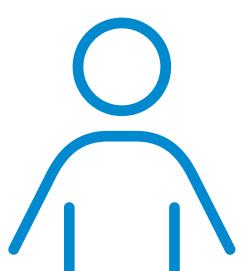




WOMEN'S HEALTH FACTSHEET





spinal.co.uk





INTRODUCTION

With women accounting for just 20% of spinal cord injured (SCI) people, a paraplegic or tetraplegic woman may find that rehabilitation is male-oriented, and she is consequently greatly out-numbered by males. Unfortunately, the implications of the difference in the sexes on a spinal cord injured person are not always understood, and this carries on even in the expectations of others in the rehabilitation progress for SCI women.AN SCI woman may also feel that she is expected to physically achieve as much as an SCI man with a similar level of injury; differences in physical strength and biological make-up mean that males are much more able to lift and transfer themselves, have greater stamina and can lift and move heavier items. SCI women need more physical assistance with activities such as transferring or need to use aids such as hoists to be more independent.

"I was shocked when the consultant at the general hospital to which I was admitted decided without consulting me, that he would not refer me on to a spinal unit 'for social reasons. I had to impress on him very strongly that the fact my daughter-who was only one year old - was not, in my opinion, reason enough to deny me the specialist treatment that I so desperately needed. I'm sure that he would not have made the same assumption for a man that he should stay in an ordinary hospital close to home for 'social reasons" SCI woman.

SCI women have other health issues to consider that may not concern men with spinal cord injury. These issues include menopause, gynaecological health, osteoporosis, and contraception.

This factsheet aims to provide a general guide to health implications of SCI to women's health and to help an SCI woman to make informed choices about her lifestyle and health. You are advised to consult your GP or gynaecologist on more specific aspects of women's health.

MENSTRUATION

After SCI it is quite normal to find that your periods are likely to stop because your body has received a traumatic shock and it will take a while to resume this function.

As with other aspects of SCI, everyone is an individual and some women will find that within 3 to 6 months, their periods will start again. For others, it can take up to a year before menstruation resumes, and even then, the regularity of your periods may not be as before your injury; with time should settle into a pattern as before... Many SCI women feel some psychological relief that they are functioning 'normally' again as a woman.

Can I get pregnant after my injury?

Although most women are understandably concerned about the implications for their fertility once their spinal cord is injured, it should not cause unnecessary worry; an SCI does not affect your ability to get pregnant or have a healthy child. It is even possible for an SCI woman to get pregnant before her periods resume after her injury and hence you should take precautions should you have sex during that period.

Your level of injury and whether it is complete or incomplete will affect your ability to tell when your period actually restarted. You may find you no longer experience menstrual cramps as before SCI but you do get cramps coupled with increased and more powerful spasms; you need to be extra careful you do not fall when transferring and moving about because of the erratic nature of the spasms. Other signs of imminent menstruation are headaches, back pain and if you have a high lesion, you may have signs of autonomic dysreflexia.





If you have no sensation in your abdominal region, you may find it hard to tell when your period has actually started. It can be possible to learn the signs, just as it is possible to understand how the bladder and bowel is functioning. It may be helpful to get to know your own body and learn to 'listen' to the different sensations.

Premenstrual Tension

Most women find that just before their periods begin, they feel bloated and heavy, which can affect your body image. Tetraplegics who may already have the common, yet unwelcome 'tummy' may feel especially large at this time. Don't be tempted to reduce your fluid intake as this will increase the risk of bladder or kidney infections. You may find it useful to take vitamin supplements or look to alternative therapies for some relief of the uncomfortable premenstrual symptoms.

The hormonal imbalance that occurs in the premenstrual tension does affect how a woman feels. Some women become much more emotional at this time and after SCI, this can be particularly difficult to cope with. Living with SCI is often emotionally draining and a stressful experience and coupled with PMT, it can feel worse.

It might be useful to learn some stress management techniques to help you cope better with the emotional and physical impact of premenstrual tension. You will also find that controlling your bladder will be especially difficult before and during your period. Some women may find their bladders become more erratic because of fluid retention. Other women may find that they become more constipated just before their period whilst others report the opposite. With time you will get to know your individual responses and find ways to manage your bladder and bowels to suit you as your body goes through changes in the menstrual cycle.

"I coped with heavy and difficult periods for years and after finding nothing gynecologically wrong, I was still offered a hysterectomy. I now go to a herbalist and have had no more problems with fluid retention, stomach cramps or heavy periods" SCI woman, T7/8.

Do I have to use a special type of sanitary protection?

The choice for sanitary protection is the same for all women, whether disabled or able-bodied: you can either use internal tampons or external pad or towels. When used correctly, it is quite safe for you to continue using tampons if that is what you are used to using.





Tampons

There are two main types of tampons available in the UK. Those with an applicator will be easier for a tetraplegic woman or an assistant to insert and ensure that it is up far enough. If you have good hand movement, you may find tampons without applicators easier to insert when you have little or awkward space for positioning. There is also a mini tampon without an applicator, designed for young girls who find other tampons difficult to insert. Although this may seem attractive, they are not as absorbent as other types. Because of the difficulty of making frequent changes, it is tempting to use more absorbent types of tampon and change them less often. This may increase the risk of bladder and vaginal infections and possibly toxic shock syndrome. Some SCI women find that straining to empty the bladder can expel the tampons so that they need to use more tampons than usual.

Positioning your body to insert the tampon is quite tricky. If you are paraplegic, leaning over far enough while sitting on the toilet or in the wheelchair to insert the tampon may be feasible. If you have enough strength to do so, you could move as far forward as possible in the wheelchair and prop your feet up on a stool or something similar. If your lesion is higher, you could like on your side or propped up on your back with legs apart on the bed. If you are inserting the tampon by yourself, you may find using a mirror will make these positions much easier.

Caution should be taken with higher level SCI women because on occasion, some women have found that using tampons can trigger an autonomic dysreflexia attack.

The likely cause is that the tampon has not been positioned correctly and is causing discomfort.

Pads

The most popular adsorbent product for protection against leaks is pads and over recent years, they have been not only developed to a high standard but there is a wide choice of types and qualities to suit most women's needs.

Pads can be disposable or washable and reusable; with majority of them have a self-adhesive strip which can stick to your pants. If you pull your pants up, you need to ensure that they stay flat and in the right position. If you use a hoist, you may find it easier to use pants with side fastenings, lay them flat on the chair with the pad on top, and then lower yourself carefully on to them.





Pads can be slim and inconspicuous when slipped inside practically types of pants, including ordinary pants, special stretch pants, waterproof pants or special pants with a built-in pouch. They can also take the form of wrap-around all-in-one nappies that maybe less unobtrusive than the slimmer kind. In the past, slimmer pads were thought to compromise its absorbency capacity but with recent advancements in material technology, thinner pads have been known to adsorb as well if not better than the traditional thicker pads.

With the variety of pads that are available on the market, you can mix and match them to suit your need, for example wearing a more absorbent pad during the night and wearing a less absorbent one during the day.

Many women need to wear pads all the time, in case of incontinent leaks. They can also help to cushion and protect any bony parts whilst sitting. They do have the added advantage of 'peace of mind' about whether you make leak or when exactly your period will start. Some women choose to wear tampons as well as pads during their period.

If you use an in-dwelling urethral catheter you need to make sure that the position of a tampon or thick pad does not put more pressure on the catheter and cause urine to leak past it. There are disposable incontinence pants available on the market. Incontinence pants, pads and sheets are also available through your local health centres or continence services.

CONTRACEPTION

"The decision to have a baby when one is disabled often arouses much shock and unease amongst family and friends, it is proof that, although disabled, one can enjoy a normal sexual relationship with its obvious consequences. Fear of complications, of inability to cope with the demands of motherhood as well as the limitations of one's condition have prevented many young disabled women from starting a family and have caused heart searching and an anxiety to others, who like me, found themselves unintentionally pregnant." - SCI woman, T5/6

Like any woman, the sexually active SCI woman must use some form of contraception if she wants to avoid pregnancy. The type of contraception chosen will depend on what works best for your body and lifestyle.No contraception is perfect or 100 % safe and effective. Therefore, you should discuss your options with your GP, who can give further information on each method and advice on the best method for you, advising on compatible medications and various risk factors.

Fertility Awareness Method (FAM)

Fertility Awareness is a means of understanding your reproductive system by observing and writing down fertility signs. The signs are: your temperature when you first wake up; your cervical fluid; and the position of your cervix. They determine whether you can become pregnant on a given day. For SCI women, temperature may fluctuate due to infections and other body discomforts, making it harder to determine fertility by this method.





Combined Birth Control Pills

Combined birth control pills contain two hormones, oestrogen, and progestogen. They work by stopping ovulation and by making the lining of the uterus thinner. For SCI women they regulate periods, so that you know when your periods will start and they reduce menstrual blood loss and possible anaemia. They may increase your risk of thrombosis. Your GP should be made aware of all medications that you are taking in case of contra-indications. As an SCI woman you are at high risk of developing blood clots due to inactivity and it is recommended that this method of contraception should be completely avoided by anyone with a history of thromophlebitis (blood clots). It is further recommended that hormonal uses should not be started until 6-12 months after injury. If you experience unexpected breathlessness, chest pains or swollen limbs, contact your GP for a check-up.

Mini Pill

It contains only progestogen. They can cause irregular bleeding. Check whether other medication is compatible.

The Intrauterine Device (IUD)

An IUD is a small plastic "T" shaped device which is placed inside the uterus.

There are different types of IUDs available. Use of an IUD commonly leads to irregular periods and an increase in the number of days some women have spotting. Some women stop having periods completely. It may be difficult to check if the strings are in place each month which may increase the risk of autonomic dysreflexia in high level SCI women and is generally discouraged for SCI women.

Contraceptive Foam

Foam, which kills or destroys sperm, is placed into the woman's vagina using an applicator (similar to tampon insertion). The foam adds lubrication and moisture, though it could be irritating to the vagina.You may have to have it inserted for you if you have limited hand movement.

Film

Film is a small 2-inch by 2-inch, paper-thin sheet with a chemical that kills sperm. It is placed on or near the cervix, the opening of the uterus and dissolves in seconds. Some people may be sensitive to film or find it causes irritation of the vaginal lining, which might increase the likelihood of or urinary tract infections. You may have to have it inserted for you if you have limited hand movement.

The Sponge

A polyurethane foam is impregnated with spermicides. It releases a protective spermicidal gel over the vaginal mucosa. The sponge forms a barrier to the sperm reaching the cervix as well as killing or immobilising sperm. It may be difficult for some SCI women to insert a sponge correctly or know if it has stayed in place.





Diaphragm

A diaphragm is a rubber dome-shaped device which the woman places into her vagina so that it covers the cervix, the opening to the uterus. The diaphragm, with spermicide blocks the man's semen from entering the cervix. It may be difficult for some women SCI to insert a diaphragm correctly or know if it has stayed in place and may increase the risk of urinary tract infections.

Cervical Cap

The cervical cap is a thimble-shape latex rubber device. The woman puts a spermicide in the cap and then places it up into her vagina and onto her cervix. Using the cap increases your risk for inflammation of the surface of the cervix. It may be difficult for some SCI women to insert a cervical cap properly or know if it has stayed in place.

Male Condoms

Condoms are made of latex, polyurethane, or natural membranes. Polyurethane condoms may be used by couples when either partner is allergic to latex. Condoms are safe and effective at preventing infection. It may be more convenient if the male partner uses a condom.

Female Condom

Female condoms are made of thin plastic called polyurethane. The condom is placed into the woman's vagina. It is open at one end and closed at the other. Both ends have a flexible ring, to keep the condom in place. They can prevent infections. It can be large, bulky and may be difficult or uncomfortable to use.

To avoid interrupting sex because you need assistance to use one of the barrier methods, it would be helpful to learn to incorporate it into your lovemaking and make it fun and exciting as a shared act.

After sex contraception

For 72 hours after unprotected sex, you can still avoid becoming pregnant if you take emergency contraceptive pills. For 5 to 7 days after sex, you can have an IUD inserted.





Where can I get more information?

British Pregnancy Advisory Service (BPAS) Austy Manor,Stratford Road Wootton Wawen Henley in Arden West Midlands B95 6BX T: 03457 30 40 30 W: <u>https://www.bpas.org/</u> @: info@bpas.org

National Charity. Treatment clinics and consultation centres offering pregnancy testing, crisis pregnancy counselling, abortion information and treatment, contraception and emergency contraception, sterilisation, vasectomy and reversal. Leaflets on all services and clinics approved by Department of Health. Registered charity providing safe, legal abortion. UK's largest single abortion provider.

Family Planning Association

2-12 Pentonville Road London N1 9FP Helpline: 0845 310 1334 (Mon-Fri 9.00am - 6.00pm) Admin: 0207 608 5240 Sales: 01865 719418 W: www.fpa.org.uk

UK sexual health information service, including family planning, reproductive and sexual health. Mail order book service. Professional training on sexuality, including courses for staff groups and those working with learning and physical disabilities.

The Outsiders Club BCM Box Outsiders LondonWC1N 3XX Helpline: 07900 957393 (Mon-Fri 11am-7pm) W: <u>www.outsiders.org.uk</u> @: members@outsiders.org.uk

Nationwide, self-help, community. Regular mailings and unthreatening events where people can meet up and practice socialising. Maintains a list of therapists and sex counsellors specialising in disability. Sex and Disability Helpline. Counselling, publication, workshop, and advice resources for people with social or physical disabilities.

spinal.co.uk





PREGNANCY

"The main problems I encountered during my pregnancy were as follows: firstly, my legs and ankles became very swollen especially towards the end and I was ordered to get plenty of 'feet up' rest (difficult with a young child around). Also, indigestion became a real nuisance, made worse because of sitting down. This catalogue of problems may sound very off putting but, in fact I really enjoyed being pregnant. I cannot deny that a small part of the pleasure came from demonstrating, that despite being disabled, I was just a normal married women having a baby. My husband John and I were often amused at the looks of shocked amazement we received on our 'shopping for baby' trips" - SCI woman, C6/C7

SCI women can and do get pregnant, regardless of the level of injury. The reason to why spinal cord injury does not affect a woman's ability to get pregnant is due to the fact that the menstrual cycle is control by hormonal control and not neurological control. Hormones are distributed via the body's blood circulation.

Newly injured SCI women may miss some periods temporarily after their injury because of the traumatic stress inflicted on the body but most women will resume regular periods within one year.

If an SCI woman engages in sexual activity during this period, she can get pregnant because ovulation may occur prior to the first period after injury. So, it is important that an SCI woman uses birth control/contraception to prevent unwanted pregnancies when having a sexual relationship.

If you are considering having a baby, the first step is to consult with the rehabilitation physician who can explain the medical, psychological, and social challenges that you may face during pregnancy and delivery, and how to manage them. The next step would be to find an obstetrician who is familiar with the unique needs that an SCI woman has, and your physiatrist may be able to recommend one to you.

The second step is to have a complete urologic examination to ensure that your urinary tract is healthy and inform your doctor of any medications you may be taking so that they can assess the effect they will have on your pregnancy.

The third step is to educate yourself on what to expect through each stage (trimester) of your pregnancy and how to manage the challenges you may face.

Pregnancy stages

In the first trimester pregnant women tend to get mood swings, dizziness, headaches, fatigue, heartburn, indigestion, and nausea, which will taper away with time. But for a pregnant SCI woman, some of these natural changes may also be signs of complications. You might discover that the headache you assumed was a prenatal symptom is really a symptom of autonomic dysreflexia and if it is coupled with nausea, it might not be morning sickness but a urinary tract infection. Another issue that should be considered is your bowel management. Diarrhoea and constipation are the two most common changes that occur during pregnancy, and so you may have to change your fibre and fluid intake, empty your bowels more frequently, take a stool softener and so forth accordingly.





As you move into the second trimester of your pregnancy, the potential for complications increases and you might discover the bowel program you have in the first semester may not be as effective in the second; your bowel and bladder management should evolve as your pregnancy progresses. Weight gain is another issue you will undoubtedly experience and may interfere with your ability to perform everyday activities like transfers or pushing your wheelchair and you may tire easily.

Bladder management is another common complication. As the foetus grows it will be putting pressure on the bladder, decreasing bladder capacity and may trigger bladder spasms. If you use intermittent catheterization, you may have to catheterize more often or in some cases, switch to indwelling catheter during pregnancy.

As an SCI woman, you will be at a greater risk of getting a urinary tract infection (UTI) during pregnancy and if not properly managed, it may trigger premature labour. It is important to put into practice ways to prevent the occurrence of UTIs by drinking plenty of water, avoiding beverages with sugar, caffeine and alcohol and catheterizing more often.

Pressure sores are another concern for pregnant SCI women as they are at a greater risk due to weight gain and change in posture. Making sensible changes like increasing pressure relief, more regular skin checks, taking special care during transfers and so forth, will help prevent pressure sores.

In the third trimester SCI women with injuries in the thoracic and cervical regions are likely to have respiratory problems such as loss of respiratory muscle control. This would weaken the pulmonary systems (pump blood between heart and lungs), decrease lung capacity and increase respiratory congestion.

In the last stages of pregnancy, you may have blood circulation problems in the lower extremities. This is because the blood flow is being hindered by pressure from the growing foetus and the blood pools in your feet and legs, causing them to swell. You can help improve blood flow and reduce the swelling by getting extra rest, wearing anti-embolism stockings, and doing passive exercise.

Labour

Labour for an SCI woman is usually different from able-bodied women. If your level of injury is T10 or above, you may not experience labour pains, if your level of injury is lower than T10, then you might experience uterine contractions but not of the same kind as those experienced by able-bodied women.

You and your obstetrician should watch for sign of labour starting at around 28 weeks and carry out a weekly cervical examination is possible.

If you are paraplegic, learning how to do uterine palpation might help detect labour and if you are tetraplegic, using a home uterine contraction monitor may be useful. All SCI women should be aware of the following signs of labour:

- Changes in spasticity or breathing
- Backache
- Abdominal tightening
- Pelvic pressure
- Unusual feelings of pain
- Autonomic dysreflexia
- Feeling of fear and anxiety
 - 10 Women's health





Delivery

Assumptions should not be made that simply because a woman is SCI, she will automatically require a Caesarean Section. Your obstetrician will advise what best for you and your baby based on the facts of your pregnancy and your personal health. Delivery is easy for some women while other will require assistance, but most women deliver vaginally.

Acknowledgment to: UAB Department of Physical Medicine & Rehabilitation – SCI Info sheet 'Pregnancy for Women with Spinal Cord Injury'.

Where can I go for more information?

SIA has produced a Motherhood factsheet available at www.spinal.co.uk

Family Planning Association 50 Featherstone Street London EC1Y 8QU Switchboard: 0207 6085240 Helpline: 0300 123 7123 W: www.fpa.org.uk

Provides advice and information on all aspects of contraception, pregnancy, and sexual health.

Fertility Network UK Forum at Greenwich Trafalgar Roads Greenwich SE109EQ T: 01424 732361 W: www.fertilitynetworkuk.org

Offers advice, support, a newsletter, factsheet and 24-hour Helpline.





The National Childbirth Trust Alexandra House Oldham Terrace Acton London W3 6NH Telephone: 0300 300 0700 8am -10pm) Txt: 0208 993 6714 W: <u>www.nct.org.uk</u> @: enquiries@nct.org.uk

Provides information, antenatal classes, breastfeeding and postnatal support through 400+ branches nationwide.

Disabled Parents Network T: 0300 330 0639 W: www.DisabledParentsNetwork.org.uk @: information@disabledparentsnetwork.org.uk

An organisation of and for disabled people who are parents or hope to become parents, and their families and friends/supporters.

Birthlink (formerly Family Care) 21 Castle Street Edinburgh EH2 3DN T: 0131 225 6441 W: www.birthlink.org.uk/

After Adoption Counselling Agency offering services to adopted adults, birth parents and adoptive parents where the adoption has a Scottish connection





MENOPAUSE

The menopause (also known as 'change of life') is a physical and emotional health transition concerning all. You only become aware of this retrospectively when you have not had your period for a full year. Menopause is caused mainly by decreases in oestrogen and progesterone, and chemotherapy or radiation.

Menopause encompasses 3 distinct stages:

- Premenopause: the beginning of menopause usually the early 40s when your periods become heavy or irregular
- Perimenopause: the transitional period lasting up to 10 years from having normal menstrual periods to having no periods
- Postmenopause: the period of time after the menopause.

Most women experience menopause between ages of 45 and 55, with perimenopausal symptoms occur throughout the 40's, including:

ageing ovaries.

A menopausal woman used to embody the end of all things female but thankfully, with the modern age, a more optimistic attitude has prevailed. Menopause can be a positive stage in a woman's life if she receives the appropriate support and addresses the health issues surrounding menopause and the years beyond.

There are 2 types of menopause: natural and induced menopause. Natural menopause occurs when you have had no menstrual periods for at least one year without being pregnant. Induced menopause occurs after surgical removal of the ovaries, or damage to the ovaries due to medical intervention such as:

Non-physical symptoms

- Depression
- Irritability caused by inadequate sleep and fatigue
- Tearfulness and inability to cope
- Loss of libido
- Insomnia
- Poor memory and concentration.





Physical symptoms

- Irregular, scanty or heavy periods
- Common sign of menopause but could be other gynaecological condition such as polyps or fibroids.
- Vaginal Dryness
- Hot flushes
- Sudden hot feeling in the face, neck and chest, blushing, faster pulse and sometimes perspiration followed by a shivering sensation or chill. Some women report having a 'crawling' sensation on their skin.
- Night sweats
- · Hot flushes at night, perspiration may be severe enough to drench your bedding.
- Fatigue and lack of energy
- Aches and pains as a result of softening bones
- Increase in bladder infections making you more prone to cystitis
- Increase in vaginal infections due to the thinning of the vaginal walls and increase in alkalinity, causing dryness and loss of elasticity and making them more prone to injury.
- Increase in skin infections
- Dry and itchy skin since lack of oestrogen makes it much harder to retain moisture.

How are perimenopausal symptoms managed?

Each woman's menopause experience is different and consequently menopause management techniques vary from woman to woman. There are various menopause treatment options available including lifestyle changes, non-prescription remedies and prescription therapies.

A healthy lifestyle can contribute significantly to improved well-being, not only perimenopause but throughout life. The most common symptoms of perimenopause are hot flushes, night sweats, insomnia, and vaginal dryness.

Here are some suggested tips for alleviating these symptoms:

Hot flushes and night sweats

- Keep cool by using a fan, and sleeping in a cool room
- Wear cotton or silk clothing as these fabrics absorb moisture and still provide warmth after the hot flush subsides. Also wear layers of clothing that can be taken off or put on as your body temperature changes.
- Exercise regularly to relieve stress and help you sleep better
- Relieve stress to prevent triggering strong emotions which in turn will set off the hot flushes, by indulging in a bath, massage or meditating
- Avoid caffeine and tannin, (which are found in tea and coffee), spicy foods and cigarette smoking.
- Have prescription oestrogen therapy to supplement a fraction of the natural oestrogen produced by our ovaries.
- Some women find supplements like black cohosh, agnus castus, dong quai and sage to be quite helpful.





Insomnia

- Avoid heavy meals at night.
- Avoid caffeine, alcohol and nicotine throughout the day and especially at night.
- Daily exercise helps some women to get a good night's sleep but avoid exercising close to bedtime.
- Make sure your room is conducive with sleeping by keeping it cool, quiet and dark.
- Some women find that the herb valerian gives them a restorative sleep.

Vaginal dryness

- Use vaginal moisturizers which are available without prescription to help maintain vaginal moisture
- Have prescription oestrogen therapy to restore the thickness and elasticity of vaginal walls and a healthy vaginal pH whilst relieving the vaginal dryness. These are specific to the inside of the vagina and are not absorbed into the circulation. These include oestrogen creams, a vaginal oestrogen tablet and an oestrogen ring.
- Avoid soap in the genital area as it is an irritant. An emollient such as aqueous cream can be used round the labial area and it is very soothing.

There are some complementary medicines said to be helpful in treatment and management of menopause including:

- Acupuncture
- Aromatherapy
- Herbal medicine
- Homeopathy
- Nutritional therapy
- Reflexology
- Relaxation techniques
- Yoga

Hormonal Replacement Therapy

Hormonal Replacement Therapy (HRT) can help to alleviate perimenopausal symptoms such as hot flushes by essentially replacing the oestrogen and progesterone hormones your body loses. If you have had a total hysterectomy (surgical removal of the uterus), you will only need to replace oestrogen but if you have a uterus, progesterone must be added to prevent excess build-up of the uterine lining, which increases your risk of developing uterine cancer.

HRT is available in different strengths as tablets, patches, implants, creams and pessaries, and the type will be tailored to your individual needs.

There has been much debate about the safety of HRT and the two principal concerns have been:

- The extended use of HRT and the risk of developing breast cancer
- The risk of heart disease and stroke.





Currently it is recommended that GPs prescribe HRT in the lowest effective doses and for the shortest duration possible to prevent and treat postmenopausal osteoporosis and alleviate menopausal symptoms. You should talk to your GP about any existing medical problems such as deep vein thrombosis, high blood pressure, liver disease and endometrial cancer before you begin HRT.

Some women have reported the following transitory side effects of HRT, which usually settle after the first couple of weeks:

- Bloating
- Breast tenderness
- Nausea
- Headaches
- Low backache
- Mood swings
- Heavy bleeding

As with any other medical treatment, it is advisable to discuss the benefits and risks on an individual basis with your GP and be monitored at least once a year.

How does menopause affect SCI women?

For SCI women, the physical manifestation of menopause may worsen health problems already occurring with SCI including pressure sores, autonomic dysreflexia in women with high-level lesions, spasticity and bladder spasms leading to difficulties in bladder management. Some also experience leaking around indwelling catheters or between intermittent catheterisations. It can be particularly confusing for SCI women to determine whether they are having an autonomic dysreflexia attack or perimenopausal hot flushes and night sweats, which may be worse for n because of the pre-existing neurological symptoms.

The Daisy Network PO Box 183 Rossendale BB4 6WZ W: <u>www.daisynetwork.org/</u> @: info@daisynetwork.org.uk

Charity and support group for women suffering from premature menopause (before the age of 40).





Women's Health Concern Spracklen House, East Wing Dukes Place Marlow Buckinghamshire SL72QH Helpline: 01628 890199 W: www.womens-health-concern.org

A charitable organisation and patient arm of the British Menopause Society. Provides an independent service to advise, reassure and educate women of all ages about their gynaecological and sexual health, wellbeing and lifestyle concerns.

OSTEOPOROSIS

"For years I kept forming kidney stones which had to be removed, even though I had a low calcium diet. Now, at the age of 41, I have osteoporosis and regret cutting down on calcium" SCI woman, C5/6

Osteoporosis is when the bone tissues deteriorate over time, resulting in the bones becoming fragile with increased susceptibility to breaking.

We have two types of cells that are constantly at work in our bones; osteoblasts which build up new bones while osteoclasts break down old bone. Up your mid-20s, the building up of bone takes precedence over bone breakdown but from the age of 40 onwards, the opposite occurs, and bone density is gradually lost as a natural part of the ageing process.

Osteoporosis is remarkably common, affecting one in two women in the UK. The most common sites for bone fractures as a result of osteoporosis are the hip, spine and wrist. It is prevalent in women who have been through menopause, owing to the loss of oestrogen which has been shown to protect bones. It is thought that this could be a major factor in the onset of osteoporosis; however, research continues to identify alternative components that could influence the onset of osteoporosis.

How does osteoporosis affect SCI women?

In individuals with SCI, osteoporosis occurs below the level of injury, the most dramatic changes occurring within months after the injury as the bone density decreases rapidly.





Being an SCI poses additional risks to developing osteoporosis because of muscle inactivity and decrease in the amount of weight put on the legs. Another factor suspected by researchers is something intrinsic to SCI is the cause of the speed at which osteoporosis appears after SCI. Soon after SCI, the body begins to lose minerals in the urine, particularly calcium and phosphorous (evidence of bone breakdown), at a different pace and order compared to mineral loss in bed-ridden non-SCI people.

What increases my risk of getting osteoporosis?

Apart from natural ageing and spinal cord injury. There are a number of factors that can increase your risk of developing osteoporosis including:

- Heavy smoking or excess alcohol intake
- · Low body weight
- Presence of a disease that directly deteriorates the skeleton, like arthritis
- · Long-term use of corticosteroids tablets to treat arthritis and asthma,
- Medical conditions that affect absorption of food, such as Crohn's disease, coeliac disease or ulcerative colitis
- Family history of osteoporosis.

How can I reduce my risk of getting osteoporosis?

The combined impact of SCI-induced osteoporosis and menopause may not be conclusively proven; SCI women should still take steps to prevent the onset of post-menopausal, accelerated osteoporosis by increasing your intake of calcium-rich foods, and eating more greens like spinach, broccoli, and iceberg lettuce, which are high in Vitamin K – one of the major bone-strengthening vitamins. You may also take a consider taking a calcium supplement to ensure you get the 1200 – 1500 mg recommended calcium intake for postmenopausal women.

Avoid eating processed foods because they are high in sodium and phosphorous which increase calcium excretion from the body. Avoid calcium robbers like caffeinated beverages, sugar and salt.Caffeine acts like a diuretic, increasing the amount of calcium you lose in your urine.

Consume alcohol moderately because it inhibits calcium absorption, interrupts oestrogen production and may decrease your liver's ability to activate Vitamin D.

Take regular weight-bearing exercises. If you already have osteoporosis, you still can prevent further damage by strengthening the remaining bone structure and preventing further thinning or loss of bone mineral density.





How is osteoporosis treated?

Treatments for osteoporosis include:

Hormone replacement therapy (HRT)

Oestrogen has been proven to reduce the risk of osteoporosis if used in the long-term. The benefits and risks of HRT must be considered before beginning the treatment. This approach may pose an added risk of blood clotting, so those who are considering HRT should consult with their GP to weigh the pros and cons.

Biphosphonates

Switch off the cells that break down bone and encourage bone rebuilding to take over. They include drugs such as alendronate, risedronate, cyclical etidronate, raloxifene or strontium ranelate.

Calcitonin

A naturally occurring hormone made by the thyroid gland, which is usually administered as a nasal spray and regulates the calcium levels in the blood. It does this by acting on the skeleton.

Calcium and vitamin D supplements

Especially useful for those on a limited diet or who are housebound.

Selective oestrogen receptor modulator (SERMs)

A new type of drug that acts like a synthetic form of hormone replacement. They mimic the action of oestrogen on bone and help keep it strong without affecting the breast or womb tissue. Consequently long-term use of one of the SERMs, Raloxifene, does not carry the risk of developing endometrial or breast cancer.

Where can I go for more information?

Royal Osteoporosis Society St James House Lower Bristol Road Bath BA2 3BH General enquiries: 0808 800 0035 W: <u>www.theros.org.uk/</u> @: info@theros.org.uk

Provides help and support to people with Osteoporosis, and information to the general public; supports research into the condition. Membership currently £10 p.a. for people with osteoporosis and £15 p.a. for others. Produces leaflets including information on diet and exercise, and how individuals can prevent the onset of osteoporosis. Network of regional support groups.





Osteoporosis Support Trust 26 Doniford Road Williton Taunton Somerset TA4 4SE T: 01984 639 416 W: <u>www.ost.org.uk</u> @: info@ost.org.uk

A registered charity promoting research into the causes and treatments of infantile osteopetrosis and providing support, advice and information via telephone, letter, email and putting families in touch with each other. Can provide some financial help to families in certain situations, in addition to support after diagnosis and linking families.

CANCER

of the body.

Cancer is when the cells in your body begin to grow in an uncontrolled fashion, usually because the genes whose function is to tell the cells how to behave are either damaged or lost. The cells contain faulty instructions and do not behave in a normal manner; they do not stop reproducing which causes a lump called a tumour. If this is left untreated, it could invade the surrounding normal tissues or put pressure on other bodily structures and cause damage. There are two types of cancer: benign and malignant.Benign tumours are not cancerous and do not spread to other parts

Breast Cancer

Breast cancer is the most common cancer among women and accounts for more than 30 percent of female cancers, affecting one in nine women at some point in their life. It is imperative that SCI women have regular breast examinations. Whilst SCI does not increase the risk of breast cancer, some effects of SCI (like reduced sensation, less likelihood of bearing children) can place SCI women in the high risk category.

What warning signs should I be looking out for?

It is recommended that women over 20 years should carry out monthly breast self-examinations comprising of two steps:

- Visual inspection
- Palpitation/touch.





Research evidence shows the majority of breast lumps are discovered during their self-examinations. If you are a tetraplegic woman, you can make your own visual inspection; if you have reduced sensation your partner, friend or caregiver can help to carry out a thorough examination. Any lumps, pain, changes in skin texture or colour or nipple discharge should be reported immediately to your GP. Your GP may then refer you to a Breast Awareness Clinic, where you will receive a Triple Assessment which involves:

- Clinical breast examination
- Diagnostic mammography(taking x-rays of the breasts)
- Biopsy (taking a small tissue sample of the breast).

How is breast cancer treated?

If breast cancer is detected, the primary treatment would be to eliminate the tumour and any other cancer cells that may be in the breast or elsewhere in the body.

The treatment may include one or a combination of:

- Surgery
- Radiotherapy (use of high energy rays to kill cancer cells)
- Chemotherapy (treatment with anti-cancer drugs)

If the cancer has spread to various parts of the body, it has become 'secondary breast cancer' and will require a different treatment.

What can I do to reduce my risk of getting breast cancer?

There are certain lifestyle choices and physiological factors that can make you more prone to developing cancer:

- Getting older- 80 percent of breast cancers cases are in post-menopausal women
- Having children late in life (those over 35 are at the highest risk), or not having any at all
- Start menstruating early in life or have a late menopause (after the age of 55)
- Receiving hormonal replacement therapy
- A significant family history of breast cancer
- Obesity in postmenopausal women.

To reduce your risk of developing breast cancer:

- Take some regular exercise and stay in shape
- Limit your alcohol intake to 2 units each day
- Go for breast screening which is made available for all women over age 50. You will be invited by your doctor every 3 years until you are age 70, after which you will have to contact your doctor/breast screening unit for a breast screening appointment.





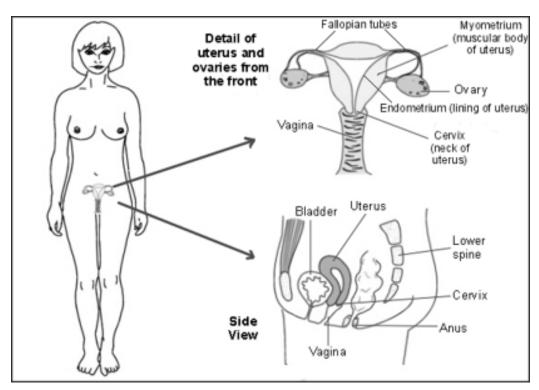
Ovarian Cancer

This type of cancer affects the epithelial (surface) layer of the ovaries and does not necessarily present any symptoms until it is in its advanced stage. As with most cancers, the precise causes of the cancers are not yet known but there are certain risk factors that come into play including:

- Most cases occur in women over 50 years.
- Immediate family member with breast or ovarian cancer or if you yourself have had breast cancer.
- Starting periods late or menopause early.
- Some studies show that taking fertility drugs, using talcum powder on genital area and taking HRT increase risk of developing ovarian cancer but the results have not been conclusive and further research is required.

What reduces the risk of getting ovarian cancer?

- Your risk of developing ovarian cancer may be reduced by the following factors:
- Taking oral contraceptives is thought to lower your risk of developing ovarian cancer quite considerably.
- Having two or more children and breastfeeding may lower your risk.
- Having a hysterectomy or having your tubes tied (tubal litigation) may lower the risk.
- Some research suggests that a diet high in vegetables and low in animal fat may have some protective factor.



Picture 1: Female reproductive system (www.patient.co.uk)





How can I tell if I have ovarian cancer?

Early symptoms of ovarian cancer are often indiscernible, making it much harder to detect. Some of the early symptoms may include:

- Abnormal vaginal bleeding
- Abdominal pain and swelling
- Pain during sexual intercourse
- Unexplainable indigestion, gas or bloated feeling that is not relieve with over-the-counter medicine
- Unusual feeling of fullness or discomfort in the pelvic region.
- Irregular periods
- Constipation
- Back pain
- Passing urine more frequently than usual

Remember that although these symptoms may not always indicate ovarian cancer, you should still consult your doctor as a precaution and get a thorough check-up.

Remember that although these symptoms may not always indicate ovarian cancer, you should still consult your doctor as a precaution and get a thorough check-up.

Since the symptoms of ovarian cancer are so vague, your doctor would feel your tummy to determine if you have:

- Pain
- Abdominal swelling or bloating
- Constipation
- Back pain
- Urinary symptoms

If your doctor has any cause for concern, a full pelvic examination would be carried out. If there is a lump in your pelvis which is not fibroids, an urgent transvaginal ultrasound scan (ultrasound probe is put inside the vagina) will be carried out.

If you have a family history of ovarian cancer, a blood test to see if you have higher levels of the ovarian tumour marker (a protein called CA-125) associated with women with ovarian cancer.

How is ovarian cancer treated?

In most cases doctors advise surgery for the treatment of ovarian cancer. Usually, unless you have very low grade cancer the womb and ovaries have to be removed to prevent reoccurrence and spread of the tumour. Some women are given radiotherapy or chemotherapy to kill of the cancerous cells.





Cervical Cancer

This type of cancer begins in the lining of the cervix (another name for the neck of the uterus or womb), which connects the uterus with the vagina. It is usually slightly shut with only a small opening to allow sperm to enter for fertilisation and the escape of menstrual. The part of the cervix closest to the body is called the endocervix, and the part farthest is called ectocervix.

Cervical cancers form gradually; the cancerous cells going through stages known as dysplasia, in which the abnormal cells begin to appear in the cervical tissue. Later the cancerous cells continue multiplying and spread more deeply into the cervix and surrounding tissue.

What warning signs should I look out for?

At first there are no obvious symptoms, and the rate of growth is slow; if left untreated the cancer will spread to nearby organs.

There are no distinctive symptoms that set cervical cancer apart from other gynaecological disorders but do consult your doctor if you experience any of the following problems:

- Vaginal bleeding
- Unusual vaginal discharge
- Pelvic pain
- Pain during sexual intercourse

How is cervical cancer treated?

The main types of treatment are surgery, radiation and chemotherapy; depending on how far the cancer has advanced. For early cervical cancer, a hysterectomy is usually carried out; all of the womb, the surrounding tissues that keep it in place, the lymph nodes and top of the vagina are removed.

If it is very early cervical cancer, most of the cervix is removed; enough is left behind to allow for future pregnancy and childbirth. Advanced cervical cancer surgery will depend on an individual. Since the cancer would be quite widespread at this stage, other surrounding organs such as the bowel, bladder or rectum and their corresponding lymph nodes may also have to be removed.

What puts me at high risk of getting cervical cancer?

The sexually transmitted human papillomavirus (HPV) is the primary risk factor for cervical cancer. This infection usually causes no other symptoms other than some barely visible genital warts if it occurs in the outer genital area. These genital warts and any others on the cervix can be destroyed, preventing them from developing into cancer.





Currently there is no cure or treatment for the HPV infection itself; usually the infection disappears if the woman's immune system is not compromised and she is able to fight the virus. An HPV vaccine is being researched and may result in vaccinations being available in the future.

It is thought it is necessary to have had HPV for cervical cancer to develop although the majority of women with HPV do not develop cervical cancer. Research now shows that other factors must come into play for cancer to develop including:

- Sexual History Certain types of sexual behaviour increase a woman's risk of developing HPV infection including having sexual intercourse at an early age and having numerous sexual partners.
- Reproductive History Women who have had multiple full-term pregnancies (7 or more) have an increased risk of developing cervical cancer, probably due to a higher exposure to HPV.
- Oral Contraceptives Using oral contraceptives for 5 years or more slightly increases risk of developing cervical cancer.
- Diet Non-conclusive studies have suggested that overweight women and women who do not eat adequate fruits and vegetables are at a higher risk of developing cervical cancer.
- Family History Women who come from families that have a significant number of family members having developed cervical cancer are more susceptible as research suggests they may be less able to fight off the HPV infection.
- Smoking Smoking exposes many women to carcinogens (cancer-causing substances) Studies have shown that tobacco by-products have been identified in the cervical mucus of smokers. Research states that women who smoke are twice as likely as non-smokers to develop cervical cancer.
- Screening frequency Women do not have regular cervical smear tests have an increased risk of cancer. For more information regarding the cervical smear test, please contact the SIA Helpline and request the SIA Cervical Smear Test factsheet.

How is cervical cancer diagnosed?

The following procedures may be used:

Cervical smear test

Under the NHS Cervical Screening Programme, all women between the ages of 25 and 65 are regularly invited for a smear test. The system is automated, so as long as you're registered with a GP you should receive a letter asking you to make an appointment.





As a result of research that evaluated the optimal frequency for cervical screening, women are now invited for their first test at 25. They are then invited every three years until the age of 49, and every five years from 50 to 64.

From 65, only those who have had recent abnormal tests are offered another test.

What does it involve?

During a smear test, some cells are taken from the cervix. These are sent to a laboratory for examination under a microscope. To be able to judge the cells properly, this is best done in the middle of your menstrual cycle, halfway between one period and the next.

The doctor or nurse will insert an instrument called a speculum into the vagina to allow them to see the cervix. A spatula is then wiped or scraped over the surface of the cervix to remove some cells, which are then transferred to a glass slide. The doctor or nurse may also do an internal examination to check for any problems.

The procedure can be uncomfortable but should not be painful. Try to relax. Talk to the doctor or nurse if you are worried.

Liquid-based cytology

A new test called liquid-based cytology (LBC) is being introduced. This involves collecting the cells from the cervix using a plastic brush rather than a spatula. The cells are then put in a small vial of liquid and sent to the lab. This allows the laboratory staff to get a clearer look at the cells, reducing the rate of inadequate smears from about nine

This allows the laboratory staff to get a clearer look at the cells, reducing the rate of inadequate smears from about nine per cent to just one to two per cent, so fewer women need a repeat test.

The results

You should receive the result of your smear test in writing within six weeks. The result will be either normal (negative) or abnormal. A small proportion of tests can't be completed because of a lack of visible cells on the slide. In such cases, you will be invited for a repeat test.

An abnormal test does not necessarily mean cancer has been found or that it's likely to develop. The laboratory has simply identified some changes in the cells that require further investigation. In many cases, these are just minor abnormalities that would disappear without treatment. However, a few will progress to cancer, which is why further investigation is warranted.

Abnormal cells are scaled from borderline normal ('not quite right') through mildly abnormal, severely abnormal to invasive cancer. Depending upon the degree of abnormality, women may be asked to have a repeat smear in six or 12 months or referred for a further test of the cervix known as a colposcopy.

Many women are worried about visiting their doctor because of embarrassment, fear of the smear test or just do not bother because they do not think it will happen to them. Do not let any of these reasons put you off having a cervical smear test, least of all because of access problems.





If you can't visit your GP there is no reason your GP cannot visit you at home to carry out the smear test; no special or bulky equipment is required.

A real problem for disabled women is the practical difficulty of getting a suitable smear sample taken by your doctor because you're severely paralysed. If your doctor isn't able to get a proper smear from you, you can be referred to a gynaecologist.

If you visit your spinal injury centre regularly for check-ups, there is no reason you cannot have a cervical smear test at the same time. Many spinal cord injured women feel more comfortable in a spinal unit where the staff understand their mobility restrictions. However, you would have to take the initiative and ask for this test as most spinal units have no policy on including internal examinations or cervical smear testing in regular check-ups.

All women are encouraged to have regular smear tests, and disabled women are no exception. It is also important to talk through any difficulties you may have with your own GP (who is responsible for your total health care). Your GP can arrange to have help available in the surgery or make a home visit.

If the cervical smear test comes back positive (abnormal cells are present), your doctor may recommend that you take the following tests:

- Colposcopy A procedure where your doctor examines the cervix using a thin, lit tube called a colposcope (comparable to a magnifying glass). The doctor opens the vagina with a speculum and examines the surface of the cervix for abnormal cells using the colposcope.
- Cone biopsy if the abnormal cells are too far up the cervical canal to be properly examined, the doctor may recommend a cone biopsy to remove a cone-shaped sample of cervical tissue under general anaesthesia.

Different cancers have different risk factors; having a risk factor or several, does not necessary mean you will develop the disease.

Although risk factors increase the odds of a woman getting cancer, many women do not develop this disease. Going for cancer screening regularly can help you prevent cancer or at least detect it early and have a better chance of overcoming it.

You should consider the risk factors you can change such as lifestyle choices like smoking, diet, and exercise, and so forth rather than dwelling on those that you cannot control such as genetics.





Where can I go for more information?

Breast Cancer Care

Kiln House 210 New Kings Road London, SW6 4NZ Helpline: 0808 800 6000 (Mon-Fri 9am-5pm, Sat 9am-2pm) W: <u>www.breastcancercare.org.uk</u> @: info@breastcancercare.org.uk

Breast Cancer Care is the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer or breast health concerns.

Cancer Research UK PO Box 123 London WC2A 3PX T: 0300 123 1022. W: <u>www.cancerresearchuk.org</u> @: supporter.services@cancer.org.uk.

Cancer Research UK provides free, comprehensive information for anyone affected by cancer.Find up to date information about all aspects of cancer, the latest research and clinical trials atwww.cancerhelp.org.uk Ask a specialist cancer nurse about any aspect of cancer on Freephone: 0808 800 4040

Cervical Cancer Community- Jo's Trust Weedon Villa Everdon Northamptonshire NN11 3BQ T: 00808 802 8000 W: <u>www.jotrust.co.uk</u> @: info@jostrust.org.uk.

Provides online cervical cancer information and counselling. Their aim is to make your search for information about precancer and cancer of the cervix simple and effective.





NHS Cancer Screening Programmes Fulwood House Old Fulwood Road Sheffield S10 3TH T: 0114 271 1060 W: <u>www.cancerscreening.nhs.uk/index.html</u> @: info@cancerscreening.nhs.uk

The NHS cervical screening programme produces basic information about smear tests that is available in 13 languages. You can download their publications from their website.

Ovacome (Ovarian Cancer Support) PO Box 6294 London W1A 7WJ Support: 0800 0087054 T: 02072996654 (Admin) W: <u>www.ovacome.org.uk</u> @: ovacome@ovacome.org.uk

Website link goes to a support group by the same name in Florida, so adding UK is very important. A nationwide support group for all those concerned with ovarian cancer, involving sufferers, families, friends, carers, and health professionals.

Acknowledgement to:

- Women's Health <u>www.womenshealthlondon.org.uk</u>
- Cancer Research UK 'Specific Cancer' online publication <u>www.cancerhelp.org.uk.</u>

National Cancer Institute Public Inquiries Office Cancer Information Service Room 3036A 6116 Executive Boulevard MSC 8322 Bethesda MD20892-8322 W: <u>www.cancer.gov</u> @: cancergovstaff@mail.nih.gov





For general information regarding women's health, you may wish to contact the following organisation:

Women's Health Concern Ltd Whitehall House 41 Whitehall London SW1A 2BY Helpline: 01628 890199 (Mon-Fri,9-5, local rate) W: <u>www.womens-health-concern.org/index.php</u> @: counselling@womens-health-concern.org

A charitable organisation which aims to help educate and support women with their healthcare by providing unbiased, accurate information.

Advice through helpline managed by experienced nurse counsellors and backed up by a team of eminent medical advisers. Referral to other specialist organisations where appropriate.

For more information, contact us at:

Spinal Injuries Association, SIA House, 2 Trueman Place, Milton Keynes, MK19 6HY

0800 980 0501 (freephone support line open Mon-Fri 10.00am-4.30pm) sia@spinal.co.uk





About SIA

Spinal Injuries Association (SIA) is the leading national charity for anyone affected by spinal cord injury. We have specialist support available, for free, to support you through the mental and physical challenges you may face, both now and for the rest of your life.

Our support network is coordinated by a team of people, across the UK, who can put you in touch with our network of experts and trusted partners, covering all aspects of mind, body and life, to help you move forward with life. Our partners specialise in services such as legal, care, housing, finance, mental health and much more.

We are the voice of spinal cord injured people, through our expertise and we can connect you to the services and organisations you need through our network for all.

You can join the SIA community by signing up for free online at www.spinal.co.uk.

Disclaimer

This factsheet has been prepared by SIA and contains general advice that we hope will be useful. Nothing in this factsheet should be construed as giving specific advice, and it should not be relied on as a basis for any decision or action. SIA does not accept any liability arising from its use. We aim to ensure the information is as up-to-date and accurate as possible, but please be warned that certain areas are subject to change from time to time. Please note that the inclusion of named agencies, companies, products, services or publications in this factsheet does not constitute a recommendation or endorsement.

Review November 2021