Factsheet
Headwest Series

ABI, sexuality
and intimacy

Changes in sexual behaviour are a common consequence of brain injury and present many problems for professional staff, families, and friends. Brain injury, in general, can disrupt the way a person thinks and when the changes are sexual in nature, problems can get swept under the carpet instead of being dealt with openly.

We are all sexual beings but when sexual behaviours are displayed at inappropriate times and/or places there is a certain stigma attached to the person and the behaviour. It is important to remember that inappropriate sexual behaviour is just a 'behaviour' and should be viewed as such and managed as any other unwanted behaviour. If put in a separate, possibly more unpleasant category, the result is often that you may inadvertently reinforce undesirable behaviours.

Some common problems experienced by patients emerging from coma may include touching one's genitals and/or masturbating. Clearly this unconscious act should be viewed in its proper context as that of an emerging primitive behaviour. Some other very primitive behaviours common to persons awakening from coma are sucking motions, teeth grinding, tongue thrusting and yawning, yet these behaviours are often accepted by families as positive signs of awakening.

During rehabilitation and within the community setting

Later, in the rehabilitation setting, therapists often deal with unwarranted flirtatious advances, such as attempts to hug and kiss, and this behaviour often gets in the way of progress. The therapy team as well as family and friends need to be instructed in ways to redirect the unwanted advances and not allow the patient to use them for attention getting purposes.

At times young men try to kiss a therapist during a therapy session. A light hearted response such as "Oh Bill, you're such a flirt!" may reinforce the unwanted behaviour Bill should be told that he was in the gym to work on his mobility skills and his unwanted advances makes the therapist uncomfortable. Frequent reminders about the staff/patient relationship may help the individual have better control over very basic impulses when placed in close proximity to a person of the opposite sex.

Higher incidence among young males

The target population sustaining brain injuries is young men 18-24 years of age, at the peak of their sexual prowess and most will need help learning appropriate ways to manage their sexual urges. This is particularly true with injury affecting the frontal lobes of the brain.

Acting out sexually is usually the result of disinhibition which creates a variety of inappropriate behaviours with sexual overtones, i.e., confabulation, (false memory and reporting), fantasising, and lewd verbal responses, disrobing and/or masturbating in public, impulsiveness, and touching others.

Need for understanding by family

Personality traits that were condoned before the injury may be intensified by injury and it may be difficult for the patient to understand when the rules change. For example, knowing when and where to tell a dirty joke may be a problem for a person with poor judgement It is hard for the family to understand that brain damage usually affects control mechanisms that monitor the sophistication level of one's social skills. Families traditionally are less tolerant of this type of behaviour than they were pre-injury because they are more aware of the consequences of such behaviour. At the same time the individual with brain injury is less aware of subtle nuances and may have little ability to benefit from feedback and will make the same mistakes over and over again.

Children and sexuality

For many youngsters, there is a lack of awareness of their bodies and youth is a time for exploration and experimentation. Youngsters need extra guidance through this period to feel secure about exploring their changing bodies and feelings with the support of caring parents and counsellors. When inappropriate sexual behaviour is a problem other members of the family need to be safe from unwanted advances. This may require placing locks on doors to ensure siblings privacy.

There is a rare condition called, precocious puberty, that results form hormonal changes after injury to the brain. With precocious puberty, children younger than nine have a rapid progression of secondary sexual development. It is very important for treating professionals and family to be aware should this condition develop.

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and intimacy

Dealing with inappropriate behaviour

As is the case with any problems related to cognition and behaviour it is important that your family member has control over those aspects of their life for which there is a reasonable expectation for responsible behaviour. When behaviour is not responsible or inappropriate, steps need to be taken to learn better ways for managing or compensating for the lapses in social skills.

A prerequisite for any discussion about sexuality requires that the family be comfortable with the subject. Some suggested ways for achieving appropriate sexual attitudes in home settings are:

- All members of the family becoming aware of and implementing behavioural modification techniques to ensure consistency in managing all behaviours.
- Frank discussions about sexual issues.
- Assuring the individual that sexual feelings are appropriate and supporting the client's choice to masturbate use alternate methods to release sexual feelings (in private) may be way to exercise/ release those feelings.
- With masturbation it is important to establish ground rules to protect the rights and privacy of others, eg, when, where, and how (what a person does behind closed doors in private is acceptable). Efforts for clients to share information with other family members must be respectful and for purposes of information, not for boastful attention seeking behaviour.
- Public displays of the crudest forms of sexuality are not permitted, and touching others without permission is unacceptable and can lead to problems with the legal system.

Further information from Headwest

Staff also need to be more aware of working with a person with diminished insight. How they act and react around the patient is important to establishing boundaries, providing ongoing feedback and successfully managing the working relationship to minimise inappropriate behaviours.

A support worker or registered nurse may be working in close proximity to the person, changing colostomy bags etc. and performing personal care tasks such as washing the genital area. It is quite normal (but does not occur in every instance) for a young person who has not been able to express normal sexual desires for many months in hospital and who has experienced frontal lobe damage, to misinterpret this situation. How then can the worker respond to this situation?

The therapist/support worker may need to explain the **task** and its **purpose** before attempting it.

This may need to be explained as part of a routine care plan, as a person's short term memory may be significantly compromised, and while they may be able to immediately indicate they have understood, they may forget a week, or a day or even minutes later.

If the client attempts to touch a worker inappropriately, immediate, respectful feedback using a clear, calm voice stating specifically what has to stop and what has to happen should occur every time. E.G. "Please remove your hand from my thigh. Put your hand on my shoulder for the lift, right now".

If the patient will not desist, you need to state that you will be halting the lift (other activity) for 10 minutes (or other suitable short time frame) then you will be back to discuss how we can work appropriately together. (Note the inclusive language as a tool to promote that you are all part of the same team).

If the behaviour persists, a policy response needs to be developed reflecting best practice service models; in consultation with staff and the client and family (where possible). It is no good slavishly copying another service provider's policy, as each provider has unique features, though reading other service providers working models often helps organisations avoid mistakes and consider practicalities they may otherwise inadvertently miss.

ABI, sexuality
and intimacy

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Further information continued

Be mindful that not all attempts to touch are sexual. Close friends, for example, may not know how to act with a person with an acquired brain injury. If the relationship was naturally quite demonstrative before the brain injury and there are no concerns about hurting the person, the close friend can often pat their disinhibited person between the elbow and the arm or on the back then step back. Research shows this area can be perceived as non- sexual for many people (before Acquired Brain Injury).

This can work when the level of disinhibition means the person has lost unwritten social rules such as how long to hold someone, and for example, they draw them too close to their body and won't let go. However, in this instance, the family member needs to understand the loss of social rules is typically due to frontal lobe damage.

They may often also need support, counselling and time to adjust before they can reasonably be expected to cope with sometimes confronting and considerable behavioural changes. Family may be reassured that a certain level of discomfort is normal, as most of us do not have to give feedback to people about close friends and family about how close to stand next to us, when to show emotion, when to talk freely and when to be more discrete about sexual feelings.

However, some people with serious acquired brain injuries may react as if **most** physical contact is sexual and will **need boundaries** for most close contact situations. Workers should never feel manipulated to 'move their hand a little closer' or put up with inappropriate contact.

It is important, however, to remember that everyone with an acquired brain injury is different. Some people may tell crude jokes, but never progress to inappropriately touch someone.

Remember, simple human touch is still a basic human need. Explaining that the disinhibition is part of the brain injury and providing practical tips on how to cope can go a long way to maintaining supportive family, social and community relationships. Do not assume that while loved ones were in the hospital the family received and understood any information or training on dealing with sexual inhibitions. It is more likely they were in a haze of shock and disbelief and were focussed on whether the person would be surviving their acquired brain injury at all. Please consider referring clients and family members to Headwest for sensitive listening and experienced understanding of these issues.

The duty of care and rights of other clients and staff in nursing home environments to feel 'safe' need to be respected. The client may have a need to talk about sexual feelings; this is not a licence for the client being able to give a step by step description of his/ her most sexually intimate moments to anybody, anywhere and in any situation.

A trained counsellor may be engaged to work with the client and should still be providing feedback about socially acceptable rules regarding 'time and place' disclosure of sexual information as a way of protecting the client's positive ongoing social interactions.

Some untrained therapists mistakenly allow all inappropriate expression; this does not allow the client to connect with the society they live in and may actually be a greater infringement of their human rights in the long term as the person is subsequently further alienated from their social connections by their inappropriate behaviours leading to relationship breakdown.

Insufficiently trained workers can interpret human rights separate from health and safety, duty of care rights and legal and community standards across a range of challenging behaviours including impulsivity, sexuality, alcohol consumption and aggression. On the other hand, draconian measures can be taken by some workers and service providers who fail to consider person- centred care that considers the individual's needs and wishes. It is important that simplistic interpretations of person- centred care and least restrictive policies do **not** ignore health and safety, duty of care rights and legal and community standards including social- awareness training.

ABI, sexuality
and intimacy

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Further information continued

Rather, the trained therapist provides a safe environment where the client can potentially re-learn appropriate sexual and intimate behaviours for a variety of situations. They are able to make mistakes without the fallout of fatally damaged relationships. This does not mean that all opportunities for sexual expression and human rights for the client should be suppressed; just that they need to be expressed in private.

Ultimately, a coordinated approach to staff training, a genuine person centred approach to meeting client needs; ongoing and timely monitoring and feedback of client behaviours needs to be linked to service and policy development including overarching code of conduct policies reflective of personal, family and community standards and legislative requirements.

Please consider referring clients and their families for ongoing support to Headwest, the Brain Injury Association of WA.

Staff may also benefit from general training in Acquired Brain Injury from Headwest. For more information please visit our website at www.headwest.asn.au or phone Headwest at 9330 6370.

Please remember you are not alone.

Headwest's trained and compassionate advocates understand what clients, their Carers and family are facing. Let us help you to gain access to the best services for you following an Acquired Brain Injury (ABI).

Our service is free and confidential

Freecall: 1800 626 370

Email: admin@headwest.asn.au
Web: www.headwest.asn.au