### Multiple sclerosis (MS) - common problems

#### Summary

- Multiple sclerosis (MS) is an incurable disease of the central nervous system that can affect the brain, spinal cord and optic nerves.
- Common symptoms include fatigue, bladder and bowel problems, sexual problems, pain, cognitive and mood changes such as depression, muscular and visual changes.
- See your doctor for investigation and diagnosis of symptoms, since some symptoms can be caused by other illnesses.

The nerves of the central nervous system are contained in sheaths made of myelin, a substance that helps nerve function. Multiple sclerosis (MS) is an incurable disease of the central nervous system that irritates the myelin and causes plaques or lesions to appear. The brain, spinal cord and optic nerves can be affected.

The disease most commonly affects young white females living in temperate (warmer) regions of the world. The cause of MS is not known, although genetic and environmental factors are involved. It is thought that a virus may be the trigger. The two major forms of MS are called ‘relapsing-remitting’ and ‘progressive’.

Symptoms of MS depend on which part of the nervous system is targeted. Common problems may include fatigue, continence problems, sexual problems, constipation, pain, cognitive (thought-related) changes, altered sensation, and muscular and visual changes.

While there is no cure, these symptoms can be eased with appropriate medications, therapies and self-help strategies. Always discuss your concerns with your doctor or specialist.

#### Genetics and MS

MS is not an inherited disease, but research suggests that genetic factors are involved. MS is far more common in people of Northern European ancestry. Ten to fifteen per cent of people with MS have a relative with the disease, but this may be a grandparent, an aunt, an uncle or a cousin. The child of a person with MS has a very small risk, around three to five per cent, of developing MS.

While genetic factors are important, they alone do not account for the development of MS. Other, yet to be determined, environmental factors are also thought to play a part.

#### Fatigue and MS

Fatigue is a side effect of nervous system damage and is one of the most common symptoms of MS. Strategies for coping with fatigue include:

- Pace yourself – be aware of your limits and try not to exceed them
- Conserve energy – make changes around the home or work environment, and to your daily schedule to avoid wasting energy. For example, put a tall chair in your kitchen so that you can sit down while cooking, carry out difficult tasks when you know you’ll be fresh, such as first thing in the morning. Ask friends and relatives to help with any physical work around the house
- Medications – some studies have found that medications used in the treatment of the sleep disorder narcolepsy are helpful in relieving MS-related fatigue. Other medications are also available. See your doctor for information and advice

Occupational therapy – an occupational therapist can advise on labour-saving devices and energy-saving skills both at home and in the workplace.
Understand the causes – ensure the fatigue is due to the MS and not secondary to other causes such as poor sleep patterns, lack of fitness or depression.

**MS and changes in relationships**

A person with MS may struggle to come to terms with their disease. They might fear for their future or suffer from low self-esteem because of the physical changes they are experiencing.

Their loved ones will also be emotionally affected, trying to deal with the diagnosis and its consequences. Stress, depression and anxiety can have a negative impact on relationships by closing the lines of communication. The natural inclination when depressed is to withdraw from others, but this is a time when open and frank discussion is vital.

The person with MS and their partner need to talk about the impact the disease is having on them and what changes might have to be made in the future. For example, the person with MS may eventually be limited to working from home, or perhaps not working at all, which could put financial strain on the relationship.

**MS and problems with sexual arousal**

MS can target virtually any part of the nervous system. It can affect the nerves of the reproductive organs, which leads to changes in sexual functioning. Slowed arousal time, reduced libido or desire, and altered orgasmic response are not uncommon experiences. Fatigue also dampens sexual desire.

Many people with MS struggle with feelings of depression. This can affect the quality of their close relationships and cause sex drive to drop. Open and honest communication is important. Professional counselling and therapy may be necessary to help the couple come to terms with the challenges of MS.

**Erectile problems and MS**

Some men with MS may experience erectile problems. This may be caused by the disease itself, side effects of certain drug therapies or psychological problems (such as depression).

Treatments can include counselling or the use of medications, which can be taken orally, injected or via mechanical devices such as vacuum pumps and penile implants.

**Impact of other MS symptoms on sexuality**

People with MS may experience a variety of symptoms that can negatively affect sexuality. Such symptoms may include fatigue, heat intolerance, spasms and spasticity, pain or changes in sensation, bladder and bowel changes, and problems with attention and concentration. Also, some medications can impact on sexuality and the sexual response.

**Fertility and family planning with MS**

MS doesn’t affect fertility. Contraception should be practiced (by either men or women) if the couple want to avoid pregnancy. Potential problems that need to be discussed when planning for a family include the partner’s disease progression and whether they will feel physically capable of dealing with the demands of a child, both in the short term and in the years to come.

Pregnancy considerations for MS

For a woman with MS, pregnancy doesn’t usually affect the long-term course of the disease. Many women with MS find their attacks are less frequent during pregnancy. This is thought to be caused by pregnancy hormones dampening the activity of the immune system. However, most women find that MS relapses (slips back) or attacks are around two to three times more common than usual in the first six months after childbirth.

Childcare assistance, either voluntary (from friends and family) or paid (babysitters and crèches), is strongly recommended. MS doesn’t influence childbirth or breastfeeding ability. However, if the woman is on an immunotherapy program, pregnancy and breastfeeding are not recommended. Some drugs can be harmful to a developing baby. Be guided by your doctor.

Bladder problems and MS

Loss of bladder control is a common problem for people with MS. Symptoms include the frequent urge to urinate, a tendency to dribble urine involuntarily and an inability to completely empty the bladder. It is important to have this symptom thoroughly investigated, because urination problems can also be caused by other illnesses (such as prostate disease) and could affect your general health.

Strategies for managing bladder problems include:

- Drink enough fluids – your kidneys need at least two litres of water each day to flush out waste products. Don’t try to manage bladder symptoms by rationing your fluid intake. This can increase the risk of infection
- Time your drinks – for example, don’t have too many drinks just before bed. Plan your fluid intake so that it is spread evenly over the course of the day
- Limit caffeine and alcohol – caffeinated or alcoholic drinks can exacerbate frequency of urination
- Special exercises – exercises such as those to strengthen the pelvic floor (the muscles that support the organs inside the pelvis) can help
- Continence aids – aids such as disposable pads are available at supermarkets and pharmacists
- Medications – can help to reduce the urge to urinate or help the bladder to empty itself.

Urinary tract infections and MS

Some people with MS are vulnerable to repeated urinary tract infections. Symptoms include frequent urination, dark-coloured and smelly urine, high temperature and pain. The risk of urinary tract infection is increased by restricting fluid intake. This is a common and dangerous way to try to cope with bladder incontinence.

Infections can be treated with antibiotics. If the problem is due to the bladder failing to empty properly, it may help to have a catheter inserted into your urethra (the tube that leads into the bladder) to empty your bladder and further reduce your risk of urinary tract infections. Catheters may be used from time to time or inserted permanently.

Constipation and MS

People with MS are more likely to suffer from constipation. Constipation is defined by hard bowel motions (stools) that are difficult or even painful to pass – it has nothing to do with how often you open your bowels. See your doctor for a proper diagnosis, since constipation can be caused by other illnesses too.

Strategies for managing constipation include:

- High-fibre diet – fibre is the indigestible parts of plant foods that pass through the gastrointestinal tract unchanged. Fibre adds bulk to stools. High-fibre foods include bran cereals, fruit and vegetables
- Drink enough fluids – stools need sufficient water if they are to be soft and easy to pass. You may be
constipated if you are deliberately limiting your fluid intake to cope with bladder incontinence. Drink at least two litres of fluid each day

- Physical activity – regular exercise helps to keep your bowels regular too
- Medical treatments – if these lifestyle changes don’t help, your doctor can offer medical treatments such as laxatives, suppositories, certain medications or enemas.

Pain and MS

Pain in MS can be primarily due to the neurological condition or may be due to secondary conditions, such as musculoskeletal problems resulting from altered posture or spasticity. Weakened leg muscles commonly trigger aches and pains in the back or knees, but people with MS may experience pain anywhere.

Strategies for managing pain include:

- Medications – such as over-the-counter pain relievers. Pain and aching brought on by muscle stiffness and cramping can also be eased with appropriate medications
- Physical therapies – including stretching exercises and massage
- Relaxation techniques – such as meditation and yoga to reduce stress levels and help you better cope with pain.

Muscle problems and MS

Muscle cramps, spasms, weakness, tremor and stiffnees are common MS symptoms. Management strategies for muscle problems include:

- Medications – prescribed to treat spasticity and tremors
- Exercises – such as stretching and flexibility exercises to ease stiffness
- Physiotherapy – including exercises tailored to the person and strategies to improve mobility
- Aids – such as walking sticks
- Physical therapies – including massage.

Psychological aspects of MS

A person with MS may struggle to come to terms with their illness and its impact on their lives and loved ones. Depression is not uncommon in MS. People with MS can also be affected by cognitive (thought-related) changes such as memory problems and difficulty with concentration. Always see your doctor for information, advice and possible referral if you are feeling depressed.

Strategies to manage cognitive changes include:

- Symptom relief – medications, physical therapies and self-help strategies to minimise the symptoms of MS and improve quality of life
- Counselling – from a professional counsellor of your choice, including psychologists and psychiatrists
- Neuropsychology assessment – to assess cognitive changes
- Self-help groups – to enable you and your family to discuss and share problems with others who are experiencing similar challenges
- Medication – including antidepressants.

Where to get help

betterhealth.vic.gov.au
Things to remember

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