that you are leaving because you think it will help them calm down, rather than just walking away with no explanation
- The Headway UK Helpline is available to families and supporters of brain injury survivors and can be a listening ear, offer information and practical tips.

0808 800 2244 or email Helpline@headway.org.uk

“

You need to be prepared for the emotional side of the situation and the grief.

”

> **Inappropriate social behaviour**

A common change early in recovery is disinhibition, which is a loss of control over behaviour and may result in socially inappropriate behaviour.

This may cause your loved one to display a range of behaviours such as:

- Divulging personal information too freely
- Laugh inappropriately
- Making inappropriate sexual advances or remarks
- Saying the first thing that comes to mind
- Using abusive or crude language

Tips for dealing with inappropriate social behaviour:

- Let them know their behaviour is not appropriate. Be clear and describe the behaviour
- Let them know how the behaviour makes you feel
- Try and predict any situations where the behaviour is more likely and workout strategies ahead of time

> **Lack of insight**

Insight can also be referred to as self-awareness. It is a person's ability to observe and reflect on their own thoughts and actions.

Your loved one may:

- Struggle to realise why rehabilitation is necessary and refuse to engage in rehabilitation services
- Show a lack of understanding about how their cognitive problems impact upon things such as relationships with family and friends

- It is very common for people to have insight for some things but not others. For example a person may be aware of their physical injuries but unaware that they have a memory problem.

Tips for dealing with lack of insight:

- Use strategies that raise awareness of your loved one's behaviour, such as videos or check-lists of their behaviour. This provides concrete evidence and may be one way to improve insight and awareness
- Involve your loved one in rating their own performance in different areas, particularly focusing on areas they would like to change
- Try and avoid directly confronting your loved one's ideas about their capacity – this can lead to conflict, disagreements and anger. If they insist that there is no change in their behaviour, allow the conversation to drop for the time being

> Rigid thinking and inflexible behaviour

This is where a person has difficulty in evaluating the results of actions and reduced ability to change behaviour or switch between tasks if needed. This may mean that your loved one will struggle to cope with a change in routine or be unable to change their mind even when circumstances alter.

Tips for dealing with rigid thinking and inflexible behaviour:

- Discuss any upcoming changes with reminders of what will change, and what will remain the same
- Gently and consistently continue to give the information that needs to be considered in decisions or ideas
- Work together to find ways to make change more acceptable and to develop ways of managing it

> **Depression and anxiety**

Depression is very common after brain injury, with roughly 50% of people experiencing depression during the first year of their recovery. People may experience depression after brain injury following changes in the brain itself, for instance if parts of the brain that control emotions are injured. Depression can also develop as the brain injury survivor begins to realise the impact that injury has had on their life.

Talk to your loved one about how they feel and get advice from your GP or a psychologist.

Tips for dealing with depression and anxiety:

- Remind your family member that these feelings are normal. They may feel guilty about these negative thoughts, however it is a completely natural response following a brain injury
- Try and get your family member to engage in activities they enjoy doing, such as listening to uplifting music, creating art or reading a book
- Try and encourage your family member to exercise for a few minutes every day. Exercise is a proven method of improving low mood

> **Being self-centred and lacking empathy**

Your family member may become egocentric after brain injury, tending to be self-centred and appearing not to consider the feelings or needs of their family members and friends.

It is important to understand that this is not an intentional behaviour. It often occurs as a direct result of injury to the brain's frontal lobes.

Tips for dealing with self-centeredness and lack of empathy:

- Provide feedback – if they do something rude or inappropriate, gently but firmly let them know. If they show empathy or compassion, give them praise
- Develop awareness – try and direct your loved one’s attention to the feelings of others. You can ask them questions about people they see throughout the day and how they might feel
- Don’t take things personally – if your loved one appears aggressive, dismissive and demanding, remember they are not in complete control

For more information about the effects of brain injury and tips for coping with the changes visit: www.headway.org.uk/about-brain-injury/individuals/information-library or google ‘Headway UK information library’.

Notes

Relationships

Relationships are a very important and intimate part of life. For some people, the emotional, behavioural, physical and cognitive changes after brain injury can have an impact on existing and future relationships.

Tips for managing relationships:

- Try to keep communication open and honest – being able to effectively communicate with one another is an important part of relationships
- Make the effort, no matter how small, to show the other person that you care for them – this could be through small gestures, such as telling someone how important they are to you or writing them a letter. However, don't be offended or upset if they do not respond to your efforts; it may be that they are unaware of the meaning behind the gesture, or they are unable to express or understand their own emotions
- Have regular date nights – set time aside to spend quality time together. You may even wish to dress up to turn it into a special occasion. Arrange child minding for young children so that there is no pressure on finishing the date night quickly
- Try to let unimportant things go. Arguments often happen because your loved one frequently feels frustrated, tired or irritable because of their brain injury and you are tired and stressed as well

Intimacy and sex

Brain injury can cause a range of physical, cognitive, emotional and behavioural issues that can affect various aspects of a brain injury survivor's sex life. Their interest in sex may be altered or they may no longer be able to engage in sexual activities the way they did prior to their injury.

- To find a registered Sex Therapist in England contact the College of Relationship and Sexual Therapists UK on **020 8106 9635** or email **info@cosrt.org.uk**
- Somerset-Wide Integrated Sexual Health Service (SWISH) offer psychosexual therapy. Speak to your GP to discuss a referral to the Swish Psychosexual Service
- To be referred to a Psychologist or Counsellor – ask your GP

“

*Don't be afraid to ask family or friends for help.
Sometimes people just need to be asked to do a specific thing.*

”

Helping children and teenagers to adjust

When a brain injury happens, you may instinctively want to protect children by not talking about what has happened. However, research suggests that children cope much better if they are told the truth and kept informed at a level that makes sense to them.

Here are some tips for talking to children about a close family member with an ABI:

- Remember that ‘super parents’ don’t exist. Just do what you can when you can. Be gentle on yourself
- Talk to children using words they understand and ask questions to check if they have understood you
- Show children how you are feeling: it helps them to know it’s okay to show their feelings too
- Encourage children to ask questions and keep answering them – even if it’s for the 100th time
- Answer questions honestly and simply and be willing to say ‘I don’t know’
- Books which may help you are: ‘My Mum Bakes the Best Cakes’ or ‘My Dad Builds the Best Boats’ by Jo Johnson, written for younger children to help them understand brain injury both on the Headway UK website.

When talking to teenagers and young adults, they will have more understanding and knowledge of serious illnesses. After giving basic details of what has happened, allow the child to guide the conversation further. Reassure them that you will tell them what you know and that you will be honest.

Looking after your own wellbeing

When your loved one is ill, you spend a lot of time focusing on them and you may feel as if you have no time for yourself. Looking at your own wellbeing is important for you and for them.

Tips for looking after your own wellbeing:

- Share your feelings with someone you trust, such as a family member or your neighbour
- Take a break and make time for yourself
- Continue with your regular dentist, optician and hearing checks, as well as for the person you are caring for
- Keep yourself physically active, make time for a walk or play a sport you enjoy

For more tips on looking after your own wellbeing visit www.headway.org.uk/about-brain-injury/individuals/caring

Support for yourself

Looking after your loved one can be tiring and at times you may need a break. Short breaks give carers the opportunity to have a break and to 'recharge their batteries'. There are a number of ways for this to happen including an increased package of home care support. Short term breaks can be arranged after you have had a Carers Assessment. This will be carried out by a social care worker from Somerset County Council. To ask for a Carers Assessment phone Somerset Direct **0300 123 2224**.

Looking to the future

It can take time to adjust to your loved one's brain injury. Once you settle into an everyday routine, you may want to think about moving forward and looking to the future.

Alcohol

Sustaining a brain injury can reduce a survivor's tolerance to alcohol, therefore drinking is not generally recommended after brain injury.

Driving

If you drive and have a brain injury it is a legal requirement to inform the DVLA. This does not mean that your loved one will never be allowed to drive again but they may require further assessment or information before they do.

See www.gov.uk/health-conditions-and-driving for a list of the notifiable conditions and for advice on what you have to do if you have one of those conditions.

Holidays

After a brain injury, planning a holiday might require even more care and it might be necessary to research new places to visit that can accommodate your new needs. Make sure to check that your holiday insurance company is advised of the brain injury and that the policy covers any aids or equipment that you might need to take with you.

See also www.headway.org.uk/about-brain-injury/individuals/practical-issues/holidays-and-travel/

Employment/Returning to work

After a degree of recovery from brain injury, your loved one may feel they are ready to return to work. However, they may find they can no longer do their old job in the same way, or do it safely.

When returning to work it is nearly always better to return to a job that you know well rather than trying a new job. Familiarity of the role, colleagues and the working environment can all be helpful, although your loved one may find that some aspects of the job require adjusting to accommodate for any new needs.

Your loved one does not have to disclose or give details of their ABI to their employer but it may be useful to do so.

Your loved one could be encouraged to have a 'return to work interview' with their employer. It may be useful to discuss

- Returning to work gradually
- Returning with shorter hours
- Taking more breaks through the day
- Returning with less workload
- Taking up a different role

If your loved one is considering finding a new job after brain injury, it would be a good idea to start off by seeking advice and support from the local Jobcentre Plus.

Some Jobcentres have Disability Employment Advisors (DEAs) who can offer specific advice about returning to work with a disability.

More information and advice on returning to work can be found at www.headway.org.uk/about-brain-injury/individuals/practical-issues/returning-to-work/

Education/Learning

Returning to education after brain injury can be a great way of acquiring the skills and qualifications necessary to return to employment. Studying can also provide a sense of purpose and an opportunity to meet people.

Somerset Local Offer provides information on the services available for children and young people with Special Educational Needs and Disabilities (SEND) aged 0 to 25 and how to access them.

www.choices.somerset.gov.uk/025/

Money/Finances

DWP Benefits - It is important to make sure you and the person you support get all the financial help you are entitled to. A good place to start can be using one of the online benefits checkers below. You input anonymous information and details about benefits which may be available to you, or the person you support are highlighted.

Turn 2 Us www.turn2us.org.uk have a benefits calculator.

Online benefits assessment tool:

www.moneysavingexpert.com/family/benefits-check

Citizens Advice – Citizens Advice, both National and in Somerset, offer free confidential advice online and over the phone. They can offer advice regarding benefits, work, debt and money, housing, law and courts and much more. You can call Citizens Advice Somerset on

0808 27 87842 or email through their website

www.citizensadvice.somerset.org.uk.

You can contact the National Citizens Advice on 0800 144 8848 or through their website

www.citizensadvice.org.uk

Money Saving Expert – The MoneySavingExpert website is dedicated to helping people find top deals, cut their bills, best buys and general tips and suggestions to help save money.

The website has guidance on cards and loans, household bills, banking and savings, mortgages and homes and insurance
www.moneysavingexpert.com

Benevolent Societies – provide financial and wellbeing support to individuals and families facing difficult circumstances.

Benevolent Societies each exist to support a different group such as current or former employees of a particular profession, people that live in a certain part of England or Somerset, armed forces charities support veterans and serving/former members and their families.

www.turn2usGrantSearch or **www.aco.net**

Capacity

Someone's ability to take decisions, sometimes referred to as their capacity may be temporarily or permanently altered by their ABI. In some cases it may be necessary to make some decisions on their behalf and the Mental Capacity Act 2005 provides a legal framework to allow this. The MCA provides safeguards to protect the independence of people who lack capacity and allows them to be involved as much as possible in the decisions. The Headway booklet 'Mental capacity: supporting decision making after brain injury' provides more detailed information.

www.headway.org.uk/about-brain-injury/individuals/caring/supporting-people-to-make-decisions/

Legal Advice

You, or the person you support may need legal advice especially if the ABI happened because of an accident of some kind or a medical procedure which has gone wrong. Our advice is to seek a specialist ABI legal firm who have knowledge and skills in making compensation claims, calculating the potential financial cost of the acquired injury in income lost or additional services and equipment needed and most importantly supporting families through the process.

Headway UK has a list of accredited ABI legal firms on their website under the 'Head Injury Solicitors Directory' where you can find the firms active in the South West. Headway UK also produce a booklet of all the legal firms they accredit.

www.headway.org.uk/supporting-you/in-your-area/head-injury-solicitors-directory/

There are two firms listed for Somerset:

- Enable Law (Taunton) - **03303 116850** or email **claire.stoneman@enablelaw.com**
- Clarke Willmott LLP (Taunton) - **0345 209 1461** or email **chris.thorne@clarkewillmott.com**

Brain Injury Identity Card

The Headway Brain Injury Card is designed to help police officers and staff more easily identify brain injury survivors and ensure that they receive an appropriate response and support.

Each card is personalised, helping the card holder to explain the effects of the brain injury and request any support they may need.

How to apply for a Brain Injury Identity Card:

- You will need a passport style photo of your loved one
- You will need verification of your their brain injury – this could be a letter from a Headway local group or from a clinical professional confirming the brain injury
- You can then apply on the Headway UK website on their behalf

www.headway.org.uk/supporting-you/brain-injury-identity-card/

Helpful Organisations and Contacts

Headway UK 0115 924 0800 enquiries@headway.org.uk

Headway, the Brain Injury Association, is a national charity set up to give help and support to people affected by brain injury including:

- A network of local Headway groups and branches
- Headway Helpline **0808 800 2244**
- Promoting the understanding of brain injury and its effects and lobbying for better support
- Producing a range of publications on aspects of brain injury

Key National Organisations

Stroke Association

www.stroke.org.uk or email helpline@stroke.org.uk

Brain Tumour Association

www.thebraintumourcharity.org or call their helpline at 0808 800 0004

Brain Tumour Support Charity

www.braintumoursupport.co.uk

Meningitis Now

www.meningitisnow.org

Encephalitis Society

www.encephalitis.info or call 01653 692583

Epilepsy UK

www.epilepsy.org.uk or call on 01494 601400

Samaritans

www.samaritans.org or call on 116 123

Tinnitus UK

www.tinnitus.org.uk or call on 0800 018 0527

Information and advice on brain injury and issues post injury can be found at www.headway.org.uk

Key Somerset Organisations

A Guide to Neurological Services in Somerset

www.somersetneuroalliance.org.uk/directory.htm

Citizens Advice Somerset

www.citizensadvice.comerset.org.uk

Compass Disability Services

www.compassdisability.org.uk for information and advice on all things related to a range of physical disabilities

Somerset Carers

www.somersetcarers.org or call on 0800 31 68 600

Village and Community Agents

01823 331 222 or visit their website www.somersetagents.org

Open Mental Health

01823 276892 or email support@openmentalhealth.org.uk

SWAN Advocacy

Visit their website for a referral form:

www.swanadvocacy.org.uk/refer/

Young Carers

0800 31 68 600 or email carers@somersetccc.org.uk

Mindline

01823 276 892 or email info@mindinsomerset.org.uk

Age UK Somerset

01823 345613 or visit their website

www.ageuk.org.uk/somerset

Men's Sheds

www.menssheds.org.uk

Talking Cafés

01823 331 222 or visit their website:

www.somersetagents.org/talking-cafes

Somerset Direct

0300 123 2224

St. Margaret’s Hospice

www.st-margarets-hospice.org.uk or call 01823 333822

Diversity Voice

www.diversityvoice.org.uk or call
0300 075 0105

Micro-providers

A very small, community based care and support services (fee will be charged) www.somersetcommunityconnect.org.uk

Mendip Health Connectors

www.healthconnections mendip.org or call 01373 468368

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Support us today

Headway Somerset is the only charity in Somerset working to support individuals with acquired brain injury (ABI) and their families, and we need your help to continue our work.

Every year we need to raise £100,000 to be here, to deliver services and continue to improve life after brain injury for the individuals directly affected, their families, supporters and carers.

Just £5 can answer a call to our information line

£25 can provide an hour of 1 -1 support

Can you help?

To donate please scan the QR code or visit our website:
www.headwaysomerset.org.uk

Thank you



01823 618519
www.headwaysomerset.org.uk

    **HeadwaySomerset**

Registered Charity No. 1097407