

PATHWAY TO A CHILD

INSIDE

Becoming fertility fit

Understanding the fertility language

Your step-by-step guide through fertility treatment



FEB 2014–MARCH 2015 ISSUE

Please contact the clinic if this version is outdated



FERTILITY associates | a better understanding
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PATHWAY TO A CHILD

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Welcome

WELCOME to Fertility Associates in Malaysia.

As Medical Director, I am proud to lead this new clinic that combines the best of international experience with a Malaysian understanding.

Fertility Associates is one of the oldest and most successful fertility clinics in Australia and New Zealand – it has very high success rates, excellent customer care and a focus on quality. By the beginning of 2014, more than 14,000 children had been born as a result of treatment from Fertility Associates. It has always been at the forefront with new ideas and new technology.

One example is this magazine, *Pathway to a child*, adapted from the New Zealand edition. As well as giving you practical information about specific treatments such as IVF and IUI, it is full of background information and useful advice. Like most magazines, you probably won't read it all at once. There are parts you'll want to read straight away, parts you will want to come back to, and parts that won't apply to you.

You'll also find stories from Fertility Associates' patients who have experienced infertility and are happy to share their insights in their own words. We look forward to adding

stories from our Malaysian patients in the next edition. You'll see that different people can have different pathways to having a child. And some have shared their story, even though treatment did not work for them. These stories also show the wisdom and self-awareness that often comes from experiencing and overcoming infertility – you are not alone with us.

The fertility journey is not always easy. It is our aim to help you have a family quickly and safely, using the most appropriate technology that meets your needs and values. Our doctors, nurses, embryologists and support staff span the various cultures in Malaysia – so feel free to tell us about your preferences and needs.

This magazine and our very comprehensive websites are only part of the story – our staff are our most valuable resource. They are always willing to help with information and support. No question is too trivial, no concern too insignificant. You can meet our staff on our website www.fertilityassociates.com.my under the 'About us' section.

Thank you for trusting Fertility Associates to help you achieve your dream of having a child.

Best wishes

Arasu

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Our New Zealand clinics:

Dr Simon Kelly **Dr VP Singh** **Dr Andrew Murray** **Dr Sarah Wakeman**
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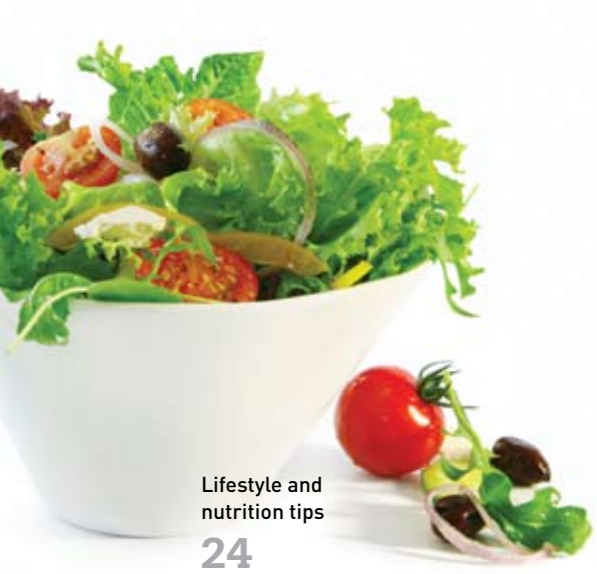
Dr Mathi Arasu Muthusamy

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RTAC Licensed

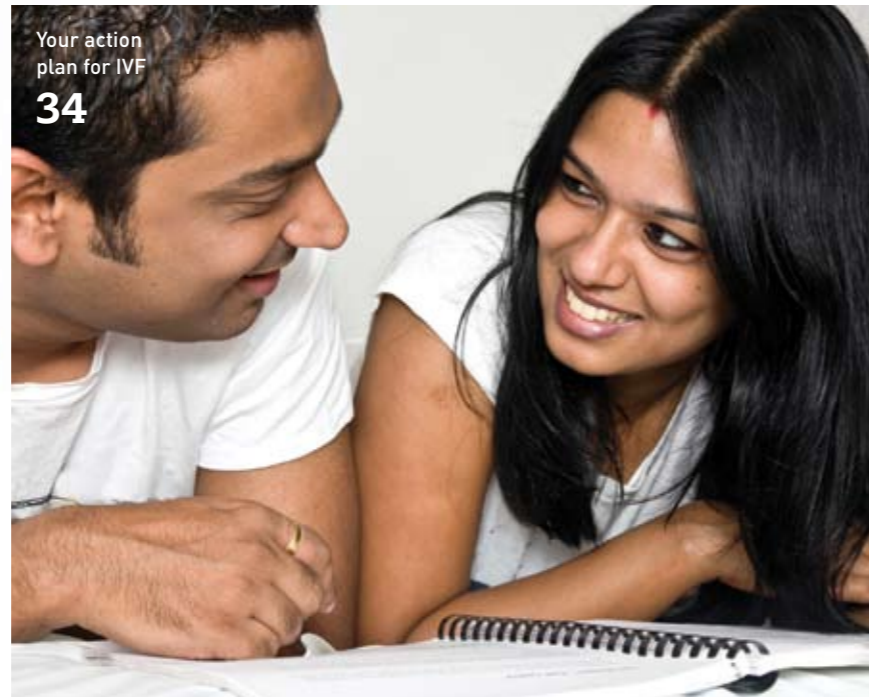
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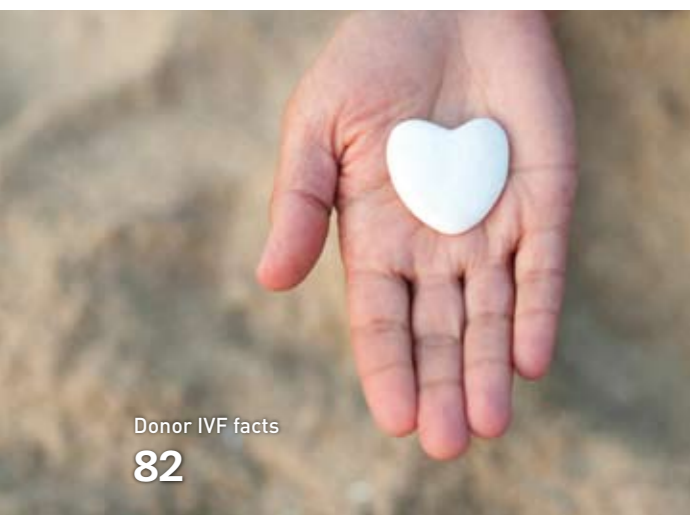
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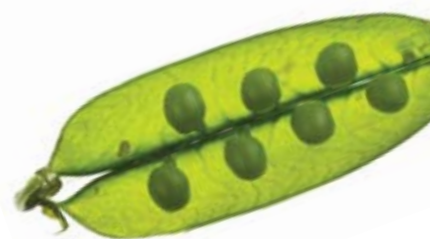
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Step by step through IVF

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FEES GUIDE

See separate fees sheet

Finding the information you want

THERE IS an overwhelming amount of information about infertility and its treatment on the web and in books. Where do you start and what is reliable?

Our website (www.fertilityassociates.com.my) has links to what we think are the best places to start your search, along with a list of recommended reading. We also welcome your recommendations. Other good sources of information are available on our New Zealand websites – www.fertilityassociates.co.nz, ivflings.co.nz and on our facebook page.



As you read this magazine you'll see various symbols:



The stop sign refers to important information to keep you safe during treatment. Please make sure you read each **Safety Message** carefully.



You'll probably want more information on some topics. We have over 30 in-depth information sheets on our website which we call **Fertility Facts**. If you can't use the web, our staff are happy to print a copy of what you are interested in. You can find the link to Fertility Facts on the front page of our website or by going to www.fertilityfacts.com.my



Our doctors and nurses will give you **Specific Information** at various steps during your treatment. This is written information you need at that point of your treatment, for instance your cycle timetable; how to give a particular medication; or care after egg collection.



Did you know? Highlights interesting facts that may surprise even the well-informed.



The Bunga Telor is a well-loved flower, symbolising the hope of children. We use it to highlight **Fertility Tips** to help you along your journey.



Many people have generously shared their stories with us. We use this symbol to indicate the **experiences and insights** of some of those who have already made the journey.

After hours emergency care

If you suffer from any side effects of treatment or pregnancy such as pain, fever, or other symptoms mentioned in various sections of this magazine, call the clinic. To speak with a doctor/nurse outside clinic hours, please phone your clinic number, and choose the option for the doctor/nurse on call. The clinic telephone number is: **03 7931 9510**

If you are unable to contact the doctor or nurse on call, please go to your nearest hospital emergency department.

Our approach and values

DR FREDDIE GRAHAM and Dr Richard Fisher started IVF in New Zealand in 1983, only five years after the world's first IVF child was born. The wait for IVF at the government hospital had grown to seven years. It was then that Freddie and Richard decided to start a private practice which they called Fertility Associates. Fertility Associates now has clinics in Kuala Lumpur and New Zealand (Auckland, Hamilton, Wellington and Christchurch). In New Zealand we provide public as well as private services. We do more fertility treatment in New Zealand than everyone else put together.

Our approach

Your Fertility Associates doctor is in charge of your care. Day to day, during treatment, you will be looked after by our team of doctors, nurses, embryologists and support staff. We try

hard to provide continuity of care, but because fertility treatment and our clinics are a seven-day a week service, you can sometimes meet several different members of our team during treatment.

When treatment is underway we take as much time as is needed. The doctors' schedules may occasionally be delayed when an egg collection or embryo transfer takes longer than expected, or for similar unforeseen circumstances. We will try to advise you if your appointment is likely to be more than 30 minutes late.

Each treatment is guided by detailed medical and scientific protocols which our doctors and scientists in Malaysia and New Zealand have collectively decided upon. These are based on what we consider best practice world-wide and from over 28 years of our own experience of fertility treatment in New Zealand. We are continually reviewing our results and looking for better ways of doing things. If you have surfed the net you will know that there are lots of opinions on all sorts of subjects – we keep to evidence-based medicine wherever possible, and are wary of the latest fads.

Family and support people welcome

People go through treatment as a couple – your partner's support is really important. You are also welcome to bring family members, friends or support people to any of your consultations and treatment appointments.

Variation and unexpected events

While the reliability of fertility treatment has increased greatly over the years, it is important to realise that there can be uncertainty at some steps of treatment and variation between one

treatment cycle and the next. For instance, the number of eggs collected in IVF and the proportion that fertilise normally can fluctuate significantly just through normal biological variation. If your treatment looks like it is not progressing as expected, we will tell you as soon as we know and help you make a decision about what to do.

Reproductive technology, like IVF, involves many steps – handling sperm, eggs and embryos and using highly specialised equipment. Almost everything needs to be done under a microscope in a carefully controlled laboratory environment. Accidents and equipment malfunctions are very rare but can occasionally occur. We have an open disclosure policy so that if an incident develops we will promptly tell you. If there is an incident within our control that significantly affects your chance of pregnancy, we will discuss options including replacement of your cycle of treatment. This is in addition to your rights under legislation.

Health and well-being of women and children

The health and well-being of children who will be born, and of women and men being treated, are very important to our doctors. Health and well-being can cover physical, social or psychological aspects – for instance an underlying medical condition such as risk of diabetes.

In our registration form we ask you to disclose all information that may be relevant to your health and well-being or to that of a child who could be born from treatment. Keeping your health and wellbeing in mind is part of our job, and staff may share relevant information with your doctor. In doing so they would keep details confidential, so you can be assured of your privacy.

If we have any concerns, we will raise them with you. We may ask your permission to obtain further information from your GP or another health provider. Sometimes we might suggest extra help from outside Fertility Associates – for instance seeing an obstetric physician.

Quality

We set ourselves very high standards, and in New Zealand that includes voluntary certification to ISO 9001 and to the Australian RTAC Code of Practice, as well as the New Zealand Fertility Standard required by the New Zealand Ministry of Health. We are applying the same quality standards to our clinics in Malaysia, and will seek certification soon after we are underway.

Auditing includes inspection of patient records by professional auditing bodies – the auditors sign confidentiality agreements to maintain your privacy.

Feedback, complaints and advocates

Because we want to give you the best possible service we can, we are always keen for feedback. We mail out freepost surveys to a selection of patients every month. The survey forms are also available from brochure stands in each clinic, or you can fill one out online anytime on our website.

Please tell us straight away if our service isn't meeting your expectations. You can talk to any of our staff or send an email. Fertility treatment can be complex at the best of times, and we know that a shortfall in our communication or explanation can be very stressful.

Identifying a problem or making a complaint will not affect your treatment in any way. We aim to confirm any complaint within two working days and to fully resolve it within two weeks or less. You are welcome to involve a support person if you have a complaint or wish to discuss any aspect of your treatment.

If you are not satisfied with our efforts in resolving a problem you may write to the Malaysian Medical Council. For more information, see www.mmc.gov.my

Our values	How we express these values for you
Care	Understanding and sharing your journey with compassion.
	Understanding the values you hold and supporting the path you take. Honouring the body and spirit in our work.
Responsiveness	Listening so that we meet your needs.
	Making services accessible and acceptable for all, and particularly for indigenous people. Giving you the best chance of a child.
Excellence	Helping you overcome the obstacles in your path.



Your privacy

ALTHOUGH PRIVACY is important for all health information, this is especially so for medical information about fertility. To help meet our obligations under New Zealand and Malaysian regulation, we have developed a variety of policies.

Collecting information

We only collect information that is relevant to the services we provide you. If we want extra information, for instance from a previous fertility provider, your GP, or another health service, then we will get your permission first. If there is any information we are obliged by law to obtain, we will tell you first.

Disclosing information

We will ask your permission before we pass on information we hold about you. In our patient registration form we ask you whether you want us to send copies of letters to your referring doctor and/or GP. Our registration form also covers sharing information between partners.

Our staff, contractors and auditors sign an agreement not to disclose any information they may come across and not to mention anybody they might see in the clinic.

We may need to give some limited information when we arrange other medical

services, such as blood tests or ultrasound scans. For instance, a request for a hormone test may state something like 'Ectopic pregnancy' so the laboratory makes the right interpretation of the result.

We may provide your name in relation to billing or debt recovery, but we would not disclose what the debt was related to.

Quality activities

If we are required under government regulations to provide non-identifying information about any treatments, we will mention this in our consent forms for the relevant treatments. None of this information is identifiable, and each user has a strict code of practice for using the information we give them.

Ownership, correction and copying your medical information

You own your medical information and can ask to see it and correct it at anytime. We set a charge to copy your medical records, but we can usually do this for free if you give us a reasonable amount of time.

There are some circumstances under which a health provider can restrict access to medical records, and we would explain this if it arose.



Questions and concerns

If you have any questions, please ask. Fertility Associates has a Privacy Officer who can help with any concerns you might have.

Although you own your medical information, we own our copy of it (e.g. the paper or computer records), and can keep that information.

Medical records about fertility are more complex than most health records because they concern a husband and wife. Generally if a relationship breaks down, then a person can only access that portion of their fertility records that relates to them. For instance, a woman could not access her former husband's semen analyses without his written consent.

Security

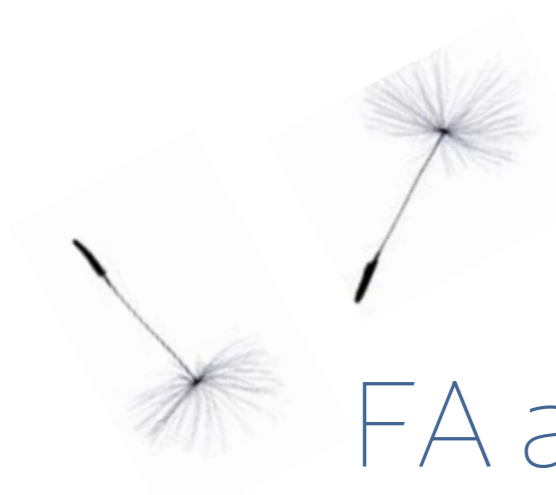
We have put in a lot of steps to try to keep your medical information secure and intact, ranging from computer firewalls to checking letters before they go into envelopes, and we regularly audit our systems. However, we

know that lapses can occasionally happen despite best intents and efforts. If you receive any information that is not yours, please notify us immediately. We will try to find the root cause of any breach to prevent it happening again.

Contact in the future

Our consent forms for treatment ask whether we can contact you in the future to see if you are interested in taking part in research. About 80% of people agree to this, for which we are very thankful. This has been extremely valuable for following up the health of children born after fertility treatment. If you do not agree to follow-up for research, we would only contact you if it was about a matter which could affect your or your children's health or wellbeing.

Although privacy is important for all health information, this is especially so for medical information about fertility.



FA and the law

TO DATE, there is no legislation in Malaysia which covers fertility treatment, although a Bill has been drafted called the 'Assisted Reproductive Technology (ART) Act'.

There are guidelines drawn up by the Malaysian Medical Council on assisted reproduction for doctors and clinics, which we follow (www.mmc.gov.my/v1/docs/Assisted%20Reproduction.pdf).

Couples must be married to receive treatment. Donated sperm and donated eggs may be used if consistent with the couple's religion. Surrogacy is not permitted.

The Malaysian Medical Association has a charter of patient's rights (www.mma.org.my/Resources/Charters/Patientscharter/PatientsRight/tabid/82/Default.aspx) These cover the right to:

- Care, consideration and dignity, without discrimination;

- Privacy and the right to a chaperone;
- Good information so that you can make an informed decision about whether to have treatment, or what treatment to have;
- An explanation of alternative treatments, side effects, chance of success and risks with each treatment;
- A second opinion at any time;
- Safe and effective treatment;
- Complain and seek redress.

New Zealand also has a Code of Rights that covers the rights and responsibilities of patients. We have summarised these in the box below.

These are consistent with Malaysian charter of patient's rights and we think they provide a useful guide for day to day interactions between you and our staff.

Your rights and responsibilities

In New Zealand there is a Code of Rights that every consumer of a Health and Disability Service is entitled to expect from their service provider. Fertility Associates abides by this code. We have summarised what you can expect from us, and in turn, what we expect from you.

As a patient you are entitled:

- To receive competent, considerate and confidential care in a respectful, culturally acceptable manner.
- To know the names and designations of the people involved with your care.
- To be given information about your condition, what treatment can be offered and what is likely to happen.
- To receive enough information to make decisions about your treatment and care to enable informed consent.
- To have access to interpreters where appropriate.
- To give or withhold consent for any treatment, operation or anaesthetic after being given information about the advantages and risks.

- To ask for the opinion of a second doctor if you feel the need.
- To be interviewed in private.
- To receive services that are safe and meet acceptable standards of quality.
- To provide feedback or make a complaint, and have access to an independent advocacy service.
- To be asked for your consent before taking part in any teaching or research programme.

Your responsibility to us:

- To tell our staff if you do not understand the information you have been given about your care or treatment.
- To tell the doctor of any changes in your health or wellbeing.
- To show consideration for other patients and to our staff.
- To respect the privacy and confidentiality of other patients you might see in our clinics.
- To ask our staff for help when you have any questions or concerns.
- To co-operate to the best of your ability in the treatment or course of care you have chosen.
- To give us feedback about our service.

Understanding fertility language

Jargon

Most areas of medicine and science have their own jargon and fertility is no exception. The most common terms are listed here. You will probably just skim this section at first and then refer back to it when you want to check out the meaning of an abbreviation or term.



Our website has a comprehensive glossary of terms and abbreviations used in reproduction and fertility treatment, and more information on medications. www.fertilityfacts.com.my

You may have already encountered some of these abbreviations, but here are some of the more common fertility treatments and the abbreviations used for them:



Clomiphene	A pill usually taken for 5 days early in the menstrual cycle that increases the number of follicles that grow in the ovary. Commonly used in Ovulation Induction.
OI	Ovulation Induction is a treatment to induce ovulation in women with irregular or absent cycles.
IUI	Intra-Uterine-Insemination is when sperm is placed directly into the uterus.
IVF	In Vitro Fertilisation. It strictly means adding sperm and egg together outside the body, but it is usually used to describe the whole process covering medications, egg collection, fertilisation, and embryo transfer.
ICSI	Intra-Cytoplasmic Sperm Injection. Surely one of the craziest bits of IVF jargon – it simply means a single sperm is injected into each egg when the sperm cannot do this job themselves.
DS	Donor Sperm (formerly called Donor Insemination). Donor sperm can be used with IUI and IVF.
DO	Donor Oocyte or donor egg – 'oocyte' is the scientific name for an egg. Donor egg is when another woman's egg is used in an IVF cycle.



IVF treatment has its own set of acronyms and terms:

Cycle	One course of treatment. With IVF, this is from Day 1 through to the pregnancy test.
OPU	Oocyte PickUp – also known as egg collection, when the eggs are taken from the ovaries.
ET	Embryo Transfer – when the embryo(s) is transferred back into the uterus.
SET	Single Embryo Transfer – when only one embryo is transferred into the uterus at a time.
FET	Frozen Embryo Transfer. Essentially the defrosting and replacement of an embryo that has been frozen and stored with us after a cycle of IVF. Also known as Thawed Embryo Replacement (TER).
Manufactured cycle	An artificial menstrual cycle used to provide the right environment for the transfer of embryos.
Blastocyst	The name given to an embryo 5-6 days after fertilisation when it consists of an outer layer of cells that will become the placenta and an inner mass of cells that will become the baby.
SSR	Surgical Sperm Retrieval – when sperm are taken directly from the testes using a fine needle.
PESA	Percutaneous Epididymal Sperm Aspiration – SSR when sperm are taken from the epididymis, which is a tiny organ sitting on top of the testis.
TESA, TESE	Testicular Sperm Aspiration, Testicular Sperm Extraction – other names for SSR.
OHSS	Ovarian Hyper-Stimulation Syndrome – a condition that can occur a few days after egg collection that is caused by too many follicles being stimulated to grow at once in the ovaries. Fluid moves from the blood into the abdomen and into tissue. Untreated, it can have serious consequences, including stroke and even death.

You will also come across:

Day 1	The first day of your period or menstrual bleeding. When you start a treatment cycle, we count day 1 as the first day you wake with your period. So if your period starts in the afternoon, the next day is called day 1.
Catheter	This is a fine tube put into the body. In fertility it nearly always refers to a catheter put into the uterus for embryo transfer in IVF or insemination in IUI.
Biochemical pregnancy	A pregnancy that ends at a very early stage. Its name comes from the fact that the pregnancy is detected by biochemical tests like blood tests.
Clinical pregnancy	A pregnancy that can be detected by an ultrasound scan.

Follicles and eggs

The eggs in the ovary are tiny – smaller than the full stops on this page. The egg starts off surrounded by a layer of granulosa cells. The granulosa cells multiply into a ball of cells, and then into a fluid-filled sac called a follicle. At the beginning of a menstrual cycle the largest follicles are 4–6mm in diameter. At the time of ovulation they have grown to 18–22mm.

Visit our website for a comprehensive glossary of terms and abbreviations used in reproduction and fertility treatment, and more information on medications: www.fertilityfacts.com.my



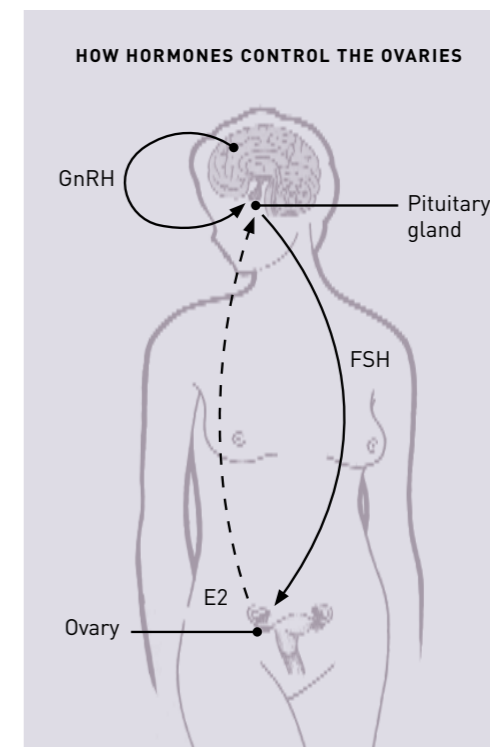
Hormones and medications

Fertility treatment makes a lot more sense if you have a basic understanding of the hormones that control female reproduction and of the medications that are used in treatment. Most of the medications are versions of the body's own hormones.

Let's start with the hormones. In the natural menstrual cycle, the brain controls the pituitary gland, and the pituitary gland controls the ovaries. The hormones made by the follicles in the ovaries feed back to the brain and pituitary to keep the whole system in control. You can think of it as a bit like driving a car. To get started you push down hard on the accelerator. Once you reach the desired speed you ease off on the accelerator.

The body does the same. The brain releases a hormone called Gonadotrophin Releasing Hormone (GnRH). GnRH makes the pituitary release a hormone called Follicle Stimulating Hormone (FSH). FSH makes the follicles grow and the follicles release Estradiol (often abbreviated to E2). When the brain and pituitary sense increasing levels of E2 they ease off the release of FSH.

Using this analogy, fertility treatments like clomiphene, IUI with ovarian stimulation and IVF are rather like driving the car faster. How it is done is quite sophisticated. The doctors and scientists who design the ovarian stimulation



methods are like the engineers who modify the car engine. The clinic staff monitor the ovary during the course of treatment using blood tests and ultrasound scans; their job is similar to driving the car at high speed. The table below summarises the hormones involved, what they do, the main medications we use, and how they work. →

More information

- www.pharmacy.gov.my – choose 'services', then 'search registered products'.
- www.emdserono.com/en – choose 'therapies', then 'fertility'.
- www.fertilitylifelines.com – good index for Serono products.
- www.puregon.com
- www.msd-newzealand.com – choose 'products'.

ABOUT US



There are a variety of types of ovarian stimulation, all of which use medications that are the same as, or mimic, the body's own reproductive hormones. See our Fertility Facts on Ovarian Stimulation. www.fertilityfacts.com.my



See our Fertility Facts Glossary of Terms and Drugs for information on side-effects. www.fertilityfacts.com.my

The hormones	What the hormones do	The medications	Medication trade names	What the medications do
Gonadotrophin Releasing Hormone (GnRH)	Release FSH and LH from the pituitary gland.	GnRH agonists	Buserelin, Lupron, Leuprolide, Lucrin, Zoladex, Synarel	Modified version of the body's own hormone. They initially stimulate the release of FSH just like GnRH, but then the body adapts and stops secreting its own GnRH. This is called 'down regulation'. By doing this, they prevent the LH surge.
		GnRH antagonists	Cetrotide, Orgalutran	Modified version of the body's own hormone. They block the body's GnRH and therefore prevent the LH surge.
Follicle stimulating hormone (FSH)	Stimulates follicles in the ovary to grow.	Follicle stimulating hormone (FSH)	Gonal F, Puregon, Elonva, Menopur	Copy or modified version of the body's own hormone, so they do the same thing.
Luteinising hormone (LH)	A surge of LH in the middle of the cycle triggers the final maturation of the egg and ovulation of the follicle(s) containing mature eggs. After ovulation it helps maintain progesterone secretion.	Luteinising hormone (LH)	Luveris	Copy of the body's own hormone. Not used much because it is so expensive.
human Chorionic Gonadotrophin (hCG)	hCG is the main hormone made by the early embryo once it implants. It has a similar biological effect to LH. hCG is the hormone detected by pregnancy tests.	human Chorionic Gonadotrophin (hCG)	Ovidrel, Pregnyl	Ovidrel is a copy of the body's own hormone; Pregnyl is purified from the urine of pregnant women. Mainly used instead of LH to trigger ovulation because it is more convenient and cost effective.
Estradiol (E2)	E2 is the main estrogen hormone made by developing follicles. It has many actions, including growing the lining of the uterus (called the endometrium).	Estradiol (E2)	Progynova, Estrofem, Climara	Copy of the body's own hormone. Used in manufactured cycles.
Progesterone (P4)	P4 is the main hormone secreted by the follicle once it has released its egg. Its major action is to maintain the lining of the uterus so an embryo can implant and cause a pregnancy.	Progesterone (P4)	Utrogestan, Crinone, Gestone, Cyclogest	Copy of the body's own hormone. Used in manufactured cycle, and to support the uterus in IVF cycles.
		Clomiphene citrate (CC)	Serophene	Blocks feedback by estradiol so the pituitary gland releases more FSH.
		The contraceptive pill	Levlén ED, Microgynon, Ava	Low dose estrogen in the pill stops the release of FSH and LH and helps make IVF more reliable.

Here you will find stories our patients have chosen to share with you about their experiences with fertility treatment, the impact on their lives and the different ways they coped with treatment. These stories are written by them and are unedited – they are in their own words...

IN MY OWN WORDS



“Everyone at Fertility Associates was trying their best to help us – constant reassurance, answering all our questions, no matter how dumb it may have sounded, and giving us that warm smile when another cycle did not work.”

We finally knew something was up. The issue sat with me for two reasons:

1. I was overweight
2. I was not firing at the right time (not sure what the right term was)

The husband was relieved about his manhood he said. When I finally got my head in the right place and lost close to 10kgs, we tried again in 2010. Success came our way because:

- We focused on living life as individuals/ couple and a family.
- Knowing that every one at Fertility Associates was trying their best to help us get pregnant. This was demonstrated in their constant reassurance, answering all our questions, no matter how dumb it may have sounded to our ears, and giving us that warm smile when another cycle did not work.

In September after another failed attempt we both agreed October would be our last attempt. We are now four months along in our pregnancy. I do not know who is happier, our son who will now have a sibling, us for sharing our love again, our parents and wider family who have been waiting years for another angel to join our family, or Fertility Clinic staff who have been on that journey with us.

To you we give our love and understanding as you take this emotional journey. As individuals and a family we have come out as better persons and a stronger family. Life never ended when we were told I had the fertility problem, it just got more colourful along the way.

Kia Manuia.

One family discovered that their quest for another baby made them better and stronger, regardless of the outcome

KIA ORANA and greetings.

If you are reading this, you are sitting where we were many years ago, seven to be exact.

Before I get ahead of myself let me share with you who we are. I am of Cook Island descent from a large family. I was brought up by my paternal grandparents in Tokoroa. University educated and career minded. My Pakeha (European) husband was born in Te Awamutu and is from a small family. Our son was born 11 years ago, conceived naturally and without difficulties. We never thought we would have fertility issues until our boy was three years old. After a number of attempts, herbal medicines, medical checks, pleas to the wider family for a baby/child in the Cook Islands and New Zealand and starting the adoption process.

Our Pathway...

