Intimacy and Relationships following Brain Injury

Introduction

All relationships are wonderful, inspiring, satisfying, and breathe purpose into all our lives. By their very nature they are also challenging, and at times overwhelming and exhausting. Relationships with partners or spouses are uniquely special and complex as they combine all aspects of friendship and a shared life with intimacy and sex.

No matter how strong and enduring our relationships are, they are filled with highs and lows, contentment and conflict. These feelings can be even more prominent after you have suffered a brain injury.

In fact, relationship problems are one of the most frequently reported long-term and devastating consequences after brain injury.

This may be because you find it difficult to relate to people the way you did before your injury. You may find changes in your appearance, weakness of parts of your body, changes to your personality or problems with communication difficult to deal with.

These are all natural reactions; however they can put a strain on forming and maintaining relationships. Being intimate in the way you communicate with potential partners, and the way you touch and hold someone may be an important part of relationships for you. However you may have found that the ease, and your desire for such interactions has been significantly reduced, or you may find it difficult to imagine being in a relationship again. Sex may also be an important part of your life and you may not be having sex just now.

Many people find that building and maintaining relationships is not a problem following a head injury. However, some people will find that their ability to form relationships is affected and they begin to wonder whether they will feel intimacy in a relationship again.

In truth, it is often difficult to build new relationships, particularly intimate relationships following a brain injury. However, difficulty with any relationship is normal and handled well it will hopefully mean that eventually you and another person may grow in a relationship together.

It is our hope that this leaflet will provide advice, support and information. It is just a start and should you wish to discuss any of the information in more detail, please do not hesitate to contact any of us at any time.

We are more than happy to work with clients whether they wish to be in heterosexual, lesbian, gay, bisexual or trans-gender relationships.

There can be lots of reasons why intimacy and sex can be affected following a brain injury. Some possibilities are explored in this leaflet.
How You Think and Behave

You may feel like a very different person now. Your personality may have subtly or dramatically changed in a way you may not be comfortable with. You may not have the same interests anymore and your view of the world may have changed. Your life aspirations may be different now, and it may seem that you are heading in a new direction.

This can be distressing and may make you feel that forming a relationship is difficult. Potential partners may also be feeling like this. You may not have spoken to anyone about this or if you have the conversation may not have gone as you had hoped.

Who or what can help?

Any team member but in particular the Clinical Psychologist and Speech and Language Therapist can provide information, advice and support on how to manage and cope with your partner or spouse’s personality and communication changes.

Changes in Communication and Language Ability

Your style of communication may have changed and you may be finding it difficult to interact with people as you once did. People close to you may seem irritated by things you say, or the way you say it. As a consequence you may struggle to imagine being intimate with another person and this can be very upsetting.

Depending on your injury you may also have some difficulty understanding what people say to you or expressing yourself verbally. This is distressing and frustrating for you as it will affect the quality and ease of conversations. You may find you struggle to share jokes and memories in the same way, and part of what makes you feel like you may seem to have been lost.

Who or what can help?

The Speech and Language Therapist can provide information and advice on how to ease communication and improve the quality of interactions. This may be via practical and therapeutic steps as well as via emotional support.

Mobility and Changes in Physical Appearance

You may now have significant weakness in parts of your body which means it is difficult for you to move. It may seem overwhelming to imagine how you would position yourself for cuddles or sex and you may not have attempted this yet.

People may need to help you with washing, dressing and going to the toilet. As a result you may not feel intimately attracted to anyone just now. Some people will need to be hoisted. Imagining how this can be romantically included at intimate times or during sex can be difficult and you may find the process of being hoisted does not make you feel very sexy.

You may be struggling to feel attractive or sexy as you are unable to move easily and allow sex to flow the way it used to. You may also be conscious of your body image.
Who or what can help?

Members of the team, in particular Physiotherapists and Occupational Therapists, can advise people individually or in couples on how to maximise your ability to position yourselves, and also on how your partner/spouse can help you.

You may find it helpful to discuss issues with regard to the change in your feelings with a Clinical Psychologist or with any member of the team with whom you feel comfortable.

Sexual Arousal

Arousal or the feeling of wanting to have sex involves both physical and thought processes. After a brain injury these process can be affected and you may experience increased sex drive, decreased sex drive, or you may behave in a disinhibited way.

Increased sex drive: sometimes a brain injury can cause feelings of increased sexual desire. You may find it difficult to express these feelings in an appropriate way. You may also find it difficult to recognise when other people don't want to think about sex, or don't want to have sex.

Decreased sex drive: sometimes a brain injury can cause a person to lack sexual feelings or desire. This can be frustrating if you want to enjoy sex. Sometimes decreased sex drive can be caused by certain medications. If you are concerned about this you will need to speak to your GP or Consultant.

Disinhibition: normally our brain controls our response to feelings of arousal, making sure we respond in a way that is socially acceptable. After a brain injury the ability for you to control your responses may have been affected.

Disinhibition can involve behaviour such as touching yourself or others in an inappropriate way or at an inappropriate time, or talking in a sexually explicit way. You may be aware of and embarrassed by this but do not know how to control it. However you may not be aware your behaviour is upsetting for other people.

What or who can help?

Many people find disinhibition related to sex extremely difficult to deal with. Your family/friends will be advised of ways of coping if this is a problem, and these will include:

- Totally ignoring inappropriate behaviour, even though this can be very difficult for them. Paying attention and providing positive regard to the kind of behaviour they find acceptable. Showing you a more acceptable way of expressing your feelings. It will also be helpful to discuss this with the Clinical Psychologist or any team member with whom you feel comfortable.

Physical Reasons Specific to Sex

Physical problems associated with sex can affect men and women. Some people are aware of these issues but are reluctant to discuss them.
Physical problems are common and can include:

- Problems getting or keeping an erection.
- Reduced vaginal lubrication (wetness).
- Difficulty reaching orgasm or being unable to have an orgasm.

What or who can help?

These issues are best dealt with in the first instance by your GP or Rehabilitation Consultant, who may then be referred to Consultant specialising in Urology if necessary.

Depression/ Anxiety

You may be depressed or anxious following your brain injury. This can make it difficult for you to communicate easily. This may be very distressing if previously you have communicated easily to work out your difficulties. Depression and anxiety are also related to lowered sex drive.

Who or what can help?

Discussing with any team member can be helpful, however the Clinical Psychologist is the most experienced and skilled Clinician in this area. In some circumstances it is likely they will also want to liaise with your GP or the Community Mental Health Team, however we will always discuss this with you first.

Fertility and Contraception

Fertility is not affected following a brain injury. However women’s menstrual cycles (periods) can be disrupted following a brain injury. Contraceptive precautions should still be used if you do not want to become pregnant during this time.

What or who can help?

Your GP and the family planning clinic at your local health centre will provide advice and information on contraception.

Problems associated with intimacy and sex can be difficult to talk about. However we are hopeful you can build and enjoy an intimate relationship again.

Acknowledging difficulties and frustrations to yourself is the first step needed to re-create the intimate and sexual part of the life you once had. This can be very hard to do and extremely upsetting at first. For some people, these conversations are best kept private with a close friend or relative, while others appreciate the support and advice which our team and wider services can provide.

Please feel free to contact any of us, at any time. All members of the Cumbria Community Acquired Brain Injury Service have received training and are comfortable to discuss any of these matters.

However if you would prefer, you may choose any team member you feel comfortable with to discuss anything of concern. Alternatively, as our team is county wide and we have distinct north and south teams, it is likely you will have only met the team members in your locality.
As such if you would prefer to discuss any of these matters with someone who is not involved in your rehabilitation, you may choose to meet a team member from the opposing locality.

Phone numbers for the Kendal and Carlisle office are at the end of this booklet.

**Useful Books**

A relational approach to rehabilitation: thinking about relationships after brain injury. Edited by: Ceri Bowen, Giles Yeates and Siobhan Palmer.

Published by: www.karnacbooks.com ISBN: 9781855757486

**Useful Websites**

- [http://www.tlc-trust.org.uk](http://www.tlc-trust.org.uk)
- [http://www.focusondisability.org.uk/relationships.html](http://www.focusondisability.org.uk/relationships.html)
- [http://www.relate.org.uk/home/index.htm](http://www.relate.org.uk/home/index.htm)
- [http://www.outsiders.org.uk/shada](http://www.outsiders.org.uk/shada)

**Useful contacts**

- RELATE: For any further information on services in Cumbria, please call 01772 717597 or email develop@relatelancashirecumbria.org.uk
- SHADA (The Sexual Health and Disability Association)
  Tel: 020 7354 8291
  Address: The Outsiders, 4S Leroy House, 435 Essex Road, London, N1 3QP
  Email: info@Outsiders.org.uk

**Contact Details:**

Cumbria Community Acquired Brain Injury Rehabilitation Team (CCABIRT)
Cedarwood, Carleton Clinic, Carlisle, CA1 3SX Telephone 01228 602155
1st floor, Barclays House, Murley Moss Business Village, Oxenholme road, Kendal, LA19 7RL Telephone 01539 718118

If you would like this factsheet in another language or format, for example Braille, large print or audio, please call: 01228 603890
E: communications.helpdesk@cumbria.nhs.uk

Or write to Engagement and Communications
Voreda House | Portland Place | Penrith | CA11 7QQ

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