

This e-booklet is an adaptation, created in August 2017, of the Headway print booklet *Sex* and sexuality after brain injury and may contain minor updates to the print version.

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acknowledgements



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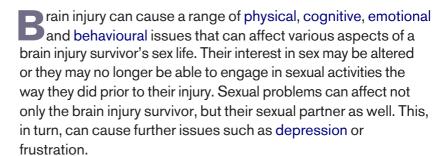
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Introduction



Sex is a topic that people often feel embarrassed to talk about, as it is a very personal and sensitive aspect of our lives. However, sexual activity is both important and completely natural. It is therefore important that brain injury survivors and their sexual partners feel able to discuss and seek support with sexual issues.

This booklet has been written for brain injury survivors who have issues with sex after brain injury, and their sexual partners. It describes how sex can be affected following brain injury, offers tips for managing sexual issues and gives information on where to seek professional support from.

You will see some words in **bold** – these are defined in a glossary at the end of the booklet.

If you wish to discuss any of the information in this booklet in further detail, contact the confidential nurse-led Headway helpline on 0808 800 2244 or helpline@headway.org.uk.

More information on how relationships are affected is available in the Headway booklet *Relationships after brain injury*.

What is sex?



Sex is a basic function of life that relies on physical, emotional, behavioural, cognitive and social skills. Aside from the reproductive purpose that it serves, sex provides a sense of fulfilment and often creates an intimate connection with someone who we feel is special to us. It is therefore an important aspect of our personal lives and many intimate relationships.

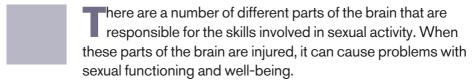
The process of sex often starts with a desire to have sex (**sex drive**, also known as **libido**). Complex emotional, psychological and social customs are often involved in both initiating and having sex. The act of sexual intercourse itself is both physical and emotional.

Sex is sometimes divided into a number of aspects, for instance: sexual functioning, which relates to the physical aspect of sex (such as sexual arousal, intercourse and orgasm), and sexual well-being, which relates to the emotional and psychological aspect of sex (such as sexual satisfaction).

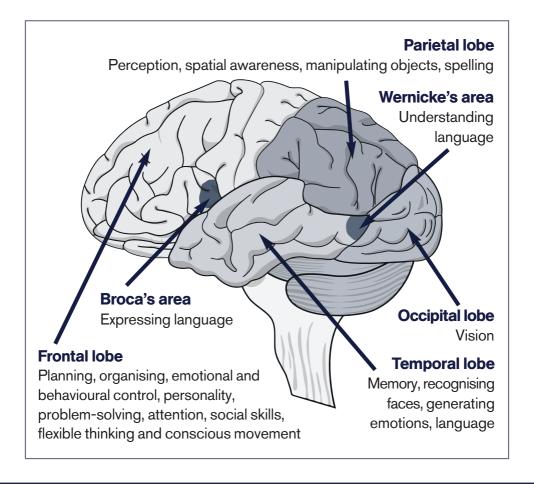
Sex includes acts of **intimacy** such as touching and kissing, and also includes other forms of sex such as masturbation and oral sex, as well as penetrative sex.

Sex can mean different things to different people, depending on personal experience, values, personality and sexual preferences.

How can brain injury affect sex?



The most common parts of the brain that are involved in sexual functioning and well-being are discussed in more detail below.



Frontal lobe

This part of the brain is responsible for our behaviour and social skills. Injury to it can cause problems such as inappropriate sexual behaviour, difficulties with initiating sexual activity or difficulties with motivating oneself to engage in sexual activity.

Injury to the frontal lobe can also cause difficulties with experiencing pleasurable and sexual sensations.

Personality change can occur following an injury to the frontal lobe. This can affect the survivor's own sexual behaviour and their sexual partner's desire to engage in sex with them.

Problems with attention and concentration can also occur following injury to the frontal lobe. This can interfere with spontaneity, and the build-up of arousal and physical intimacy between two people.

Temporal lobe

Injury to this part of the brain has been linked to an increase in sexual interest and emotions (hyperactive sexuality), although it can also result in a reduced sex drive (hypoactive sexuality).

Some people who have had temporal lobe injury have also been found to develop **paraphilias**.

Damage to pathways in the frontal and temporal lobes has been linked to difficulties in understanding whether someone else is interested in sexual contact, for example through body language and 'reading' emotions. These same difficulties can interfere with the emotional connection between romantic partners, which can affect **intimacy**.

Parietal lobe

Seizures in this part of the brain can cause some brain injury survivors to experience sensations in their genitals, including heightened sexual arousal or sensations that are not pleasurable. For some survivors these sensations can even be irritating or painful.

Internal areas of the brain

Hypothalamus/pituitary gland – these parts of the brain are responsible for producing hormones in the body that regulate sex drive. Damage to these parts can therefore result in hormonal problems, for instance a reduction in hormone production that can lead to reduced or increased sex drive. More information on this is available in the Headway factsheet Hormonal imbalances after brain injury.

Amygdala – this part of the brain is largely responsible for managing emotions. Damage to the amygdala can result in problems with the emotions typically associated with sexual well-being, such as **orgasm** sensations or sexual feelings. The amygdala has also been associated with **sex drive**.

Effects of brain injury on sex

- here are four main categories of the effects of brain injury. Any of these can cause sexual problems:
- Physical how the body works
- Cognitive how the person thinks, learns and remembers
- Emotional how the person feels
- Behavioural how the person acts

There are a number of sexual issues caused by the above effects that are common to individuals regardless of their gender, and these are discussed in more detail below. However, due to typical differences in physiology and sexual behaviour, men and women can have different sexual issues. Separate sections of this booklet have therefore been designated to address physiology-specific sexual problems.

Sexual issues common in both men and women

This section covers common effects of brain injury that can cause sexual issues in both men and women. More information on many of these effects can be found in Headway's booklets and factsheets at www.headway.org.uk/information-library.

Physical effects

Some common physical issues that can affect sex are:

 Problems with balance and dizziness – this can make it difficult for a survivor to position themselves to enjoy sex or engage in sustained sexual activity.

- Fatigue this can affect a survivor's stamina during sex, or cause them to feel too tired to initiate or engage in sexual activity at all.
- Hormonal problems changes in the body's hormone production can alter the survivor's interest in sex. Hormonal problems can also affect physiological feedback so that the body does not generate feelings of arousal.
- Pain the survivor may no longer feel aroused or comforted by the sensation of touch. Continuous pain, such as ongoing headaches, can be distracting and interfere with the survivor's interest in sex.
- Incontinence this may cause embarrassment, fear or disinterest if a survivor is incontinent before, during or after sexual activity.
- Weakness or paralysis on one side of the body the survivor may find it difficult to position themselves during sex or engage in physical activity such as foreplay or masturbation.
- Limited mobility this can also make it difficult for the survivor to position themselves for sex.
- Communication problems the survivor may struggle with expressing or articulating their sexual needs, desires, or satisfaction. Sexual partners may feel that being unable to understand their partner interferes with sexual activity or quality.
- Seizures some survivors may be concerned about experiencing a seizure during sexual activity.
- Medication some medications can have side effects that affect sexual functioning, such as drowsiness, headaches or a loss of libido.

Cognitive effects

Some common cognitive issues that can affect sex are as follows:

- Memory problems these can cause a survivor to forget intimate moments that they have shared with their sexual partner. In some severe cases of memory problems, a survivor may be unable to remember their sexual partner.
- Reduced initiative and problems with motivation this can make it difficult for the survivor to initiate and engage in sex, especially spontaneous sexual activity.
- Lack of insight this may cause a survivor to fail to recognise how their sexual performance or behaviour is affected by their injury.
- Difficulties with making decisions this may cause the survivor to struggle with making decisions regarding their sex life, for example on issues such as contraception.
- Prosopagnosia (see glossary) this may make it difficult for the survivor to recognise their sexual partner.

Emotional effects

Some common emotional issues that can affect sex are as follows:

- Depression this can cause the survivor to lose interest in activities, including sex. Depression can also cause other problems that can affect the survivor's sex life, such as altered sleeping patterns or lowered self-esteem.
- Emotional lability this might make the survivor's moods unpredictable, affecting their continued interest in sex, and can make it difficult for sexual partners to follow their moods.

- Loss of self-esteem this may cause a survivor to feel unattractive or undesirable, despite still being interested in or able to engage in sexual activity.
- Impaired empathy this can affect the survivor's ability to understand and appropriately respond to their sexual partner's feelings, which can be particularly upsetting for sexual partners and can negatively affect intimacy.

Behavioural effects

- Lack of inhibition this can cause some survivors to behave inappropriately, for instance touching someone inappropriately, making inappropriate sexual remarks or engaging in exhibitionism.
- Anger problems difficulties with controlling anger can cause the survivor to lose interest in sex, become unpredictable with moods, or be too aggressive with their sexual activity.

While any of the above effects can have an impact on sexual functioning, current research suggests that the most common negative influences on sexuality after brain injury are low mood and self-esteem, side effects of medication and communication difficulties between sexual partners.

Other effects

In addition to the above, the following problems have also been commonly reported by both males and females after brain injury:

- Reduced frequency of sexual activity
- Reduced quality of sex
- Reduced satisfaction from sex

- Lower or higher sex drive
- Difficulty in reaching orgasm
- Changes in sense of self, causing some survivors to no longer feel like themselves, or no longer feel adequate at sexual activity.

The above effects can affect not only the act of sexual intercourse itself, but also acts of **intimacy** that precede or follow sexual intercourse.

Male physiology-specific sexual issues

Some of the most common sexual problems typically reported by men with brain injury are as follows:

- Inadequate energy for sex
- Low sex drive
- Problems initiating sex
- Problems reaching orgasm, or less intense orgasm
- Getting and maintaining erection
- Premature ejaculation
- Body positioning and movement
- Decreased sensation
- Dissatisfaction with sex organs

Psychological problems can cause a loss of confidence which may affect physical performance. For instance, depression can reduce both the desire for sexual activity and the ability to get or maintain an erection. Various types of medication have been reported to affect erections and the ability to reach **orgasm** as well.

Female physiology-specific sexual issues

Some of the most common sexual problems reported by women with brain injury are:

- Inadequate energy for sex
- Low sex drive
- Problems with initiation and arousal
- Painful sex and inability to masturbate
- Problems with orgasm, or reduced feeling
- Problems with lubrication, leading to vaginal dryness
- Discomfort in positioning
- Decreased sensation
- Changes in menstruation

Medication can also have an effect on reducing or preventing **orgasm**. Anxiety and depression may reduce both the desire for sex and the ability to achieve full orgasm.

Impact of sexual problems on sexual partners



Sexual activities are often undertaken with a partner. The sexual partner is therefore often also affected by any sexual issues experienced by the brain injury survivor, such as those listed in the previous sections.

The survivor's effects may cause the partner to no longer be sexually interested, aroused or satisfied. This can often produce feelings of guilt, confusion and sexual frustration, which can be particularly upsetting if they feel unable to speak to the survivor openly about such feelings. This, in turn, may have an impact on the relationship itself.

Conversely, a brain injury survivor may also lose interest in their sexual partner, for instance if they cannot remember key moments of intimacy or are no longer interested in sex. This can be deeply upsetting for a sexual partner who is still sexually interested in the survivor and wants to be intimate with them. Unsuccessful attempts to arouse or engage the survivor may cause the partner to question themselves as an adequate lover, which might negatively affect their own self-esteem.

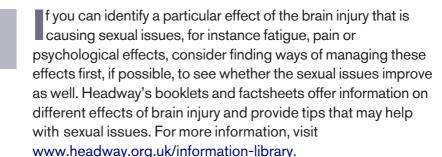
The sexual partner may also struggle to satisfy or no longer enjoy the pace of sexual activities if the survivor has developed a change in their sexuality or has developed different sexual interests. An overall personality change in the survivor can be particularly distressing, as the partner may feel that they are in a sexual relationship with someone they no longer have the same sexual feelings for as before the injury.

These types of situations can be particularly challenging for sexual partners if the survivor lacks insight into the effects of their injury, or if they are affected by issues such as **emotional lability**, problems with managing anger, or impaired empathy.

In some instances, a sexual partner may also take on the role of a carer, for instance if they support the survivor with undertaking tasks of daily living such as washing and dressing. This can cause a change in the sexual partner's perception of themselves as a lover, and it may be difficult to adjust to both roles.

It is important for sexual partners experiencing such issues to know that support is available, either independently or as a couple. Talking therapies can often be helpful, such as counselling or sex therapy. More information on the professional support available to both survivors and their sexual partners is available in the section *Professional support*, while general tips can be found in the following section.

Tips for coping with sexual problems after brain injury



Some general tips that can help with managing sexual issues are given below.

Remember that different things will work for different people, so try a range of things depending on what is suitable and relevant.

Prepare for sex

- Set time aside for sexual activity and make sure there are no distractions in the environment. You could also consider specifically arranging a 'date night'.
- Initiate sexual activity with foreplay, such as touching and kissing one another. This can create a sense of intimacy that can help with preparing for sex, both psychologically and physically.
- Create a relaxing, sensual environment. For instance, consider having a warm bath together beforehand, lighting candles, using pleasant aromas and soft textures, and playing gentle music.

- If you have difficulties with arousal, consider reading or watching material with sexual content before engaging in sexual activity.
- If penetration is difficult due to problems with vaginal lubrication, consider buying a lubricant. Many pharmacies and shops sell a variety of lubricants nowadays, so take some time to explore different products depending on your requirements and interests.

Communicate with one another

- Talk to one another about sex. If you are not comfortable with any part of sexual activity, be honest about your thoughts, interests and needs with your sexual partner. Don't assume that your sexual partner will know this already.
- Express regular intimate or romantic feelings towards your sexual partner, as this can help with developing intimacy.
- Communicate with one another and support each other to strengthen your relationship in general. Remember that supporting each other emotionally can have a positive impact on your physical relationship. For information and tips on relationships, see the Headway booklet Relationships after brain injury.
- Remember to discuss important issues such as practicing safe sex and sexual hygiene.

Explore causes of sexual problems

- Start off by seeking information and support from services such as your GP or the Headway helpline on how the effects of brain injury can cause sexual problems.
- If you suspect medication is having an impact on your sexual activity, speak to your GP.

- If you suspect hormonal changes are having an impact on your sexual activity, speak to your GP about getting a referral to an endocrinologist. More information on this is available in the Headway factsheet Hormonal imbalances after brain injury.
- Information about seeking help for sexual problems caused by psychological issues is available in the section Professional support.

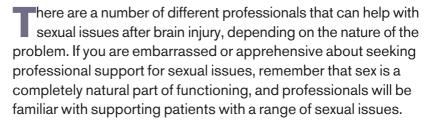
Try new things

- If you have physical difficulties, consider exploring the use of sex aids. These are pieces of equipment that are designed to make sex more comfortable for people. Suggested sex aids for individuals with a disability are available in the Disabilities. Health Research Network's Sexual Health Manual, which is available at www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf. You can also access this document by contacting the Headway helpline. Alternatively, Disability. Horizons offers some information and suggestions of sex aids at www.disabilityhorizons.com/2014/07/disability-and-sex-lets-be-frank-about-sex-toys/.
- Common items around the house can be used as sex aids as well, for instance cushions, chairs and comfortable counters.
- Consider trying different positions that are comfortable for both yourself and your sexual partner. For instance, you could try having sex with one partner on top, straddling on a chair (including a wheelchair) or lying on your sides.
- Experiment with new sensations such as aromas and textures, as these can add variety to sexual sensations.

Seek advice

- There are a number of other organisations and services that exist to offer sex-specific information and advice to people with a disability. Details of some organisations are available in the Useful organisations section.
- Talk to close friends or family about any concerns or queries you have about sex. Remember that people have different opinions and preferences about sex so they may feel differently about things and you may need to approach the topic sensitively. However, this does not mean that either of you are wrong, and it can still be useful to have discussions with someone you trust.
- Contact the Headway helpline for information on sex after brain injury, or any other issues you are concerned about. The helpline is available on 0808 800 2244 or helpline@headway.org.uk.
- Don't be afraid to discuss any concerns you have about sex or your sexual functioning with your GP or other relevant therapist. You could also seek specialist support from a sexual health clinic or a urologist if relevant. More information on this is available in the following section.

Professional support



Remember as well that sexual partners can also receive professional support from some of the below services.

Clinical Neuropsychologists

These are professionals that specialise in supporting brain injury survivors with cognitive, psychological, emotional and behavioural effects of brain injury. Some Clinical Neuropsychologists may specialise in supporting survivors with sexual problems, or can support a survivor with monitoring emotions, behaviour or inappropriate sexual behaviour.

You can speak to your GP about getting a referral to a Clinical Neuropsychologist. Alternatively, a directory of private Clinical Neuropsychologists can be found on the British Psychological Society's website at www.bps.org.uk/bpssearchablelists/SRCN.

The Headway helpline can also assist with providing information about local neuropsychological services in your area.

Psychosexual counselling

Some counsellors are trained to support people with sexual and psychological issues. Psychosexual counselling encourages the person to talk about how they are feeling, and aims to explore

what causes the sexual problems through open discussion. This type of therapy may be suitable for brain injury survivors who experience sexual difficulties due to psychological issues such as depression or anxiety.

It is important to note that counsellors may not specialise in supporting people with brain injury. You could therefore consider sharing information about your brain injury prior to sessions starting, or showing the counsellor Headway literature beforehand, such as this booklet.

Sex therapists

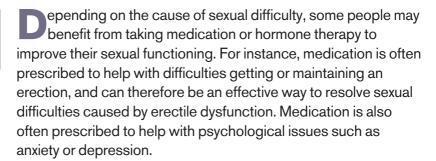
Sex therapists are trained in providing therapy for either couples or individuals. They can support clients with both physical and psychological issues that result in sexual difficulties and can do this through a combination of talking therapy and exercises, or activities to try at home. If you feel uncomfortable with anything a sex therapist suggests, do not hesitate to let them know, as they will be experienced in handling things sensitively and can offer alternative suggestions that you may be more comfortable with.

As with counselling, sex therapists may not be experienced in supporting clients with brain injury but there is nothing preventing you from bringing information about brain injury to therapy sessions.

You can speak to your GP about getting referrals to psychosexual counselling or a sex therapist. Alternatively, you can search the College of Sexual and Relationship Therapists directory for local therapists at www.cosrt.org.uk.

The organisation Relate also offers sex therapy. For more information, visit www.relate.org.uk.

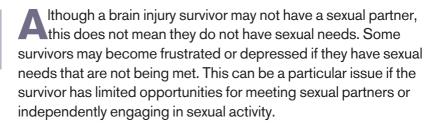
Medical treatment



Any consideration of medication should be discussed with your GP or neurologist as they will be able to tell you whether medication or hormone therapy is a suitable option depending on a number of factors, such as what may be underlying your sexual issues or whether you are already taking any medication.

Remember that some medications have side effects that may worsen other effects of your injury, such as headaches or fatigue. Speak to your GP or neurologist about any concerns you have with potential side effects.

Alternative sex services



Some survivors may benefit from using casual dating websites that are dedicated to finding and meeting sexual partners. It is always important to be cautious when using such online services, so seek guidance along the way from someone you trust, or a professional, and research different websites first. For guidance on being safe online, visit www.getsafeonline.org/protecting-yourself/online-dating.

In some cases, it might be useful to consider alternative sex services such as escorts, sex workers, or massage parlours that offer sex services and specialise in working with people with disabilities. Professionals such as occupational therapists, Clinical Neuropsychologists or sex therapists may be able to assist with finding safe and suitable sex services in the area.

Close friends and family may also be able to assist with this, but might be less comfortable about getting involved. They could, however, consider contacting some services listed in the section *Useful organisations* for support with arranging sex services. For instance, TLC-Trust is an organisation that offers a range of sexual services specifically for people with a disability. For more information, visit www.tlc-trust.org.uk.

Headway – the brain injury association ■

In all cases, maintaining sexual health and practicing safe sex is very important. The health professionals listed in this section and Professional support will be able to offer useful advice on this topic. Local sexual health clinics offer advice and support with sexual health as well. You can also find information about sexual health on the NHS Choices website at www.nhs.uk/ Livewell/Sexualhealthtopics/Pages/Sexual-health-hub.aspx.

Sex after brain injury and the law

It is against the law to restrict people with a disability from enjoying the same rights as non-disabled people; this includes their rights to sexual activity of their choice. It is therefore important for sexual partners, carers and professionals to recognise that brain injury survivors have the same rights as non-disabled people of having their sexual needs met and making their own decisions about their sexuality.

If a brain injury survivor lacks capacity and therefore cannot make a safe, informed decision about sex, a best-interests decision should be made with the support of appropriate professionals to ensure that the survivor's sexual needs are being met in their best interests.

Capacity can fluctuate, and while a person may have the capacity to make a certain type of decision, they may lack capacity to make decisions in other areas. Capacity should therefore be reassessed regularly, and considered independently depending on the decision being made. More information on this is available in the Headway booklet *Mental capacity: supporting decision making after brain injury*.

Conclusion



Prain injury can affect sexual interest and performance in a number of different ways, which can be difficult for both the brain injury survivor and their sexual partner. Different strategies can be used to make sex easier. Alternatively, professional support may be necessary to address the cause of the sexual problem.

It is hoped that the information in this booklet has helped you to identify ways of supporting yourself or your partner with sexual problems after brain injury. For more information or support, contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk.

Glossary



- Emotional lability expression of rapidly changing and often exaggerated emotions that do not necessarily reflect the brain injury survivor's internal emotional state
- Endocrinologist a professional that specialises in the assessment and management of hormones
- Exhibitionism sexual gratification from sexually exposing oneself to non-consenting others, for instance showing ones genitals in public
- Hyperactive sexuality drastically increased sexual interest or desire for sexual activity
- Hypoactive sexuality diminished or a complete lack of interest in sex
- Intimacy emotional, physical and psychological closeness between people accompanied by romantic feelings
- Libido see Sex drive
- Orgasm a point of climax during sexual activity that is accompanied by intense sexual pleasure and satisfaction
- Paraphilia abnormal sexual interests that can sometimes be dangerous or illegal
- Prosopagnosia face blindness. More information on this is available in the Headway factsheet *Prosopagnosia face blindness after brain injury*.
- **Sex drive** the emotional and psychological desire and drive to have sex
- **Urologist** a professional that specialises in the assessment and management of the urinary system.

Useful organisations



British Psychological Society (BPS)

Tel: 0116 254 9568

Email: enquiries@bps.org.uk Web: www.bps.org.uk

College of Sexual and Relationship Therapists

Tel: 020 8542 2707 Email: info@cosrt.org.uk Web: www.cosrt.org.uk

Counselling Directory
Tel: 0844 8030 240

Web: www.counselling-directory.org.uk

Disability Horizons

Web: www.disabilityhorizons.com/category/relationships-and-sex

Enhance the UK – ask questions, seek information

Web: www.enhancetheuk.org/ enhance/sex-and-disability

Find a Therapist – UK & Ireland Directory of Counselling and Psychotherapy

Web: www.cpdirectory.com

Marriage Care

Tel: 0800 389 3801

Web: www.marriagecare.org.uk

Mary Clegg Clinic

Web: www.maryclegg.co.uk

NHS Choices

Web: www.nhs.uk/Livewell/ Sexualhealthtopics/Pages/ Sexual-health-hub.aspx

Relate – the relationship people

Tel: 0300 100 1234 Email: Relate.Enquiries@

relate.org.uk

Web: www.relate.org.uk

Sexual Health and Disability
Alliance

Tel: 07770 884 985

Email: Trust@Outsiders.org.uk
Web: www.shada.org.uk

SupportLine

Tel: 01708 765 200

Email: info@supportline.org.uk Web: www.supportline.org.uk

Outsiders

Tel: 07410 544 318

Email: info@outsiders.org.uk Web: www.outsiders.org.uk

TLC – offers a range of sex services

Web: www.tlc-trust.org.uk

The Pituitary Foundation

Tel: 0845 450 0375

Email: helpline@pituitary.org.uk Web: www.pituitary.org.uk

The Lover's Guide

Web: www.loversguide.com

UK Council for Psycotherapy

Tel: 020 7014 9955

Email: info@ukcp.org.uk

Web:

www.psychotherapy.org.uk

About Headway

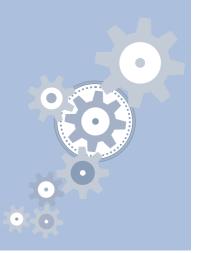


eadway – the brain injury association is a charity set up to give help and support to people affected by brain injury.

A network of local Headway groups and branches throughout the UK offers a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The Headway helpline provides information, signposts to sources of support and rehabilitation services, and offers a listening ear to those experiencing problems. Other services provided by Headway include:

- Supporting and developing local groups and branches
- Promoting understanding of brain injury and its effects
- An award-winning range of publications on aspects of brain injury
- Accreditation of UK care providers through the Approved Provider scheme
- A comprehensive, award-winning website
- Campaigning for measures that will reduce the incidence of brain injury
- Providing grants from our Emergency Fund for families coping with financial difficulties
- Headway Acute Trauma Support (HATS) nurses to support families with loved ones in hospital
- Freephone helpline: 0808 800 2244 (Monday-Friday, 9am-5pm)
- Telephone: 0115 924 0800
- Website: www.headway.org.uk
- Fax: 0115 958 4446
- Email: helpline@headway.org.uk

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