FACT SHEET

BrainLink

Better Caring
Better Outcomes

Intimacy and Sexual Activity

THIS FACT SHEET discusses how intimacy, sexual activity and sexuality can be affected by chronic conditions that involve brain damage. It offers suggestions on how partners can communicate their needs, approach difficult issues and adapt their lives.

When a condition is first diagnosed, there are so many things to work through that sex is often low on the list of concerns. Eventually, the urge to return to intimacy and a sexual life is likely to be important for most people - of all ages.

Then the questions begin: Is it possible? Is it safe? Am I being selfish even considering it? Will he or she still find me attractive? Can I be a good lover? Will my erection last? Can I have an orgasm? What if I lose bladder control during sex? How can I have a sex life when I'm always tired? Will my partner continue to love me? How do I get interested in sex when I'm dealing with everything else?

Keeping channels of communication open and discovering appropriate avenues for sexual expression can have significant benefits to your overall feelings of happiness and wellbeing.

If you are having problems, do ask your doctor or condition-specific support organisation for advice or more information.

How Brain Injury Affects Sexual Activity

Many types of acquired brain injury (ABI) and neurological conditions can affect a person's sexual response directly. Some progressive conditions only affect sexual abilities as time goes on.

Stroke: A common worry for people after stroke is whether sexual activity will cause another one. The concern here is blood pressure. We all experience a sudden rise in blood pressure as excitement increases but if it is already high, this can cause problems. Check with your doctor. It also helps to make having sex more effortless - the well partner may need to take the more active part.

A partner with high blood pressure is also likely to be on tablets to control it. These may affect their ability to have intercourse. If this is a problem, talk to your doctor. There are tablets that do not have this side effect.

Motor Neurone Disease (MND): MND does not generally prevent men from having erections or women from reaching orgasm, but a person with MND gradually becomes frail from muscle wasting and weak joints. The well partner may become fearful of causing pain or damage. Adapting the positions you use to accommodate physical difficulties may help.

Parkinson's: The combination of physical and cognitive (thinking and behavioural) changes that affect people with Parkinson's over time often affects their sexual response. Some men experience impotence, anti-Parkinson's medications can have an impact and disruptive symptoms, such as tremor, can be intrusive.

Multiple Sclerosis (MS): MS may damage nerves that control sexual response. Men may have changes in sensation and experience difficulties with erections and orgasm. A number of medical procedures and medications can assist to gain an erection. All have advantages and disadvantages – discuss them with your doctor.

Women may have less vaginal lubrication, less genital sensation and difficulty reaching orgasm.

Vaginal lubricants, available from the chemist, will help with dryness.

How Chronic Conditions Affect Sexual Activity

Often it is only as chronic neurological conditions progress that difficulties arise, such as:

- Physical changes
- Cognitive changes
- Fatigue
- Incontinence
- Emotional responses
- Personality changes
- Self-esteem and self-image

Physical changes: For example, symptoms such as paralysis, weakness, spasticity, poor balance, muscle wasting or pain may require couples to adjust their positioning or types of sexual activity.

Cognitive changes: Brain damage can affect cognitive (thinking and behavioural) abilities that have an impact on a person's sex life. For example, emotional instability, which is often part of ABI, and poor communication due to speech difficulties, which is often the case with Muscular Dystrophy, can be disruptive.

People with Alzheimer's speak of forgetting to have sex or forgetting it has occurred. It may look to the unaffected partner as if the person is no longer interested. Yet a simple reminder may be all that is needed.

Fatigue: Fatigue can have a significant impact but if you know when it is most likely to occur, you can plan time together around it. Medications can also increase or decrease tiredness or change muscle function, which you may need to take into account as well.

Incontinence: The fear of bladder or bowel accidents makes some people uneasy but there are ways to minimise the likelihood: going to the toilet immediately before love-making, adopting positions that minimise the chance of reflex-emptying of the bladder (particularly with Multiple Sclerosis) and having towels and a sense of humour on hand, just in case.

Emotional responses: Depression, anxiety and stress that occur either as a result of changes in the brain or in reaction to illness can also reduce sexual desire. If depression is an issue, treatment can make a huge difference. Do talk to your doctor. Strategies for reducing stress may also help. (See Fact Sheet: *Coping with Stress*).

"If circumstances hadn't forced us to develop our sexual relationship, we might never have discovered the depth and variety of feelings and experiences that are now part of our entire life, not just our sex life."

Personality changes: When brain injury affects aspects of someone's personality, it can feel like you are living with a stranger. Occasionally, demanding or inappropriate sexual advances are an issue. This area is also discussed briefly in the Fact Sheet: *Changes in Thinking and Behaviour*, but a neuropsychologist can help with strategies that minimise difficult new behaviours. (See also Fact Sheet: *Coping with Stress*).

Self-esteem and self-image: Sexual response is also tied up with our self-image and self-esteem. Both depend on our ability to accept ourselves and to not be influenced negatively by the perceptions of others, but both are challenged when someone becomes chronically ill.

Self-image can take a battering when a person's physical appearance changes. Self-esteem can falter if the person is less physically able to engage in sexual activities. If these are serious issues for you, consider seeing a sex counsellor or joining a support group. Your doctor or condition-specific group can help with referrals.

The well partner: Well partners often experience guilt, frustration, resentment, anger, exhaustion, depression or combinations of these states. It's hard to switch from the role of carer to the role of lover.

Some carer-partners play down their own concerns for fear of seeming selfish or complaining to a loved one whose ego may already be fragile. All these elements can generate anxiety and dampen interest and pleasure in sex. (See Fact Sheet: *Coping with Stress*).

Discussing Sex

Many couples feel embarrassed talking about sex – telling each other what they like and what they

don't like. It's important to try to get past this. How can you help your partner to enjoy sex if you don't know what gives them pleasure?

Timing: Find out from your partner when he or she would be most comfortable talking. Right after an unsatisfying encounter may not be the best time for some, but right for others.

Approach: Think through what you want to say and use "I" language. Don't accuse or criticise. For example: "I'd like to spend more time kissing and cuddling before we have sex" is more helpful than, "You seem to be in a hurry without thinking about my enjoyment".

Topics to try: Different people will want to talk about different things – how often you have some type of sexual activity, what activities you can both manage and enjoy, the use of fantasy or a need for more emotional intimacy. Try to talk together about any problems you have and share your feelings and needs with each other.

Depending on your situation, you may need to discuss changing what you have done together in the past - perhaps less focus on intercourse and orgasm and more on intimacy. Touching, tenderness and gentleness, the reassurance that you are loved and needed are equally important.

Speech problems: When a person's speech is affected, showing affection physically will be even more important

for both of you. Similarly, you may need to show, rather than tell, each other what you find pleasurable.

Discussion don'ts: Try not to talk when you are angry, have had too much to drink or have too little time or privacy – it only makes matters worse.

Strategies to Improve Intimacy and Sex Life

There are no magic answers to improving your intimacy levels and sex life, but certain strategies may help.

It's important that couples do not lose their sense of physical intimacy - it can be such a wonderful way of comforting each other and expressing feelings.

Role awareness: Be aware of the role each of you plays in your relationship and how your partner's condition may change this. Be flexible and ready to shift roles. For example, which of you usually initiates sex? Would it help to change this?

Respect boundaries: We must all balance the need for closeness with the need for independence and privacy. A disability can disrupt this by throwing you together more than usual. Make sure you get time alone.

Broadening horizons: There are many ways of achieving intimacy, warmth and sexual satisfaction without intercourse or orgasm. Touching, kissing, stroking and cuddling provide the physical contact we all need and can be immensely reassuring and satisfying.

Mutual masturbation: This simply means stimulating each other to orgasm. Some couples have never done anything like this before and find the idea difficult to accept. But people of all ages find sexual satisfaction together through this method. It is never too late to learn.

For most women, rubbing or kissing the clitoris – where the folds of flesh come to a point above the opening to the vagina – is the easiest way to help them reach orgasm. Some may prefer vaginal stimulation. A holistic approach is generally best, which might include the above, music, body-kissing and massage. Every woman is different.

A man's partner can bring him to orgasm/ ejaculation by stimulating his penis. Even without a chronic illness, older men need more direct penis stimulation than younger men to become erect. Try using lubricant or saliva to make this easier.

Express sensuality: Looking good helps. Wear clothes that you both find attractive. Consider sensual triggers such as perfume, aromatherapy or massage oils. Try setting the scene with music and candles. Talk about and enjoy the sexual experiences you can have. Try not to concentrate on what you can no longer do.

Sex isn't everything: Make sure you have enough time simply to enjoy each other's company.

Counselling

If talking together about sexual issues is too difficult or it is not solving the situation, consider seeking outside help, either together or separately.

For some people, talking about their sexual relationship with a stranger can be difficult. Often however, a few sessions with a capable therapist can help you to see problems in new ways and to find workable solutions.

Seeking the advice of a counsellor or therapist does not mean you are "sick" or that you need prolonged treatment. If you feel uncertain about professional help, remember that you are doing the hiring and firing – you can stop the therapy any time you wish.

Caring for Family Members

If the person you care for is a family member or friend, be aware that they may have sexual needs that are not being met. This can apply particularly to older people, such as parents. It can be very difficult for this person to express their sexual needs to a family member. Find someone they trust who can broach this subject with them.

Contacts

To find a suitable therapist or counsellor, ask your own doctor or contact your condition-specific support organisation.