

INFERTILITY & IVF

An emotional rollercoaster

It is important for those on IVF to be able to access counselling when they need to. All IVF clinics in Australia and New Zealand offer counselling by registered ANZICA (Australian and New Zealand Infertility Counselling Association) counsellors and there is no charge for counselling. In Victoria, counselling prior to IVF treatment is a legal requirement for all couples. In other States, couples' participation may be recommended but not compulsory. The role of infertility counsellors is to: help people deal with the stress and emotions involved in trying to achieve a pregnancy or in dealing with other fertility issues; help couples or individuals explore better ways of dealing with anxiety or stress; and provide support with relationship difficulties, a common issue for infertile couples. IVF counsellors do not assess couples' suitability for infertility treatment.

Infertility diagnosis

Infertility can be a major crisis involving a massive readjustment, and the power of the emotional impact of this diagnosis generally comes as a surprise to an individual or couple. Unfortunately, our society fails to recognise how extensive this adjustment is, affecting as it does privacy, attitudes, expectations, lifestyle, goals, finances, relationships, support networks, work and one's body.

Infertility is often not recognised, understood or even shared with others, thus normal support systems may not be accessed by the couple.

The initial diagnosis of infertility is stressful and can result in emotions of:

- shock, surprise or denial;
- anger, frustration and envy;
- anxiety, fear or panic;
- depression and confusion;
- isolation and feeling different from others; and
- sense of loss

TREATMENT:

Effects of IVF treatment

IVF is a very stressful process: not being able to have a child when you really want one is extraordinarily difficult. IVF not only demands couples consider and decide upon medical options, but also forces them to deal with many social and emotional issues. A common community misconception is that IVF treatment is 100 per cent successful, though the real success rate falls well short of this. Couples commonly describe a sense of living 'in limbo', of experiencing a strong sense of frustration, or of 'hoping against hope'. Couples often say that when they commenced IVF they lost all control over their lives: they have a complete lack of control over achieving something that seems so easy for others and nothing they can do can alter the outcome.

IVF is not a single event but rather a series of hurdles or stages where each has to be completed before tackling the next, which can make it a very tiring process. If a cycle has not been successful—'failed'—disappointment is doubled because it means having to decide what to do next. IVF treatment is often described as a 'rollercoaster' ride as it is full of emotional highs and lows: the first part of the cycle being full of optimism and hope, the long and anxious wait after the embryos are implanted, then an enormous crash if there is no pregnancy.

Initially women may fear the treatment process, but waiting for results is often the most difficult part of the process: days seem to pass very slowly and it can be a time of acute vulnerability and sensitivity. Relationships may suffer and it can be extremely difficult to concentrate on work or ordinary life. IVF treatment is very physically demanding. It is normal for a woman undergoing IVF to feel: sad, angry, frustrated, out of control, vulnerable and sensitive—hormone treatment exacerbates all of these emotions.

Stress

A level of stress and anxiety is almost inevitable in IVF and some individuals will experience chronic stress. Research has shown that women undergoing treatment for infertility have a similar level of stress as women dealing with life-threatening illnesses such as cancer or heart disease. While there is no convincing research evidence that stress levels affect the outcome of treatment, stress levels during IVF treatment can become obstacles to effective living.

Fertility problems and IVF treatment can impact:

- sense of control;
- future dreams;
- sense of a competent self;

In 1981, Kay Oke became the first IVF counsellor in the world.

In these very early pioneering days of IVF in Australia she worked alongside Ian Johnston, Carl Wood and Alan Trounson at the Royal Women's Hospital, Melbourne. Ian Johnston, influenced by his prior donor insemination work, placed a high priority on counselling, and mandated that everyone who entered the IVF program was counselled.

Infertility counselling is a constantly growing field: genetics and donor-related issues are set to be the most significant and complex issues in the foreseeable future. Egg donation has recently increased thanks to a recent scenario on the Australian evening television 'soap' *Home and Away*, which seems to have very effectively familiarised viewers with and 'normalised' the concept. But with the increased numbers of donors—coupled with developments in genetic knowledge—comes increased responsibility and ramifications.

Over the last quarter century, IVF has become both much more successful (no waiting period, fewer multiple pregnancies) and gained wider community acceptance. But, says Kay Oke, 'the stigma, heartache, wanting and not getting of IVF are all still very much part of the process.'

- intimate relationship with partner;
- other relationships
- sense of normality—so much technological intervention and 'interference with nature'.

The results of stress and anxiety can manifest in physical symptoms (hyperventilation, palpitations, nausea and insomnia), changes to thinking patterns (chaotic thoughts, irrationality, irritability, catastrophising, extreme sensitivity, bewilderment) or behavioural change.

Miscarriage is even more difficult to deal with when the pregnancy has taken so much time and treatment to achieve. It is hard to hope that a pregnancy will happen in the future, and the usual

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support networks may not have been told about the IVF or pregnancy so they are not available for help. It is not uncommon for women to feel surprised and guilty that they do not feel joyful about their pregnancy: fear that the pregnancy may not continue makes it difficult for women to relax.

Infertility is often compared to a merry-go-round. Things can seem to be spinning out of control and it can be hard to take back this control and get on with life.

Impact on relationships

Infertility can put a great strain on relationships: with a partner and with other significant people. Issues of communication and gender differences with coping and feelings of guilt and blame may impact on the relationship. Interestingly, however, there is no evidence that the incidence of separation or divorce is any higher for couples undergoing fertility treatment; though couples who do separate are highly likely to name infertility and its treatment as a causative factor.

A diagnosis of infertility may affect a couple's sexual relationship. Firstly, many couples may have been attempting to conceive for many months or years. Often increasing attention is paid to timing of intercourse and more medical intervention is tolerated. Not surprisingly, the impact of this is to focus sex more on the function of conception rather than pleasure: it is not unusual, therefore, for sex to become a 'job to be done'. For many this will be experienced as a sense that the relationship has changed.

- One in six Australian couples suffer from infertility—the inability to achieve conception after a year of unprotected intercourse, or the inability to carry pregnancies to a live birth (Fertility Society of Australia)

- Infertility is shared equally among men and women, and in the vast majority of cases, a physical problem can be diagnosed and successfully treated with medical or surgical techniques, or lifestyle changes (Fertility Society of Australia)

- In 2002, 2.3 per cent of Australian babies were born following the use of assisted reproductive technology (ART) (*Australia's Mothers and Babies 2002* AIHW)

- Mothers of babies born following ART were on average 33.7 years, older than the average age of Australian mothers, 29.4 years. (*Australia's Mothers and Babies 2002* AIHW)

- In 2002, 32,958 treatment cycles were attempted in Australia and 3,424 in New Zealand, resulting in 7,577 pregnancies & 6,816 live born babies of which 1,103 (18.9 per cent) were multiple deliveries (1,070 sets of twins and 33 triplets) (*Assisted reproductive technology in Australia and New Zealand 2002*, AIHW Oct 2004)

Stopping treatment

Deciding to stop treatment is a very difficult and emotional time. Most couples know when it is time to stop and seek relief from the exhaustion of constant procedures and disappointments. It is important to realise that it will take time for a couple to accept that they won't have a child via this treatment, and that sadness and anger is normal at this time. It may also be hard for the couple to realise that they may never know why IVF didn't work. Among the mixed emotions of relief and sadness, there is also the realisation that the time of being 'in limbo' has ceased and it is now possible to regain control of their lives.

Some couples find they have lost sight of the real reason they started treatment in the first place—sometimes becoming pregnant can become a goal in itself. Others may be unconsciously avoiding grief by continuing with treatment, an understandable reaction for those who may feel too vulnerable to face the inevitable grieving process that occurs when treatment ends.

Grieving for an unborn child is complicated: there is no body, no funeral, no ritual to mark this event—it is a loss of possibilities. Not being able to have a child can feel as painful to some women as if their baby had died. Grief comes from loss of pregnancy, loss of motherhood, loss of fatherhood and loss of 'genetic links to the future'—intangible losses that can be very difficult to deal with.

Genetic counselling and infertility

All Australian IVF clinics now offer preimplantation genetic diagnosis (PGD). PGD has primarily been used for detection of chromosomal aneuploidy or rearrangements in cases of known parental translocation. It can also be used to determine the sex of embryos for couples who carry a sex linked disease, such as haemophilia or muscular dystrophy, (which affect only males). An increasing number of diseases can be diagnosed in early embryos by PGD including cystic fibrosis and thalassaemia. Also, using FISH technology it is possible to diagnose chromosome errors such as Down syndrome.

Information about genetic predisposition to disease through pre-implantation genetic diagnosis (PGD) is constantly increasing, though the ramifications of this information are not so easy to predict.