

### Workshop outline

#### Aim

This workshop aims to increase awareness of the impact of traumatic brain injury (TBI) on people's sexuality, and increase participants' awareness of their own attitudes towards sexuality. It also aims to teach strategies to enhance the sexual lives of people with TBI, and to manage sexually inappropriate behaviour.

#### Outcomes

At the end of this session, you should be able to:

#### Awareness

- define sexuality
- identify sexuality issues for people with TBI, and how these issues affect their family members and workers in the field
- clarify personal and professional values on sexuality

#### Sexual rights and treatment strategies

• recognise the sexual rights and needs of clients with TBI

#### Talk about sexuality and treatment options

- recognise verbal and non-verbal components of communication about sexuality
- identify clients' special needs in verbal communication
- match verbal and non-verbal communication for clarity in dealing with clients' sexuality
- monitor non-verbal interactions with clients (eg. tone of voice) for more effective communication about sexuality
- identify strategies to address clients' sexual health concerns

#### Manage sexually inappropriate behaviour

- understand different causes of sexually inappropriate behaviour
- identify strategies for establishing professional boundaries between client and worker
- develop strategies for verbal feedback to clients about disinhibited sexual behaviour
- develop effective ways of responding to inappropriate sexual behaviour.



### **Common changes to sexuality** after TBI

#### Lower sex drive

Up to 41% of men report having a lower level of sex-drive after TBI. Only 15% report having an increased or greatly increased sex-drive (Ponsford, 2003). Up to 33% of women reported that they had a lower sex-drive after the injury.

#### **Decreased frequency**

Up to 54% of both men and women report that they had sex less often than before the injury. There are a number of reasons for this including relationship breakdown, difficulties starting new relationships, lower sex-drive.

#### **Changes in arousal**

Up to 30% of men report erectile difficulties after the injury (Kreuter et al., 1998)

Erectile difficulties vary, with some people able to achieve only partial erections, or erections in some situations but not others, and others unable to achieve erections in any situation. It is not yet known whether environmental factors (eg. performance anxiety, depression) may be the cause of these difficulties as often as the brain injury itself.

Up to 18% of women reported lower levels of vaginal lubrication after the injury (Hibbard et al., 2000)

#### **Orgasmic problems**

Up to 40% of both men and women reported decreased or no experience of orgasm post-injury (Kreuter et al., 1998)

#### Disruption to the menstrual cycle

It is common for a woman's period to stop after a brain injury. It usually starts again after four to six months.



# Primary and Secondary causes of change

#### **Primary causes**

The whole of the Central Nervous System is involved in sexual activities, from low in the spinal cord up to the most evolved part of the human brain. The brain is a sexual organ. It has been said that the brain is the ultimate sexual organ: the seat of sexual urges, thoughts, sensations, inhibitions and behaviours.

A number of reflexes including the sexual responses of erection, ejaculation, and vaginal lubrication are located in the spinal cord or brain stem. In evolutionary terms these reactions are understood to be similar to the responses of our most primitive vertebrate ancestor.

The brain also developed elaborate and complex higher cortical functions located in the midbrain, limbic system and frontal area. And thus sexuality is emotional, social and relational, about the self, values, attitudes and beliefs as well as sexual functions. And these factors can impinge on that primitive reflex response.

Therefore, brain damage can impact directly upon sexual functioning. Other components and factors of sexual functioning can also be affected that impact upon individual sexual performance and sexual functioning.

#### Secondary causes

Stress can cause problems for people's sexual functioning. Stress is a common reaction to TBI.

**Depression and anxiety** have also be found to be very common after TBI and can affect a person's sexual life.

Medication used for various conditions after TBI may also affect sexual functioning.

Chronic pain is common after TBI and pain affects people's enjoyment of sex and feelings of sexuality.

Relationship difficulties are common after TBI and impacts on the couple's sex life.

Other physical injuries apart from the TBI can also affect the person's sex life.



# Range of changes

Domain	Disability	Impact on sexuality
Physical	<ul> <li>Weakness or paralysis on one side</li> <li>Restricted movement in hands, arms or legs</li> <li>Tremor, chronic pain</li> <li>Loss of sensation to touch</li> <li>Bowel dysfunction</li> <li>Bladder dysfunction</li> <li>Fatigue</li> </ul>	<ul> <li>Difficulty in transferring to and from bed</li> <li>Clumsiness in love making</li> <li>Some movements or positions increase pain</li> <li>Body may not be aroused in response to touch</li> <li>Problems with applying contraceptives</li> <li>Fear of accidents, anxiety, embarrassment.</li> <li>Inhibits sexual desire and increases feeling of vulnerability and anxiety.</li> <li>Fatigue interferes with the sexual desire and the physical ability to initiate and sustain sexual activity</li> </ul>
Cognitive	<ul> <li>Memory problems, reduced concentration</li> </ul>	<ul> <li>Person with brain injury forgets having sex</li> <li>Person with brain injury gets distracted during sex</li> <li>Forgets about contraception</li> </ul>
Psychosocial	<ul> <li>Sexual disinhibition, lack of initiation</li> </ul>	<ul> <li>Complaints made about person's sexual disinhibition</li> <li>Non-injured partner upset having to always initiate sex</li> </ul>
Psychological	<ul> <li>Depression, increased anxiety, fatigue, loss of confidence, poor self image</li> </ul>	<ul> <li>Person with brain injury looses interest in sex or too tense to enjoy sex</li> <li>Non-injured partner feels frustrated or rejected</li> <li>Thinking that an appliance interferes with participation in sexual ability (eg. catheter)</li> </ul>
Sexual problems	<ul> <li>Reduced sex drive, increased sex drive, problems with erections, ejaculation problems, vaginal dryness, orgasm problems</li> </ul>	<ul> <li>Cannot enjoy sex as before the injury</li> <li>Frequency of sex reduces or stop having sex</li> <li>Become concerned about capacity to have children</li> <li>Makes sex unpleasant</li> <li>Too embarrassed to ask for help</li> </ul>
Social	<ul> <li>Social isolation, relationship breakdown</li> <li>Partner may feel burdened with responsibility as carer</li> <li>Dependency, institutionalisation</li> </ul>	<ul> <li>Feel lonely, have trouble meeting people</li> <li>End up visiting a sex worker to have sex</li> <li>Lack of desire by lover related to difficulty separating carer role from that of partner</li> <li>Lack of privacy</li> </ul>

# Sexual rights and responsibilities

People with a disability are entitled to the same rights as are enjoyed by every other citizen. It is the responsibility of service providers to enforce and protect these rights.

People have the right to:

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- have their sexual needs and preferences accepted and treated with respect
- privacy and confidentiality in all aspects of their lives including their personal relationships
- a sexual relationship with another person if both are over the age of consent
- stop having sex with someone at any time
- get the following information in ways that they can understand:
  - social relationships and communication skills
  - sexual matters including contraception, masturbation, sexual hygene, pregnancy and prevention of sexually transmitted diseases
  - social and legal responsibilities regarding sexual relationships
  - ways of avoiding exploitation and abuse
- marry or live with a partner of their choice and have children.

Principles of sexual responsibility

- Do not sexually harass another person
- Never pressure someone to have sex
- Respect your partner and their feelings
- Share responsibility for contraception with your partner
- Share with your partner the responsibility for maintaining yours and their sexual health
- Activities involving self-pleasuring should be conducted in private.
- If you are having sex, the following should apply:
  - sex should be for mutual pleasure, never used for punishment
  - never hurt someone you are having sex with
  - stop having sex with someone if they say 'stop'.

Taken from You and Me: An education program about sex and sexuality after traumatic brain injury (1999).



## Sexual needs and rights

People with TBI have the same relationship and sexual rights and responsibilities as everyone else. Isolation and myths about the sexuality, or lack of it, of people with disabilities have deprived many people of information, skills or opportunities and made it difficult for them to exercise their rights and responsibilities in sexual functioning.

Workers in this field need clear information about sexuality as well as practice in talking about sexuality, so that they can be good allies to people with TBI. Being a good ally means working with their clients to support and maintain their human and sexual rights. It also means helping to break down myths and misinformation that people in the community may still believe about the sexuality of people with TBI.

Adapted from *Double Taboo: Sexuality and Disability* produced by the Family Planning Association of NSW, 1990.

#### Common myths are that:

- people who have a cognitive or physical disability are asexual they can't do it and they don't want it
- people who become disabled are no longer attractive to their partners
- sex is physically painful for people who have disabilities
- having to plan new positions and strategies for having sex destroys intimacy
- allowing people with cognitive disabilities access to sexual information or activity will lead to uncontrolled and inappropriate sexual behaviour
- there are no avenues for sexual expression available to people with disabilities
- people with cognitive disabilities cannot learn appropriate sexual and relationship behaviour
- they are best protected from exposure to any experience that might have a sexual aspect
- people who have severe disabilities are so unattractive to others that there is no need to protect them against sexual exploitation nor to teach them self-protective behaviours.



#### Countering the myths

- People with TBI or other disabilities have the same range of needs for relationships and sexual expression as others in the community.
- People who acquire a disability may still be sexually attractive to their partners; although changes in roles in their relationship may affect the level of sexual desire, for example where one person becomes the carer for the other.
- There is no evidence to suggest that sex is more painful for people who have a disability. Experimenting with new positions for sexual intercourse can reduce discomfort where there is a physical disability.
- Having to plan position and timing may reduce spontaneity, but sex remains an important physical expression of intimacy even without previous levels of spontaneity.
- Access to information, skills acquisition and appropriate psycho-sexual opportunities are safeguards for both people who have had head injuries and the community. Even family members who are strongly opposed to sexual information being given, may see the sense in ensuring that their relative with a TBI has enough information to be safe from sexual exploitation.
- There are opportunities for sexual expression for almost everyone. These may include masturbation, erotic literature and videos, fantasy, long-term sexual relationships and visits to sex workers.
- Most people with cognitive disabilities can learn appropriate sexual behaviour. The content and method of teaching information needs to be tailored to fit their needs and best means of learning new information.
- All people are sexual beings. Protecting people with TBI from exposure to sexual experiences will not stop them from having sexual feelings; it will only limit their understanding and experience.
- Sexual abuse or exploitation occurs because of a power imbalance between individuals, not because of physical attractiveness in a stereotypical sense. Thus everyone needs to have some self-protective behaviours, as well as living with defined rules that limit the opportunities for others to exploit them sexually.



#### **Responding to individual needs**

People with TBI are as varied in their sexual knowledge and experience as are the rest of the community. Some will have sound knowledge and broad experience from before the injury that helps them deal with post-injury sexual issues. Their confidence in their ability to have sexual relationships is likely to be affected if they have lost some social sensitivity, or have developed sexual dyscontrol as part of a general pattern of disinhibition, or have suffered loss of self-esteem and changed body image. In these circumstances they will need help to deal with their losses.

Other individuals will have had very little information and less experience before their head injury. If they are still young, they will need to be given appropriate sex education in accordance with their family's values, as well as follow-up opportunities to develop psychosocial and sexual skills.

All people, including those with TBI, are entitled to have basic needs in human relationships and sexuality met.

#### 1. Development of self-awareness and self-esteem

- Sense of oneself as a unique individual, who is an acceptable person, after a head injury. Development of personal beliefs and values.
- Awareness of own feelings and an understanding that everyone has them (anger, love, embarrassment, hate, confusion, loneliness, guilt, fear, etc.)
- Being able to express feelings in acceptable ways and to change them if required.

#### 2. Body awareness

- Development of a positive body image after a head injury.
- Sense of ownership of, right to, or control over, one's body.
- Information about how the body works, including sexual and reproductive parts.

#### 3. Awareness of others

- Awareness of others, including their difference and sameness to us.
- Awareness of the way we affect others via our actions and feelings, and development of responsibility for our own actions.

#### 4. Relationships

- Understanding of what relationships are, different kinds of relationships, different kinds of behaviour involved in them.
- Understanding of, and skills involved in, making and maintaining relationships.



#### 5. Awareness of social custom/rules/values

- What is considered acceptable behaviour in the general community, and variations in relation to particular communities where appropriate.
- Specific awareness of appropriate physical touching in relationships and of one's own body.
- Discussion about different values people hold, particularly in areas of sexual morality.

#### 6. Self assertion

- Developing confidence in interacting with others and asserting one's own views and needs. This results in:
  - less vulnerability to exploitation
  - less compliance
  - greater responsibility for self
  - problem-solving and negotiating skills
  - understanding the consequence of one's actions.

#### 7. Awareness of self as a sexual being

- Understanding that sexuality is a normal and healthy part of life and that we have choices about its expression.
- Understanding the differences between love and sexual desire (they are not the same thing) and appropriate ways of expressing them.
- Accurate, non-judgemental information about sex, including possible consequences, such as pregnancy and sexually transmitted diseases including HIV.
- Issues of rights and responsibilities and issues connected to sex and different kinds of relationships.

Adapted from *Sexuality: Rights and Choices* produced by Philomena Horsley and Sylvia Azzopardi for the Family Planning Association of Victoria, 1990



### **Our responses**

It is normal to feel emotional discomfort in response to socially and sexually inappropriate behaviour. Our own memories of experiences with sexual connotations colour how we respond to similar encounters with other people, including people who have had head injuries.

Have there been situations where you have felt uncomfortable?

Ways of dealing with our feelings include:

- talking about what has happened and how we feel to other workers or a supervisor
- giving ourselves permission to feel what we feel, i.e. saying to ourselves, "I feel quite shaky after what happened," rather than saying, "I shouldn't feel this way, he/she can't help behaving like that" or "I'm a professional, I shouldn't get upset"
- remembering that feelings do not have to be acted out, eg. we can feel angry but may decide not to show the anger to the client if the anger would be unhelpful
- remembering not to take it personally
- saying something to reassure ourselves, eg. "It's over now"
- using a quick relaxation procedure to help ourselves calm down, so that one upsetting event does not contaminate the whole day. A few slow, deep breaths are useful for calming down quickly.



### **Interviewing about sexuality**

- Have you noticed any changes in your sexuality since the brain injury?
- Is sexuality an important issue for you at this time?
- If you are not having sex, do you think ...
  - erotic magazines
  - sex videos
  - sex workers
  - masturbation
  - phone sex lines
  - ... will help to meet your sexual needs?
- If you have been sexually active with another person/other people:
  - was it good or not so good?
  - why?
  - did you take any safe sex precautions, eg. contraception?
  - did you experience erectile difficulties?
  - difficulties with ejaculation?
  - problems with orgasm?
  - was intercourse painful?
- Have you noticed a change in your sex drive?
- Do you think you are as sexually attractive as before the injury?
- What sort of rules/values do you think are important in sexual relationships?
- Where do you think sex should be placed in a relationship?
- Since the injury, have you been taken advantage of or abused sexually?
- Have you had any interactions with your family about sexuality issues?
- What issues do you think arise for staff in relation to your sexuality? Have you had any interactions with your staff about sexuality issues?



# Sexual functioning: treatment options

This handout includes information about:

- low sex-drive
- erectile difficulties
- ejaculatory problems
- sexual difficulties encountered by women
- sexuality and physical disabilities
- masturbation
- sexuality and incontinence

#### Low sex-drive

No treatments for low sex-drive after TBI have been documented or researched. Some of the following strategies can be helpful.

#### **Stimulate interest**

Practice – if things have changed sexually, it may take some practise to improve the quality of lovemaking and rekindle an interest.

Try to make love when there are no distractions, so that the person with TBI only has to concentrate on enjoyment.

Make sure that if things in environment turn the person off, that they are dealt with and are not going to get in the way during lovemaking (eg. open drawers, partner odour, etc.).

Use erotic videos, games, or erotic magazines, to help arousal. Relaxation or caressing parts of the body that the person finds sexually stimulating can also help.

#### **Psychological factors**

If the loss of interest is due to depression or anxiety, the treatment of those problems with a counsellor or doctor may help.

#### **Medical options**

If the problem is due to hormonal abnormalities, hormone replacement may be an option.

If it is due to particular medications, discontinuation or replacement of those medications could be discussed with a doctor.

If the loss of interest is due to chronic pain, then pain control techniques may assist.



#### **Erectile difficulties**

There are a number of treatment approaches. No treatments for people with TBI have been published. The current approach has been to use existing treatment approaches.

#### See a doctor

A doctor may be able to help or refer on to an urologist for more specialised assessments.

#### Medication

If medication is the cause of the erectile difficulties, discontinuation or replacement of responsible medications may be an option.

#### Sexual counselling

Going to see a sexual counsellor. Research has suggested that even self-help strategies work more effectively with some contact with a sexual counsellor. Sexual counsellors can be found at local sexual health clinics, or by contacting ASSERT [Australian Society of Sex Educators, Researchers and Therapists] or the Family Planning Association.

#### Viagra

Viagra can be a useful option for men. Clinically, a number of men with TBI have found it helpful. However, there have been no studies at this stage testing the efficacy of Viagra for men with TBI.

#### Constriction bands and vacuum erectile devices

Vacuum or constriction devices both assist the penis to become erect.

#### **Penile injections**

Either the person themselves or their partner can inject medication into the penis before the anticipated sexual activity. Scarring of the penis may be a long-term complication of this approach.

#### **Surgical options**

Men with irreversible erectile problems may be able to access surgical options, although this is rare. For example inserting a penile prosthesis into the penis using a simple surgical procedure. This penile prosthesis helps the penis to become erect when the person wants to have sex.



#### **Ejaculatory difficulties**

There are three different ejaculation problems. 'Premature ejaculation' is ejaculation either before or very soon after starting sexual intercourse. 'Retarded ejaculation' happens when a man has to have sex for a very long time before he ejaculates, or cannot ejaculate at all. 'Retrograde ejaculation' is when the man feels he has had an orgasm, but no semen comes out of the penis, because it has passed backwards into the bladder.

#### Strategies:

#### Premature ejaculation [Coming too quickly]

Try to extend the time you can masturbate before ejaculating.

Think of non-sexual things while having sex.

Minimise thrusting, occasionally withdrawing altogether (stop/start technique). Speak to a sexual health counsellor or doctor.

#### **Retarded ejaculation**

See a doctor to make sure there are no physical causes why you can't ejaculate. If there are no physical causes, learn to ejaculate first through masturbation. You can use erotic fantasies and/ or sexually stimulating magazines to help you masturbate. A lotion applied to the penis can also enhance sensations and reduce likelihood of soreness.

#### **Retrograde ejaculation**

You need to see your doctor.

#### Self-help book

These can be bought or borrowed from a library. *Men and sex* by Bernie Zilbergeld is a useful book for men experiencing difficulties with ejaculation.

#### Sexual counselling

Sexual counsellors can be found at:

- Brain Injury Rehabilitation Unit, Liverpool Hospital
- Local sexual health clinic
- ASSERT [Australian Society of Sex Educators, Researchers and Therapists]
- Family Planning Association
- Australian Psychological Society have a list of psychologists who specialise in sexual counselling



#### Sexual difficulties encountered by women

#### Not reaching orgasm

Many women experience orgasm for the first time through masturbation. To learn more about this, see a sexual counsellor.

#### Vaginal dryness

This can be due to side-effects from medication. Check with your doctor about this. Lubricants can help with vaginal dryness and are available from the supermarket or the chemist. Look out for some of the newer water-based lubricants, that include fruit extracts and don't get as sticky as some of the old water-based lubricants (eg. K-Y jelly)

#### Painful intercourse

Painful intercourse is sometimes, but not always, related to vaginal dryness. See a doctor or a sexual health counsellor for this problem.

#### Self-help books

These can be bought or borrowed from a library. *Becoming orgasmic: A sexual and personal growth program for women* by J.R. Heiman and J. LoPiccolo (Simon Schuster Australia, Sydney, 1988) is a useful book for women with orgasmic difficulties.

#### Menstruation

Many women find that after an injury, their menstrual cycle may stop for a while (eg. 4 - 6 months) and then starts again.

Some women may need assistance in using tampons due to cognitive problems, such as impaired planning, or physical problems, such as reduced fine motor skills or range of movement of the arm. Family members or carers may need to be trained to assist the women to address this area of her self-care.



#### Sexuality and physical disability

Here are some physical impairments and strategies for managing them in relation to sexuality:

- Weakness/paralysis on one side (hemiparesis, hemiplegia)
  - lying on affected side with pillow support if not painful can allow movement of unaffected arm or hand to caress partner and vaginal entry from side
  - male alternative is lying on back, although many men do not find this as enjoyable
  - women who have difficulty spreading their legs due to tight hip muscles, may find if they bend their knees and bring their feet up close to their body that this may help
  - firm mattress or larger mattress
  - consider alternatives to sexual intercourse
  - partner may take a more active role in love making
  - see material on positioning (see 'back pain or other chronic pain', below).
- Muscle spasms
  - relaxing to try and avoid increasing spasms
  - try and ride the spasm out and incorporate it into the lovemaking
  - antispasticity medications such as Baclofen taken one hour before sexual activity can be helpful in alleviating spasms
  - positioning can help to reduce spasming.
- Incoordination, restricted range of movement in hands, arms or legs due to spasticity or contractures
  - experiment with sex positions that incorporate the contractures
  - partner is encouraged to take an active role in helping the person
  - if hands weak or uncoordinated, use a vibrator to caress partner. If have trouble grasping objects, strap to hand.
  - use sexual positions that do not require strong supporting movements by weakened muscles
- Tremor in arms or legs
  - if parts of the body tremble when movement is tried, allow partner to take more active role in love-making
  - find positions that support the part of the body affected by tremor
  - if parts of the body tremble when they are not active, then try and take a more active role in love making: trembling may decrease when you move that part of the body
  - look at whether mild restraint such as interlocking arms of partner may help control the trembling
  - check whether tremor is a side-effect of medication.



- Back pain or other chronic pain
  - think of positions that are comfortable when doing other activities this can help in finding positions for sex
  - use body positions during sex that place minimal strain on the person in pain
  - use body conservation exercises (BCE) learned for kneeling, sitting down and getting up to reduce stress on body. BCE aim to train people to move in ways that put least amount of stress on their bodies
  - avoid jarring movements or being too forceful remember that smooth, flowing, gentle movements are less painful
  - let partner know when you are in pain and what increases pain
  - take gradual approach to rebuilding sexual activity
  - are there times of the day when pain is less, more relaxed, more interested in sexual contact
  - reduce your pain prior to sexual activity if possible by a hot shower, massage or stretches
  - if sex has been used for other things (eg. reconciliation after fights) can these needs be met through other ways, to help reduce pressure on sexual performance
  - practice relaxation exercises 3 to 4 times daily to keep muscles/nervous system relaxed
  - back pain and sexual positioning try extension positions for sex; flexion positions for sex, giving people options whether greater comfort arching back, inwards or outwards.
- Changes to sensation
  - be aware of which body parts have new or reduced sensation and to what degree
  - make partner aware of the change to sensation
  - emphasise stimulation to other parts of the body where sensation is intact through experimentation, many people have found new parts of their body which can be sexually arousing (body mapping)
  - loss of sensation more vigorous stimulation of penis
  - sensory disturbance burning, tingling or pain. Sometimes symptom relief with prescription medication (Carbamazepine; phenytoin).
- Oral and communication problems
  - use non-verbal communication such as touching and gesturing
  - use of Speech Therapy to improve communication or oral motor skills
  - for people with aphasia, lack of expression of emotions and sexual communication is a potential problem, however, keep in mind, research has shown that the physically intact person with aphasia, who had relatively good auditory comprehension and non-verbal communication ability, exhibited the least problems in sexual adjustment, irrespective of expressive language ability.



#### Masturbation

#### Privacy

People need to have privacy, whether this is done by knocking before entering a person's room or by allowing set times during which a person will not be disturbed.

#### Uridome or pads

If a person is fitted with a uridome or pad at night, there may need to be some negotiation to allow for the opportunity to masturbate.

#### Non-dominant hand

If you have to use a non-dominant hand, or hand with a limited range of movement to masturbate, exercise the hand to build up co-ordination and strength.

#### **Chronic pain**

If you have chronic pain, make sure you are in a comfortable position. If energetic or rapid movements trigger pain, relax and continue the self-stimulation with gentle movements. Allow the time to stretch out – don't hurry and you will be able to achieve peaks of pleasure.

#### Vibrators/dildos

If you have difficulty grasping or holding on to objects, a vibrator can be strapped to your hand to be used for self-stimulation. Modifications can be made to dildos to enable them to be used, even if you have physical disabilities. Find out if this is possible in your situation.

#### Assistance with masturbation

If there is no way of masturbating yourself, the other possibility is to organise someone else to do it for you, for example, your partner or a sex worker.

#### Loss of sensation

If you have experienced a loss of sensation to touch that you used to find arousing, experiment to see which parts of your body still respond to touch. People with disabilities have found other sensitive areas of the body. They can learn to experience touch in those areas as sexually arousing.

#### Massage

If you are unable to touch your body in places where it is arousing [not the genital areas] organising a massage can be another option.

#### 'Cleaning up'

If a man is not able to 'clean up' the ejaculate after masturbating, then some strategy to address this issue will need to be negotiated with family or staff.



#### Sex and incontinence

#### Communication

People with incontinence problems need to communicate openly with partners about their needs and the possibility of leakage.

#### Medication

Medication can sometimes help manage incontinence by reducing spasms of the bladder and urethra. If vaginal dryness is experienced as a side effect of the medication, some water-based lubricant may be needed.

#### Intermittent catheterisation

Be catheterised before sexual activity. Keep towels handy if worried about leakage and protect the mattress. If there are only small amounts of leakage, this can be managed by a condom with a reservoir tip.

#### Suprapubic catheters

Use longer drainage tube to allow room to manoeuvre. Tape drainage tube to stomach to prevent excess pulling or pressure on catheter. Certain sex positions make it easier to keep drainage tube and collection bag out of the way. Ask doctor/nurse whether it is possible to disconnect the drainage tube and collection bag and clamp the catheter during sex.

#### **Indwelling catheters**

Sometimes possible to remove catheter occasionally for sexual activity – if this is possible make sure to empty bladder first. If there is a need to leave catheter in, the woman can bring the tube back up over the stomach. Men, once the penis is erect, can fold the tube down the penis, tape it on with non-stick tape, and place a condom over the penis. Additional lubrication may be needed to allow comfortable entry into the vagina.



# Conclusions

- People with TBI have sexual needs that should be met (see *handout 6.8: Sexual needs and rights*).
- Even when a person's sexual needs are met, they may still behave in sexually disinhibited ways.
- The level of sex drive only rarely increases after TBI more usually it remains the same or decreases.
- Problems with disinhibition are far more common than problems with increased drive ('hypersexuality').
- People can exhibit disinhibited sexual behaviour even when their sex drive has remained the same or decreased after injury.
- Sexually disinhibited behaviour is normally part of a broader pattern of disinhibited behaviour.
- Workers and family members often misunderstand sexually disinhibited behaviour as a driverelated problem (sexual frustration or increased drive).
- Sexually disinhibited behaviour will not be extinguished by the person having more access to sexual activity.
- Sexually disinhibited behaviour is best managed through the consistent use of simple behavioural techniques.



### Resources

#### Sexuality resources available in Australia

Dawson H, Hendy J, Simons M, Epps A. *Sexuality and acquired brain injury in children and adolescents: A guide for health professionals and the family.* Kids Health, New Children's Hospital, Sydney, 1999.

Simpson GK. You and Me. An education program about sex and sexuality after traumatic brain injury. (2nd ed.) Sydney: South Western Sydney Area Health Service, 2003.

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Simpson GK, Blaszczynski A, Hodgkinson A. Sexual offending as a psychosocial sequela of traumatic brain injury. *Journal of Head Trauma Rehabilitation*. 1999; 14: 1–16.

Zencius A, Wesolowski M, Burke W, Hough S. Managing hypersexual disorders in brain-injured clients. *Brain Injury.* 1990; 4:175–181.

#### Books

Griffith ER, Lemberg S. *Sexuality and the Person with a Traumatic Brain Injury*. A guide for families. FA Davis Co, Philadelphia, 1993.

#### Physical disability/catheterisation

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