Acquired Brain Injury Service

Intimacy and Relationships following Brain Injury

Partners Leaflet

Introduction

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 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 your partner or spouse has 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 your partner the way you did before their injury. You may find changes in their appearance, weakness of parts of their body, changes to their personality or problems with communication difficult to deal with.

These are all natural reactions, however they can put a strain on a relationship no-matter how strong and enduring it is.

Being intimate in the way you communicate with your partner, and the way you touch and hold one another may be an important part of your relationship. However you may have found that the ease, and your desire for these interactions has been significantly reduced.

Sex may also be an important part of your relationship and you may not be having sex just now.

Many couples find that their relationships strength and quality is unaffected, or even stronger following a partner or spouses brain injury. However, some couples will find that at times their relationship is put under huge strain and they begin to wonder whether they will ever again feel the love and contentment they once had.

In truth, many relationships do suffer following a partner or spouses brain injury. However, conflict within a relationship is normal and handled well it can help you and your partner grow 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 and their partners, whether 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 your partner thinks and behaves**

Your partner may seem like a very different person now. Their personality may have subtly or dramatically changed in a way you are not comfortable with. You may not share the same interests any more or have the same view of the world. Your life aspirations may be different now, and it may seem that you are heading in very different directions.

This will be very distressing for you and may make you feel that your relationship is falling apart. Your partner or spouse may also be feeling like this. You may not have spoken to one another 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 spouses personality and communication changes.

**Changes in Communication and Language Ability**

Your partner or spouses style of communication may have changed and you may be finding it difficult to relate to them and feel loving towards them. You may even be highly irritated by things they say, or the way they say it. As a consequence this may be affecting how intimate you are with them and this can be very upsetting.

Depending on their injury your partner or spouse may also have some difficulty understanding what you say to them or expressing themselves verbally. This is distressing and frustrating for you both and will affect the quality and ease of conversations. You may find you can no longer share jokes and memories in the same way, and part of what makes you a special couple 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 well as via emotional support.

**Mobility and Changes in Physical Appearance**

Your partner may now have significant weakness in parts of their body which means it is difficult for them to move. It may seem overwhelming to imagine how to position yourselves for cuddles or sex and you may not have attempted this yet. You may need to help, or have needed to help your partner with washing, dressing and going to the toilet. As a result of this huge change in your relationships dynamics you may not feel as intimately attracted to your partner 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 hoisting your partner does not make you feel very sexy.
Your partner or spouse may be struggling to feel attractive or sexy as they are unable to move easily and allow sex to flow in the way it used to. They may also be conscious of their body image.

Who or what can help?

Members of the team, in particular Physiotherapists and Occupational Therapists, can advise couples individually or together on how to maximise your partners ability to position themselves, and also on how you can help them.

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. In brain injury these process can be affected and your partner or spouse may experience increased sex drive, decreased sex drive, or they may sometimes behave in a disinhibited way.

Increased sex drive: sometimes a brain injury can cause feelings of increased sexual desire. Your partner or spouse may find it difficult to express these feelings in an appropriate way. They may also find it difficult to recognise when you don’t feel like having sex.

Decreased sex drive: sometimes a brain injury can cause a person to lack sexual feelings or desire. This can be frustrating for you both 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 partner’s or spouse's 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 your spouse or partner to control his or her responses may have been affected.

Disinhibition can involve behaviour such as touching themselves or others in an inappropriate way or at an inappropriate time, or talking in a sexually explicit way. Your partner or spouse may be aware of and embarrassed by this but does not know how to control it. However your partner may not be aware their behaviour is upsetting for you.

What or who can help?

Many partners and spouses find disinhibition related to sex extremely difficult to deal with. Some ways of coping if this is a problem may be:

Totally ignoring inappropriate behaviour, even though this can be very difficult.

Paying attention and providing positive regard to the kind of behaviour you enjoy and find acceptable.

Showing your partner a more acceptable way of expressing their 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 even with their partner/spouse. 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 partner or spouses GP or Rehabilitation Consultant, who may then be referred to Consultant specialising in Urology if necessary.

Your Partner or Spouses Depression/ Anxiety

Your partner may be depressed or anxious following their brain injury. This can make it very difficult for them to communicate effectively. This may be very distressing if previously you have communicated well together to sort out 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. Clinical Psychologists often work with partners and spouses individually. In some circumstances it is likely they will also want to liase with your partner or spouses GP or the Community Mental Health Team.

Your Stress/ Depression/ Anxiety

Being the partner or spouse of a person who suffered a brain injury is an extremely stressful job. After you have suffered the stress, shock and panic of the early days in hospital, you must adapt to a changed person with whom you share your life.

Your lifestyle, roles and responsibilities are also likely to have dramatically changed. You may find that you are now the main breadwinner or the main carer for your family.

You may feel stressed because you have to cope with worries about their recovery, your finances, your families wellbeing, the household and work commitments. You may feel angry or resentful towards your partner for being ill or needing care.

You may have significant physical or mental health issues yourself which compromise your ability to cope with these new demands.

In these situations it is very common for you to become stressed, or anxious, low in mood or even depressed. Physical symptoms can also be exacerbated. This can make it even more difficult to sustain a relationship in the way you would like to.

What or who can help?

If you feel like this it is essential you discuss this with either your own GP or someone on the team, maybe the Clinical Psychologist or someone with whom you feel you can easily relate to.
Fatigue

Many people who suffer a brain injury are significantly affected by fatigue for prolonged periods during their recovery. Some people will suffer the effects of fatigue for many years to come.

Mental and physical exhaustion is overwhelming and likely to leave your partner or spouse unable to consider sex for weeks or even months. This can be upsetting and frustrating for you both, and if not considered thoughtfully can have a detrimental effect on your relationship.

What or who can help?

Acknowledging these difficulties and explaining how you feel is always a positive step. For some people it may be best to discuss this only with your partner. Other people however, will find talking to friends or family and supportive professionals a huge support and a necessary outlet.

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 as it is still possible to become pregnant during this time.

What or who can help?

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

Summary

Problems associated with intimacy and sex can be difficult to talk about. However there is no reason why you and your partner cannot begin to enjoy an intimate relationship again.

Acknowledging difficulties and frustrations to yourself, and then to one another is the first step needed to re-create the intimate and sexual part of the relationship you may have lost. This can be very hard to do and extremely upsetting at first. For some people, these conversations are best kept private and “within the relationship”. 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, clients and their partners or spouses may choose any team member they 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 partner or spouses 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 leaflet.
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](http://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](mailto: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](mailto:info@Outsiders.org.uk)

Contact Details:

Cumbria Community Acquired Brain Injury Rehabilitation Team (CCABIRT)
Cedarwood, Carleton Clinic, Cumwhinton Drive, Carlisle CA1 3SX

1st Floor, Barclays House, Murley Moss Business Village, Oxenholme Road, Kendal LA9 7RL Tel: 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](mailto:communications.helpdesk@cumbria.nhs.uk)

Or write to Engagement and Communications

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