

# Sex and relationships in mnd



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20 Sex and relationships The content of this information sheet is for people diagnosed with motor neurone disease (MND) and their partners. Although much of the information may be particularly relevant for the person with the disease, certain sections are aimed at partners/carers of people with the disease. Being part of a committed relationship and sharing the love that can bring is something many of us strive to achieve. A positive relationship between two people can bring happiness and contentment. But what happens if illness or disability strikes? The dynamics in a relationship inevitably change if one partner needs to care for the other or if illness prevents one person from expressing their love as they did previously. Many people feel their sexuality is diminished by illness or disability and they no longer see themselves as desirable. This is usually only their perception of themselves and not their partner's. Many couples can find fulfilment again. They may need to find comfortable positions to enable them to fully experience sexual relations, or they may find other ways to express their love. For many, cuddling and kissing play an important part of their relationship. For others, these may have become less frequent over the years. Rekindling these ways of expressing love can help to re-establish loving bonds, boost confidence and provide security. It is important to realise that if love is present it will remain and although a relationship will be forever changed it can change for the better. A greater understanding of one another's needs may open up the excitement of experimentation and can even lead to a more fulfilling sexual relationship. This may not happen immediately, as people need time to come to terms with the diagnosis of an illness or disability. For people diagnosed with MND, the disability may have progressively worsened over time or, for some, may have happened

seemingly overnight. Everyone will have a different experience and everyone will cope in different ways. It is important to remember that you are still the same person and that someone who loves you will still see the person you were before the diagnosis. There is no reason why you should not still have an intimate relationship with your partner, you may just need to adapt and be open to new ways to express your love. This can be achieved through open communication and by talking to your partner about how you feel. How might MND affect a sexual relationship? There are many reasons why a diagnosis of MND may affect your ability to make love as you did before, these may include: - - - - - Tiredness and weakness Pain Spasticity Behavioural Changes Depression Medication Self Image The remainder of this information sheet concentrates on each of these effects in turn.

**Tiredness and weakness** The extreme tiredness you can feel with MND can mean that you do not always feel you have the strength to participate in any type of sexual activity, or that your libido is reduced. This may cause some confusion for your partner who may feel you no longer desire them. Talk about how you feel, explain that it is not because you do not want him/her but that your physical condition is preventing you. Give your partner a loving cuddle instead and tell them you still want them. 2 It could be that your physical energy levels are higher in the morning, so perhaps this could be the time for showing your partner how much you care. Maybe consider different sexual positions or practices which are physically less demanding. Just touching someone can make all the difference and make them feel that you do care. **Pain** Pain can appear in many different guises with MND. Although the disease itself is not painful, many of the associated symptoms can be. Cramp can affect any one of us and can occur at the most

inappropriate time. For people diagnosed with MND, cramp can pose a real problem. Speak to your doctor, as they may be able to prescribe muscle relaxant medication that could help to relieve this distressing problem. If you do experience any sensory pain, this can be very distressing and make being touched, especially in sensitive areas, an unpleasant experience. Again the doctor can prescribe appropriate medication which will alleviate this problem. It may also help to discuss the problem with your partner who can avoid touching the most painful areas. Simple painkillers can help to lessen pain, but if the pain is severe your GP will be able to prescribe stronger pain relief. Spending time stroking and touching one another's body can help to relax stressed and tense muscles. As the muscles relax, pain is lessened and you can respond to each other. Gentle kissing over the body combined with the warmth and nearness of your body will create a harmony of relaxed lovemaking. You do not have to achieve full penetration to reach fulfilment. There are less demanding ways to demonstrate your love or you may wish to try out different positions until you find one that is comfortable for you both. You need to be open and frank and discuss new ways to make love. Being inventive can be fun, but if you don't tell your partner what you want, he or she will never know how you want to be touched. Spasticity People with MND have varying degrees of spasticity. In love-making the main areas of concern are possibly rigidity in the back (lumbar region) and in the legs. Massaging the affected parts can help your muscles relax making you more responsive. Taking time for stroking and kissing, can help to soften stiff legs and allow them to open naturally. Bending one or both legs will also help 3 them to open gradually. Encouragement rather than expectation is needed, as forcing the issue will only cause the legs to tense further. Spasticity is very

often reduced after a warm bath or shower, the warmth eases stiff muscles and promotes relaxation. Trying out new positions can be stimulating and there are many positions which are less strenuous than the usual ones. Pillows can be used to support limbs and help to hold them in different positions. Sitting is an easy position for both partners, you can hold onto one another for support. There is no one position that will suit everyone, it really is a case of try it and see. It's always useful to remember that these changes may not be successful first time. Experiment, talk to each other about what works and doesn't work and, if possible, laugh together.

### Behavioural Changes

A number of people diagnosed with Motor Neurone Disease may also experience personality change, which can range from very small changes in behaviour to severe cognitive behavioural changes. These changes are not connected to the depression many people experience when they are first diagnosed. They are fundamental changes which occur because of the disease. Any change in personality can have an effect on a sexual relationship. It takes two people to have a fulfilling relationship and it can be very difficult to realise that the person you love is not as attentive or lacks the concentration to engage in sexual activities. Some problems can be helped. Speak to your GP or consultant if uncontrollable laughter, crying or mood swings are affecting your relationship. Medication can help people regain control of their emotions. Your partner may lose interest quite quickly if lack of concentration is the problem. Trying to minimise outside distractions may help or keep any sexual activity short, but romantic. Severe changes may be more difficult to cope with. A referral to a clinical psychologist will allow you to access help and support from services who understand behavioural changes. Losing a loving intimate relationship can

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be very difficult to come to terms with, but it is important to understand it is the disease that is causing these changes and not because your partner is no longer interested in you. 4 Depression It is understandable that anyone diagnosed with MND may become depressed after the diagnosis is given. The person concerned may withdraw into themselves, not knowing how to cope with the news themselves or how to speak about it with their partner. This will undoubtedly affect your relationship, when one partner withdraws the other can often feel un-loved and may misinterpret their partner's moods as hostility. Now more than ever you need to communicate, as depression can be helped. Try to encourage your partner to seek professional help. The GP might prescribe a short course of anti-depressants, which can help to lift the mood. This may provide the assistance needed to enable partners to talk about things and gradually resume the closeness they had before. Don't rush things, try to remain patient and encourage your partner to cuddle. The closeness of cuddling and touching can make all the difference to how a person is feeling. Depression often causes a loss of libido and if people feel less attractive, this may result in a lack of interest in sex. With time this will improve. Try to show your love and appreciation to your partner, as this will be rewarded when they begin to feel better about themselves. Medication Many medicines can have side-effects. Nausea, tiredness and fatigue are the most widely experienced. Many of these can be avoided by asking your GP or consultant to review your medication. Sometimes it might be possible to change to another one with fewer side effects. Some medications cannot be changed and may have been prescribed specifically for MND. You may need to be more aware of how the medication affects you. It could be you feel better at certain times during the day than at other times. Try to make use

of this time — if you feel like making love there is no right or wrong time, just a time when it feels right to you. If you no longer feel up to making love, explain to your partner that a cuddle is all you need. Everyone needs affection and there are many ways to show this.

5 Self Image Images of people with perfect bodies invade our daily life, which can cause feelings of inadequacy. These images can be particularly distressing if you feel that you are different. This could be because you have a disability or because you may be reliant on a feeding tube (PEG) or non invasive ventilation (NIV). Restricted mobility or the use of a PEG and/or NIV, may change your selfimage and feelings of dependency can occur. This may cause you to doubt your own sexuality. Both men and women may find it more practical to modify their clothes a little, to make dressing and undressing easier. High heels may prove a problem for those who find walking difficult. For both men and women, their role in the household hierarchy may have changed. These changes will all have an impact on sexual feelings and activity. Self image is all about confidence. It can be really hard to shake off feelings of self-doubt or loss of confidence, that being dependent on your partner or a piece of equipment may bring. You need to take time to come to terms with the reason for your lowered self esteem. Talk to your partner and explore your feelings with them. If you feel their feelings for you are not altered, it can help you to regain your confidence in your sexuality.

Practical issues If you have restricted mobility your hand and finger movements may not be as adept as they used to be. Try using sex aids or toys, as they can be easy to grip and may help to bring fun back into your relationship. If you use a ventilator or your breathing is difficult, try less active sexual positions. Semi-reclining, side lying and seated positions may help to reduce the respiratory

effort needed to participate in sexual activity. Many people find that they need to take a slower approach to lovemaking. They may need to rest, just talk to one another romantically, then try again. Love making is not all about reaching climax in a frenzied rush, it is about expressing your love for someone and that can happen in any way you choose. It is never easy to talk to people about sexual difficulties, but it remains a huge part of any relationship, so seek help to make it work for you. 6 Other organisations Talk to your GP or health professional if you have concerns about any sexual issues. It may be that you need more information on different positions, or you may require medication to help you feel more aroused. Many health care professionals may not broach the subject of sexuality or intimacy. If you are experiencing difficulties, it may be helpful to raise these concerns. If a particular health care professional is not able to help, they should be able to direct you to someone who can. The Outsiders Club For those of you who are not with a partner, but would like to find someone to share your life with there are organisations that can help. The Outsiders Club is a self-help group for people with physical and/or social disabilities. You can call their helpline with Sex and Relationship problems or join their group to find others looking for a relationship. The Outsiders 4s Leroy House, 435 Essex Road, London N1 3QP Telephone: 020 7354 8291 Email: [info@Outsiders.org.uk](mailto:info@Outsiders.org.uk) Website: [www.outsiders.org.uk](http://www.outsiders.org.uk) Or contact their Sex and Disability Helpline, 11am-7pm Weekdays: Dr. Tuppy Owens, BCM Box Lovely, London WC1N 3XX Telephone: 0707 499 3527 Email: [sexdis@Outsiders.org.uk](mailto:sexdis@Outsiders.org.uk) SHADA Sexual Health and Disability Alliance SHADA was created by the Outsiders Trust to provide a network for professionals who work with disabled people, to empower them to support disabled people in their sex and relationship

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needs. They also provide a list of information titles on this subject. SHADA  
BCM Box Lovely, London WC1N 3XX Telephone: 0707 499 3527 Email:  
Trust@Outsiders.org.uk Website: www.shada.org.uk Reference List  
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ALS: Sexual Concerns Further information If you have any questions about  
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