



# MANAGEMENT FILE

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This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine. MEA membership costs £18 a year for people living in the UK/BFPO. For contact details, see foot of this page.



## PREGNANCY, CHILDBIRTH AND ME/CFS

The general view among doctors that have been involved in the care of women with ME/CFS who have become pregnant is that around three quarters either remain the same or find that their symptoms improve, sometimes quite significantly. But pregnancy is a move which obviously requires a great deal of careful thought and planning.

### WHAT FACTORS NEED TO BE TAKEN INTO ACCOUNT IF YOU ARE CONSIDERING PREGNANCY?

Most important of all is your current state of health and how long you have been ill with ME/CFS.

If you are still in the very early stages of the illness (ie months, not years), then it is advisable to wait until the symptoms have started to improve or at least stabilised for around six months. I would not recommend going ahead if you are still experiencing a lot of flu-like symptoms such as sore throats and enlarged glands, temperature control problems, night sweats, etc.

It is also important to discuss all the medical pros and cons with your GP or ME/CFS specialist before making any decision.

Second is your age. If you are under the age of 20, then there should be no concerns about fertility. And, if time is on your side, it

is probably best to wait until a reasonable degree of recovery has occurred.

Once a woman approaches her mid-thirties, fertility does then start to decline steadily. This is something which will obviously have to be taken into account at this stage.

Third is the level of emotional and practical support that you are going to need and are likely to receive from a partner, your family and your friends. Although most women with ME/CFS do feel better during pregnancy, remember that you will require a great deal of support in the weeks and months after the birth.

### WHAT IS THE EFFECT OF PREGNANCY ON THE MOTHER'S HEALTH?

The general view among doctors that have been involved in the care of women with ME/CFS who have become pregnant is that around three-quarters notice that their symptoms improve, sometimes quite significantly.

It is an interesting finding that also occurs in some other illnesses, such as multiple sclerosis, where there is an immunological component.

The precise explanation for this improvement remains uncertain but it probably involves a degree of immune system suppression that occurs during pregnancy (this helps to stop the foetus being rejected)



along with some major changes in the balance of female hormones. Unfortunately, a small minority of women find that they really do not cope with pregnancy and experience a deterioration in health.

### IS THERE ANY SPECIAL ADVICE DURING PREGNANCY?

Generally speaking, women with ME/CFS should try to manage their pregnancy in a very similar way to anyone else in this situation.

This means good nutrition, taking adequate rest, and making sure that there is plenty of emotional and practical support available when it is needed.

Over-the-counter medications – and these include nutritional supplements, vitamins and herbal

remedies – are best avoided if at all possible, especially during the first three months when the foetus is most at risk.

The one exception to this rule is folic acid supplements as a deficiency of this vital nutrient has been reported in ME/CFS (ref: *Neurology*, 1994, 44, 2214-2215). Low levels of folic acid in the blood increase the risk of a baby being born with spina bifida.

The Department of Health recommends that pregnant women should take 400 micrograms of folic acid daily and eat a diet rich in folic acid from the time they start trying to conceive up until the 12th week of pregnancy. The 400mcg tablets are found among the vitamin displays in your local pharmacy and in health food shops.

This level of supplementation cuts the risk of women carrying babies with spina bifida and other neural defects (like anencephaly) by 75%. Women taking anti-convulsants for epilepsy, or who are being treated for Vitamin B12 deficiency (pernicious anaemia), should consult their doctor before taking folic acid supplements.

When you are trying to conceive, it may also be necessary to cut out or change certain prescription-only medications.

For example, if readers are taking an antidepressant, it may be advisable to stop using this drug but the dose should be gradually decreased. This is a decision which needs to be discussed with your doctor.

**Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your own doctor. We recommend that you always consult your own doctor or healthcare professional about any specific problems. We also advise that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.**

## **IS THE BABY AT RISK IF THE MOTHER HAS ME/CFS?**

There is a small, theoretical risk of passing a persisting viral infection across the placenta which could affect an unborn baby in the womb. Consequently, it may be better to err on the side of caution if you are continuing to experience a lot of on-going 'infective'-type symptoms (ie sore throats, enlarged glands, temperature-control disturbances and flu-like feelings) or are in the early stages of a clear-cut post-viral onset to your ME/CFS.

## **WHAT HAPPENS DURING LABOUR AND IMMEDIATELY AFTER THE BIRTH?**

Not surprisingly, this is the time when there is a real risk of a worsening of symptoms or major relapse of ME/CFS. So you must inform the obstetrician and midwife about the practical aspects of living with this illness and how a sudden and major expenditure of energy during the process of labour can produce a relapse.

They may think that, because you have coped so well during pregnancy, there will not be any real difficulties when it comes to the onset of labour.

## **WHAT ABOUT PAIN RELIEF DURING LABOUR?**

Adequate pain relief during labour is particularly important, as this allows for a relatively painless dilation of the cervix (neck of the womb) and also helps to conserve some energy.

Pain relief options – including the use of an epidural – should be discussed with the obstetrician or midwife well in advance of the delivery.

## **HOW DO MOTHERS WITH ME/CFS COPE AFTER THE BABY IS BORN?**

Once back home, looking after a newborn baby is an extremely demanding job – both mentally and physically. So arranging adequate levels of family and social support is vital.

Again, it is important to make sure that all the arrangements with friends, family, and neighbours are planned well before you go into hospital.

As far as feeding is concerned, breast-feeding has many advantages, including the transfer of vital antibodies and the absence of preparation time. On the other hand, bottle-feeding means that other people can be involved with the feeding (especially at night) so allowing you to get more rest and a solid night's sleep.

The first few months are going to be a particularly demanding time as mothers are trying to cope with all the practical and emotional demands of looking after a new baby. It is a good idea to talk to another mother with ME/CFS who has been through the experience and can pass on some helpful practical advice about feeds, nappies, energy management, etc.

## **WHAT ABOUT THE MALE PARTNER?**

Firstly, a note of reassurance: there is no evidence that ME/CFS has any adverse effects on male fertility. Neither is there any evidence that a man with ME/CFS can pass this illness onto his children – as I can testify from having three perfectly healthy children while having ME/CFS!

During the actual pregnancy, a woman with ME/CFS may well have additional emotional and practical needs which require more support than usual from their partner. As a result, a partner may have to change some of his normal social and

working arrangements. But the most helpful thing that a male partner can probably do is to try and arrange for some paternity leave to cover the time of birth and the immediate post-natal period.

## RESEARCH INTO PREGNANCY AND ME/CFS

Researchers working in Boston, USA, questioned 86 women about 252 pregnancies that had occurred both before and after the onset of ME/CFS. Seventy women completed the study.

Overall, the results indicate that pregnancy is not inherently more dangerous for a mother with ME/CFS than it is for a normal healthy mum.

During pregnancy, there were no changes in ME/CFS symptoms in 29 (41%); an improvement in symptoms in 21 (30%); and a worsening in symptoms in 20 (29%). After pregnancy, there was no change in symptoms in 21 women (30%), improvement in 14 (20%), and a worsening of symptoms in 35 (50%).

The rates of complications were similar in pregnancies both before and after the onset of ME/CFS.

One complication that was noted was the possibility of a slightly higher risk of miscarriage during pregnancy. But this may have been due to the older age of the mothers being questioned.

- Ref: A comparison of pregnancies that occur before and after the onset of CFS. *Archives of Internal Medical* 2004; 164: 401-404.



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## OTHER RELIABLE SOURCES OF ADVICE

### [www.mecfsparents.org.uk](http://www.mecfsparents.org.uk)

A beautifully-designed website which carries a lot of good information about pregnancy, childbirth and parenting issues. Since the launch of the website,, the organisers have closed the chat forum there andt moved it across to Facebook at <https://www.facebook.com/groups/723681451020085/>

### [www.Foggy Friends.org](http://www.Foggy Friends.org)

The aim of Foggy Friends is to provide a free, fun, safe environment where ME/CFS sufferers, their parents, carers and friends can seek help, support and advice, free from harassment. It has a much valued chat forum, where there a special section for parents with ME/CFS.

### [www.facebook.com/meassociation](http://www.facebook.com/meassociation)

This – one of the busiest open sites on the planet that discusses ME/CFS – is always willing to take posts relating to ME/CFS parenting issues. If you wish your post to be placed without you being identified, please 'like' our page, then send a private message to our moderator asking for your post to go up anonymously.

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### Personal Story

Read a personal account of pregnancy and ME/CFS by Frances Woodward in *Living with ME* on pages 310-313 (Dr Charles Shepherd, Vermilion, 1999 edition, ISBN 0 09 181679 3). Available through The ME Association (price £10.50); borrow a copy from your public library or order your own at bookshops or through Amazon UK

**LEFT: Our clinical and research guide. Give us the full name and address of your GP and we will send them a copy, entirely free of charge. Tel: 01280 818 963**