



**infertilitynetwork UK**

Advice, Support & Understanding

# GP & Practice Manager Information

## **Information for GPs and Practice Managers**

on infertility provision and the services  
provided by Infertility Network UK

Infertility Network UK

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# Introduction

**I**nfertility Network UK (I N UK) is a national charity created by the merger of CHILD and iSSUE. We are now the largest network in the UK for those experiencing fertility problems, offering face to face and telephonic support and information at Regional and National level.

Our goals are to help couples make informed decisions throughout the infertility process, and to provide practical and emotional support. Whatever help is needed, we will endeavour to provide it – even if it is simply showing the way forward.

I N UK offer a number of services to couples suffering the effects of infertility, from the first day they start to worry they might have problems, right through their investigations, treatments or whatever route they choose. Our services are listed at the back of this newsletter, which we hope you make full use of to inform yourselves of the current issues within the field. **Please help your patients by providing them with our leaflet and allowing them the opportunity to access the services which can help inform and empower them.**

## THE DEVASTATING IMPACT OF INFERTILITY

Infertility is an emotive subject, which many do not fully understand, because the vast majority of us take having a baby for granted. It is, after all, the natural progression of life. Couples these days spend several years setting up a home and a career, totally unaware that they have a fertility problem, but when they decide to start a family, some find they have difficulties in conceiving.

Most people have a deep and distinct desire to have children, and when they find themselves unable to fulfil that desire, they often suffer psychological and emotional distress. Infertility causes a form of grief likened to that of bereavement. The infertile grieve for children that never were, and the grief goes on and on, usually

suffered in secret while putting on a brave face or some diversionary excuse as a defence. Many feel unable to even speak to family and friends about their suffering; such is the nature of the illness.

There are many hurdles to get over before couples even reach the stage of having treatment whilst all around others seem to either be pregnant or have had a baby. Imagine the desperation and overwhelming sense of failure, especially if treatment does not prove successful. So it starts all over again. Maybe there was money saved for the initial treatment, but this time where is the money coming from? Infertility is often likened to a roller-coaster ride. You are on a high when having treatment and awaiting the outcome and sink to the depths of despair upon failure of treatment or when for some, they find themselves unable to access the treatment they need.

## FEAR! GUILT! ANGER! SHOCK! SHAME! ISOLATION!

These are some of the feelings expressed by couples when they have a fertility problem:

**Fear** – of treatment, of failure, of a future without children.

**Guilt** – This is my fault, something I did

**Anger** – towards doctors when treatment fails, science for holding out a carrot of success and then failing them, Society for not warning them about infertility, partner for being a constant reminder of mutual failure, at oneself – Why me!

**Shock** – can this be true followed by numbness and withdrawal and denial

**Shame** – I have let my partner and family down

**Isolation** – Everyone else is normal and has a family. On the fringe of life. Feel they cannot participate in life. The most dreaded question in any social gathering is “Do you have children.” **This is the worst feeling of all but one that Infertility Network UK can help ease.**

*“Why can’t I be happy, I’m alive.  
I can’t stop wanting to have a child”.*

*“The pain and emptiness is a constant reminder of my failure as a wife and as a woman”*

*“I have not only an empty womb,  
but an empty heart.”*

*“I find living with this illness near impossible, all that keeps me going is hope that one day the treatment will work”*

**Just some of the quotes expressed by those trying for a family**

Recent studies show that there are potentially 1.5 million people seeking specialist help in trying for a child. *An astonishing 1 in 7 couples seeks specialist help at some time in their lives because of the difficulty in conceiving.* Infertility is frequently referred to as an isolating condition where one feel totally alone and that no one can possibly understand the effect it has on a couple unless they have been through it themselves. By establishing a support network around the UK, we aim to take away that feeling of isolation and replace it with a feeling of support and friendship.

# Fertility treatment:

## WHAT THE GP NEEDS TO KNOW

By James Kingsland MB ChB DRCOG

*The decision to allow eligible couples one cycle of IVF treatment at NHS expense by April 2005 has focused attention on fertility services. A couple struggling to conceive need early support and well informed advice from their GP, and James Kingsland sets out the key issues.*

In the UK, up to one couple in seven experience trouble conceiving and need medical help. Studies of the impact of infertility on the psychological well-being of couples have found that it adversely affects at least one third of women and one-fifth of men. Hence an important first step in the management of these couples is support from a knowledgeable GP, which helps alleviate anxiety and reduces stress.

### WHEN SHOULD TESTS BE STARTED FOR THE COUPLE FINDING IT HARD TO CONCEIVE?

Focus first on identifying any specific factor that might be affecting the ability to conceive, such as:

- Menstrual history
- Frequency and timing of sexual intercourse
- Contraceptive and obstetric history
- Lifestyle issues, eg, alcohol intake, drug use, smoking
- Occupation and exposure to stress
- Body weight
- Medical and sexual history

If none is found, counsel the couple on lifestyle factors such as alcohol consumption, weight and smoking, to help improve general health and the chances of conception. Pre-conception advice should include folic acid supplementation, rubella screening and screening for cervical cancer.

Conception should occur in 84% of women within one year and 92% within two years. Guidance recommends that clinical investigation should be started only if conception fails to occur after two years of regular, unprotected sexual intercourse. Be sensitive, however, to the couple's individual circumstances; base intervention on their need, particularly with respect to age and psychological well-being, not on inappropriate time restrictions. For example, success rates with in-vitro fertilisation (IVF) decline rapidly from the late 30s and so all women in this age group should be considered for referral much earlier, possibly not later than one year of trying to conceive.

### WHAT TESTS CAN USEFULLY BE ORGANISED BY THE GP?

Initial laboratory investigation of the infertile couple includes:

- Semen analysis to help identify male factor problems
- Menstrual gonadotrophin level to confirm the integrity of the pituitary-ovarian axis

- Mid-luteal serum progesterone level to help identify ovulatory dysfunction
- Serum prolactin, testosterone and SHBG (sex hormone binding globulin) may also be helpful, as may FBC, TFTs and fasting blood sugar to exclude concomitant disease affecting fertility. Testing to exclude tubal occlusion and endometriosis should be arranged and in some areas GPs have direct access to secondary-care procedures.
- Refer the couple if tests reveals an abnormality or an anatomical disorder affecting conception.

### OVULATION INDUCTION

Hormonal manipulation of ovulation, using drugs such as clomiphene, tamoxifen or recombinant gonadotrophins to stimulate egg development and release, is now best performed in secondary care. Multiple pregnancy is a significant risk with ovulation induction (OI), which is not recommended in primary care unless scanning is available.

Normally, up to six cycles of clomiphene are tried, followed by up to six cycles of gonadotrophin treatment. OI is normally combined with timed intercourse or artificial insemination (IUI) to increase the chance of successful fertilisation, and is successful in more than 80% of women treated. If the couple still does not manage to conceive, they should be referred for assisted reproductive technology treatment in a specialist centre.

### INDICATIONS AND CONTRAINDICATIONS FOR ASSISTED REPRODUCTION TECHNOLOGY (ART)

NICE issued the clinical guideline *Fertility: assessment and treatment for people with fertility problems for those who work in or use the NHS in England and Wales*. The guideline outlines the clinical criteria for referral of a couple for ART. These include couples with anatomical problems of infertility, male-factor infertility, widespread endometriosis and unexplained infertility.

NICE recommended that couples in which the woman is aged 23-39 at the time of treatment and who have an identified cause for their fertility problems or who have infertility of at least 3 years' duration should be offered up to three stimulated cycles of in vitro fertilisation (IVF). John Reid, The Secretary of State for Health has stated that, as a first step in implementation, eligible couples must be offered one cycle at NHS expense by April 2005. The NICE guideline does not address the social criteria, such as length of relationship, other children and previous sterilization that have traditionally been subject to regional variations and contributed to the diversity and inconsistencies in care.

The guideline also stated that IVF should not be considered for women with high levels of follicle-stimulating hormone (FSH) or where there is a susceptibility to ovarian hyperstimulation syndrome.

### PRESENTING THE OPTIONS FOR ART

ART can be painful, emotional and stressful for all involved and there are no guarantees of success. Verbal and written information should be given of the treatment options available and of the risks, implications of the procedures, including hyperstimulation syndrome (OHSS), multiple births and ovarian cancer. It is also essential to offer both partners counselling at this stage.

### WHAT OTHER FORMS OF ART ARE AVAILABLE?

Other forms of ART are donor insemination (DI) and oocyte (egg) donation.

DI can be considered where the man has no or few sperm or where there is inherited disease. Donor sperm is injected into the cervical canal or uterine cavity, sometimes in conjunction with ovulation induction.

Egg donation can be considered for women with primary ovarian failure, premature menopause or ovarian damage after surgery, radiation or chemotherapy. In addition, women who repeatedly fail to respond to ovarian stimulation in an IVF programme can benefit. Donated eggs from volunteers are fertilised with sperm from the recipient's partner. After fertilisation, embryos are transferred into the uterus or fallopian tubes of the recipient.

Not all couples wish to pursue such intervention to have a child. In these circumstances, lifestyle advice to improve chances of conception, together with counselling, is the advice option. Alternatively, referral to social services to discuss possible adoption may be preferred.

People who experience fertility problems should be informed that they may find it helpful to contact a fertility support group such as Infertility Network UK [www.infertilitynetworkuk.com](http://www.infertilitynetworkuk.com).

GPs continue to be the first point of contact for couples struggling to conceive. We need to make sure that we are equipped to advice and counsel for the journey ahead, and ensure prompt and appropriate referral for as many couples as possible.

*Dr James Kingsland – General Practitioner, Wallasey and Liverpool Member of the Executive of the NAPC. Member of the General Practice Committee of the BMA, and chairman of its PMS sub-committee.*

# Impact of the NICE Guideline for Fertility

England and Wales, saw the first step in the provision of comprehensive, NHS-funded fertility treatment with the launch of the NICE guideline earlier this year. Infertility Network UK (I N UK), wanted to know just what impact these guidelines would have on Primary Care Trusts (PCT'S) and what plans they had for implementation, and to this end, surveyed all PCT'S in England.

We asked for their views on the NICE guideline in terms of content, practical guidance and financial impact, about their current commissioning of fertility services, their anticipated commissioning needs and costs associated with implementation, the financial impact and their progress towards implementation.

## COMMISSIONING DEPARTMENTS WITHIN PCT'S

We found that within the PCT'S the person responsible for infertility services varied greatly including public health and commissioning departments and very few PCT'S had a department dealing specifically with infertility services. The survey was sent to 282 PCT'S in England, and the response rate was just 19%, with the geographical spread of respondents being fairly even. We believe that the low response rate probably reflects the high workload of PCT'S and the confusion that exists regarding who should be responsible for implementation and commissioning of the NICE guideline. It may also however, reflect the lack of priority of infertility amongst PCT commissioners.

## SOCIAL CRITERIA

There is a lack of central guidance on what the social eligibility criteria should be.

The fact that these social criteria are seemingly being left to individual PCT'S is of great concern to I N UK and to patients. We believe that this will lead to continued variation and inequality around the country. Ultimately this will mean the continuation of that same postcode lottery which these guidelines were meant to end and which is so unfair to patients.

- Our research showed that 74% of PCT'S said that they already have or intend to have social criteria, and one third said they will change them if the guideline is implemented. Of the 39 PCT'S that have already established social eligibility criteria for fertility treatment, there were five main criteria either being adopted or under active consideration.
- 95% of the PCT'S who responded said they would include criteria which stated that couples who had a child from that relationship or from a previous relationship would be excluded from NHS treatment
- 74% said they would not treat couples where one partner had been previously sterilised.
- 36% said they would have criteria which would not allow access to treatment for same sex couples
- 62% indicated that they would have criteria based on the duration of the couple's relationship
- 36% said single people would not receive NHS treatment.

We have called on The Department of Health to take the lead in providing one set of criteria for all. It is the only way we will truly rid ourselves of this postcode lottery.

## PROVISION OF IVF AND ICSI

77% of respondents said that they provide both IVF and ICSI. This may seem quite high, but it means that just under a quarter of those PCT'S who responded to the survey were not providing IVF and ICSI. Approximately half of those providing IVF and ICSI commissioned these services from within the NHS, and 12% went to the private sector to provide their infertility services.

When asked to describe the availability and quality of the service their PCT provides, only a third felt that they offered comprehensive availability

It is very apparent from these figures, that there are many of your patients across the country who are being denied treatment, but then we already knew that anyway. When you take into consideration that within each of the 12 PCT'S who said they did not provide assisted conception, there are approximately 182,000 people, and then take into consideration that one in seven couples in the UK seek help in order to conceive, the numbers are staggering.

**Then what about the 229 PCT'S who failed to respond to this survey? We leave you to make your own assumptions on that!**

## CLINICAL AUDIT

Clinical audit is key to ensuring and demonstrating continuous improvement in the quality of patient care and outcomes, Yet only 57% of the PCT'S responding audit the quality of infertility services offered to their patients. The survey also showed that audit is severely lacking in independence, with 40% saying that their audit is carried out by the PCT or lead commissioner, and 90% saying it is conducted by the same organisation who provides the service, something which we believe is of great concern. Only 17% of PCT'S use an independent third party to audit performance.

# Quality Treatment on Primary Care Trusts

## IMPLEMENTATION AND THE TIMING OF IMPLEMENTATION

- Only one third of PCTs say that it is their intention to fully implement the NICE guideline, just under half of PCTs have not finalised their plans and 15% do not plan to fully implement
- From a patient perspective, this means that almost 200 PCTs serving a total patient population of 35 million have not yet committed to implementing the NICE guideline.
- Using Scottish data, we can estimate that 60 new couples per population of 250,000 would be expecting referral for IVF or ICSI in the coming year, meaning as plans remain undecided, 8,200 couples who believe there to be a chance of treatment following the publication of the NICE guidelines, who could be very disappointed.
- Of the 32% of PCTs planning full implementation of the NICE guideline, almost half were in the north of England and less than a fifth were in the south.
- Historically it has been the case that the further north you go, the better the provision of NHS services for infertility.
- John Reid, The Secretary of State for Health, welcomed the NICE guideline earlier this year and stated, "As a first step, by April next year I want *all* PCTs, including those who at present provide no IVF treatment, to offer at least one full cycle of treatment to all those eligible. In the longer term I would expect the NHS to make progress towards full implementation of the NICE guidance. (3 full cycles of treatment)"
- Only 24% said they planned implementation within 1 – 3 years, and 36% said they were planning to implement the guideline within the next 12 months ie. by May 2005.
- We must ask the question then – Have the PCT's not heard what the Health Minister has said, or are they simply ignoring it?

## IMPLEMENTATION OF OTHER ELEMENTS OF THE GUIDELINE

An important point to make is that the effective management of infertility is not just 'IVF for all'. It may be that many PCTs are distracted by the focus on IVF when there are other aspects of treatment that can improve patient outcomes and, if subjected to closer monitoring, could reduce the overall cost of infertility management.

They were asked to indicate what elements of the guideline would most and least likely be implemented. Results show that screening for Chlamydia is likely to be implemented by 73% of the responding PCT's, and assessing tubal damage by 74%. Only 39% of PCTs said they were likely to implement six cycles of IUI, and just 32% were likely to implement three cycles of IVF.

Not screening for Chlamydia has huge implications. We all know that it is on the increase and that it can cause infertility if untreated. According to The National Survey of Sexual Attitudes and Lifestyles in 2000, new diagnoses of acute sexually transmitted infections in genito-urinary clinics rose by 20% among men and 56% among women between 1990 and 1999.

By not screening we are storing a problem for the future in terms of providing infertility treatment, more importantly, for the future fertility of our patient population. That is why it is recommended in the NICE guideline.

## FACTORS HAVING AN IMPACT ON SERVICE PROVISION

The cost of service provision was highlighted as the factor with the biggest impact. 74% of PCTs highlighted that this would have a high or moderate impact, with planning and priorities having the next most significant impact.

## BARRIERS TO IMPLEMENTATION

We must ask what are the barriers to implementation? Well, the answer is quite simply money. Seven out of ten PCTs indicated that more funding is needed to implement the recommendations contained within the NICE guideline.

## SUMMARY

- There is widespread confusion within PCTs as to what commissioning fertility services actually means and who should be doing it;
- More audit of existing and future quality provision is needed;
- The lack of centrally agreed social criteria will mean the continuation of treatment by postcode;
- Perceived high additional costs and lack of funding will blight implementation;
- The patient may have to be the driver of quality service provision.

This survey was relevant only to services in England and Wales, in Scotland and Northern Ireland they have different procedures in place for infertility services.

In Scotland the situation is slightly different and for those who work in or use the NHS in Scotland it is recommended that couples in which the woman is aged less than 38 at the time of treatment and have infertility with an appropriate diagnosed cause of any duration or unexplained infertility of at least 3 years duration should be offered up to three stimulated cycles of IVF.

In Northern Ireland, the Department of Health, Social Services and Public Safety have recently completed a consultation entitled, "The Future of Fertility Services in Northern Ireland" and the results are awaited.

# The Welfare of the Child

**U**nder the terms of the Human Fertilisation and Embryology Act (1990) (HFE Act), any fertility centre in the UK offering treatment that involves mixing sperm and eggs outside the body or using donated eggs, sperm or embryos must take account of: *'The welfare of any child who may be born as a result of treatment (including the need of that child for a father) and of any other child who may be affected by the birth'* (HFE Act 1990, section 13, 5)

Before any treatment can commence the clinic will approach you as their GP to ask whether you are aware of any factual information, medical or otherwise, that might be relevant. Relevant information may include health factors relating to your patient and in addition, any other factors that might influence the health or welfare of any resulting child(ren). The information you provide will be one of a number of factors that maybe taken into account before any decision to offer treatment is made. The responsibility for making the decision about whether treatment is offered rests with the clinician responsible for the fertility clinic.

The HFE Act does not exclude any women from being considered for treatment. However, in situations where the child will have no legal father the clinic should pay particular attention to the prospective mother's ability to meet the child's needs throughout childhood.

## WELFARE OF THE CHILD ISSUES

You should note that you are not being asked to speculate on lifestyles or on the probability that a patient of yours might behave in certain ways. You will not be asked to assess your patient's suitability to act as a parent. The clinic should only ask you for relevant factual information, medical or otherwise, within the scope of the information available to you, which you think the clinic needs to know before they consider providing fertility treatment.

The fertility clinic will be discussing the following Welfare of the Child issues with the patient/couple.

- Their commitment to having and bringing up a child, or children
- Their ability to provide a stable and supportive environment for any child produced as a result of treatment
- Their medical history and the medical history of their families
- Their health and consequent future ability to look after or provide for a child's needs
- Their age and likely future ability to look after or provide for a child's needs and their ability to meet the needs of any child or children who may be born as a result of treatment, including the implications of any possible multiple births.
- Any risk of harm to the child or children who may be born, including the risk of inherited disorders or transmissible disease, problems during pregnancy and of neglect or abuse
- The effect of a new baby or babies upon existing child(ren)

In addition, if treatment involves the use of donated gametes, the following will be discussed.

- A child's potential need to know about their origins and whether or not they are prepared for the questions which may arise while the child is growing up.
- The possible attitudes of other members of the family towards the child, and towards the status in the family
- The implications for the welfare of the child if the donor is personally known within the child's family and social circle
- An explanation of who will be the legal parents of any child produced as a result of treatment with donated gametes.
- The impending removal of donor anonymity.

## WHY TREATMENT MAY BE REFUSED

The clinic responsible for administering the fertility treatment is responsible for making the final decision about whether or not treatment will be offered. Treatment may be refused on clinical grounds, or if the clinician believes that it would not be in the interest of any resulting child, or any existing child, to provide treatment. Treatment may also be refused if the fertility clinic is unable to obtain sufficient relevant information or advice to reach a proper conclusion.

# I N UK's Services Include:

**Regional Network** – Regional Organisers throughout the UK help set up support groups, plan and host patient information events in their areas, liaise with health professionals offering infertility treatments and generally provide a localised service.

**Website** – A new, exciting and interactive website providing quality information and access to I N UK's services. There is also a section for health professionals.

**Evening Telephone Counselling** – Professionally accredited counsellors run a support line each evening

**Advice Line** – run by a qualified nurse Mon-Wed-Fri

**More To Life** – A National support network, coming under the umbrella of I N UK and dedicated solely to providing a support service to couples who will remain childless

**Clinic Outreach Scheme** – This scheme allows clinics to affiliate to the charity and show their commitment to patient support.

**Linkline Service** – Outside office hours we have an answer machine in operation which gives the name and number of volunteers called 'Linkliners' who work on a rota system to provide 24 hour cover.

**Helpliners** – Members of I N UK who have personal experience of a certain type of infertility or treatment and who are happy to share their experiences and offer information to others. I N UK's helpliners are trained on listening skills.

**Regional Support Groups** – Information on support groups all over the UK

**Medical Advisors** – Members can write for independent advice from infertility specialists

**Quarterly Magazine** – Distributed to members, affiliated clinics, corporate partners and sister organisations and is available to any interested parties.

**Factsheets** – We have over 40 factsheets on most infertility related subjects.

**Publications** – Books which can be purchased through I N UK

**Video** – "A Journey Through Infertility" intended to help give infertility patients an insight into what the journey through investigations and treatment is like and to provide them with information on how to access support and information from I N UK.

**I N UK leaflets in Urdu, Punjabi and Chinese** – Our information leaflet is available in these three languages. Also available is a Booklet, which gives a synopsis of many of our factsheets, again available in all three languages.

**Presentations** – We have two presentations which are available to health professionals. *How to get it right for us, the patients* is an interactive presentation where we feedback patients views, promote best practice and explore ways of ensuring that patients needs are met. *The emotional impact of infertility* is a presentation, which can be used in staff training sessions and explores the emotional side of infertility.

**Information Events** – I N UK's Regional staff organise information days in their areas. These vary in format, according to what is required and can include talks by health professionals, workshops and an exhibition area where companies and clinics can have stands and provide patients with information. Some are evening events and some whole day events. These events are moved around each region to ensure that they are made as widely available as possible

**Please place an order for I N UK literature by filling in the form overleaf, and feel free to contact us at any time if there is any aspect of our services you would like to discuss.**

**Tel: 08701 188 088 Fax: 01424 731 858.**

**Email: [admin@InfertilityNetworkUK.com](mailto:admin@InfertilityNetworkUK.com)**

**[www.InfertilityNetworkUK.com](http://www.InfertilityNetworkUK.com)**

# Fax Back Order Form

Infertility Network UK's (I N UK) services are outlined overleaf. We would like you to display leaflets and posters for I N UK and More to Life in your waiting room so that your patients can have access to these services. Our research

has shown that the vast majority of our members felt that by joining I N UK, they are better able to manage their illness because of the support and information we have provided. Please order any of the following by filling out

the form and faxing it back to us at the number shown below. Alternatively, you can order via the "Health Professionals" section of our website at [www.infertilitynetworkuk.com](http://www.infertilitynetworkuk.com)

<b>I N UK Services</b>	<b>Cost</b>	<b>Tick</b>	<b>Details/Numbers required</b>
I N UK Leaflets	Free		
Leaflet Stand ( <i>subject to availability</i> )	Free		Limited to one per practice
I N UK Publication/Book List	Free		
I N UK Posters	Free		
More to Life Leaflets	Free		
Further Information on NICE and the provision of treatment	Free		
I N UK Leaflets In Punjabi	Free		
I N UK Leaflets in Chinese	Free		
I N UK Leaflets in Urdu	Free		
Video " The Journey Through Infertility" (payment details will be sent to you)	£6.99		
Visit from a member of I N UK staff	Free		Limited to one per practice
Clinic Directory published by the HFEA	Free		Limited to one per practice

## **YOUR DETAILS**

Contact Name.....

Address.....

.....

.....

Telephone.....

Fax.....

Email.....

## **Fax back on 01424 731 858**

Or via the "Health Professionals" page on our website at [www.infertilitynetworkuk.com](http://www.infertilitynetworkuk.com)

Or post to: Infertility Network UK,  
Charter House, 43 St Leonards Road,  
Bexhill on Sea, East Sussex, TN40 1JA

### **Infertility Network UK's Services**

I N UK provides good, medically accurate information as well as practical and emotional support to infertility sufferers throughout the UK.

These services are offered to anyone who needs them, irrespective of membership of I N UK.