

Women's Health and Multiple Sclerosis



Written by Chloe Neild

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COVER ARTWORK

Jürgen Ludwig Callas, Watercolours

Jürgen Ludwig's interest in watercolours began in his early school days, but long hours in his profession as an hotelier never left him time to pursue it. Following Jürgen's diagnosis of MS, he was unable to continue playing tennis, jogging, hiking and biking, the activities and sports he relied on. With the love and support of his wife Sandra, Jürgen discovered new hobbies and sports. This is when he found his passion for painting. Thanks to Gibson's artist Lenore Conacher, his teacher and now mentor, he gravitates to his painting table daily. It is there, through art, that he meditates, creates and finds peace, satisfaction and accomplishment.

"Life on any latitude is merely a matter of attitude. Attitude, be it positive or negative, is a choice you take and give."

To see more of Jürgen's work, please visit his website at www.abstractwatercolouroriginals.com

Jürgen donates a portion of the proceeds made from the sale of his art to the MS Society of Canada.

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FOREWORD

MS affects more women than men and is most frequently diagnosed in women in their twenties and thirties. It is not known why this is the case but the reasons are thought to be complex. There are a number of issues that specifically concern women with MS. Why are more women affected? Do hormones play a role? Does menstruation make symptoms worse? Will medications affect the ability to become pregnant? Will the condition affect pregnancy or childbirth? Will MS impact on hormone replacement therapy and the symptoms of menopause?

In this publication, these questions, and many others, are answered

MS AND HORMONES

MS is thought to be an autoimmune illness, and like many other autoimmune conditions, affects more women than men.¹ In Canada, the ratio of women to men with MS is about 3:1 and is most frequently diagnosed in pre-menopausal women. This has caused many people to ask if hormones play a role. Female hormones — estrogen and progesterone — affect much more than a woman's reproductive system. It is thought they may also influence the immune and nervous systems, and, some scientists believe that they play a role in MS, though research has yet to show what this role might be.¹,²,³,⁴

Women also have the hormone testosterone in their bodies. One small study reported that women with MS may have lower levels of testosterone than women without MS, but showed no significant difference in the levels of testosterone between men with and without MS.⁵ There have been no large scale studies in this area, and more research is needed to see if the endocrine system — the bodily system that produces hormones — is compromised in people who have MS.

MENSTRUATION

Women with MS often report that their symptoms feel worse around their menstrual periods, but there is little research data available about the effect of menstruation on MS. In one study a questionnaire was given to 149 women; of these women, 70 per cent noted that their MS symptoms seemed to change at a regular time in their cycle. They reported that the changes, usually involving a worsening of symptoms, occurred up to seven days before, and up to three days into, their period. Symptoms most commonly affected were weakness, imbalance, fatigue and depression.

While other small studies have produced similar results, more research is needed to confirm the relationship between MS and menstruation.^{7,8} Worsening of symptoms around a woman's menstrual periods may be related to other factors such as heat. It is well known that just before a menstrual period, and during the second half of a women's menstrual cycle, the core body temperature rises by about one degree Celsius. This increase in temperature can make MS symptoms feel worse in the same way that hot environments and fevers can.

Effects of drugs on the menstrual cycle

Certain drugs used to treat MS symptoms can cause irregular periods. These include a group of antidepressants called selective serotonin reuptake inhibitors (SSRIs).

Mitoxantrone, a drug sometimes used to treat progressive forms of MS, has been known to cause some menstrual irregularities. Beta interferon can also cause problems such as 'spotting' in between periods. If you experience any side effects, it is a good idea to mention them to your doctor or MS nurse. However, these side effects often improve on their own after several months of taking the treatment.² Natalizumab (Tysabri®) may also cause menstrual irregularities; meanwhile, glatiramer acetate (Copaxone®) has no known effects on menstruation.

Problems with managing menstrual periods

Some women with MS find that managing periods can become problematic or difficult. For example, some may find using feminine hygiene products becomes awkward due to symptoms such as tremor or limited mobility in the arms, yet would rather not have help with this task. If dealing with periods becomes problematic, you may consider ways of minimizing periods or even stopping them altogether. There are various ways of doing this, such as using certain types of contraceptive pill or hormone-based intrauterine devices (sometimes known as 'IUDs'). If you are considering this, it's important to discuss all the options with your physician.

CONTRACEPTION

As MS doesn't affect fertility, the usual decisions about birth control need to be made. Finding the right method of contraception is important for all women, and women with MS can generally use any of the contraceptive methods available.

When considering contraception, it is important to find an MS nurse or doctor who you feel comfortable talking to, and be aware that you can always ask to be referred on to a specialist clinic. When making choices about contraception it's a good idea to consider factors such as manual dexterity and coordination, other medications you are taking, possible risk of infections, as well as your personal preferences. It is also important to discuss your options with a doctor as some methods of contraception may not be appropriate in your individual case or you may need additional precautions.

For example, diaphragms may increase the likelihood of urinary tract infections and may not be advisable if you have bladder problems. They can also be difficult to insert if you have limited dexterity. If you have limited mobility and choose oral contraceptives, you may need extra monitoring as there is an increased risk of blood clots occurring in the veins located in the legs. The usual checks on weight, smoking and so on will also be needed, as they would for any other woman contemplating oral contraceptives.

Contraceptive pills

There is a very low risk of pregnancy associated with oral contraceptives, and many women find either the combined pill (estrogen and progesterone-based) or progesterone only pill suits them. Women need to be aware that certain medications for MS symptoms, such as Tegretol® (carbamazepine) used to treat spasms and pain, and Modafinil® to treat fatigue, can make the contraceptive pill less effective. The same applies for certain complementary therapies, such as St John's Wort (Hypericum extract) used for depression. Antibiotics can also affect the way contraceptive pills work. You should therefore talk to your doctor or MS nurse about any other medications you are taking, so they can assess potential interactions or if there is a need for additional protection (such as condoms or other barrier-type contraceptives).

Contraceptive Injections

Progesterone injections are available on a three-month basis and are also very effective, but may not be suitable for all women.

Research on oral contraceptives and MS

Women can be reassured that there is no research to show that oral contraceptives have an effect on the risk of developing MS.^{1,4} Research regarding the effects of oral contraceptives on relapse rate is less clear. While one study has suggested that oral contraceptives may delay first clinical attacks of MS, another study found oral contraceptives have no protective effect.^{9,10} Again, more research is needed to establish the relationships between hormones, such as estrogen and progesterone that are found in oral contraceptives, and MS.

All hormone based types of contraception can have side effects, so it is important to discuss these options with your doctor.

SEX, INTIMACY AND RELATIONSHIPS

Nerve damage caused by MS can have an impact on sexual function, and the symptoms of MS can affect sexual activity. These physical problems with sex and the impact of MS on people's feelings about sex and relationships are discussed in more detail in the MS Society of Canada publication *Intimacy and Sexuality in Multiple Sclerosis*.

DECIDING TO HAVE A BABY

The majority of women who have MS are diagnosed in their twenties and thirties, at a time when they may be thinking about starting a family. The major factors in the decision to become pregnant for women with MS are likely to be the same as for other women: how will having a child affect my life and is this the right time? It is a very personal decision and when thinking about it consideration should be given to current and future emotional, financial and medical factors.

Having MS is no reason not to have a baby, although it may mean that careful planning with family, friends and your doctor becomes more important. It will help if you find a health professional such as a doctor, neurologist, MS nurse or obstetrician who will discuss any issues or concerns with you in a supportive manner.

PREGNANCY

Does MS affect my ability to get pregnant?

MS does not affect women's fertility. However, some drugs used to treat MS may have an effect on the menstrual cycle; and some medications are unsafe during pregnancy. If you are taking any medications, and you decide to try for a baby, the usual advice is to wait at least three months after stopping treatment before trying to conceive. It is important to discuss your medications with your doctor before making any changes as it can be dangerous to stop taking some medications suddenly.

MS itself does not affect sperm production in men. However, some men with MS may experience erectile problems and difficulties with ejaculation. There are also some treatments for MS that have been reported to lower sperm counts, 11 and some symptomatic treatments, including antidepressants, can affect ejaculation. There are, however, various methods to allow sperm to be collected and used for insemination.

You can discuss the different options with your doctor, who can also refer you to a fertility clinic if necessary. For more information about these problems and how to manage them, see the MS Society of Canada publication *Intimacy and Sexuality in Multiple Sclerosis*.

What are the risks of my child having MS?

Unlike conditions such as cystic fibrosis or Huntington disease, MS is not directly inherited. The general population in North America runs about a 1-2% risk of developing MS. When a parent has MS, the risk of the child and siblings developing MS is small, increasing to between 3 and 5%. In other words, 95 to 97% will not develop MS. If both parents have MS the risk for offspring developing MS jumps to about 30%. ¹²

How will having MS affect pregnancy or giving birth?

Having MS will not directly affect pregnancy, labour or giving birth.² Several studies have shown that mothers with MS are just as likely as any other mothers to have healthy pregnancies and babies, and there is no research to show MS may increase risk of ectopic pregnancy (where a fetus develops in the fallopian tube), miscarriage, premature birth, still-birth or birth abnormalities.^{2, 13}

It is generally advised that, as with other women, natural birth is a good option. Having MS does not mean there is a need for a caesarean section.¹³ During birth itself, problems with weakness, spasms or stiffness in the legs can be managed with the assistance of the nurse or midwife. Many women opt for having an epidural for pain relief during birth. Both epidurals, and anaesthetics for caesarean births, are as safe in women with MS as in those without.^{14, 15}

Pregnancy and relapses

There have been many research studies examining the impact of pregnancy on MS. They all show that pregnancy appears to have a positive protective influence, with relapse rates going down, especially during the third trimester (that is between six and nine months). The reasons for this are not fully understood, but it is thought that hormone levels play a role. Improvements during pregnancy may also relate to the fact that immune system activity is lowered in pregnant women to stop them from rejecting the baby. Just 1997.

Similar effects are seen in women with other autoimmune conditions.¹³ However, in the first three months after the baby is born, the risk of relapse rises.^{1, 17} This is thought to occur as hormones return to pre-pregnancy levels. Research suggests that these post-pregnancy relapses do not increase long-term levels of disability.¹³ In other words, pregnancy has no effect on the progression of MS in the long-term, rather the overall effect is neutral.

Symptoms and pregnancy

Although women may have fewer relapses during pregnancy, other MS symptoms can be affected. Many women report that their fatigue becomes worse during pregnancy, but this can be managed by careful time planning. Balance and back pain can also get worse during pregnancy, as the extra weight of carrying a baby can cause a shift in the centre of gravity. Walking aids may be useful at this time and help prevent stumbles and falls. Any preexisting bladder and bowel problems may also feel worse or become aggravated during pregnancy. A continence nurse or adviser can offer advice on how to manage these symptoms.

Medications and pregnancy

Before you start trying for a family, you should talk to your doctor about your symptoms and any medications you are taking. As some medications are not advised during pregnancy, your doctor may wish to review your prescriptions. If you find you become pregnant unexpectedly and have not had your medications reviewed, it is important that you consult your doctor as soon as possible.

When determining whether you should stop taking a medication during pregnancy, the doctors will look at the risks that this would pose to you and the baby. However, the risks of many medications during pregnancy are unknown, as it is unethical to carry out clinical trials to assess the effects of drugs on developing fetuses. The evidence of harmful effects in

humans comes from a small number of cases where a woman has become pregnant when taking a particular medication.

In the case of disease modifying drugs, two research studies have looked at the effects of beta interferon during pregnancy. One found there may be a slight increase in miscarriages when a woman has taken beta interferon during pregnancy, ¹⁸ the other found there was no significant difference. ¹⁹ As there is still limited information in this area, women are advised to stop taking disease modifying drugs, including beta interferons (Betaseron®, Avonex® and Rebif®), glatiramer acetate (Copaxone®), or natalizumab (Tysabri®) at least three months before trying to get pregnant. ^{15, 16, 19}

If you do become pregnant while taking disease modifying drugs, you should consult your doctor as soon as possible. Steroids are considered to be relatively safe during pregnancy. They are, however, generally avoided during the first three months when fetal organs are developing and extra caution may be needed. In case of medications for other health conditions or symptoms, the general rule is to err on the side of caution.

However, if coming off medications would pose a serious risk to mother or baby, doctors may advise that they should be continued, or opt for alternative drugs. Your doctor or other health care specialists may be able to advise you of ways to manage the symptoms that do not involve medication. All treatments can be resumed immediately after giving birth, although some may not be appropriate if you choose to breastfeed.

PLANNING FOR AFTER THE BIRTH

Whether or not you have MS, the period immediately after the birth can be very tiring and it can take time to adapt to the demands of having a baby to care for. For women with MS, planning to ensure there is support during this time is particularly important. You may wish to contact and make lists of family and friends who can help with specific tasks, and find out about health services, local service provisions for mothers and support groups. Many women find it reassuring to know local sources of support are available, and find early planning makes life easier when the baby is born.

Is it possible to breastfeed?

MS should not prevent a woman from breastfeeding her baby. It is good nutrition for babies and it is generally recommended women breastfeed for the first six months (26 weeks). Breastfeeding can help build a baby's immune system; as well providing other health benefits for both mother and child.²⁰ Mothers with MS can be reassured that there is no increased risk of relapses associated with breastfeeding.²¹

Some mothers with MS may choose to breastfeed for a shorter time of three or four months as they find it contributes to fatigue. Alternatively, bottle feeding may make it a little easier to get help from others, which some women find essential in order to allow them longer stretches of sleep so they can in turn cope with their fatigue.

If you are planning to breastfeed, you may also wish to seek advice on specialized techniques such as positioning, as some MS symptoms may make standard breastfeeding positioning uncomfortable.²¹ You will also need to review your medications with your doctor as some medications are not appropriate because of a risk they may be passed on to the baby via breast milk.¹⁵ For example, women are advised not to breastfeed if they are taking disease modifying drugs as they may be excreted in breast milk. In such cases women may wish to delay returning to using disease modifying drugs and breastfeed for a few weeks — which is still beneficial. Alternatively, women may wish to bottle feed from birth and can be reassured that bottle feeding provides babies with all the nutrition they need.

Managing relapses after the birth

Some women choose to return to using disease modifying therapies very soon after the birth as they may reduce the number of relapses. However, this is not appropriate if breastfeeding. If you would rather breastfeed your baby, but are concerned about relapses you are experiencing, moderate doses of some steroids, such as prednisone, are considered to be a safe treatment option.²¹

Given the increased risk of relapses in the first couple of months after the birth, when nearly all new mothers are feeling particularly tired anyway, it is important for extra help and support to be made available. You might find it useful to plan how family, friends and social services could help in advance. Health visitors, community based children's centres and local disability organizations can also help.

MENOPAUSE

Menopause is a time of hormonal upheaval and for many women, with or without MS, it can be a difficult time. During menopause the body stops producing estrogen in any significant quantity. There is no evidence to show this has either a positive or negative effect on relapse rate or progression of MS. Certain symptoms, such as fatigue and bladder problems, can however, feel worse.

Hormone replacement therapy

Some women question whether hormone replacement therapy — which replaces estrogen — can help with MS symptoms during menopause. One small study showed that among 19 post-menopausal women with MS, 54 per cent reported a worsening of symptoms with menopause, and 75 per cent of those who had tried hormone replacement therapy felt their symptoms had improved.²²

Hormone replacement therapy is, however, not suitable for all women. In particular, it is not recommended for women with a history of heavy smoking, thrombosis, certain cancers, or severe heart, liver or kidney disease. Hormone replacement therapy is also associated with an increased risk of developing breast cancer, heart disease and stroke.⁴

Therefore, it is generally advised that women only take hormone replacement therapy if they are having difficulty in dealing with the symptoms of menopause. It is recommended that women who decide to take hormone replacement therapy have regular health checks and mammograms. For women with MS there are some additional issues to be considered when deciding whether hormone replacement therapy may be suitable. Periods of immobility, lack of exercise and prolonged use of steroids can increase the risk of osteoporosis. Hormone replacement therapy can help with this as it can reduce further bone loss. Where women are severely disabled, perhaps using a wheelchair much of the time or having prolonged bed rest, there may be an increased risk of thrombosis or blood clots, so hormone replacement therapy may not be suitable.

All types of hormone replacement therapy can be used by women with MS (pills, patches and gels), though pills may not be advisable for those with swallowing or dexterity problems. All women considering hormone replacement therapy should consult their doctor, MS nurse or other health care professional before making a decision.

OSTEOPOROSIS

Osteoporosis can be a problem for some women with MS. This is particularly the case for women who are less mobile. There are many ways you can help prevent osteoporosis including eating a healthy diet and regular exercise. The MS Society has publications on both these topics, and Osteoporosis Canada can also provide more information (1-800-463-6842, www.osteoporosis.ca).

MS, DISEASE MODIFYING DRUGS AND CANCER

Some women have asked whether there is any link between MS, disease modifying drugs and cancer. This area has been researched and there is no evidence to show increased rates of cancer, including women specific cancers, linked to MS or to current disease modifying drugs.²³

FURTHER READING

Multiple Sclerosis and Having a Baby by Judy Graham. Published by Healing Arts Press, Rochester, Vermont, USA (1999), ISBN 9780892817887.

This book covers everything from conception and pregnancy to parenthood. It also offers practical advice, and explores the issues of sexuality and the impact of MS on relationships.

The Disabled Woman's Guide to Pregnancy and Birth by Judith Rogers. Published by Demos Medical Publishing, New York, USA (2006), ISBN 1932603085.

This comprehensive and useful American guide is based on real-life experiences of women with disabilities who have chosen to have children. Over 90 women contributed, including eight with MS.

Multiple Sclerosis, A Guide for Families Third Edition. by Rosalind C. Kalb, Ph.D. Demos Medical Publishing: 2006 Third Edition ISBN: 1-932603-10-7

This guide discusses a wide range of topics including, emotional and cognitive issues, family relationships, sexuality, pregnancy and childbirth, parenting, caregiving, and financial concerns.

RESOURCES

To obtain additional information regarding any of the topics discussed in this publication, please contact your local MS Society of Canada division or chapter office, or visit **www.mssociety.ca** for a list of MS Society of Canada publications.

Canadian Mental Health Association

A national association that promotes mental health and supports individuals living with mental illness through service delivery, education, advocacy and research.

Telephone: (416) 484-7750 Website: **www.cmha.ca**

Osteoporosis Canada

A national organization that provides support and education to individuals living with, or at risk of developing osteoporosis.

Telephone: (416) 696-2663

Toll-free (English): 1-800-463-6842 Toll-free (French): 1-800-977-1778 Website: **www.osteoporosis.ca**

Public Health Agency of Canada (PHAC)

A federal government agency that promotes and protects the health of Canadians. A comprehensive list of public health issues is provided on the PHAC website.

Website: www.phac-aspc.gc.ca

The Society of Obstetricians and Gynaecologists of Canada (SOGC)

A national medical society that produces Canadian clinical guidelines for both public and professional education on women's health issues.

Telephone: 1-800-561-2416 Website: **www.sogc.org**

Canadian Association of Family Resource Programs (FRP Canada)

A national association that offers a wide range of resources to support and enhance the well-being of Canadian families.

Telephone: (613) 237-7667 Toll-free: 1-866-637-7226 Website: **www.frp.ca**

Disability, Pregnancy and Parenthood International (UK)

Disability, Pregnancy and Parenthood International provides information and support on the topic disability, pregnancy and parenthood. The organization offers support to anyone who is disabled and has, or is thinking about having children. Information available in English only.

Website: www.dppi.org.uk

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NOTES

How to reach the MS Society of Canada Current as of August, 2009

Call toll-free in Canada: 1-800-268-7582 www.mssociety.ca

British Columbia Division

1501-4330 Kingsway Burnaby, British Columbia V5H 4G7 (604) 689-3144 info.bc@mssociety.ca

Alberta Division

#150, 9405 - 50 Street Edmonton, Alberta T6B 2T4 (780) 463-1190 info.alberta@mssociety.ca

Saskatchewan Division

150 Albert Street Regina, Saskatchewan S4R 2N2 (306) 522-5600 info.sask@mssociety.ca

Manitoba Division

100-1465 Buffalo Place Winnipeg, Manitoba R3T 1L8 (204) 943-9595 info.manitoba@mssociety.ca

Ontario Division

175 Bloor Street East Suite 700, North Tower Toronto, Ontario M4W 3R8 (416) 922-6065 info.ontario@mssociety.ca

Quebec Division

550 Sherbrooke Street West Suite 1010, East Tower Montréal, Québec H3A 1B9 (514) 849-7591 info.qc@mssociety.ca

Atlantic Division

71 Ilsley Avenue, Unit 12 Dartmouth, Nova Scotia B3B 1L5 (902) 468-8230 info.atlantic@mssociety.ca

National Office

175 Bloor Street East Suite 700, North Tower Toronto, Ontario M4W 3R8 (416) 922-6065 info@mssociety.ca



Contact the Multiple Sclerosis Society of Canada:

Toll-free in Canada: 1-800-268-7582

Email: info@mssociety.ca

Website: www.mssociety.ca

Our Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.