Headway
the brain injury association

Sex and sexuality after brain injury

This publication has been written for brain injury survivors who have issues with sex after brain injury and their sexual partners. It describes the various ways in which sex can be affected by brain injury, offers guidance for managing sexual issues and gives information on where to access professional support from.

www.headway.org.uk
0808 800 2244

Contents

Introduction 1
What is sex? 2
How can brain injury affect sex? 3
Organic damage 3
Effects of brain injury 5
Life changes 8
Changes in relationships and interactions with others ... 9
Physiology-specific sexual issues 9
Male physiology-specific sex issues 9
Female physiology-specific sex issues 10
Impact of sexual problems on partners 11
Tips for coping with sexual problems after brain injury 12
Professional support 15
Medical treatment 17
Mental capacity and sex 18
Conclusion 19
Glossary 19
Acknowledgements 20

Introduction

A brain injury can cause a wide range of issues that can affect various aspects of a brain injury survivor's sex life. The brain injury survivor's interest in sex may change, or they may no longer able to have sex in the same way as they did before their injury. Sexual problems can affect not only the brain injury survivor themselves, but their sexual partner as well.

Sex is something that people often feel embarrassed or unable to talk to others about, as it is a very private and sensitive topic.

However, it is also a very natural part of life and can offer comfort, pleasure, a sense of closeness with someone important to us and general positive well-being. It is therefore important that brain injury survivors and their sexual partners feel comfortable enough to discuss and get support with sexual issues if this is important to them.

This publication has been written for brain injury survivors who have issues with sex after brain injury and their sexual partners. It describes the various ways in which sex can be affected by brain injury, offers guidance for managing sexual issues and gives information on where to access professional support from.

The information in this publication does not replace clinical guidance from medical professionals. You should always get advice from your GP or other suitably qualified professional for help with managing the effects of 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 gives many people a sense of comfort, pleasure and fulfilment, and often creates a sense of closeness with someone who we feel is special to us. It is therefore an important part of life for many people.

Sex is sometimes divided into:

- sexual functioning - this relates to the physical parts of sex such as intimacy (touching, kissing, etc), sexual intercourse and orgasm;

- sexual well-being - this relates to the emotional and psychological parts of sex such as sex drive (also known as libido) and sexual satisfaction.

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

How can brain injury affect sex?

A brain injury can affect sex by causing…

- organic damage to parts of the brain directly responsible for sexual activity;
- physical, emotional, cognitive and behavioural effects that impact on a survivor's ability to engage in sex;
- life changes that affect a survivor's interest in sex;
- changes in relationships and interactions with others.

We will discuss each of these causes in turn below.

Organic damage

There are a number of different parts of the brain that are directly responsible for the skills involved in sexual activity. When these parts of the brain are injured, it can cause problems with sexual functioning and well-being.

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

Frontal lobes

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 starting sexual activity or difficulties with motivating oneself to engage in sexual activity.

Injury to the frontal lobe can also affect feeling pleasure during sexual activity. A brain injury survivor's personality might seem to change after an injury to the frontal lobes, as this part of the brain is responsible for behaviour and mood.

This can affect the survivor's sexual behaviour, as well as their sexual partner's interest in having sex with them. For example, before the injury, a person might have been active in their sex life but kept this private. Since their frontal lobe injury, they talk about their sex life openly with friends, which causes their sexual partner to feel embarrassed and less comfortable with having sex.

Problems with attention and concentration are also common after injury to the frontal lobes. This can interfere with the build-up of sexual arousal and intimacy between two people, causing the survivor to become distracted during sexual activity.

The frontal lobes are also responsible for problem-solving. Brain injury survivors that have difficulties with sex may struggle with figuring out ways around the issue and forming helpful solutions.

Temporal lobes

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

understanding someone's body language or 'reading' their emotions. For example, a brain injury survivor with damage to these pathways might misinterpret someone's behaviour as flirtatious and make sexual advances towards them, when in fact the person was simply being polite to them.

These same difficulties can interfere with the emotional connection between romantic partners, which can affect intimacy between them.

Parietal lobes

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 be irritating or painful. Sex might therefore become uncomfortable for them, or cause them to feel anxious.

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 imbalances that cause a decrease or increase in sex drive.

Amygdala

This part of the brain is largely responsible for managing emotions. Damage to the amygdala can cause problems with 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

There are four main ‘types’ of brain injury effects; these include:

- physical (how the body works)
- cognitive (how the person thinks, learns and remembers)
- emotional (how the person feels)
- behavioural (how the person acts)

Any of these can cause difficulties with sexual functioning.

Physical effects

Common physical effects of brain injury that can affect sex include:

- Mobility problems, or problems with dizziness/ balance - causing difficulties with positioning oneself to enjoy sex comfortably or safely.

- Fatigue - affecting a survivor’s stamina during sex, or causing them to feel too tired to have sex at all.

- Hormonal problems - changes in the body’s hormone production can alter a survivor’s interest in sex or affect physiological feedback so that the body does not generate feelings of arousal.

- Pain - causing sex to be uncomfortable or causing distractions. A survivor may also no longer be comforted or aroused by the sensation of touch.

- Continence problems - causing embarrassment, anxiety or disinterest in case the survivor has a leakage before, during or after sexual activity.

- Communication problems - affecting a survivor's ability to make their sexual desires, interests or satisfaction understood.

Cognitive effects

Common cognitive effects of brain injury that can affect sex include:

- Memory problems - causing a survivor to forget intimate moments with their sexual partner or arrangements made for sexual activity such as pre-scheduled 'date nights'.

- Reduced initiative and motivation, and problems with switching mental gears - making it difficult for a survivor to initiate and engage in sex, especially spontaneous sexual activity.

- Reduced insight - causing a survivor to struggle with understanding or recognising how their brain injury has affected their sexual behaviour.

- Decision making difficulties - causing difficulties with making decisions regarding one's sex life, such as using contraception.

Emotional effects

Common emotional effects that can affect sex include:

- Depression - causing a survivor to lose interest in activities, including sex. Depression can also cause other problems that affect a survivor's sex life, such as altered sleeping patterns or lowered self-esteem.

- Anxiety - causing a survivor to worry about having sex or the consequences of having sex.

- Emotional lability - causing a survivor's moods to become unpredictable, for example being interested in having sex one moment but bursting into tears the next.

- Loss of self-esteem - causing a survivor to feel unattractive or undesirable, affecting their confidence with sexual activity.

- Impaired empathy - affecting a survivor's ability to understand and appropriately respond to their sexual partner's feelings, impacting intimacy between them.

Behavioural effects

Common behavioural effects that can affect sex include (but are not limited to…):

- Disinhibition - causing some survivors to behave inappropriately, for instance touching someone without their consent, touching themselves inappropriately in front of others or making inappropriate sexual remarks. They may also engage in exhibitionism.

- Anger problems - difficulties with controlling anger can cause a survivor to lose interest in sex, become unpredictable with moods or be too aggressive with their sexual activity.

Life changes

A brain injury can cause many changes to a person's life, which can in turn affect their sex life.

For those people who undergo a period of hospital treatment and rehabilitation after brain injury, there may not be time or

opportunities to think about or have sex. This may continue to be difficult if the survivor spends further time in a residential or care setting after discharge rather than returning home.

Many brain injury survivors struggle with returning to work following their injury, which can cause a change in their financial status. They may have their driving license taken away. Such practical changes can be distracting and

anxiety-provoking, and survivors or their sexual partners might not feel interested in sexual activity while adjusting to these changes.

Brain injury survivors may be on medication which has side effects on sexual functioning, such as causing drowsiness, headaches or a loss of libido.

Changes in relationships and interactions with others

The effects and impact of brain injury can cause changes in relationships and interactions with others – more information on this is available in our publication Relationships after brain injury. These changes can also impact on sexual activity between the survivor and their sexual partner, as described throughout this publication.

A brain injury might also affect the survivor's opportunities to meet others with whom they go on to develop sexual relationships with, for example affecting their ability to socialise and meet new people.

Physiology-specific sexual issues

A brain injury can cause differences in sexual functioning depending on the physiology of the brain injury survivor.

Male physiology-specific sexual issues

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

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

Psychological problems can cause a loss of confidence which may affect physical performance. For example, 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 females 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

If you can identify a particular effect of the brain injury that is causing sexual issues (for instance fatigue, pain or psychological effects), consider finding ways of managing these effects first, if possible, to see whether the sexual issues improve as well.

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 to yours and your sexual partner's personal circumstances.

Communicate with one another

- Talk to your sexual partner about sex. If you are not comfortable with any part of sexual activity, be honest about your thoughts, interests and needs. 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 our publication *Relationships after brain injury.*

- Remember to discuss important issues such as practicing safe sex and sexual hygiene.

- If fatigue is an issue, let your partner know in advance that you might struggle with sexual activity on days when you suspect you might feel fatigued (such as after an outing) as this can help with managing expectations.

- Agree on a word or phrase you can say if sex starts to feel uncomfortable and you need it to stop.

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 possibly getting a referral to an endocrinologist. More information on this is available in our publication *Hormonal imbalances after brain injury.*

- Information about seeking help for sexual problems caused by psychological issues is available in the section *Professional support.*

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 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 browse through different products depending on your requirements and interests.

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. Common items around the house can be used as sex aids as well, for instance cushions, chairs and comfortable counters.

- Try different positions that are comfortable and safe for both yourself and your sexual partner. For instance, you could try having sex with one partner on top, straddling on a chair or lying on your sides.

- Experiment with new sensations such as aromas and textures, as these can add variety to sexual sensations.

Professional support

There are a number of different professionals that can help with sexual issues after brain injury, depending on the nature of the problem. If you are embarrassed or nervous about seeking professional support for sexual issues, remember that sex is a completely natural part of functioning, and some professionals will be familiar with supporting patients with a range of sexual issues.

Remember that sexual partners can also receive professional support from some of the below services. It can sometimes be helpful to attend these together as a couple.

Clinical neuropsychologists

These are professionals that specialise in supporting brain injury survivors with cognitive, psychological, emotional and

behavioural effects of brain injury. Only a few clinical neuropsychologists specialise in supporting brain injury survivors with sexual difficulties, but neuropsychologists can generally support survivors with the effects of brain injury that may be underlying the sexual issues.

You can speak to your GP about getting a referral to a clinical neuropsychologist or search online for private clinical neuropsychologists 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 can ask counsellors what their experience in supporting someone with brain injury is before beginning sessions, and offer to send helpful information relevant to your personal case.

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 relevant information about your 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/therapists-nearest-me-search-results.

The organisation Relate also offers sex therapy. For more information, visit www.relate.org.uk/what-we-do/counselling/sex-therapy.

Medical treatment

Depending on the cause of sexual difficulty, some people may benefit from taking medication or hormone therapy to improve their sexual functioning. For instance, medication is often prescribed to help with difficulties getting or maintaining an erection, and can therefore be an effective way to resolve sexual difficulties caused by erectile dysfunction. Medication is also often prescribed to help with psychological issues such as anxiety or depression.

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.

Mental capacity and sex

All sexual activity requires the consent of everyone involved. Brain injury can sometimes affect a person's ability to understand information and make decisions, which may affect their capacity to consent to sexual activity. A person who lacks the capacity to make this decision cannot legally give consent.

Engaging in sexual activity with someone who lacks capacity to give their consent is against the law.

Survivors who have capacity to make their own sexual decisions may still need to be advised on the risks of certain decisions that are considered to be ‘unwise’.

Capacity is a complex issue and it may be that a survivor has capacity in one area of sexual wellbeing, such as the capacity to form a relationship, but not in another, such as understanding the importance of safe sex.

In cases where there is a question around the survivor’s mental capacity, it is important to gain professional advice, either from professionals working directly with the survivor or from the Court of Protection.

Information about the Court of Protection is available on the UK government website at www.gov.uk/courts-tribunals/court-of-protection.

Further information on mental capacity is available in our publication *Mental capacity: supporting decision making after brain injury*.

Conclusion

A brain injury can affect interest in sex and sexual functioning in a number of different ways. This can be difficult for both the brain injury survivor and their sexual partner if sex was an important part of their lives before the injury.

Different strategies can be used to address the underlying issues, or it might be necessary to get professional support.

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
- **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.

Acknowledgements

Thank you to Dr Giles Yeates, Clinical Neuropsychologist and Couples Therapist for co-authoring this publication and assisting with its subsequent review.

We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2023.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

0808 800 2244
helpline@headway.org.uk

0115 924 0800 | enquiries@headway.org.uk
www.headway.org.uk

Head office: Bradbury House, 190 Bagnall Road,
Old Basford, Nottingham, NG6 8SF

Headway – the brain injury association is registered with the Charity Commission for England and Wales [Charity No. 1025852] and the Office of the Scottish Charity Regulator (Charity No. SC 039992]. Headway – the brain injury association is a company limited by guarantee registered in England [No. 2346893].