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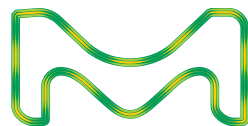
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YOUR GUIDE TO SEXUAL HEALTH AND INTIMACY

For people who are living with Multiple Sclerosis
and those who love them.

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ABOUT THE AUTHOR

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Dr Elna Rudolph has been working exclusively in the field of Sexual Medicine since 2010. She is the Clinical Head of My Sexual Health – the biggest multidisciplinary team of Sexual Health Professionals in South Africa.

She has a **Higher Diploma in Sexual Health and HIV Medicine** through the Colleges of Medicine in South Africa and obtained a **Masters in Sexual Health** through the University of Sydney, Australia. She became one of the first **Fellows of the European Committee for Sexual Medicine** – the highest attainable international qualification in Sexual Medicine.

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INTRODUCTION

Sexuality is an integral part of every person. Whether you are in touch with it or not, whether you enjoy it or not, whether you can still do it or not - you remain a sexual being. We all have the need to feel loved and give love in return. Apart from that, most people experience great joy from being close to another person - physically and emotionally.

We also all go through different stages in life when it comes to our sexuality. There is the hormonally driven and very awkward teenage-stage, the young adult stage where most people start to form long-term committed relationships, then comes babies and a few years after that, supposedly the best sex of your life just before you hit menopause as a woman, or a significant decline in your sexual

functioning as a man.

If you or your partner suffer from multiple sclerosis (MS), it has most likely interfered with one or more of these stages in your sexual journey. There are challenges and changes associated with MS, but it does not take away your sexuality or your need for love and intimacy. At some stage, you might feel that it is easier to abandon your sexuality than to deal with these changes and challenges, but that is not necessary. If individuals and couples make an effort, your sex life can be one of the most rewarding areas of your life. MS does not have to rob you of that.

For all couples, good sex is about creating special experiences, not about being able to use

hundreds of positions or reach certain goals. Excitement is important and so is having fun together and really connecting. If you are living with MS and struggling with these aspects in your sex-life, don't worry, many couples without MS also struggle with it! It takes a bit of thought and planning, but it can be done.

There are however a few challenges in the bedroom that are specific to MS. We refer to them as primary, secondary and tertiary sexual dysfunctions. Please keep in mind that MS will affect patients differently so you might experience some of these symptoms, a group of symptoms, or none at all. They are discussed in the following section and based on the Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ-19).

You and your partner can go through this booklet together and mark the challenges that apply specifically to you. Feel free to discuss these with your doctor or nursing sister at your next visit. There are also other professionals that are specifically trained in the area of sexuality that can be of great help to you as an individual and a couple. A list of therapists is provided at the end of this booklet.



PRIMARY SEXUAL DYSFUNCTION

This form of sexual dysfunction happens directly due to the effect of the MS on the nervous system.

Primary sexual dysfunction can result in the following:

- Less feeling or numbness in your genitals
- Lack of sexual interest or desire
- Less intense or pleasurable orgasms or climaxes
- Takes too long to orgasm or climax
- Inadequate vaginal wetness or lubrication (women)
- Difficulty getting or keeping a satisfactory erection (men)

SECONDARY SEXUAL DYSFUNCTION

Secondary sexual dysfunction is not directly due to the nerve damage caused by the MS, but it is due to the consequences of the MS and therefore still very closely related to the disease.

Secondary sexual dysfunction can result in the following:

- Muscle tightness or spasms in your arms, legs, or body
- Bladder or urinary symptoms
- Bowel symptoms
- Tremors or shaking in your hands or body
- Pain, burning, or discomfort in your body
- Problems moving your body the way you would like to during sexual activity
- Problems with concentration, memory, or thinking
- Exacerbation or significant worsening of your MS

TERTIARY SEXUAL DYSFUNCTION

Tertiary sexual dysfunction is the result of psychological and social challenges that arise due to the fact that you suffer from MS. The media portrays a certain image of what is "sexy" and it usually does not involve people with disabilities and diseases. This makes it difficult for the person who is living with MS and his or her partner to come to terms with the changes and challenges brought on by the MS. Reading through the comments below, might be all that you need to make peace with it, but if these challenges remain and are influencing your well-being, please see a professional to help you to deal with them. Clinical psychologists and sexologists have specific research-based techniques and exercises to help you deal with the challenges effectively. In fact, you don't even need to have MS in order to



benefit from sessions to improve your self-esteem, body images and the quality of your relationship.

Tertiary sexual dysfunction can result in the following:

- Feeling that your body is less attractive
- Feeling less masculine or feminine due to MS
- Fear of being rejected sexually because of MS
- Worries about sexually satisfying your partner
- Feeling less confident about your sexuality due to MS
- Feelings of dependency because of MS

The following sections of this booklet aim to give you information and suggestions to equip you to deal with some of the challenges you might be experiencing in your sexual journey due to your, or your partners diagnosis of MS.

1. LESS FEELING OR NUMBNESS IN YOUR GENITALS

1.1 Body Map

Take time to create a sensual environment like a bubble bath with candles where you can touch your own body to discover what feels better where. Also give your partner a chance to do this and make sure you let him or her know what feels good. Light touch might not do anything, or even be irritating, but deep touch in certain areas like the inner thighs, just below the cheeks of the buttocks or the lower back might be very sensual. Focus on these areas during love-making, not only the genitals.

1.2 Sensation Enhancing Gel:

There are various products on the market that

tingle or heat up or enhance the stimulation of the clitoris or G-spot or the head of the penis. Just be careful: if you are prone to infections, make sure you use these only externally and that you wipe it off completely afterwards.

1.3 Oral Sex:

Many people with MS report that they find oral stimulation more pleasurable than any other form of stimulation. Gels and vibrators can be used in conjunction with oral sex.

1.4 Vibrators:

You can use a vibrator to enhance sensation. This is not only for women, men can use

a small bullet-size vibrator to stimulate the clitoris or the head of the penis as well as other sensitive areas like the nipples in men and women as well as the area between the genitals and the anus or the anus itself. You might also want to use a bigger internal vibrator for better sensation or even the very popular We-vibe. The We-vibe is c-shaped with an area that stimulates a women's clitoris and the other side that pushes against a women's G-spot. What is great about this vibrator is that men also get stimulated by it, because penetration can take place with the We-vibe in the vagina. This then stimulates the man to make erection and ejaculation easier.

1.5 Suction devices:

Sometimes the sensation is improved by just facilitating the filling of the penis and clitoris with blood. Vaculect is a very good penis pump available in South Africa and there are also a

few suction devices available for women with names like Eros and the Pink Vaginal Pump.



2. LACK OF SEXUAL INTEREST OR DESIRE

This is often due to the direct effect of MS on the brain, but can also be due to many other causes like hormonal abnormalities caused by oral contraceptives, menopause or lowering testosterone in men. Many people with MS also need to take anti-depressants which can have a significant impact on your libido. Untreated depression and anxiety is a major cause of low libido in MS patients. Lack of sleep and stress in general can cause it as well.

Tips:

2.1 Exclude hormonal causes:

If you are on oral contraceptives, you might want to change to a non-hormonal method like using condoms or a copper intrauterine device (IUD). The levonorgestrel-releasing intrauterine system is a great choice for women. It lasts for 5 years and does not interfere with your libido. In some women, especially if they are post-menopausal, we also use trans-dermal testosterone cream if they suffer from a low libido and have decreased levels of testosterone in their bloodstream.

In men, testosterone levels go down with age and it happens more rapidly if there is severe stress or chronic disease. If your libido is low, ask your doctor to test your testosterone level before 10h00 in the morning. Testosterone can be replaced with injections.

2.2 Deal with the depression and effects of anti-depressants:

Medication traditionally used for depression like SSRIs or SNRIs are known to cause a loss of sexual desire in some patients. Drugs like bupropion, trazodone and agomelatine have been shown not to have sexual side-effects. Ask your doctor if it is not possible for you to rather take one of these drugs or to add these drugs to your current medication. If you think that you might be depressed or anxious and you are not being treated for it, ask your doctor for treatment. Treating depression has a very positive effect on libido.

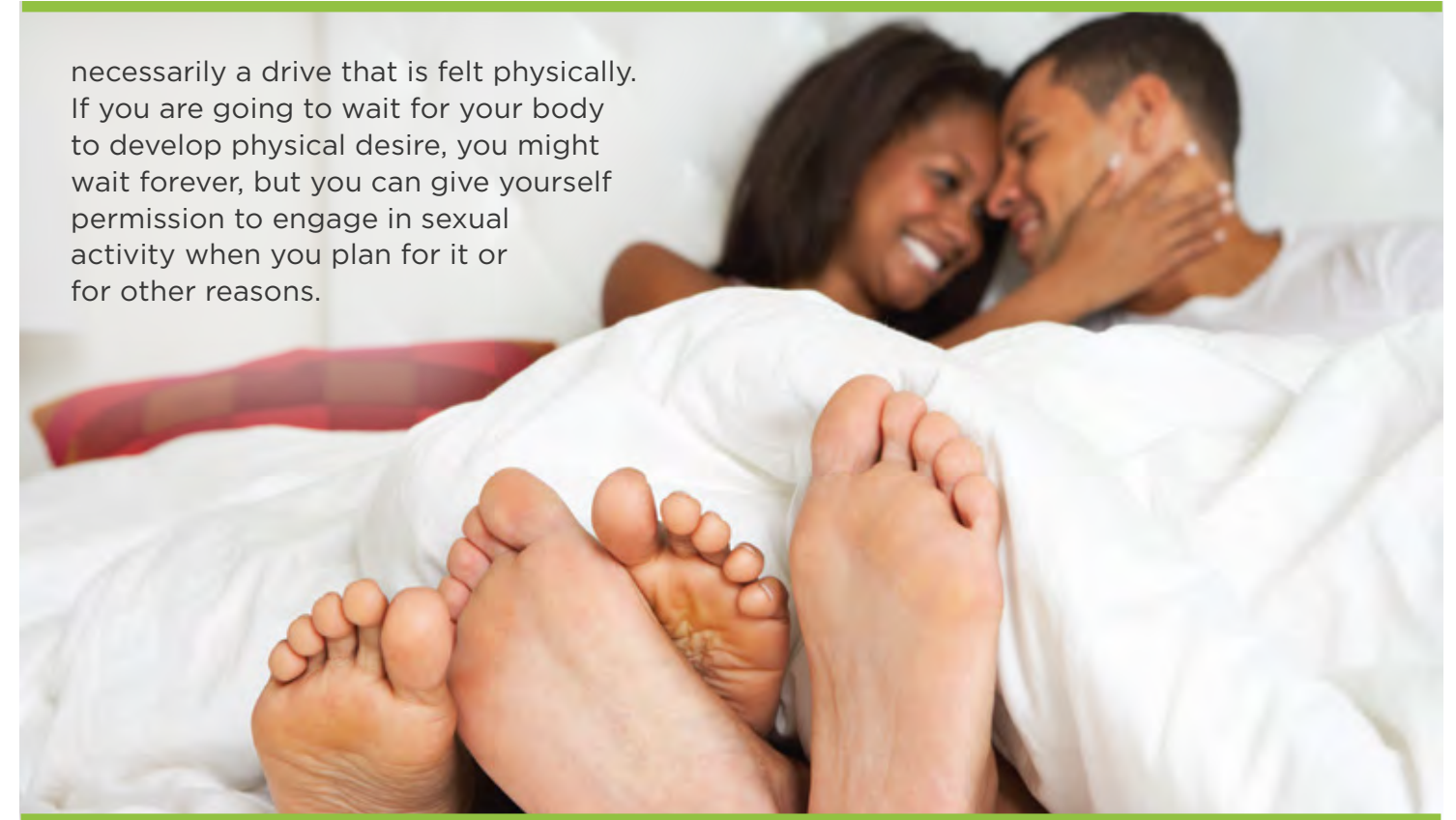
2.3 Sexual Fantasy:

Make time for sexual fantasy. Due to the effect of MS on the brain, there is also a decrease in sexual thoughts. By just making some time to think back about great sex you have had in the past and by imagining sex, you can rekindle sexual desire. You are probably not going to feel like it, so make a point of doing it when you are in the bath or shower for instance.

2.4 Rethink desire:

In the older sexual response models by Masters and Johnson and later Kaplan, desire or excitement was a prerequisite for sexual arousal. After the research of Rosemary Basson, we now know that it is not true. Sex can be initiated or consented to without any pre-existing desire, just a willingness to become receptive, knowing that sexual stimulation will result in pleasure eventually. The desire can also be for physical closeness or the intimate connection, not

necessarily a drive that is felt physically. If you are going to wait for your body to develop physical desire, you might wait forever, but you can give yourself permission to engage in sexual activity when you plan for it or for other reasons.



3. LESS INTENSE OR PLEASURABLE ORGASMS OR CLIMAXES

This is due to a combination of factors involving changes to the nerves, the muscles and most likely also biochemical changes in the brain. Remember: sex is not only about having orgasms (and an orgasm is an orgasm). It is however nice if you can have orgasms more often and have ones that are more intense.

Tips:

3.1 Create a so-called "slow burn"

Orgasm is less likely to happen if you try to go from zero to a hundred in a few minutes. You need to take your time by creating a romantic atmosphere hours before the sexual activity starts and then make sure you take it slow and utilise all your senses to get fully aroused. Focus on those other erogenous sites on your body map, not only the genitals. Create a special experience. It will make your chances of reaching an orgasm easier, but it will also make the sex more satisfying - whether you have an orgasm or not.

3.2 Do Kegel exercises or get Pelvic Function Physiotherapy

The sensation of an orgasm is partly biochemical and partly due to muscle contraction. If the muscles in the pelvic area are very weak or in spasm, it decreases the intensity of the orgasm. By strengthening the muscles, you can enhance your orgasmic ability. Kegel exercises basically feel like stopping your urine stream and then letting it start to flow again. You do longer holds and short ones on a daily basis or even a few times a day for about 10 minutes. Try to do more and more of them every week. If you are struggling with these exercises, you are not alone. Many people have no idea how to contract and relax their pelvic floor muscles, but it can be more difficult for patients who suffer from MS. You can find loads of information about Kegel exercises on the internet and if that does not help, do consider seeing a specialised pelvic function

physiotherapist to help you locate and exercise the muscles. It also helps with incontinence and painful intercourse. A list of therapists are included in the back of the booklet.

3.3 Use aids:

Vibrators and special lubricants, ointments and creams might help with the intensity of orgasm.

3.4 Use medication:

There is no registered medication to enhance orgasm, but drugs that have been used are nasal oxytocin, PDE5-inhibitors like tadalafil, sildenafil and vardenafil (even for women), bupropion and testosterone. Remember, these medicines are not registered for this specific purpose and are prescribed so-called "off-label" for patients that do not respond to other forms of therapy and only by practitioners that are comfortable to do so.

4. TAKES TOO LONG TO ORGASM OR CLIMAX

This can be a very frustrating problem for both partners. Remember: It is every person's right to have an orgasm during sex, but you do not have to feel obliged to have one. Sometimes sex can be fun or intimate enough without even having an orgasm. Don't see it as failure on your side if you don't have an orgasm or if your partner can't have one.

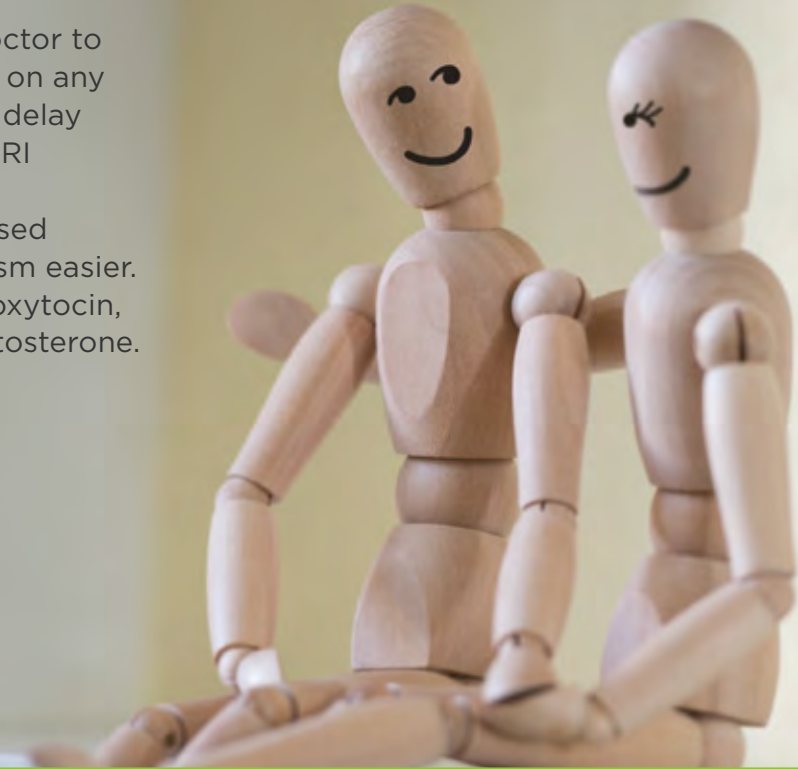
Tips:

4.1 Provide intense stimulation:

Sometimes the stimulation provided by normal intercourse is just not intense enough. Using your hands or mouth can often provide much more intense stimulation that could lead to orgasm faster. Practical advice like putting two fingers in a v-shape around the penis, during penetration or using various available sex aids can all enhance sensation during penetration. Kegel exercises and pelvic function physiotherapy might also help.

4.2 Medication:

Ask an experienced doctor to check that you are not on any medication that might delay your orgasm like an SSRI anti-depressant. Some medications are also used off-label to make orgasm easier. Those are bupropion, oxytocin, phenylephrine and testosterone.



5. INADEQUATE VAGINAL WETNESS OR LUBRICATION (WOMEN)

Vaginal lubrication is part of the body's response to good physical stimulation and good mental sexual arousal. It depends on an intact nervous system, good blood flow and a normal hormonal environment as well as really feeling in the mood. With MS the ability to lubricate decreases despite efforts to have good foreplay and mental arousal.

Having sex without adequate lubrication can cause significant pain. Having painful intercourse has a whole cascade of negative consequences from causing reflex muscle spasm and nerve irritation, to causing physical trauma, emotional trauma and a fear of sex

and eventually relationship problems. Don't allow this happen. If additional lubrication is not enough to make sex comfortable, use other forms of stimulation and get to a doctor that specialises in the management of painful intercourse.

Tips:

5.1 Use additional lubrication:

There are various products on the market: there are water based lubricants that are very affordable and good enough for many couples as well as more expensive water-based lubricants. If these are not effective, silicone

lubricants are suggested. They are more expensive but last longer and feel much more natural (you can refer to www.mysexualhealthshop.co.za for more information)

Natural substances can also be used for lubrication. Egg white and grape seed oil work particularly well. Just a bit of saliva can also be enough.

Be careful: There are many lubricants on the market that are flavoured or coloured. Those can cause irritation and even infection in some men and women. They are better used to enhance oral sex or for massaging but should rather be avoided for internal use if the woman is sensitive to irritation and gets infections easily.

5.2 Make sure the hormonal balance is correct:

Women with MS also go through menopause at some stage and vaginal dryness is a one of the major symptoms of the menopause. You can treat the vaginal dryness with systemic hormone replacement therapy (HRT) or just locally. Using systemic HRT (taking hormones orally or through your skin) is something you have to discuss with a knowledgeable doctor. It is not nearly as dangerous as was previously thought and has major advantages like prevention of osteoporosis as well as being anti-aging, protective of Alzheimer's disease and helps to maintain a good libido. All women have to be aware of their risk for breast cancer and other cancers and have to go for regular screening .

If you are not going to use systemic HRT, you can use local oestrogen for dryness. Conjugated estrogens vaginal cream is available over the counter as is applied around the

vaginal opening and into the vagina every day for 2 weeks, then every second day and most women only need to take it twice a week eventually. Estradiol vaginal tablets are convenient intra-vaginal ovules that are used according to the same dosing schedule as conjugated estrogens vaginal cream. In some women this is not enough and then creams containing not only estradiol are used (estriol is added and in some cases also DHEA). There are no commercially available products containing these hormones - they are compounded on a specialist's request.

It is not only menopause that can cause an oestrogen deficiency in women. Being on an oral contraceptive, the patch, the implant and injections can all also cause a relative oestrogen deficiency around the vaginal opening and inside the vagina. Changing to the levonorgestrel-releasing intrauterine system or

a non-hormonal form of contraception like the copper intrauterine device (IUD) or condoms usually helps. The balance can be restored by using a local oestrogen cream, but sometimes some additional testosterone is also required to correct the imbalance.

5.3 Use vaginal moisturizers:

There is a product on the market in South Africa called "Replens" that is a non-hormonal substance that is inserted into the vagina to moisten and soften the vaginal mucosa and make sex more comfortable and chances of normal lubrication higher. This is especially good for women who cannot use hormones or prefer not to do so.

6. DIFFICULTY GETTING OR KEEPING A SATISFACTORY ERECTION (MEN)

Any man stands the risk to develop erectile dysfunction (ED) but it might happen sooner in men with MS. One of the most common misconceptions is that erections develop spontaneously. It is true when you are younger, but as you age and nerve damage sets it, good physical stimulation is needed to get an erection. The definition of ED is failing to get and maintain an erection that is good enough for satisfactory intercourse.

Tips:

6.1 Non-medical treatment:

Using a device that can help the blood that flows into the penis to stay in the penis can be all that you need. A plastic ring that fits tightly around the penis can be bought. The ones that are particularly valuable are the adjustable ones that can be applied loosely onto the penis and then pulled tight when needed. It is extremely important to only use plastic rings, never metal or other forms of rigid ones. One has to be able to cut it off in case of an emergency.

A small vibrator is also often used to stimulate the penis at the site of the frenulum (the skin tag at the bottom of the head of the penis), the shaft or on the perineum (the area between the scrotum and the anus) and inside the anus. This intense stimulation might make getting and maintaining an erection easier.

A penis pump can be used with great success. It is part of first-line treatment of ED according to the international treatment guidelines. There is a very good medical grade penis pump on the market in South Africa called Vaculect. A ring is applied over the head of the penis and then the pump is applied onto the ring. The pump works by creating a vacuum through stroking movements. During the stroking, the penis gets pulled into the pump and as the vacuum develops blood gets sucked into the penis and an erection is formed. The blood cannot escape due to the tight plastic ring that now sits at the

base of the penis. The great thing about this pump is that it is extremely reliable in creating erections and not dependant on whether you feel sexually aroused or not. Even if you are tired and not really mentally in the mood but would still like to get an erection to have intercourse, it will work because it is merely mechanical.

6.2 Medical treatment:

There is a notion out there that using a product like tadalafil, sildenafil or vardenafil is bad for you. This is simply not true. These drugs are called PDE5 inhibitors. They help with the relaxation of smooth muscles in the walls of blood vessels - in the penis, but also in the rest of the body. They prevent the breakdown of nitric oxide, the chemical that causes the relaxation.

The only instance where it should not be used is

if you have angina and are using a spray or a tablet for angina called a nitrate (this drug is usually prescribed by a cardiologist for people who get intense heart cramps and need them to open the arteries of the heart). If used together, these drugs can cause a significant drop in blood pressure. Some prostate medication can also cause a drop in blood pressure if used together with a PDE5 inhibitor, but it is not as dangerous and with your doctor's consent they can usually be used together.

All three PDE5 inhibitors can be used on demand and tadalafil 5mg can also be used on a daily basis. The one drug might work better for you than the other two and the one might cause more severe side-effects or less side-effects than the other two. It is worth trying all of them until you find a product that you are happy with. In severe cases, we even combine a daily dose of tadalafil with an on-demand dose of sildenafil

or vardenafil. Vardenafil ODT works particularly well in these cases because its onset of action is within ten to fifteen minutes.

The most common side-effects are headaches and flushing of the face. It might feel like you get a blocked nose or some indigestion and some men complain of muscle pains. In general the tablets are tolerated very well.

Be careful to use over-the-counter (OTC) treatment for erectile dysfunction. OTC products are not regulated and therefore we don't have a clue what is in them. Research shows that many of them contain a PDE5 inhibitor illegally and that is why they work so well. There are natural substances like L-arginine that enhances the production of nitric oxide for instance or herbs that can have a good effect on libido. These substances can be used, but they are often not good enough.

Rather spend your money on reliable medication with known side-effect profiles and proven safety. "Natural" certainly does not necessarily mean safe. If you are taking other medication for your MS, you do not want to take something that could interfere with your medication and with herbal products we cannot be sure that there will be no interactions because it has not been researched.

If oral treatment fails, injections can be used. An experienced doctor will show you how to do it in his or her office and once you are comfortable you can do it yourself at home or your partner can help you. It is a little painful, but the needle that is used is extremely thin and once you get used to it, it works very well for most couples. If these injections are not good enough, your doctor might contact a special pharmacy to mix more than one drug for you. This should only be done by a specialist with

extensive experience in the field. Priapism, a dangerous condition where you have a prolonged erection that lasts for hours, is the major risk factor with these injections.

As an absolute last resort, surgery by a very experienced Urologist can be used to treat erectile dysfunction.

6.3 Screen for and treat metabolic syndrome:

Don't just assume that you have ED due to your MS. ED should be seen as a sign of heart disease. Please see a doctor to check your cholesterol level, your blood sugar, uric acid, testosterone, ultra sensitive CRP, blood pressure, abdominal circumference and weight. These tests all look for signs of a group of diseases called the metabolic syndrome and are associated with an increased risk for heart disease. Each of these conditions have to be diagnosed and treated effectively. This is not

only very important for your overall health but also for your sexual functioning. Don't let the MS symptoms and medication make you forget about these other very important aspects of your health.

If there is any indication, see a cardiologist to confirm that your heart is healthy. The cardiologist has special skills and equipment to determine the health of your heart.

6.4 Check for low Testosterone levels:

Decreasing levels of testosterone is part of normal ageing, but it is also strongly associated with metabolic syndrome and particularly with ED. Ask your doctor to test your testosterone level before 10h00 in the morning and discuss testosterone replacement therapy with an experienced doctor if it is lower than twelve. (Please note: the reference ranges of the lab might say that it is normal if it is above six or



eight, but sexual dysfunction and other health problems start to develop if it is below twelve.

7. MUSCLE TIGHTNESS OR SPASMS IN MY ARMS, LEGS, OR BODY

Spasm and tightness cause physical pain, difficulty in moving and contribute to fatigue due to high energy consumption. It is important that you and your partner understand that spasticity is velocity dependent - the faster you try to move a stiff muscle or joint, the stiffer it will become. This means applying your mind a bit during sex to avoid reflex spasm and to stop the spasms from getting in the way of enjoying yourself.

Tips:

7.1 Use the right positions:

Make sure you use a position that is comfortable for the partner with MS. It will most likely not be possible to change positions frequently, like you might have done before the MS. The symptoms of MS can also vary and therefore, what is comfortable the one day might be very uncomfortable the next day. Communicate about this and make sure that you take enough time to make sure that both are comfortable. An extra pillow here and there might go a long way in making you more comfortable. You might also want to buy a book that explains

with different sex positions just to give you a few ideas about the possibilities. Rear entry with the partner lying on her side might not have been something you tried before, but you might find that this might be the most comfortable position to make love in.

Do not put the focus on having an orgasm during penetration if spasticity makes it too difficult. Give and receive orgasm in the way that is most comfortable for both of you and use the penetration part of sex for intimacy only if necessary.

7.2 Physiotherapy:

Physiotherapy can go a long way in improving the quality of life of people living with MS. A specific stretching program can be designed specifically for your needs and can be changed as time goes on. A pelvic function physiotherapist can also assist with the

spasticity inside your pelvis to make penetration easier and sex less painful in females. In males the spasticity can also lead to painful orgasms and ejaculation and the physiotherapy can help with that.

7.3 Use the right medication to treat the spasms:

Your neurologist will be able to prescribe a medication to help you deal with the muscle spasms. Most of these medications are used off-label again and many of them cause sedation. They are ideal to be taken before bedtime but might not be ideal to be taken before sex if you find them too sedating. Most of these medications can also influence your ability to reach an orgasm and therefore you might want to avoid them before sex.

Drugs like baclofen, gabapentin, carbamazepine, ropinirole and even clonazepam you get used to and therefore they can often be taken before sex. A drug like diazepam is too sedating and will probably not work before sex, but every person must take the time to figure at what drug at what dose and what time works best for them. On your doctor's request, diazepam can be prepared as a vaginal cream by a compounding pharmacy and that can help a lot with muscle spasm in the pelvis.



8. BLADDER OR URINARY SYMPTOMS

The nerve damage that results in bladder problems happen in most people living with MS. The bladder can become spastic and struggle to hold normal amounts of urine; the bladder cannot empty properly and retains some urine in it leading to repeated infections and kidney damage or the communication to the sphincter of the bladder can be damaged resulting in difficulty in holding in your urine or to start urinating.

If you are worried that you might pass urine during sex or if you have significant discomfort over your bladder during sex, you are likely to avoid it all together. It is important to manage these symptoms optimally to give you confidence during sexual activity.

Tips:

8.1 Good bladder management:

General bladder tips are to keep your urine light yellow, limit caffeine and alcohol intake and plan to urinate every two hours while awake. Pelvic floor exercises and physiotherapy can also be very helpful as is wearing a sanitary pad to give you more confidence.

For storage dysfunctions (having to go too often) medications with brand names in South Africa like darifenacin, solifenacin succinate, oxybutynin and imipramine are used. Botulinum toxin injections into the bladder is also registered by the FDA (United States Food and Drug Administration) for patients who fail oral treatment for storage dysfunctions.

For an emptying dysfunction (when some urine stays behind in the bladder and you get repeated infections), Intermittent Self Catheterisation (ISC) is suggested. A small catheter is inserted in to the bladder on a regular basis to empty the bladder completely.

8.2 Plan better for sex:

You might not be able to control your bladder, but you can control when you have sex. Use good female hygiene products like Femagene to give you the confidence you need that everything is in order before you start with sex. Men can also use these products or just wash with soap and water to make sure everything is in order before you engage in sexual activity.

Stop taking fluids about two hours before you have sex and make sure you empty your bladder before you start with sex. Some patients chose to have sex in the shower if they are incontinent.

You do need good mobility for that, but if you have a bench in your shower for instance, it might work for you.

Some patients who do not have to use Intermittent Self Catheterisation all the time, choose to do so before sex, just to be 100% sure that there will be no leaking during sex.

Remember that if there is a urine leak during sex, it is not the end of the world. Many women and also some men, lose control of their bladder during sex and especially during orgasm. This can be incredibly embarrassing, but if both of you know that, as long as you don't have an active infection, urine is sterile and cannot cause any harm to you or your partner, it becomes more acceptable. If you take enough fluids, the smell is also not too intense and a linen saver can deal with the mess on the bed.

It is important that your doctor makes the right diagnosis of your bladder problem: a storage dysfunction, an emptying dysfunction or a combination and then provide the right treatment.

8.3 Diagnose and treat urinary tract infections (UTI) promptly.

If you suddenly develop urinary symptoms or your urinary symptoms worsen suddenly, it is most likely due to an infection. Increase in general spasticity is also often due to an undiagnosed UTI - look out for that. The best way to diagnose a UTI is do a culture to determine which organism is causing the infection and which anti-biotic will work, especially if you have been having repeated infections. If you only get it once in a while, your doctor might only use a urine dipstick and give you a broad spectrum antibiotic.

Some patients need to be on long-term antibiotic therapy in order to avoid recurrent UTIs. Many people find that using daily cranberry tablets or D-Mannose protects them against recurrent infections.

9. BOWEL SYMPTOMS

Bowel symptoms interfere with sex for two reasons: Constipation is one of the leading causes of painful intercourse and Involuntary Bowel or faecal incontinence leads to embarrassment which keeps people from being sexually active.

Tips:

9.1 Good bowel habits:

Drink enough water (about two litres a day), take in at least 30g of fibre per day, avoid drinks that contain caffeine and alcohol, make time for bowel movements twenty to thirty minutes after a meal (preferably breakfast), use digital stimulation if necessary and use medication if conventional methods do not work.

Using the right position on the toilet can make a big difference: your knees should be higher than your buttocks, your elbows resting on your knees, your back straight and your belly pushed out. A pelvic function physiotherapist can help you learn how to use your pelvic floor to prevent constipation and to help with faecal

incontinence too.

Diarrhoea is often an overflow of untreated constipation. In those cases, the constipation needs to be managed first.

9.2 Make sure your bladder symptoms are managed:

One of the biggest reasons for constipation in patients with MS is uncontrolled bladder symptoms. You avoid taking enough water if you are struggling with your bladder and the whole pelvic floor function as a unit, so dysfunction in the one can lead to dysfunction in the other.

9.3 Plan better for sex:

Empty the rectum before sex to avoid discomfort. Take medication or an enema if the conventional methods do not work. In MS the sensation around the anus is often decreased and that can result in incontinence

but also make good hygiene more difficult. If that is a problem, clean the area with soap and water or hygiene wipes before intimacy.

In cases of severe incontinence, an anal plug can be used. It works like a tampon and can be inserted into the anus with the help of a little lubrication. Many patients find that it gives them the confidence they need when it comes to sexual activity. It can even work for people where involuntary flatulence is a problem. In patients where there is complete incontinence and none of the other methods work or they sound like too much effort, remember that you can still have non-penetrative sex with your partner where you just rub your bodies against each other in order to achieve intimacy and an orgasm. You can keep your nappy and your pants on to keep you comfortable and enjoy closeness with your partner with the rest of your body.

10. TREMORS OR SHAKING IN MY HANDS OR BODY

Tremors are one of the most difficult symptoms of MS to manage, but it does not have to make sex impossible. There are intention tremors (only happens when you want to do something specific with your hand or step onto a certain spot), postural tremors (only happens when you are in certain positions) and resting tremors (does not happen when you are moving, only when you are at rest) and each of those will affect your sexual functioning differently.

Tips:

10.1 If you have intention tremors:

Try not to use your hands specifically to stimulate your partner. During foreplay, you can use lots of oil and move your bodies over each other to create bigger movements. For direct stimulation you can rather use your mouth, let your partner rub him or herself against your body or use penetrative sex.

10.2 If you have a postural tremor:

Make sure that you assume a position during sex that does not elicit your postural tremor. Most people have them when they are sitting or

standing but not when they are lying down. In that case, make sure you are the partner at the bottom and that your whole body is supported on the bed.

10.3 If you have a resting tremor:

Weighted bracelets work for some people with resting tremors in the hands and can do the same for the feet. With a resting tremor you might also want to keep moving during sex. Usually big movements are not required - small stroking movements might be all you need to get rid of the resting tremor or to make it less obvious to your partner.

10.4 Other measures:

You might find that improving your core muscles through exercises like pilates, improves your tremor.

All kinds of medication have been tried with

varying degrees of success: isonicotinyldiazine (an anti-TB drug); hydroxyzine (a very sedating anti-histamine); propranolol (a kind of blood pressure medication called a beta blocker); the diuretic acetazolamide; anti-convulsants and anti-anxiety drugs like buspirone. Deep brain stimulation is also being experimented with at the moment. You can ask your doctor to go through this list of medication and see which one might be worth trying until you find something that works for you.



11. PAIN, BURNING, OR DISCOMFORT IN MY BODY

The pain associated with MS often varies over time and in intensity. It is mainly caused by the nerves firing a pain message when they shouldn't be. You can experience sudden shooting pains typically in the face or down the neck and back or more chronic type of pain in the muscles and joints.

Tips:

11.1 For chronic pain:

Drugs like anti-inflammatories, massages and physiotherapy might relieve the symptoms sufficiently to feel good enough to have sex.

In many cases though, the off-label use of anticonvulsant drugs are necessary because it is a central nervous system problem. The drug that is used for pain most often is gabapentin, but pregabalin, carbamazepine and other drugs might also be tried. They have different side-effects profiles and work through different mechanisms, so if the one drug does not work,

one of the others might.

If burning is the major complaint, the tricyclic antidepressant amitriptyline works particularly well in low dosages.

Alternatives like hypnotherapy and cognitive behavioural therapy are also used to control pain and many centres are investigating the use of botox and cannabinoids in the management of chronic pain in MS.

Taking extra painkillers about an hour before sex or just after sex might also help you to cope better with the symptoms.

11.2 For painful intercourse:

For females: make sure you use additional lubrication and are adequately aroused before you allow penetration. Being on hormonal contraception or being peri- or

post-menopausal might also cause pain due to oestrogen deficiency that can easily be corrected by applying a topical oestrogen cream around the vaginal opening and inside.

If penetration remains painful, see your gynaecologists to exclude gynaecological reasons for painful intercourse like cysts, fibroids, endometriosis and infections.

If these have been excluded you are encouraged to see a doctor and a pelvic function physiotherapist who specialise in the management of painful intercourse. Some women get so petrified of sex due to the pain they have been experiencing that they either avoid it completely or their vaginal canal physically closes up at an attempt at penetration due to the anticipated pain and the fear thereof. This condition is called vaginismus and can be due to the MS or could have been

there even before the MS was diagnosed. It is highly treatable but is best managed in the context of a multi-disciplinary team.

Men can also have pain during intercourse, especially during orgasm and ejaculation. This can usually be treated with physiotherapy.



12. PROBLEMS MOVING MY BODY THE WAY I WANT DURING SEXUAL ACTIVITY

Everybody loves the idea of having completely uninhibited sex where our bodies move with perfect rhythm and in perfect synchronicity as is seen in Hollywood movies. The reality of normal sex between able-bodied couples is that it often does not look good, does not work perfectly well, does not fit together nicely and that we can feel quite awkward during sex. When you have MS and struggle with weakness, muscle spasms and pain, this can be made worse, but it does not have to make it impossible.

Tips:

12.1 Lie still!

You do not have to move to be intimate with your partner and have fun together. You can find a position that you are comfortable in and lie completely still while your partner moves. It does not mean that you are not participating if you are not moving your body. You can still express your arousal and pleasure by the way you breath, the things you say and other forms of vocalisation. You can also use or move parts



of your body that are comfortable to move and keep the other parts still.

It is important that there is good communication between you and your partner so that he or she does not see it as you not participating if you

are not moving as vigorously as before. Of course your movement also helps with reaching your orgasm. If you can no longer move enough to orgasm, use manual or oral stimulation to reach it or the help of a vibrator.

13. PROBLEMS WITH CONCENTRATION, MEMORY, OR THINKING

It is surprising how much cognitive ability goes into having sex, especially if you have to plan for it and if you do not become aroused easily. This is also a common problem, not only associated with MS.

Tips:

13.1 Plan better for sex:

When you have MS, many things in your life cannot just happen like they used to. You have to plan things around your energy levels, your medication, your bladder and bowel habits and how severe your symptoms are on the day. The same goes for sex. Make sex a priority and plan for it. It would have been wonderful if you could have spontaneous sex, but the reality is that planned sex is usually better than no sex at all

and if you don't plan for it, it does not happen. Write in your diary when you plan to have sex. Set up the meeting with your partner and make a list of things that you have to do before sex and at what time those things need to happen. Do you need to buy a lubricant? Or fill your prescription for your PDE5 inhibitor? Do you need to a bowel prep? What time would be the right time to do that? Do you need to have a nap in order to have enough energy? Do you need to set a reminder to take certain medication or post-pone a dose for an hour or so? Write all these things down and plan for them. If you don't, the sex will just never happen.

13.2 Stay in the moment:

If you struggle to concentrate, you might struggle to get sexually aroused. Make sure that you are using all of your senses - use music, soft lighting, scented candles and oils and products

on your body to enhance sensation like a tingling or heating gel. While you are busy try to be mindful of the environment and the sensations. Tell yourself in your head what is happening in the moment: "He is softly touching my inner thigh, I am stroking his back, I can feel the warmth of her body on me". Focus on the sensations to keep you in the moment and when arousal start to develop, stay focussed on the positive sensations.

If you lose concentration, start by telling yourself what is happening in your head again instead of getting mad at yourself. It also helps to focus on the way that you breathe. As your arousal increases, your breathing changes, but it can also work the other way around. By making your breathing deeper and loader, your arousal can also increase.

14. EXACERBATION OR SIGNIFICANT WORSENING OF MY MS

This is an inevitable part of MS and something that both you and your partner will have to make peace with. All couples go through stages where the one is sick and unable to have intercourse for a while. During these times communication and understanding of each other is extremely important.

Tips:

14.1 Take a break

Don't put pressure on yourself to perform sexually and be sexually available for your partner in times when your health really does not allow it. Make sure that you maintain a form of intimacy between you by doing things like sticking to your weekly date-night, but having it in bed, watching a funny movie together or sharing a candlelight dinner with no expectations afterwards. Cuddle if you can, kiss, hold hands - do what you can, but don't put too much pressure on yourself or your partner.

It can be very difficult for the partners to cope emotionally during these times where sex is not possible. If it is too difficult and you find yourself feeling neglected and resentful, please see an experienced psychologist or sexologist to help you cope with it.

14.2 Communicate about alternatives

The reality is that there will be times where sexual activity is out of the question. This can leave both partners very frustrated. It is advisable to have a chat about masturbation if you have not had one already. It is better to deal with physical sexual needs by yourself if your partner is not available than to become frustrated and resentful towards your partner. It takes a lot of pressure off both of you. The times that you are together can then be about intimacy and creating a special experience rather than just physical release. The self-stimulation can take place in the partner's

presence as part of the intimacy or alone.

Masturbation is not acceptable in all cultures and religions, but in most, exceptions can be made for illness or other special circumstances. People also have other forms of arrangements that work well for both - it just needs to be negotiated. If you need help with this, see an experienced and well-qualified sexologist.



15. TERTIARY SEXUAL DYSFUNCTION

Tertiary sexual dysfunction is the result of psychological and social challenges that arise due to the fact that you suffer from MS. The media portrays a certain image of what is "sexy" and it usually does not involve people with disabilities and diseases. This makes it difficult for the person who is living with MS and his or her partner to come to terms with the changes and challenges brought on by the MS.

Reading through the comments below, might be all that you need to make peace with it, but if these challenges remain and are influencing your well-being, please see a professional to help you to deal with them.

Clinical psychologists and sexologists have specific research-based techniques and exercises to help you deal with the challenges effectively. In fact, you don't even need to have MS in order to benefit from sessions to improve your self-esteem, body images and the quality of your relationship.

16. FEELING THAT MY BODY IS LESS ATTRACTIVE

The media and the multi-million dollar cosmetics industry is to blame for the picture that we have of sexuality: and extremely skinny girl with perfect hair and airbrushed make-up with a masculine guy with equally perfect hair and make-up becomes the standard that everybody has to try to live up to. If you can't, it somehow makes you less capable of love. This is simply not true. You can experience and give real and intense love and sexual pleasure with a body that looks, functions and feels miles away from the unrealistic picture sold to us by the media.

Tips:

16.1 Have the chat:

Have a chat with your partner about these concerns. In a loving relationship, attraction has much less to do with physical appearance than with an emotional connection. Let him/her tell you what he likes about your body, what he/she finds attractive about you, what turns him/her on. You might be surprised to hear how many things there are.

16.2 Maximise your assets:

How about covering up the areas that you don't like and emphasising the ones that you do like? All of us do that anyway!



17. FEELING LESS MASCULINE OR FEMININE DUE TO MS

Traditional roles do change when you suffer from MS and you might not be able to do all the things that made you feel like a man or like a woman like certain sporting activities, duties around the house and grooming habits.

When it comes to sexual functioning, you might also have lost some aspects that you took for granted earlier. That loss can cause frustration, anger, embarrassment, sadness and a whole host of other emotions, but as was seen in the section on primary sexual dysfunction, it can be addressed.

Tips:

17.1 Make that gender-affirming list:

Make a list of things that makes you a man or a woman. Don't stop until you have at least ten and then add one every day for the next month. There are things about your body that makes you a man or a woman, but there are also things about the way that you feel, you think, your desires and your nature that makes you a man or woman. Focus on those.

18. FEAR OF BEING REJECTED SEXUALLY BECAUSE OF MS

The roles do change when one of the partners has MS and that can make it difficult for the one who has to do the care giving to see their partner as sexy and capable of giving and receiving sexual pleasure. This fear is therefore a very realistic one and needs to be addressed.

Tips:

18.1 Continue to see yourself as a sexual being:

Don't let this fear or any other aspect of MS keep you from still believing in and embracing your own sexuality. You can still wear beautiful underwear and expensive perfume, you be anywhere and anyone you like in your fantasies and you can certainly give and receive intimacy and pleasure.

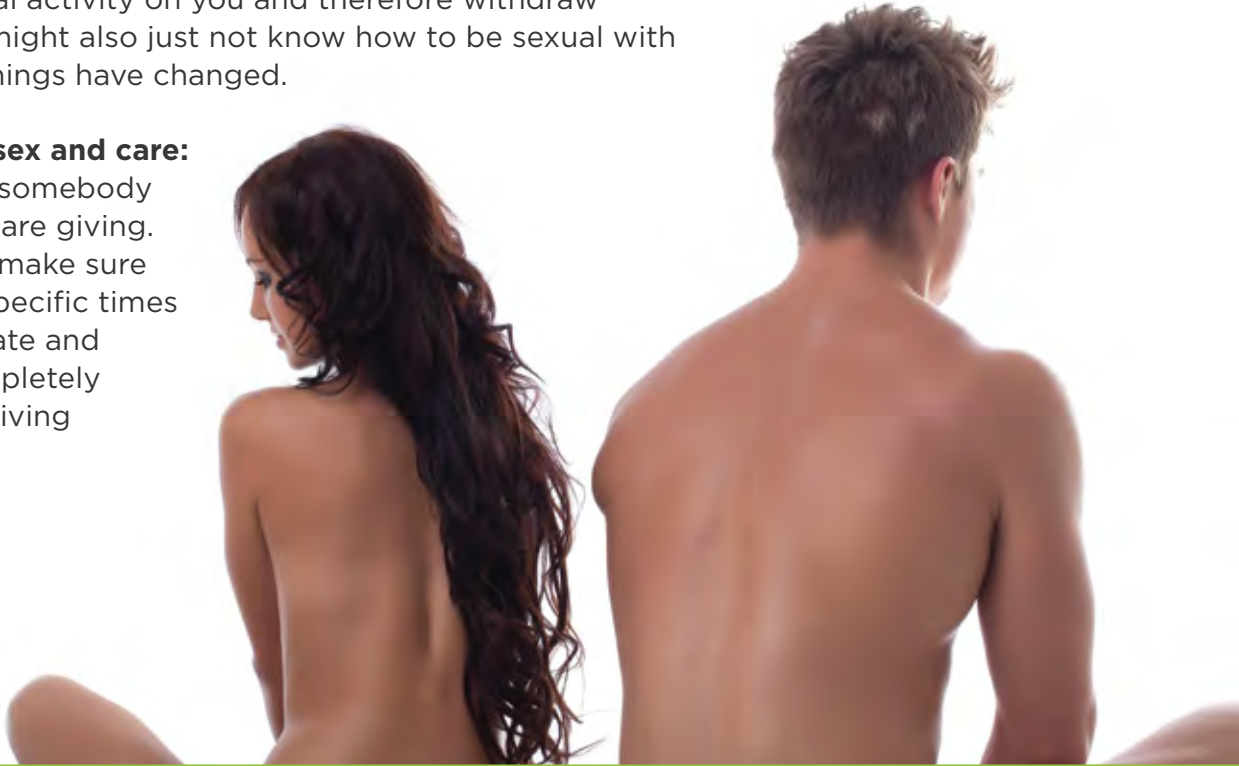
18.2 Communicate:

Make sure that you communicate your need to remain sexually active to your partner. He or she might feel that they don't want to put the

burden of sexual activity on you and therefore withdraw sexually. They might also just not know how to be sexual with you now that things have changed.

18.3 Separate sex and care:

If possible, get somebody else to do the care giving. If not possible, make sure you set apart specific times for being intimate and separate it completely from the care giving aspects.



19. WORRIES ABOUT SEXUALLY SATISFYING MY PARTNER

If you have been with your partner for a long time and you are no longer engaging in sexual activities the way you used to and use the exact same techniques you used to satisfy him or her, it is not the end of the world. It might be the start of a whole new exciting era where you discover new possibilities and some sexual potential you never even knew you had!

If you don't have a partner currently, this might be particularly worrying for you. To be honest - most people are worried about that! Sex is not something performed from a textbook. It is the natural outflow of intimacy between two people... If you find the right person, you will

figure the sex-part out. The options are more than what you can ever imagine!

Tips:

19.1 Communicate:

Talk about it, take it slow. After every session of physical intimacy, tell your partner one or two things that you really liked about the experience and ask him or her to do the same. You will see that there are many ways in which you are satisfying your partner and that he/she still has the ability to satisfy you. This will give you confidence for the next session and also creates some excitement to think of new things to do to

to satisfy your partner during the next session.

19.2 Expand your definition of satisfaction:

If the definition of satisfaction is "orgasm" you might be disappointed at times. However, there is so much more to sex and intimacy than only orgasms and therefore you might need to expand your definition of satisfaction. Discuss this with him or her: what does sexual satisfaction mean to you? You might be surprised at the answer and find that it is easier to achieve than you think.

19.3 Move the goal posts:

You might find that your partner has unrealistic expectations of you. If communication does not bring on understanding and a compromise, you will have to seek the help of a professional. You cannot have the added stress of unrealistic expectations to throw into the mix of dealing with your MS.



20. FEELING LESS CONFIDENT ABOUT MY SEXUALITY DUE TO MS

This is the part where you have to take active steps to get your confidence back!

Tips:

20.1 Do some research:

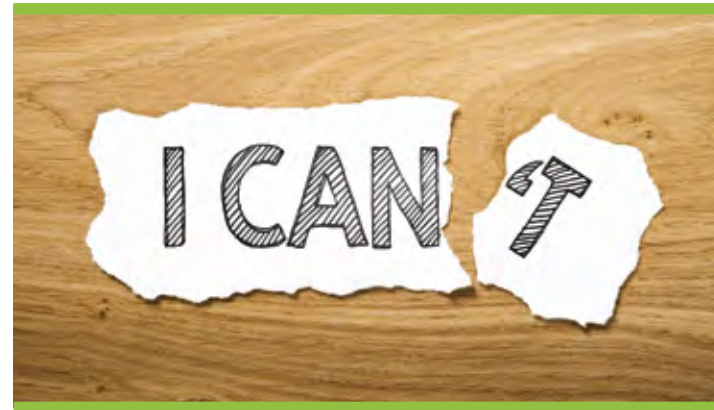
There are so many good books, products and helpful information out there - get searching! You can buy these things online and they are delivered in discreet packages, so you don't have to worry about who is going to see you. Buy nice lotions and potions, lingerie, erotic novels, instructions manuals - anything you can find to give you some ideas. When you have information, you feel empowered and more confident. Be prepared that the books and products are not primarily produced with people with disabilities in mind. Everything

does not have to work for you, but you will certainly find some things that do work.

20.2 If you can imagine it, you can do it:

The idea of doing a lap dance for your partner makes most people blush! If you can't imagine yourself doing something, you are not very likely to try it in real life either! Use your imagination and see yourself do something sensual in your partner's presence - whether it is wearing a specific piece of lingerie or performing a sexual favour or anything else. Imagine yourself doing it. Keep changing the picture in your mind until you are comfortable. You might not be comfortable walking around the room in sexy lingerie, but you might be okay to wear it under your gown and let your partner discover it in candlelight.

A man might need to use a penis pump and the idea of using with your partner makes you want to run away. First try it by yourself, or get your doctor to help you to apply it and show you how to use it, just to get used to it, before you involve your partner. Then imagine using it with your partner, see yourself doing it a few times before you try it in front of him or her. It will make it much easier.



21. FEELINGS OF DEPENDENCY BECAUSE OF MS

One of the realities of MS is that you are no longer as independent as you would like to be. A prerequisite for sex is not complete independence. You can find ways to work around it.

Tips:

21.1 Do as much as you can for yourself:

Start to make a list of all the things that you can actually do for yourself when it comes to sex. If your partner just has to help you into the right position or to give your injection to achieve an erection, it does not mean that you are fully dependent on him or her. Take your time, plan for it and do what you can. The rest, can be done for you and that is also OK. We all can do with a little help from time to time!

A FINAL WORD ON SEXUAL HEALTH

Living with MS can be overwhelming and you can get really tired of all the medication, doctors visits and tests. Please don't let this keep you from going for your regular screening tests and examinations to maintain your sexual health. You still need breast examinations and pap smears as a woman and prostate examinations as a man.

You can also certainly pick up sexually transmitted infections. Make sure you use a condom if you are not in a stable relationship and first go for tests together if either of you have ever been in a sexual relationship before.

You can also fall pregnant or make your partner pregnant if you have MS. Make sure

you use adequate contraception to prevent pregnancy if you want to. You don't have to feel that the fact that you suffer from MS disqualifies you from having children. Discuss this with your doctor before you decide to fall pregnant though.



You may contact the Healthcare Providers at My Sexual Health (MSH) for further assistance.

Phone: +27 61 302 6730

E-Mail: info@mysexualhealth.co.za

Each provider at MSH also has their own contact details. Please go to the link below to find the provider that is appropriate for your needs.

<https://mysexualhealth.co.za/about-us/>

USEFUL WEBSITES

<https://mysexualhealth.co.za/blog/>

www.mysexualhealth.co.za

www.drelnarudolph.com

RELATED LINKS

<http://www.ncbi.nlm.nih.gov/m/pubmed/18336059/>

<http://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms/Tremor>

<http://www.mymsaa.org/about-ms/symptoms/spasticity/>

NOTES

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

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