

Relationship Changes Following Traumatic Brain Injury

Information for Patients and their Families



Talis Consulting Limited

Why can a Head Injury affect Whole Families?

All of us live our lives embedded within a network of relationships. This means that a brain injury will have an influence on many more people than just the person who has been injured, A brain injury has been likened to throwing a pebble in a pool, affects of the brain injury spread outwards from the injured person.



Some might even say that it is the families who are the real victims of a head injury as they retain accurate insight into the problem and are all too aware of what things may have changed, and what challenges need to be faced.

How can a Brain Injury Affect Relationships?

In a nutshell, a brain injury affects relationships because the injured person may have changed, or the role of the injured person may have changed within the relationship or family. One of the most frequent complaints heard is that living with the injured person is like *'living with a stranger'*.

These changes within a person can be brought about through problems with social skills (such as saying inappropriate things, or no longer noticing when others are upset or angry), emotional regulation (such as being more irritable, or having sexual problems) or an altered personality.

Cognitive changes associated with a brain injury can also affect relationships. It can place strain on families if an injured person cannot remember time spent together, or if they find it difficult to learn new things. Brain injury can also make it difficult for someone to express their thoughts and feelings and so communication within a relationship may suffer.

The role of the injured person within the family may change because adjustments have to be made on the demands placed upon the injured person. It may now be difficult for the person to deal with the household chores they did before. However often the most dramatic change is that a spouse or other family member must take on a new role of caregiver, and it can be very difficult to come to terms with the loss of an equal adult partnership.



Problems can also be worsened by the fact that no family is ever prepared for a brain injury. Stresses such as looking after children, or financial troubles, which operate alongside the head injury can also impact on relationships.

However it is always important to remember that there are many stages which must be worked through during recovery from a brain injury, and improvements can almost always be made.

How does a Brain Injury Affect the Spouse or Family?

The brain injury of a loved one is a significant life event, and unfortunately has a huge impact on those close to the injured person. It is common for families to complain of changes to the injured person's personality, behaviour or emotions. However the effects on close family members or partners are often overlooked.



There is considerable stress placed upon close family members or partners and there may be elevated levels of depression or anxiety following the brain injury. These problems may not be immediately evident and they often appear some time after the initial injury. A major problem is that even while the injured person may be relatively stable, the burden of prolonged care-giving can have an increasingly detrimental effect. This means that it is very important that professional help is sought when problems arise, to help to address the situation.

There can be additional problems with feelings of guilt from the caregivers. They may feel like they should be doing more, or they may feel guilty when they find themselves reacting negatively to the behaviour of the injured person. It is important to remember that no-one is perfect and to accept that guilt is widely experienced by many in similar situations.

If the injured person has children, then they too are affected by the brain injury. Younger children may have problems understanding what has happened to their parent, or understanding why their parent is now more irritable and impatient with them. The problems of older children often involve the sudden necessity for them to take increased responsibilities for the family. Grown up children have problems with dividing attention between the needs of their injured parent and their own relationships, especially if they too have children of their own.

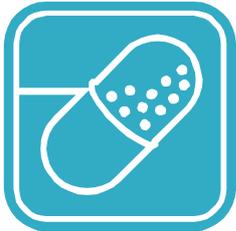
The problems caused by brain injury will reach out even to the extended family. Unfortunately there may be conflicts between family members over what is the most appropriate course of care for the injured person. This can be particularly distressing for unmarried partners of the injured person, who may feel like the family is excluding them from decisions which need to be made concerning the care of the injured person.

The very fact that we all have so many relationships with other people makes dealing with the injury a thorny and unpredictable issue. Some of these problems can be overcome through involving the whole family in the rehabilitation process and making sure that help is sought if it is needed.



What Sexual Problems can Arise Following a Brain Injury?

Sexual problems can be common following a brain injury, and the most common reported problem is a lack of interest in sex. This can arise from direct damage to the brain areas responsible for sexual regulation. However it is more usually due to psychological problems (such as a loss of confidence) or due to medication the person may be taking (or may be a combination of both factors).



Direct physical sexual dysfunction is not usually that common. For example it is estimated that over a quarter of cases of erectile dysfunction are a result of medication the injured person is taking (however it is vital you do not stop taking your medication if you think it is causing you sexual problems - consult your doctor if you are worried and they will be able to help you).

Often sexual problems are psychological and emotional in nature. They may be caused by a lack of confidence following the injury, or people may worry that others will no longer find them attractive. However one of the advantages of sexual dysfunction being psychological in nature is that it is comparatively easier to overcome, although it may still require professional help to achieve this.

Sexual problems can also arise following cognitive deficits. For example memory is often affected following brain injury and this can sometimes lead to the injured person forgetting when they last had sex, causing them to request it at inappropriate times. There can be problems with fine motor control or a tremor following a brain injury which can make sex difficult.

Some people find that they feel a lack of motivation following a brain injury. This need not be linked directly to sexual behaviour, for example neglecting to shower or bathe may be issues which are just as important.

Finally there may be problems with disinhibition following a brain injury. The injured person may display inappropriately open sexual behaviour, or may make sexual comments. It is important to remember that these behaviours are not meant to be hurtful, they occur because a brain injury can disrupt complex control and regulation procedures which operate on our behaviour and which we often take for granted.

Many sexual problems can be overcome through honest and open communication between partners. If this is difficult then this communication may also need to be with an appropriate professional. However when the overall relationship is improved this will often improve sexual problems, and tips on improving the overall relationship are given at the end of this booklet.



Domestic Violence and Brain Injury



Unfortunately behavioural control mechanisms can be damaged during brain injury, and this can cause some people to become short-tempered, aggressive and violent following their injury. If this is the case it is important that such behaviour is not ignored. violent behaviour requires constructive feedback to prevent it from becoming the usual reaction to a difficult situation.

It can be highly aggravating to see that the injured person is polite and appropriate with strangers, but abusive and aggressive at home. It is far more difficult to accept the abusive behaviour when it is clear the person can act appropriately if they are required to. However it is important to realise that this behaviour is not anyone's fault. We all tend to behave differently when with close friends or family than with strangers, and increased emotional behaviour is a facet of this process. Following a brain injury it is increasingly difficult for the injured person to recognise what is appropriate behaviour and what is not.

A brain injury can also lower tolerances to stress and anxiety. This means that the injured person can no longer deal with stress or frustration in the same way that they used to, and so therefore are using aggression and violence as a coping mechanism. The injured person often has little insight into how their behaviour will affect others.

What Can be Done to Help? - Seek Professional Help.

Do not allow the pattern of abuse to become established in your home. The injured person must try and relearn communication skills and anger management. Helping to relax will help this process, so take time out to do things which you enjoy.

However sometimes the injured person lacks the self awareness to consciously control their behaviour. In these situations try and look for triggers which can set off aggressive behaviours, and then see if these triggers can be avoided or minimised.

It is also important to treat each aggressive outburst as an isolated incident. The person may not remember that they were aggressive a short while ago.

Make sure that all the family treats aggressive behaviour consistently, so that the injured person knows the behaviour is universally unacceptable.

If professional help is not enough you may wish to consider not spending time alone with the person or arranging separate accommodation for you and the injured person. There are agencies which can help you to do this.

How can Relationships be Improved Following a Brain Injury?

The following ideas are some general tips on how you can improve your relationship. These ideas will not work for everyone, so it is important that you take the ones which will work for you and tailor them to your individual situation.

Keep the lines of communication open

It is very difficult for changes to be made in your relationship if your partner is unaware of what your problems are. Communicate together openly and honestly about what needs to change. If this on its own is not sufficient then professional help may be required to communicate effectively.



Don't fight against changes to your relationship

There will be changes to your relationship and therefore it is important that you accept them as much as possible. This doesn't mean that you can't grieve your losses, in fact it is healthy to do so. However try to realise that some aspects of your relationship will now be different.



Remember that you're not a patient and carer

Make sure that you take time to connect not just as a patient and carer. Find situations where the injured person is not the centre of attention and enjoy these times. You may wish to take up new activities or indulge in old ones you used to enjoy. The more fun you manage to have together the better things will seem.

Stay as independent as possible

One of the most common difficulties is that the family must act as caregiver, while the injured person resents their loss of autonomy. Therefore try and remain as independent as possible and work at retaining an independent social life.

Keep up levels of awareness

It can be difficult for someone to retain accurate awareness of how their behaviours affect others following a brain injury. Therefore it is important that the injured person listens to feedback from others. It may be a good idea for the injured person to find someone they trust to give them honest feedback about how they are behaving, and to accept recommended changes.

Keep motivated

Prevent apathy from creeping in. Recognise that things need to be done to improve the situation. Write down goals, make action plans and structure your day. A health professional should be able to help you work through these coping strategies.

Take Care of the Carers, and Respite Care

It is important that anyone taking care of an injured person takes time out to look after themselves. It is common for caregivers to feel sad or discouraged from time to time, so it is important that you recognise these feelings and address them.

Include some pleasant activities in your daily schedule to lift your spirit. Also make sure you take one day at a time, stay flexible and accept the things you can't change. Make sure you take a break from situations which make you feel angry; focus your anger on the situation, not the injured person.

It is also important that you keep yourself physically and mentally healthy - if you are unwell then you can't care for someone else!

Try get some from of regular exercise. A brisk walk is an excellent way to relieve stress, as well as the additional health benefits of lower blood pressure, reduced weight and better quality sleep.

In addition to this make sure you get enough rest. If you can't get a full night's sleep then consider getting someone to help take some of your responsibilities. Lack of sleep is one of the most common reasons for entering someone into a nursing home.

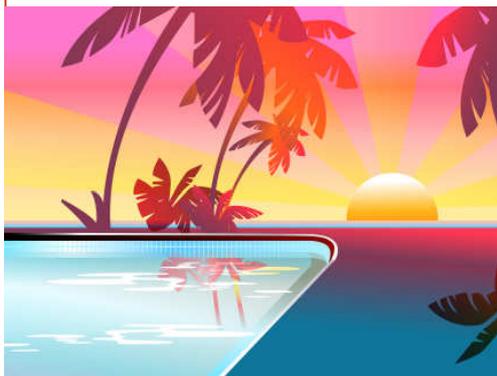
Finally, make sure you eat well. A good diet will give you more energy and help keep your immune system functioning well.



Respite Care

Respite care is an essential part of the overall support families might need. It involves someone else taking responsibility for the injured person, this might be for just a few hours a day or for longer periods, and any carer can request it. It is usually flexible and can be provided in your home or in a variety of out of home settings.

Respite care can be free for some services, others request a token fee, whilst others may be expensive. Some services will have a sliding scale which is dependent on your income.



Many people who use respite care do so regularly and they may also have a regular pattern set up for annual holidays.

Whilst respite care is vital for anyone under a stressful situation, the ideal is to organise respite care before the situation becomes more difficult. There are agencies and health professionals which can help you to organise it.

Useful Websites:

www.headway.org.uk

- A useful web site with much information about brain injury and rehabilitation in the UK.

www.birt.co.uk

- Another useful web site concerning brain injury, with downloadable leaflets about brain injury and its implications.

<http://www.birf.info/home/library/relationships/reindex.html>

- A website dedicated to the relationship problems faced after a brain injury

