Becoming a MOTHER with MS

A first guide

SCLEROSI MULTIPLA
associazione italiana

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A first guide

Italian Multiple Sclerosis Society APS-ETS

Becoming a MOTHER with MS

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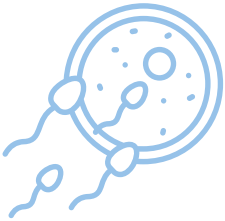
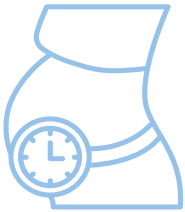




«I am 35 years old and have been diagnosed with relapsing-remitting multiple sclerosis since 2011. I live alone in a small rented apartment, I have a job, and I have an independence that I would never give up. But I wonder if it's enough for me, and lately the answer is no. Because I can hear the ticking of my biological clock in my ear. There are so many questions and doubts: the fear of new relapses, the fear of not being able to get pregnant... and above all, I wonder if I will be able to raise my child and be a good mother despite everything.»

Elisa

INTRODUCTION

Pregnancy: A Unique and Personal Journey for Women with MS

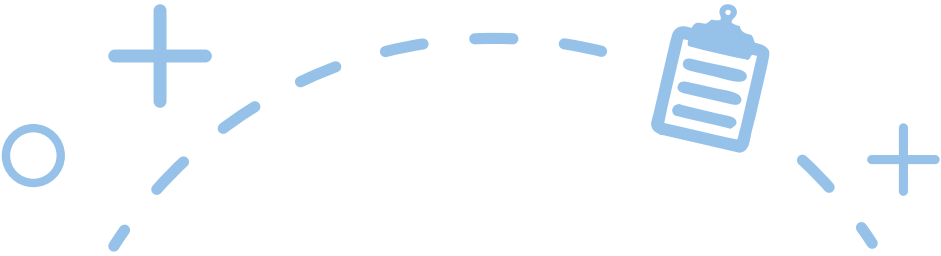
While pregnancy is a universal experience that has been shared by women for centuries, it remains an intimate, private, and deeply personal journey for each individual. The truth is, no one is ever truly ready to face the immense transformation that motherhood brings, especially when it's your first time. This is particularly true for women with chronic illnesses like multiple sclerosis (MS).

Pregnancy raises a multitude of questions for all women, but for those with MS, these doubts and fears often revolve around the limitations imposed by their condition. It is as if society questions whether women with MS can handle the significant life changes that parenthood entails. However, it's crucial to recognize that women with MS can indeed become mothers if motherhood is a deeply held value and desire for them.
The key lies in seeking guidance from a specialized multidisciplinary team. This team can collaborate with the couple to design an individualized treatment plan that considers essential yet straightforward adjustments.

In today's world, motherhood and parenthood are often portrayed as adhering to an unattainable standard of perfection. However, in reality, there exists no such thing as a perfect mother, father, or child. What we have are individuals with their own unique stories, experiences, anxieties, and fears, especially regarding the future that motherhood brings. With MS, these concerns are often amplified: Will pregnancy worsen my condition? Will I be able to deliver and breastfeed? Will others understand? Will my partner be supportive? Will my child support me when they grow up?

These are the questions that women with MS grapple with, when faced with the desire for motherhood. But there are no one-size-fits-all answers. When dealing with MS, we navigate a realm of extreme subjectivity; each person is a unique case, and each situation is specific. All future parents yearn for maps to guide them on this journey, but the terrain is uncharted and demands immense adaptability, drawing upon each individual's resources.

Therefore, this text does not offer ready-made solutions but rather provides food for thought and frameworks for interpretation. These can be shared with your partner and a trusted team of experts, including psychologists, neurologists, and gynaecologists specializing in MS and fertility.
Before making your decision, it is essential to gather as much information as possible. Above all, that you connect with the deepest part of yourself to understand what you truly desire, what you are willing to compromise on, and the extent to which you feel governed by fear in making your choice. Remember, anxiety and fear are common among all expectant mothers, not least because pregnancy and childbirth have the power to reawaken our primal instincts. The birth of a child is and will always be something magical. This is what you will ultimately face.



Index

01 | NAVIGATING THE FEARS: BECOMING A MOTHER WITH MS

In the world of multiple sclerosis (MS), no two cases are alike, and each individual's experience with the disease is unique. This is why there are no one-size-fits-all manuals when it comes to family planning and motherhood for women with MS. This uncertainty can be particularly disorienting for a woman considering having a child. The unpredictability of the disease's progression can often create even more anxiety than a dire prognosis. It's like embarking on a journey without a compass. However, today we have scientific evidence that allows us to plan a pregnancy while minimizing the risk of the disease worsening. It is therefore crucial to discuss this with your trusted neurologist from the outset.

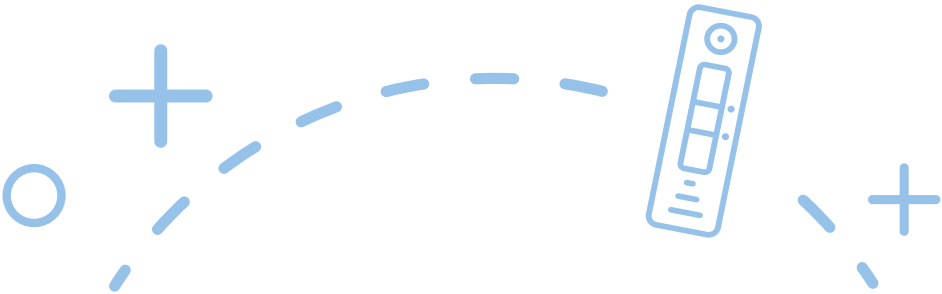
Even within the same personal history, there can be significant differences. The thought of having a child at 30 with a recent diagnosis is very different from considering it at 40, perhaps after living with the disease for 10 or 15 years. A woman who receives her diagnosis during the years when she is gaining her independence and planning a family will have many more fears than an older woman who is more familiar with the course of her disease and may already have had the opportunity to understand the role of MS in her life.

A young woman must confront not only the anxiety of relapses – how, when, and if they will occur? How will I feel? What will I be able to do? – but above all, the consequences these could have. On the other hand, those who have already experienced relapses have a greater awareness of them in some way. The dominant thoughts in any case are related to their own autonomy: will I lose my functions? How can I take care of a child? Will it change the dynamics of my family?

What if I'm afraid I won't be good enough?

These are legitimate questions, common to many expectant mothers, often dominated by a deep sense of inadequacy. No one thinks they can be enough for their child, let alone for those around them, from their partner to their family and friends. This is even more true for a woman with MS: the fear of relapses triggers a cascade of others, including the fear of not being up to the task, of not making it, of not being able to hold her own child in her arms.
In reality, if the disease is diagnosed early and treated by an experienced team, complications are reduced. And they are further reduced if the woman, together with her partner, manages to plan her pregnancy, so that she can start specific therapies even before conception. In this way, the risk of possible relapses is minimized, and the well-being that pregnancy brings to women with MS is prolonged.

It is true that no story is written in advance and that every woman has her own unique experiences, but when faced with motherhood, the first very common thought is that of having to choose: on the one hand, being a free and independent person, on the other being a mother, with new responsibilities and duties. If you think about it, the fear of giving up work and one's economic independence with the birth of a child is common to many women: we are talking about those tens of thousands with precarious contracts, or even without contracts, and therefore without the protection provided by Italian law for working mothers. But we are also referring to new mothers who often give up work due to the lack of help and support in caring for their child, in a country where even today it is still difficult to share parental roles.
Of course, in the presence of the disease, everything is amplified because becoming a mother with MS involves greater sacrifices, can put economic stability at risk due to the medical expenses that may have to be faced, and above all, it stirs up deeper ghosts and fears, linked to pain and the fear of disability.



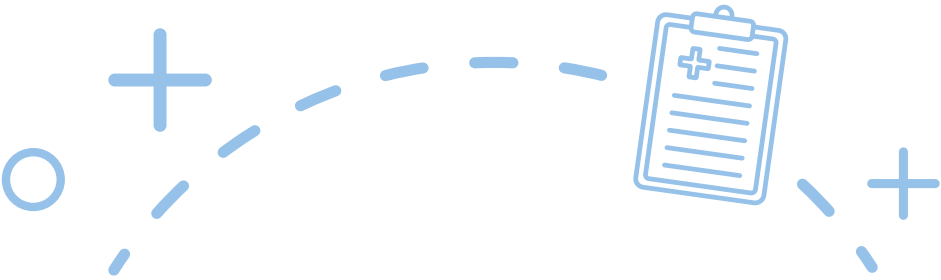
I already have anxiety about the future

MS is a sometimes unpredictable and uncontrollable disease. For this reason, it pushes people to live in a sort of continuous expectation that leads them to the dimension of thinking more than doing. Does this happen to you too? The fact is that in many cases you end up living projected into the future, in the anxiety of what might happen, without being able to enjoy the present. In these projections, you risk amplifying your expectations, losing pieces of the present. In the case of a woman with MS who is considering motherhood, this means that she risks making a choice dictated more by fear than by her real will. Or, on the contrary, by a desire induced by social pressures that want her to be a mother at all costs.

The most crucial aspect is to fully comprehend your own desires and values, regardless of your decision. There is no universally right or wrong answer; what matters is what is right or wrong for you. For instance, you might decide against having children because you place a higher value on other aspects of your life, such as self-preservation and your relationship. On the other hand, you might choose motherhood because you and your partner believe it represents a greater value, one for which you are both willing to take a chance. The key is to avoid becoming trapped in anticipatory anxiety, which is the fear that symptoms may manifest even when they are not present, as well as the fear of disability and pain, which can significantly influence the decision to become a parent.

Can I Pass on My MS?

If the prospect of passing on the disease is one of your primary concerns regarding pregnancy, it is important to understand that MS is not contagious and cannot be passed directly from parent to child. Instead, a genetic predisposition to developing



MS may be inherited. Therefore, while MS is not an inherited disease, if one parent has the disease, the child's statistical risk of developing it is slightly higher than that of a child from a healthy couple. However, it is important to remember that these are just statistics.

What if I Want a Child and My Partner Doesn't?

MS is more prevalent in women, so it is more likely that a woman in a couple will be the one affected. Nonetheless, when considering parenthood, it is crucial for the couple to have open discussions and reach a mutual decision. It's possible that the partner may be more protective of their spouse, leading them to forgo the idea of having children. Conversely, the partner may strongly advocate for parenthood regardless of the woman's wishes, highlighting opposing viewpoints within the relationship. The goal, however, is to reach a decision that works for both of them and aligns with their shared vision of family. This necessitates thorough couple therapy and open communication of each other's fears, seeking professional psychotherapy if necessary.

Ultimately, the decision to have a child is not solely the woman's responsibility; it is a shared choice that must be subjective and always based on the couple's values and priorities regarding parenthood. How prepared are they to handle the situation practically? How willing are they to put themselves out there, as a couple, whether the new condition affects the woman or the man? How aware are they that a new mother may also find herself taking care of her partner, just as the man may find himself taking care of her? How well-informed are they about the potential financial repercussions? These are all questions that need to be asked, and answering them requires time as a couple, possibly seeking assistance from an experienced psychotherapist to shed light on their deepest needs.

What if I Feel Guilty Towards the Child?

This disease constantly demands that we raise the bar of our expectations, projecting us forward into thoughts of what might happen, pushing us to live with our heads in the future. As a progressive disease, meaning it is destined to worsen, over the years you risk seeing yourself constantly teetering on three timelines: the past of who you were, the present in which you are, but above all the future in which you do not know how you will be, with the looming danger of worsening. In reality, postpartum relapses, especially those responsible for a progression of disability, are fortunately few today if experienced neurologists and gynaecologists

support you, and the hope is that they will be even fewer in the future. In the face of a possible limitation of functionality due to disability, it may happen that you feel guilty towards the child, for example because you are unable to share certain experiences, such as a game or a motor race. The truth is that there are many ways to be a mother, and all of them are valid.

What if I Care About What Others Think?

The fear of judgment from others - and that others may not understand the choice of motherhood - is very strong in younger people who may have recently received their diagnosis. This fear initially targets close family members, then spreads to the outside world, where the stereotype of the sick woman who decides to have a child out of selfishness is deeply rooted. The truth is that no one can make this choice outside of the couple, even though it is normal for the family to fear that the disease may worsen, that disability may burst into a couple struggling with a child and its needs, that the woman may lose her job and therefore have to face an economic crisis as well. But who has the right to decide for us?

When the Father Has MS

While couples may decide not to have children or the man may be the one with MS, in many cases, a male partner's MS does not seem to be an obstacle to parenthood. It is not considered a factor that could influence the decision to have a child or worsen the couple's stability, as is often the case when the woman has the disease. In a sense, the issue of having children still tends to be seen as a woman's issue. The proof is that there is very little research on fatherhood with MS in scientific literature.

02 | BEYOND YOUR FEARS: WHAT SCIENCE SAYS

It's normal to be afraid of choosing motherhood. And that right now you feel like a crazy spinning top, prey to fears and worries. In reality, in recent years, knowledge about MS has progressed and today the idea of having a child is no longer entrusted to the imponderable, or put aside altogether as happened in the past. Having a child today is more conceivable than ever before. Until not long ago, in fact, multiple sclerosis and pregnancy were not reconcilable conditions. The scientific world tended to discourage women with this diagnosis from becoming mothers: the known drugs were not very powerful and not very diversified, and the interactions of the various molecules with pregnancy and breastfeeding were not well known. Therefore, the priority was to guarantee a satisfactory quality of life for women affected by the disease: motherhood, in short, still appeared to be a marginal issue to deal with. Today it is no longer like that and this, perhaps, can reassure you a lot.

You can think about having a child but you need to plan it carefully

Today, thanks to constantly evolving tools and knowledge, the disease is recognized more and more early and the diagnosis more often concerns young women of childbearing age, that is between 20 and 40 years old, or in the period of maximum planning, in which the foundations of your own life are laid: the theme of pregnancy is therefore very topical. But why is it so important to plan a pregnancy with MS? If it is true that MS is a chronic disease, for which we currently do not have a cure, it is also true that today there are numerous drugs approved for its treatment: these are molecules that have proven to be able to modify the course of the disease by preventing the onset of disability. The use of these pharmacological principles capable of controlling the course of the disease in most cases must be evaluated on a strictly individual basis, in a personalized medicine perspective.

New discoveries have also been made on the interactions between drugs and pregnancy and there is great news about breastfeeding. Therefore, when a woman receives a diagnosis at a young age, it is important to investigate how much the motherhood project is in her thoughts and in the couple's future, because today this can guide therapeutic choices. Among the many molecules available, in fact, there are drugs that, with equal efficacy, are compatible with conception, gestation and breastfeeding and others that are instead contraindicated in view of a pregnancy.

Planning Ahead for Men with MS

While there is a growing body of research on the impact of MS on women's fertility and pregnancy, studies on men with MS and fatherhood are not as extensive. However, available research suggests that men with MS may experience fertility issues and sexual dysfunction, such as erectile difficulties. Additionally, certain MS medications could affect the sperm production process (spermatogenesis), due to their potential impact on the gonads. Some studies have also raised concerns about the theoretical possibility of reproductive toxicity, leading to fetal malformations, associated with certain MS medications taken at the time of conception.

Information on the safety of MS medications for male fertility, especially newer drugs, remains limited, although ongoing research is expanding our understanding. Therefore, it is crucial for men with MS, just like women, to consult with a neurologist who collaborates with an andrologist and urologist. This team of specialists can provide comprehensive guidance, including addressing sensitive MS symptoms that may affect intimacy, such as sexual dysfunction or bladder and bowel issues.

No Longer a Choice Between Pregnancy and Health

In the past, women with MS were often forced to choose between pregnancy and their own health. Due to limited knowledge about the safety of MS medications for the developing foetus, women were typically advised to discontinue their disease-modifying therapies (DMTs) before conception. This decision, while made with the best intentions for the child's well-being, exposed women to an increased risk of relapses and disease progression.

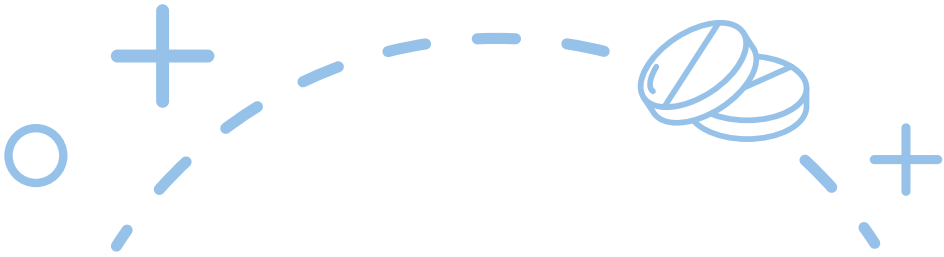
Today, thanks to advancements in research and a deeper understanding of MS, women with MS can plan their pregnancies while continuing to receive effective and safe DMTs. The goal is to achieve disease stability with appropriate medications before conception and, in certain cases, continue treatment throughout the pregnancy.

Managing Relapse Risk During Pregnancy

Today, with careful planning and collaboration, a woman with MS and her neurologist can effectively manage the risk of relapses during pregnancy. Studies have shown that a longer period of disease control with DMTs prior to conception is associated with a lower risk of relapses during pregnancy and the postpartum period. Ideally, women should aim to conceive after at least one year of successful treatment with DMTs, which in some cases may be continued during pregnancy under close medical supervision.

Managing Relapse Risk During Pregnancy

Interestingly, pregnancy has been shown to have a protective effect against MS relapses. During gestation, it is as if the woman is shielded from her own disease:



many immune-related conditions, including MS, tend to go into remission during pregnancy, especially in the second and third trimesters. This phenomenon occurs because the maternal immune system must adapt to hosting an organism genetically different from its own, entering a sort of “standby” mode. As a result, pregnancy can represent a truly serene period for women with MS, free from the symptoms of the disease.
To prolong this state of stability as much as possible and reduce the risk of relapses after childbirth - a period when disease activity may resume - it is crucial to plan conception following a period of clinical and radiological equilibrium. However, ongoing communication with the healthcare team remains essential. Together, they can evaluate the timing of restarting therapy after delivery, considering individual breastfeeding choices and the specific characteristics of the woman’s disease.

Pregnancy Planning and Fertility Considerations

While planning a pregnancy with MS is crucial, this process can become more challenging after the age of 35. Beyond this age, fertility naturally declines for all women. Therefore, if a child is desired, it becomes more difficult to delay conception in hopes of achieving disease stabilization. In such cases, close collaboration between the neurologist and a gynaecologist experienced in reproductive medicine is essential. Together, they can assess the woman’s condition in relation to a possible pregnancy and develop a tailored treatment plan to maximize the couple’s reproductive chances.

For more information, please refer to our comprehensive Fertility Guide.

Postpartum Reactivation Risk and Precautions

While pregnancy provides a protective effect against MS relapses, the risk of disease activity can increase in the postpartum period as the maternal immune system transitions back to its pre-pregnancy state. However, this risk can be significantly reduced by continuing with effective disease-modifying therapies (DMTs) during pregnancy and extending them into the postpartum period, if appropriate.

Minimal Impact on Pregnancy and Fetal Health

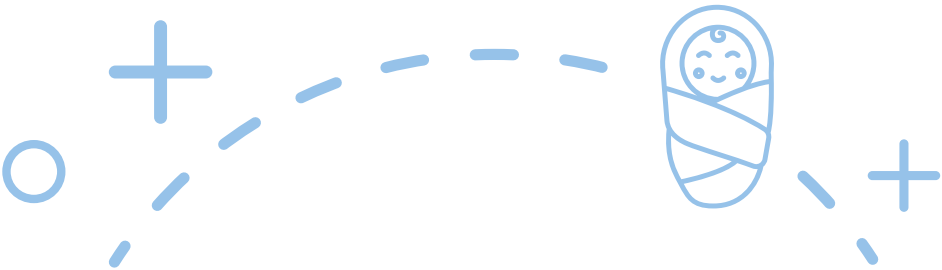
Multiple sclerosis does not inherently increase the risk of complications during pregnancy or affect foetal well-being. Studies have shown that the vast majority of women with MS have healthy pregnancies, with no increased rates of miscarriage, premature birth, or caesarean deliveries. The duration of labour and the mode of delivery (vaginal or caesarean) are also generally similar to those of women without MS. Women with MS can safely choose either natural childbirth or caesarean delivery, and the use of spinal anaesthesia or epidurals during delivery is not contraindicated. Research has shown that epidural anaesthesia does not increase the risk of postpartum relapses in women with MS.

In cases where a woman with MS has pre-existing disabilities that may affect her ability to deliver vaginally, a multidisciplinary team, including her neurologist and obstetrician, will carefully assess her individual situation and determine the safest and most appropriate delivery method, taking into account her neurological condition and overall health.

Breastfeeding While Managing MS: A Modern Approach

Today, there is positive news regarding breastfeeding for women with MS: it is no longer necessary to discontinue disease-modifying therapies (DMTs) to breastfeed. Several DMTs, including long-established medications with a proven safety record, are compatible with breastfeeding. Additionally, emerging evidence suggests that newer, highly effective DMTs also have a low transfer rate into breast milk. This progress opens up the possibility of motherhood for all women with MS, including those with more aggressive forms of the disease.

Some studies have indicated that exclusive breastfeeding may have a protective effect for women with MS, potentially reducing the risk of relapse. Others have suggested that breastfeeding has a neutral effect on the postpartum disease course. Therefore, a careful evaluation of the individual woman's risk-benefit profile is crucial. For women with mild MS, exclusive breastfeeding for the first few months followed by the resumption of DMTs may be a viable option. For women with a more active and severe disease history who are currently on highly effective DMTs, resuming therapy as soon as possible after delivery should be encouraged. Individualized considerations may include the possibility of continued breastfeeding.
To guide decisions regarding DMT resumption in the postpartum period, scheduling a brain and spinal cord MRI within three months after delivery is recommended. This MRI can provide valuable information about disease activity and assist in tailoring treatment decisions.



The Desire for a Second Child: Is It Possible?

The idea of having a second child is no longer as distant as it once was for women with MS. The feasibility of a second pregnancy largely depends on the type of MS, its severity, and the current treatment plan. Each case must be carefully evaluated based on its unique circumstances. As always, the key words are planning and sharing your couple's goals with your multidisciplinary medical team (neurologist, psychologist, and gynaecologist).

The pill and MS: no interference found

Current research has shown that there is no evidence of any interference between oral contraceptives and the progression of multiple sclerosis (MS). Therefore, women with MS who do not currently wish to become pregnant do not need to discontinue their birth control methods upon diagnosis. On the contrary, it is recommended that women with MS continue using an effective form of birth control if they are taking DMTs that are contraindicated during pregnancy.
Furthermore, recent studies have demonstrated that DMTs, which have proven to modify the course of MS, do not have any negative impact on female fertility. This means that having and treating MS does not diminish a woman's chances of becoming pregnant.

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BIBLIOGRAPHY

Effect of multiple sclerosis and its treatments on male fertility: cues for future research C Massarotti, E Sbragia, I Gazzo, S Stigliani, M Inglese, P Anserini Journal of Clinical Medicine, 2021 10(22), 5401

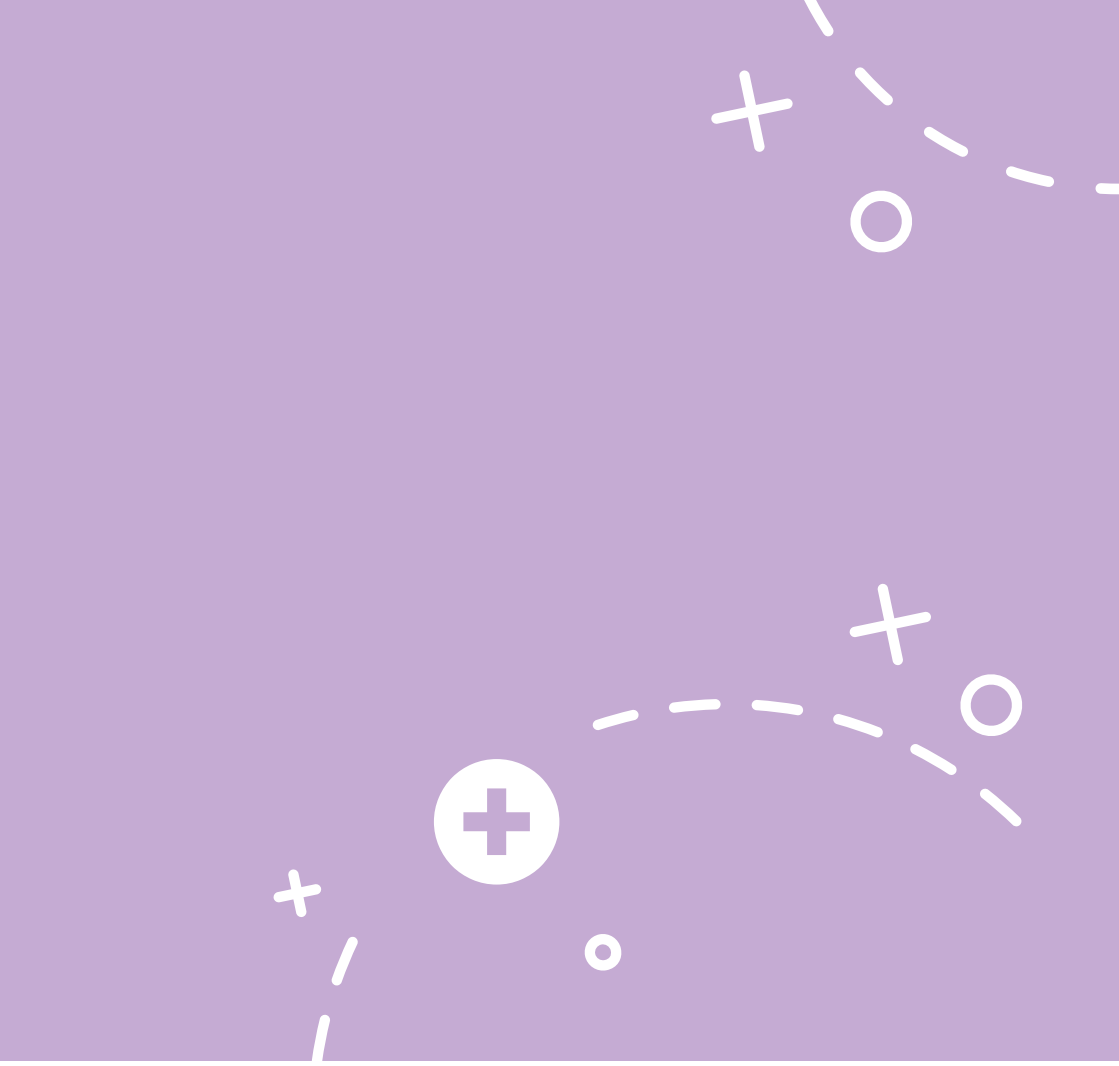
Impact of multiple sclerosis on male sexual and reproductive health, Hao Geng a Qinglin Ye b 1 , Xin Lin c , Steve Simpson-Yap c d e , Yuan Zhou c , Dongdong Tang Multiple Sclerosis and Related Disorders Volume 79, November 2023, 105059

A. Giordano, A. Lugaresi, E. Pietrolongo, M. M. Uccelli, A. Solari, Decidere la maternità un ausilio per le donne con SM, AISM 2013

Silvia Vitello: L'impatto della sclerosi multipla sulla famiglia - AISM

Multiple sclerosis in men: management considerations Riley Bove1 Allison McHenry2 Kerstin Hellwig3 Maria Houtchens2,4 Neda Razaz5 Penelope Smyth6 Helen Tremlett7 A. D. Sadovnick7,8 D. Rintell2,4 - 2 January 2016

Parenting Difficulties and Resources: The Perspectives of Parents With Multiple Sclerosis and Their Partners Kenneth I. Pakenham, Julia Tilling, and Julia Cretchley University of Queensland Rehabilitation Psychology - 2012, Vol. 57, No. 1, 52– 60



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