

MANAGING THE STRESS OF INFERTILITY

INSIDE:

- Being diagnosed with infertility
- Coping with IVF
- Communicating with your partner
- Dealing with family and friends



ABOUT THIS BOOKLET

Merck Healthcare thanks the many individuals, couples and Australian healthcare professionals, including fertility specialists, specialist nurses and psychologists who shared their knowledge and expertise during the production of these booklets.

Important notice: The information provided in this booklet does not replace any of the information or advice provided by a medical practitioner and other members of your healthcare team. Your doctor will determine the best medications and course of action for you based on your requirements and circumstances.

Prescription medicines have benefits and risks. Use all prescribed medicines strictly as directed by your doctor and raise any questions or concerns with them before, during or after using them. If you experience side effects consult your doctor.

Medication availability and funding criteria may differ between Australia and New Zealand.



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INTRODUCTION¹⁻³

Being diagnosed with infertility can be an extremely confronting and challenging experience. People often talk about the 'roller coaster', or ups and downs of emotions associated with infertility. It is normal to feel stressed and sad about what is often considered a life crisis.¹ However, there are some important points to keep in mind when you are feeling overwhelmed:

- you are **not** the only one going through this. Up to one in six couples worldwide have difficulty conceiving in the first 12 months of trying but many of them go on to have children, some with and some without treatment.²
- infertility can cause all sorts of emotions. It is normal to feel shock, anger, anxiety, fear, sadness, guilt and many other emotions.¹
- there are many coping techniques and avenues of support, which you can use to help you manage the stress of infertility and IVF treatment.³



This booklet looks at some of the common emotions that you may experience when confronted with infertility and also describes some techniques and tools for managing them. There are certain stages or situations, which most people find particularly difficult and we will discuss what you can do to help you cope during those tough times.

*"It really helped me to know that what I was feeling was normal and that I wasn't going mad." – Sue**

*The personal statements throughout this booklet are the opinions of real individuals. Individual experiences will vary from person to person.

BEING DIAGNOSED WITH INFERTILITY⁴⁻⁶

*“Diagnosing infertility is all about what isn’t happening, and it is hard to know what to feel.” – Karen**

Everyone reacts to the diagnosis of infertility differently. It is normal to ask ‘Why me?’ and to feel sad, angry, worried or just totally shocked. However, for most people, it is the strength of the emotional impact that often takes them by surprise.

Here is how some people describe feeling when they find out that they need fertility treatment:^{4,5}

shock, surprise or denial – a sense that the diagnosis is not really true. This can also be described as feeling numb or not knowing what to do

anger and frustration – this can be expressed as ‘Why is this happening to me?’ or feeling angry at others

anxiety, fear or panic – worrying about the possibility of never being a parent

isolation – feeling different from others and feeling out of touch with your partner

sense of loss – grieving the losses caused by infertility including loss of pregnancy, loss of motherhood and fatherhood.

The way you react and cope with your emotions is influenced by many things including:

- how you interpret the situation
- how you have responded to past stresses
- other events that are also happening in your life
- how well you are supported.



While feelings like the ones described here are perfectly normal in the face of such a major life crisis, it is important to try to limit how much they affect your everyday life. Learning to recognise and manage your feelings about infertility is as crucial as looking after yourself physically.⁶

WHAT TO DO IF YOU'RE FEELING DOWN⁷

Sometimes the negative feelings about infertility become very intense and potentially dangerous. If you are feeling extremely sad or hopeless for more than a couple of weeks and your feelings are interfering with your usual daily activities, you may be suffering from depression and should seek help from a healthcare professional.⁷

Some of the warning signs of depression include:⁷

- lack of interest or motivation to perform your normal activities
- decreased energy
- inability to concentrate
- not being able to sleep or sleeping too much
- significant weight loss or gain
- extreme anger and resentment
- persistent thoughts of suicide or death.



See details at the back of this booklet for information on some of the organisations to contact if you suspect that you are depressed.

The testing process^{2,8,9}

Fertility treatments often involve numerous tests, results and re-testing. These can cause conflicting emotions including fear and hope. Many say it is better to get results, even if not very good ones, because it helps to know what is the cause of their infertility.⁸ However, for some couples, there is no obvious cause of infertility even after thorough investigation of both partners and this can be frustrating.²

Dealing with infertility can be highly challenging due to the numerous uncertainties involved. The process can exact an emotional toll on both couples and individuals grappling with these unknowns. The unpredictability associated with infertility testing and treatments can create significant psychological stress, regardless of the eventual outcomes.⁹

What can help?

Coping with a diagnosis of infertility^{3,10}

- Gather as much information as you can. This might be through online discussions with others who have experienced infertility or through books, a counsellor or support organisations. This will make you feel more in control of your situation and allow you to ask your doctor knowledgeable questions.
- Attend medical appointments together whenever possible and if not, bring a trusted friend or family member. A second 'pair of ears' is always welcome when there is a lot of information to absorb. Don't be afraid to take notes or even record the conversation. It's also recommended that you write down a list of questions to ask your doctor.
- Talk about your feelings and fears with others, especially each other. Talking helps you to clarify the situation and identify areas of concern.
- Find stress management techniques that are effective for you, such as exercise, yoga and meditation.
- It may be helpful to see a counsellor to identify your fears and get advice on how to manage them. It is better to talk about issues as they arise rather than bottle things up.
- Try not to think too far ahead. Deal with the here and now rather than worrying about too many 'what ifs'.

HOW WILL YOU FEEL DURING IN VITRO FERTILISATION (IVF)?^{4,11,12}

*“An IVF cycle is all about balancing hope, reality and hormones.” – Margaret**

Some find that starting treatment is a positive experience because something is finally happening. Others might feel fearful and disappointed that they need an intrusive medical intervention to have a baby.⁴

For most women, the most difficult part of having treatment is the wait to find out if it has worked and the worry that it might be unsuccessful. Days seem to pass very slowly and it can be a time of vulnerability and sensitivity. You may feel anxious and find it hard to concentrate on ordinary life (see page 10 for more advice on how to get through the ‘two-week wait’).⁴



IVF is not a single event but rather a series of steps or hurdles where each stage has to be crossed before tackling the next one. This is a very tiring process. If after all the effort the treatment doesn't work, it can be extremely sad and disappointing and the thought of having to do it all over again can be overwhelming.¹¹

*“You go from being an articulate and clear thinking person to feeling that life is out of control, you can't make any plans – and this is very scary and frustrating.” – Emma**

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People often say that when they are undergoing IVF treatment they lose control over their lives. They have no control over achieving something that seems so easy for others, and may feel that there's nothing they can do to help. Partners often feel a bit left out during IVF treatment as the process mainly focuses on the woman undergoing treatment and her body. While they may be just as anxious, they may not want to show this because they want to stay strong and support their partner.^{4,12}

These are some of the reactions people can have during the treatment:⁴

- intense emotions including feeling more vulnerable, sad, anxious, or angry than usual
- taking less interest in things that they normally enjoy
- avoiding situations where they encounter babies and pregnant friends
- arguing with their partner over matters that previously seemed trivial
- flaring up at their friends over little things they've said.



*“It is very hard to cope with cycles that fail.
I feel very depressed and alone and feel that
I have let everyone down.” – Tanya**

THE IMPACT OF HORMONE MEDICATION⁸

In addition to dealing with feelings of uncertainty and trepidation, as well as hope, the female partner will be dealing with the impact of hormonal changes on the body. Responses to the medications used to stimulate the ovaries during IVF treatment vary enormously. Some women have no symptoms while others feel emotional and much more prone to tears, anxiety and irritability. Others feel uncomfortable with bloating, headaches, tiredness and other physical symptoms.

Surviving the ‘two-week wait’¹³

After the embryo transfer, it takes around two weeks to find out if the treatment has worked. This ‘two-week wait’ is what most people find the most challenging part of IVF treatment.

Here are some ‘survival’ tips to help you get through this time:

- try not to obsess about pregnancy symptoms – feeling pregnant does not always mean that you are. Some of the medications can have side effects that resemble symptoms of pregnancy
- keep busy – this may mean working more, or planning meaningful or fun distractions
- some find it helpful to write down their thoughts
- talk to each other and supportive friends or family members about how you feel
- try some relaxation techniques such as breathing exercises or meditation (see page 22)
- avoid pregnancy tests – the chance of getting a positive result before your period is late is very slim. The medications may also cause a false positive result
- try using the Positive Reappraisal Technique (see page 12) to encourage yourself to find some positive points in what you are experiencing.



IVF COUNSELLING¹¹

People have different emotions when facing infertility and how they deal with these emotions can also be quite different. When someone is getting treatment for infertility, they have to figure out their own way to handle it, and sometimes they may need some assistance. Before starting IVF treatment, it's a good idea to think about talking to a counsellor.

A counsellor's role is not to assess your suitability for infertility treatment, but to help you deal with the stress and emotions involved in trying to achieve pregnancy. Seeing a counsellor may help to identify feelings and useful ways to deal with them. See page 21 for more information on how a counsellor can help you.

What can help?

Dealing with the challenges of IVF¹⁰

- Information is power: the more you know about IVF and what others have been through, the more you can prepare yourself to deal with the inevitable challenges of IVF. Understand as much as possible about what will happen during treatment and what the likely outcomes are. You can access other **Pathways to Parenthood** booklets through the website www.fertilityportal.com.au/merck
- Ask the IVF staff questions. There are a wide variety of people to help in an IVF clinic – nurses, doctors, counsellors, receptionists and accounts staff. Find someone who can answer your questions – it is sure to have been asked by someone else previously.
- It often helps to have someone at work you can confide in – in case you have a difficult patch or receive bad news while you are at work.
- Plan ahead for where you want to be when you receive the news of your results – at work or in a public place may not be the best location.
- It may be better not to tell too many people where you are in a cycle. You don't want to deal with too many questions and advice.
- Pace yourself and have breaks between cycles.
- It is important not to take on too many other things when undergoing treatment. If you have a big event, such as moving house, a new job or relatives staying, then try to plan treatment for when things are quieter.
- It can be useful to join a support group and talk to others who know what to expect.
- Try to keep life in balance and don't let IVF take over every month.



The Positive Reappraisal Technique^{14,15}

The **Positive Reappraisal Technique** can help you manage some of the negative emotions that are associated with infertility.^{14,15}

All situations involve some good and some bad aspects and the aspects we pay attention to often determine how we feel. Thinking more about the positive points of a difficult situation and dwelling less on problems or uncertainties for the future helps people feel better.

This does not mean we should pretend that everything is wonderful when you do not feel it is, or thinking that you will definitely get pregnant when you feel unsure. What it does mean is that you are choosing to remind yourself that even very challenging situations have some positive elements.¹⁴

Remember that it will take time for you to come to terms with your emotions, and you will most likely have your good days and your bad days. Choose a few statements from those below (or in consultation with a counsellor) that will help you cope better each day. Try to make the time to rest and recuperate every day, as you will be better able to manage your emotions when you are not feeling tired.¹⁵

5 Coping statements to help you think positively*

Print this page, cut out this card and keep it in your purse or pocket to remind yourself to try to focus on the positive points of your situation.

Read this card once in the morning and once at night and any other time you feel the need.

During this experience I will:

1. **Focus on the benefits and not just the difficulties**, e.g. 'I am using this time to get fit and healthy' or 'This experience is bringing my partner and I closer together'.
2. **Try to think more about the positive things in my life**, e.g. 'I have been able to manage my time very efficiently and that makes me feel good'.
3. **Try to do something meaningful**, e.g. 'Once a week, I will put aside some time to do something for me, like taking up a hobby'.

4. **Learn from the experience**, e.g. 'This is difficult to go through but it is helping me learn skills for the future, such as time management, managing my emotions and communicating with my partner.'

5. **Try to do something that makes me feel positive**, e.g. 'I will make time each day to read my book, walk the dog, phone a friend'.

Thinking differently can feel strange and unnatural at first. However practice will help so try to persevere.

*©Lancastle & Boivin, Cardiff University. Adapted from The Positive Reappraisal Technique¹⁵

THE IMPACT ON YOUR RELATIONSHIPS¹²

*"I didn't know what to say to her but whatever I said was wrong...so I stopped trying...it was quieter that way... but we are still unhappy." – Steve**

Communicating with each other¹²

Good communication is essential in all relationships but this can be strained when you are undergoing IVF. It can be hard to talk about something that is so painful, and sometimes people say hurtful things to each other that they don't mean.

Partners sometimes grieve in different ways and it can be difficult to understand each other's feelings. We often think that our partner should know how we are feeling or be able to 'read our mind'. It is unfair to assume this if you haven't talked about it.

Communication usually has to be worked on. It may be helpful to write down feelings and show these to each other, or make an extra effort to find time to talk. Sometimes going away for a few days together can help.



Sex¹²

It may be difficult to have spontaneous loving sex when there is so much intimate medical intervention going on. Spontaneity gets lost.

Sometimes it is better not to worry about sex for a while. It is important, however, to take the time to enjoy some intimate moments, such as cuddling and holding hands. For others it may be comforting to have an intimate relationship when everything else seems out of control.

Again, talk to each other about fears and feelings – this will help you work out the best solution for you.

Shame and guilt¹²

When one partner has an identified fertility problem they sometimes feel shame and guilt. This of course gets worse if they feel that their partner blames them for the infertility. It is important to tackle the problem together, for example going to appointments and talking afterwards about what was discussed. Approach the situation as 'our problem', and something to work on together.

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PEOPLE COMMUNICATE DIFFERENTLY¹²



People often deal with emotions and solve problems differently. Both partners may care just as deeply about becoming a parent, but handle the challenges of infertility in different ways.

Some people feel better if they talk about how they feel, and some may feel better not talking. Being aware of these differences can help you avoid misunderstandings and allow you to tackle the challenges as a team.



Despite the strain, most couples who have been through fertility treatment say they're brought closer by the experience and their relationship is stronger at the end.

You may find it helps to:

- decide on how you want to communicate and support each other. Filling in the chart on the next page may be helpful
- draw up a plan for the future. It helps to put things in perspective and focus on what's important should you need to make difficult decisions
- don't allow fertility to rule your life. Instead, if there's something you need to discuss, set aside a specific time and give the venue some thought. A walk in the park may be less intense than a fixed table for two
- during conversations try to avoid 'blaming' statements such as 'you always' or 'you never'
- put a conscious effort into planning something fun where you don't need to talk about your fertility. It's important to create some balance in your life.

Working as a team

The months ahead will be easier if you and your partner work as a team. Using each other's strengths can benefit you as a couple. After all, you are both hoping for the same result.

Use this chart to help you decide how you want to communicate and support each other.¹²

Choose when and how you want to talk about your treatment so it doesn't take over your life.

★ For example, on a chosen day each week, somewhere relaxing.

★ _____

★ _____

Discuss what you expect and don't expect from your partner.

★ For example, support but not constant reassurance that the treatment will work.

★ _____

★ _____

Decide what topics should remain private, shared only between you.

★ For example, the full details of our infertility.

★ _____

★ _____

Plan activities you can enjoy as a couple.

★ For example, hiking.

★ _____

★ _____

Dealing with family and friends¹⁶

Discussing infertility with family members and friends may be uncomfortable, but expressing how you feel may help you release your stress. It's important that you reach out for support. Infertility is a sensitive subject and sometimes people don't know how to react. Even family members who are aware of your situation can often say the wrong thing unintentionally. Guide the conversation and help them avoid topics that may be hurtful or make you feel uncomfortable. Feel free to say you're not in the mood for a heavy chat and ask what's new with them.

It may help if you can talk to your friends and family about the role they can play. Let your friends know how they can support you and give them some detail about what you need, e.g. 'When I call you and I'm crying, I need you to listen to me. You don't have to give me advice or try to fix anything. I just need you to be there for me'.

Some friends may be good listeners. Others may be top of your list with whom to have fun when you are feeling down. Think of what you expect from your support network and let them know. Filling out the chart on this page may be a good starting point.

My support network

The right friends and close family members can provide great comfort and support. However, it may be hard for them to know precisely what you need. Don't leave them guessing. Use this chart to decide what you need from them and start building your support network.

Write your friend / family member's name here

What I expect from you

★ *For example, to cheer me up when I'm down*

★ _____

★ _____

What I won't discuss with you

★ _____

★ _____

★ _____

How I want to spend time with you

★ *For example, as if we were on holiday*

★ _____

★ _____

What can help?

Dealing with insensitive comments^{16,17}

You may often hear comments that you find upsetting or hurtful, such as:

"Just relax and you'll get pregnant..."

"You just need a holiday!"

"You're trying too hard."

The advice may be well-meaning but these kinds of statements are hurtful because they imply that you would have a baby if you just relaxed. This is of course not true. While being able to manage stress is important for your wellbeing, there is no evidence that relaxing solves infertility.

Unfortunately, you can't change somebody else's behaviour or make them do or say what you want. But it might help to think about how you can respond to tactless comments and what you can do to avoid being hurt by them.

It helps to have a bag of phrases that you can practise at home. For example, if someone says, 'Why don't you have children yet?' or 'You're leaving it late to start a family', you could simply respond, 'Well, we are still looking into it'. You may then like to change the subject or move away saying, 'Just excuse me, I'm going to go say hello to so and so' or 'I need to find the ladies/a drink of water...' Practising these types of statements at home can help you to avoid being caught off guard or feeling upset.

There are several other ways to respond to insensitive comments:

- educate the other person, i.e. "No, this is a common medical condition and no amount of relaxing/holidays/or bottles of wine will help"
- stand up for yourself and point out that their remarks are hurtful. This approach is especially appropriate for family members and close friends. Tell them that what you would have liked them to have said was something like:

"I am sorry that you are going through this."

"I am here for you."

"Could you use a hug?"

"Call me if you want to talk."

"Is there anything that I can do?"

Use as many sources of support as you need. Each friend or family member will have something different to offer and you will find what works best for you.

Protecting your feelings¹⁶

It's reasonable to feel vulnerable at the end of an unsuccessful treatment cycle. It may help you feel better to avoid situations which are emotionally triggering for you such as children's birthday parties or baby showers. However, you may find it just as helpful to share your feelings with family and friends that can support you emotionally.



WHO AND HOW MUCH TO TELL?¹⁶

Decide as a couple how much you want to share and set privacy boundaries. You don't owe anyone an explanation. You can even tell your family that the infertility treatment is now an 'offlimits' subject, that you appreciate their support, and that they will hear good news just as soon as you have some to share.

Have some responses prepared. You may not always feel you can face another round of enquiries. Have a few short answers ready, like 'we'll keep you posted', or 'you'll be the first to know' – responses that don't require a follow up question.

Adjust your expectations. Friends and family who care about your well-being will want to support you and say the right thing. Sometimes, their efforts may seem clumsy, despite their best intentions. Try to be a little patient and forgiving if they say the wrong thing.

COPING WITH STRESSFUL SITUATIONS^{16,18-20}

Other people's pregnancies/births¹⁶

It can be hard to be happy for others who are having babies, and it can seem that everyone around you is pregnant or pushing prams. It's perfectly normal to feel distress at others' pregnancies and births. You are not a bad person to feel like this and this experience will one day be behind you.

Some strategies for limiting your distress include explaining your situation; visiting families with newborns when they're at home without other people around; and avoiding situations where there may be many young children. If you really feel you have to attend a family event, e.g. a christening, then stay for as long as you feel comfortable and leave quietly if you need to. Explain beforehand that this is what is going to happen and ask people to respect your feelings.

Celebrations which focus on family life¹⁸

Celebrations that involve families getting together seem to emphasise what you don't have. Some people undergoing IVF treatment can still enjoy Christmas, birthdays and other family events whilst others prefer to make alternative arrangements.

If it is too difficult for you, try not to:

- shop at large shopping centres where families, children and Santa's abound
- feel guilty about not participating in all the traditional family celebrations
- pretend that there's nothing wrong and carry on with 'business as usual'
- expect others to understand your pain. Refer to it briefly and ask that they support you by respecting your choices.

Pregnancy¹⁹

You may feel surprised and guilty that you are not overjoyed when you first find out that you are pregnant. Fearing that it may not continue can make it hard to relax and enjoy. Talking about these fears with people you trust can be helpful. Once you are a bit further into the pregnancy, you will most likely start to feel more confident about a happy ending and be able to enjoy the pregnancy.

Miscarriage²⁰

Losing a pregnancy is always hard but it is even more difficult when it has taken so much time and treatment to fall pregnant. It is hard to have hope that pregnancy will happen again.

Some people withdraw and are private in their grief. Others reach out to friends to discuss their painful loss over and over again. Some people deal with intense feelings by becoming very busy. Others become very rational and appear able to cope by denying the depth of their pain. Ways of coping are many and varied. A counsellor and other organisations, such as Access Australia and SANDS -Red Nose Australia (miscarriage, stillbirth and newborn death support) or SANDS NZ , will be able to help you through this period of grief and readjustment – see contact details at the back of this booklet.

Stopping treatment²⁰

Stopping treatment can be a time of mixed emotions. Most know when it is time to stop and seek relief from the constant procedures and emotional toll. However, it's important to realise that it will still take time to accept that the treatment didn't work, and that sadness and anger is normal.

With the mixed emotions of relief and sadness there is also the realisation that the time of being in limbo has stopped, and that it is now possible to take back control.

Some things that you may talk about at this time are:

- planning other ways to have children including adoption or fostering
- spending special times with friends' or relatives' children
- re-training for a different career
- re-focusing on your personal goals
- taking a well-deserved rest or holiday
- planning a completely different lifestyle together.



"It is immensely comforting for us to know that we gave it everything we had – it wasn't to be but we tried."
– Mel and Dave*

HOW CAN A COUNSELLOR HELP?²¹

Often people undergoing IVF treatment cope well most of the time, but at times a bit of help is needed. Counselling offers the opportunity to talk about how you are feeling, identify areas that are causing you distress, and find strategies to manage your feelings. Sometimes just being able to talk about your fears with someone who is impartial and non-judgemental, finding out how others cope and whether your reactions are 'normal' can be helpful.

Counselling will focus on ways of getting back some control and feeling more at ease with your situation. Sometimes it will be useful to have several sessions with a counsellor. At other times a phone call or single session will be sufficient to allow you to handle things again.

It is important that you feel comfortable with your counsellor to be able to talk openly with them. We all have different people we 'click' with and sometimes you may decide to see someone else.

GENETIC COUNSELLING²⁰

Some people access IVF because of a genetic condition that may affect the baby. They will have additional questions and issues to consider, which is best discussed with a specialist genetic counsellor who may be attached to your clinic or to a genetic service in your city.



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COPING WITH STRESS CHECKLIST^{6,9,10}

- ☐ Communicating to others how you feel and what support you would like is crucial. Don't expect others to be mind readers.¹⁰
- ☐ Educating yourself as much as possible about your situation and treatment helps in giving you back a feeling of control.¹⁰
- ☐ Whenever possible, partners should go to appointments together. It is helpful to support each other and compare understandings.¹⁰
- ☐ Because infertility can make you feel out of control, paying extra attention to other areas of your life where you do have control, such as your work and friendships can be helpful.⁶
- ☐ Exercise and relaxation techniques (see below) are helpful. Try walking, swimming and going to the gym. They are not only physically helpful but can also help in moving thoughts.⁶
- ☐ Don't be afraid of tears. They can be a good way of releasing tension.¹⁰
- ☐ Find someone you can talk to and confide in, e.g. trusted friend, counsellor, family member, support group.⁹

What can help?

Relaxation techniques²²

- Yoga – there are many different styles but most classes combine a series of postures, breathing and relaxation techniques. You are able to choose how far you push your body in a peaceful environment.
- Meditation – trains you to focus your thoughts on one relaxing thing for a sustained period of time thereby resting your mind and giving the body time to recuperate.
- Deep breathing – a simple and effective method of relaxation which is also at the core of yoga and meditation techniques.
- Progressive relaxation exercises – involves progressively tensing and relaxing the muscles in your body.
- Mindfulness – a form of self-awareness training that is based on Buddhist meditation principles. It is about being aware of what is happening in the present on a moment-by-moment basis, while not making judgements about whether we like or don't like what we find.



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