KING's FUND CENTRE

# Counselling
for
# Regulated Infertility Treatments

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## The Report of the King's Fund Centre Counselling Committee

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January 1991

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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.

The King's Fund Centre is a part of the
King Edward's Hospital Fund for London.

# Foreword

As medical technologies and procedures increase in sophistication it becomes ever more important that the users of these services are well informed about the implications of their use for their own lives and health. Nowhere is this more true than with the recent developments in reproductive technologies. People considering assisted methods of conception not only require appropriate information but often need support in making choices among complicated alternatives and in coping with the consequences of the decisions made.

The King's Fund Centre has a commitment to increasing patient information and choice, and when the Department of Health approached us about the counselling requirements contained in the Human Fertilisation and Embryology Act 1990 we were pleased to be able to help. The new Human Fertilisation and Embryology Authority brought into being by this Act is required to produce a code of practice for the conduct of certain infertility services which will include guidance on the provision of counselling for couples considering or undergoing regulated treatments, for the children conceived through the use of these treatments and for gamete and embryo donors.

It was thought that a detailed consideration of such counselling by a small multi-disciplinary group of specialists would be of benefit to the new Authority, to those working in infertility treatment centres and to the users of these services. Membership of this committee was based on the known experience or expertise of the individuals concerned. The King's Fund Centre and the Committee recognise that planning the organisation, form and content of a formal counselling component in infertility services is a new experience. The possibility of change following its implementation should be recognised. The report addresses relevant issues and makes a number of recommendations which should contribute to the development of appropriate counselling services. I commend it to all who have an interest in the provision and use of infertility services.

The King's Fund Centre is very grateful to the Committee for its hard work, to the Department of Health for its support, to the consultants who advised the Committee and to Robert Snowden, Professor of Family Studies, University of Exeter who acted as Chairman.

*Barbara Stocking*
**Director**
**The King's Fund Centre**

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# Terms of Reference of the King's Fund Centre Counselling Committee

To provide advice for the consideration of the Human Fertilisation and Embryology Authority on the counselling needs relating to the provision of infertility services for couples considering any of the regulated infertility treatments; for children born following gametes or embryo donation who seek information about their origins, and for all donors.

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# 1 Introduction

## Counselling and the H F & E Act 1990

1.1 Since the birth in 1978 of the first baby to be born using *in-vitro* fertilisation (IVF) there has been continued debate about the use of these techniques, the research which supports them and the use of donor gametes and embryos. This debate led the Government to set up a Committee of Inquiry in Human Fertilsation and Embryology chaired by Mrs Mary Warnock (now Baroness Warnock) which published its report in 1984. The responses to the consultation on this report and to the subsequent Government discussion paper strongly supported the view that adequate counselling provision should be made available for people considering the use of the new reproductive techniques. The Human Fertilisation and Embryology Act 1990 (hereafter called 'the Act'), requires such people, and those donating gametes to be "given a suitable opportunity to receive proper counselling". The added requirement that account must be taken of the welfare of any child who may be born (and any other child who may be affected by the birth) following use of the regulated infertility treatment reinforces this need for counselling to be available.

1.2 The availability of counselling is related to the giving of consent to procedures associated with the provision and use of donated gametes, and to the use of embryos where fertilisation outside the body takes place. The Act makes explicit the requirement that the opportunity to receive counselling must be present prior to the provision of licensed infertility treatments, the giving of consent to certain uses of embryos or gametes and prior to the release of certain information to a person over 18 years of age (and in some circumstances younger persons) when seeking information about their genetic origins from the Human Fertilisation and Embryology Authority (from here on referred to as 'the Authority') which was set up by the Act.[1]

1.3 One difficulty when attempting to define the counselling component in the provision of the infertility services regulated by the Act is that four perspectives need to be kept in mind at the same time. These perspectives relate to the welfare of the resulting child and other children who may be affected, the needs of infertile people, the needs of the prospective donor and the desire for assurance at societal level that the infertility services are conducted responsibly and in accordance with the provisions contained in current legislation. In addition, there is a need to take note of what is practicable within the context of providing infertility services and what is feasible in terms of regulation and monitoring by the newly established Authority.

1.4 The needs of the infertile couple seeking treatment are usually taken as the starting point but the desire for assurance on the part of the general public in relation to the availability of counselling must be treated seriously. While it might acknowledge the scientific advances underpinning the new reproductive procedures designed to assist infertile couples, society as a whole must be assured that ethical and social safeguards are fully integrated into the services being provided.

1.5 The work of the counsellor takes place within the context of these differing (and sometimes conflicting) needs and interests. Clearly, an approach to counselling in which the welfare of the potential child has to be taken into account will include an assessment of the infertile couple as potential parents; this assessment would receive less emphasis if the needs of the infertile individual or couple were the only concern. Infertility counselling, by having to take into consideration a multiplicity of needs, will need to take a number of forms depending on the nature of each case. We

[1] Relevant sections of the Act are reproduced in Appendix 1.

consider that the question of assessing what is in the best interests of the welfare of the child is of major importance. While it may not be explicitly within the terms of reference of the Committee, the exercise of skills required to inform such important decisions are inextricably bound up with the skills of counselling and the counselling process. The Authority might wish to consider the need for formal procedures in addition to the application of appropriate skills to ensure that those to be assisted in conceiving a child do not have a history of major problems which would contra-indicate such assistance. This might include a history of serious mental illness or other disorders of behaviour which might only come to light through medical or criminal records.

1.6 In any discussion about the provision of counselling it soon becomes apparent that there are significant differences of interpretation and emphasis as to what the term 'proper counselling' (the term used in the Act) means. These differences of interpretation are present among counsellors, those providing treatment, infertile people, the general public and among professional people possessing qualifications in and knowledge from other disciplines. These interpretations range from a discussion which might take place as factual information about medical procedures is provided, to the provision of counselling as a therapeutic service, often of a non-directive nature and of lengthy duration.

1.7 For the purposes of the Act, guidance as to what constitutes 'proper counselling' will be provided by the Authority in the code of practice it is required to prepare but most observers are likely to accept that such counselling should include provision for:-

- giving of relevant information;
- an opportunity to discuss and explore the personal implications associated with this information;
- an opportunity to come to an informed and considered decision concerning the choice to be made amongst the options which may be available.

## Counselling in a Medical Setting

1.8 The need for counselling in medical situations is gaining increasing prominence. There is a growing awareness that if the best outcomes are to be achieved, patients need to be involved in decisions about their own treatment. In order to do this they need to have access to information which will enable them to assess the risks and likely outcomes, so that they can make informed choices about their treatment. Counselling can also provide emotional support for patients and their families and the value of support groups is increasingly recognised. Counselling offers an opportunity to explore, in depth, personal responses to ill-health or disability and possible treatment; this enables the patient to become more self aware and thus to make better informed individual decisions and choices.

## Counselling for Infertility

1.9 In our society the desire to have a family through conceiving, bearing and rearing one or more children is regarded as a natural and important stage in human development. Couples are expected, and most expect, to reproduce. Those who do not have children often feel that others regard them as selfish and abnormal. Most couples intend to have a child at some time and usually take for granted their ability to do so. The main decision associated with child-bearing is usually concerned with *when* they will have a baby.

1.10 A failure to conceive with a subsequent diagnosis of infertility and the need to consider various forms of assisted conception treatments, come as a shock which can cause considerable disruption to the lives of those affected. Infertility is not only a physiological disability; it represents a major crisis in the life of a couple. Feelings of personal failure and inadequacy often ensue, threatening the affected person's self-image and self-esteem. The frustration of the drive to produce a genetic child is experienced as a profound loss. Psychological reactions to hearing the news of infertility are thought to be similar to those triggered by other anticipated profound losses. Both the individual diagnosed as infertile and his/her partner can experience strong feelings of disbelief, denial, anger, isolation, guilt, grief and despair. A time for grief and mourning is often necessary in order to resolve these feelings of loss and to come to a position of acceptance of the situation. The provision of a combination of

time and emotional support can facilitate this process and help the couple look to the future and make decisions about how to proceed in the light of the new circumstances. This may include not continuing in the partnership, opting for a child-free life, or seeking to parent by another route. It has to be recognised that, for some, the pain of infertility is never fully resolved and a life-time of regret is experienced which, even having a child through the use of donated gametes, does not assuage.

# 2 The Organisation of Infertility Counselling

## Introduction

2.1 The Committee has explored, both widely and in depth, the question of counselling within infertility services and considers that the range of tasks contained within this generic term should be seen as a continuum with considerable overlap between the different tasks. There is also a continuum in terms of the mix of medical, scientific, psychological and social inputs to infertility treatment; at one extreme the tasks are mainly of medical concern but at the other they are mainly social and psychological. Medical, nursing and counselling expertise are complementary, and the Committeee would not wish to draw rigid and bureaucratic boundaries between disciplines. It is important that members of different disciplines work as a team and that in the interests of patients, role definitions and tasks may become blurred at the margins. At the same time, however, it is important to recognise that each discipline is separate and independent, and brings a quite different contribution to the process. The ethos and derivation of counselling, coming as it does from social work and psychology, helps to produce the degree of independence necessary to satisfy public interest. They also ensure the necessary skills and objectivity to meet the needs of patients in reflecting upon their situation with someone sufficiently independent from treatment procedures and associated research activity.

## Types of Counselling

2.2 In order to establish some degree of clarity about the range of counselling tasks likely to be encountered and the relevant personal skills needed to undertake these tasks, a more precise description of infertility counselling is proposed.

2.3 The Act differentiates between the provision of information and counselling about the implications of treatment.[2] In order to assist the development of appropriate training for infertility counselling, the Committee has identified four types of counselling which should be available:-

- Information counselling.
- Implications counselling.
- Support counselling.
- Therapeutic counselling.

***Recommendation 1.*** **The Committee recommends that 'proper counselling' required by the Act should contain four components and should be made available by treatment centres. These components are: information counselling; implications counselling; support counselling and therapeutic counselling.**

## Information counselling

2.4 The provision of factual information (which is a requirement of the Act), and the advice which normally accompanies it are a necessary part of the general discussion which should take place with those seeking treatment, those considering the donation of gametes or embryos and those seeking information about their genetic origins. For convenience, we are describing this combination of information, advice and discussion as 'information counselling'.

2.5 The Committee felt that information presented orally should, whenever possible, be accompanied by appropriate written material. Infertility investigation and treatment is a stressful process and information presented orally may only be partially absorbed.

2.6 It is recommended that the Authority should consider the present state of written information provision and how it might be improved. The

[2] Section 13(6); 31 (3)(b); 31(6)(b). Schedule 3 para. 3 of the Act.

Committee identified eight areas where leaflets containing factual information describing various aspects of the regulated infertility service[3] would be useful:-

- Providing advice about infertility.
- Infertility treatments.
- Semen donation.
- Egg donation.
- Information for younger children.
- Information for older children.
- How to tell your child about gamete donation.
- Approaching the H.F.& E. Authority for information.

Written information should not be a substitute for information to be given orally.

***Recommendation 2.*** **The Authority should set minimum standards for the provision of written material over a range of issues which should be available to prospective parents and donors, and for young people conceived by the use of donor gametes.**

2.7 Some centres have made their own arrangements to produce some of this written information but none presently provides the full range. The suggested leaflets should be made available to those agencies likely to receive enquiries about infertility services; that is, their distribution should not be confined to the infertility centres. This written material should be updated regularly and provided in languages other than English in those centres where this requirement is relevant.

***Recommendation 3.*** **Written material should be made available to General Practitioners and others who may be expected to provide information to people enquiring about regulated infertility treatments.**

***Recommendation 4.*** **Written material should be updated regularly and provided in languages other than English as necessary.**

***Recommendation 5.*** **The Authority should consider the appropriate source of financial support for producing and distributing relevant written material.**

2.8 The Act requires that centres providing regulated infertility services must be licensed and that the person who is to take responsibility for the supervision of the regulated activities must be named in the licence application.[4] It remains the responsibility of "the person responsible" to ensure that patients receive adequate information about their treatment options and that they have consented in a free and informed way to a particular treatment. When giving their consent patients should be informed that such consent can subsequently be varied or withdrawn.

2.9 Information counselling may be provided by any suitable member of the infertility team. While formal training and a qualification in counselling are not required, the Committee would wish to encourage those providing information counselling to at least have attended one of the specialist training courses described in this report.[5]

## Implications Counselling

2.10 Implications counselling facilitates an exploration of the personal and family implications of infertility and infertility treatments. It differs from information counselling in that it deals with the *meaning* of the information to the individual concerned and goes further than a discussion of the likely consequences and outcomes of the options available.

2.11 Implications counselling may be appropriate at various times in the treatment process; it can assist people in understanding and resolving the painful feelings that may arise from their own or their partner's infertility. Later, this type of counselling can assist people to comprehend the meaning and implications of specific treatment programmes. People who donate gametes or embryos, and young people who make an enquiry about their genetic origins

[3] See Appendix 3.
[4] Section 16(2)(a).
[5] See para. 2.28ff and Appendix 4.

under s.31 of the Act will require an opportunity to receive this type of counselling to enable them to explore the implications (for themselves and for others) of their proposed actions.

2.12 Implications counselling, because it explores potentially painful emotions and is dealing with treatment procedures which have complex implications, cannot be hurried. This type of counselling is likely to be relatively time-consuming and has to be given suitable physical space, adequate financial resources and staff time.

***Recommendation 6.*** **Sufficient time should be allocated for counselling when offering regulated infertility treatments.**

***Recommendation 7.*** **Counselling should take place in comfortable and relaxing surroundings where the discussion is unlikely to be disturbed.**

2.13 Implications counselling is of particular importance to those people contemplating receiving donor gametes. If other, more conventional, treatments for infertility are inappropriate or fail, the step to acceptance of donor gamete techniques is very great. It may appear as the next logical step in the progression of treatment but the social and psychological implications for the couple and for the child are profound. Infertility counselling must be available in these circumstances to ensure that the significance of this action is fully understood and accepted by both partners.

2.14 Likewise, donors of gametes or embryos must have an opportunity to explore the implications of such donation for themselves and for their present and future family relationships. The Committee considers access to implications counselling for donors to be essential.[6]

2.15 Implications counselling requires a high level of counselling skill as well as a detailed knowledge of infertility and infertility treatments. It is therefore recommended that such counselling should be provided by an infertility team member who has successfully completed the required training in infertility counselling skills.[7]

***Recommendation 8.*** **Implications counselling must be provided by a trained infertility counsellor.**

## Support Counselling

2.16 As previously described, the experience of infertility is a distressing one. Infertility investigations and treatment are often stressful and many patients will experience a need for emotional support. This need may become more acute at different times in the treatment process. It is likely to be particularly evident when there is a failure to achieve a pregnancy, treatment is finally terminated without achieving a pregnancy or where a pregnancy is not viable. It has also been found that such support may be needed when treatment is likely to result in a multiple pregnancy.

2.17 People will inevitably seek and gain support from those with whom they feel comfortable. Support counselling may be provided by the range of professionals working in the infertility team. In addition, understanding friends and relatives may also be a valuable source of support. The value of support groups composed of people sharing similar experiences is being increasingly recognised; counsellors should be encouraged to facilitate the setting up and operation of such groups among people experiencing infertility and infertility treatments.

***Recommendation 9.*** **Treatment centres should recognise that support counselling may be needed throughout the treatment process.**

***Recommendation 10.*** **Treatment centres should encourage the development and operation of patient support groups.**

## Therapeutic Counselling

2.18 Therapeutic counselling focuses on

[6] Counselling for donors is discussed in Section 4.
[7] Training strategies are discussed in para.2.23ff.

healing, on the gradual adjustment of expectations and on the eventual acceptance of life circumstances. It is a treatment process in its own right.

2.19 People cope with stress in different ways and by no means all will require this type of counselling. However, people seeking infertility treatment may sometimes require prolonged therapeutic counselling. Many people coping with the personal implications of infertility and treatment may need more sustained and in depth counselling to help them resolve the problems and difficulties which may be expected to emerge in this context. Counsellors in the treatment centre will require to be sufficiently skilled to be able to assess and recognise the essential differences between patients requiring more comprehensive counselling from those who do not. Some may suffer from acute emotional distress and disruption of social functioning which, given their situation, may nevertheless be within normal bounds of human behaviour. In our view these people should receive counselling services provided by the treatment centre. Others may be suffering from problems which the treatment centre should not be expected to try to resolve. Such difficulties might include marital disharmony, psychosexual, neurotic or psychotic disorders which may have been exacerbated but not caused by infertility or the treatment process. Treatment centres cannot be expected to provide continuing services in these situations. However, it is felt that treatment centres, when faced with such patients should accept some responsibility for offering to refer them on to a more appropriate agency, perhaps for psychiatric or other specialist help.

2.20 It should also be recognised that the emotional problems associated with infertility do not always disappear if intervention is successful and a baby is produced. Many people who are infertile still experience problems stemming from their feelings about infertility which may be triggered by later life events. The development of the child's sexuality in adolescence can be particularly difficult and stressful for the infertile couple and this at a time when the young person may also be under stress associated with concerns about identity over and above the normal trauma of adolescence. Treatment centres need to recognise the possibility of these problems and be prepared to respond to people seeking help by referring them to an appropriate counselling agency.

> ***Recommendation 11.*** **The counselling arrangements in treatment centres should be capable of assessing and differentiating between (a) those patients with extensive and complex needs for counselling, but who nevertheless fall within the bounds of normal reaction to their situation and (b) those patients having major and deep-seated problems not specifically deriving from infertility.**

> ***Recommendation 12.*** **Treatment centres should make arrangements for referring patients in Recommendation 11, category (b) to appropriate specialist help.**

## The Timing of Counselling

2.21 The Act requires that relevant information is given and that counselling is available to individuals and couples prior to using the new reproductive techniques or donating gametes. While emphasis is placed on the prior access to counselling, it is recommended that this service should also be available both during and on completion of the infertility treatment or gamete donation.

> ***Recommendation 13.*** **While counselling must be available before regulated infertility treatment or gamete/embryo donation takes place, it should also be available during and on completion of such treatment.**

## The Financing of Counselling Provision

2.22 The provision and take-up of counselling should be seen as a normal component of treatment, therefore the financial costs of counselling provision should be included in the overall treatment budget. The salary of the counsellor employed in the treatment centre should be funded as part of the core costs in the same way as the salary of other team members.

***Recommendation 14.*** **The financial costs of counselling should be regarded as part of the overall treatment budget.**

## The Training of Counsellors

2.23 It is recommended that all centres employ at least one trained infertility counsellor and further counsellors in line with a patient/counsellor ratio recommended by the Authority. Infertility counselling requires considerable skill and a particular knowledge base. There is a scarcity of suitably trained counsellors at the present time. A strategy to meet short, medium and longer term arrangements for providing this training is therefore proposed.

***Recommendation 15.*** **All treatment centres should employ at least one person trained in infertility counselling and others according to HFEA recommendations.**

2.24 The short term is defined as a maximum period of two years from the date of publication of the first code of practice by the Authority. During this period, treatment centres should arrange to obtain specialist training for existing staff who are to take responsibility for providing the implications counselling described in paragraphs 2.10 to 2.15. All those possessing an appropriate counselling qualification will require further specific knowledge and skills about counselling in this specialist setting. Such training is likely to be of relatively short duration and designed to supplement the existing knowledge and skills of the various team members.[8]

2.25 By the beginning of the third year following the date of the publication of the Authority's first code of practice, all licensed treatment centres should employ one or more counsellors who are trained in infertility counselling or who have completed this short specialist training course satisfactorily.

2.26 The mid-term covers a period of up to five years from the first code of practice publication date. During this time, treatment centres should encourage those counsellors who do not already possess a general professional counselling qualification to obtain one. This general counselling course will be of longer duration than the short training course described above and, if successfully completed, will lead to an accredited professional qualification to practice counselling.

2.27 The long-term arrangements for training should be fully implemented by the beginning of the sixth year following publication of the first code of practice by the Authority. The aim is to have in post within six years, one or more counsellors who are fully trained; i.e. who have completed specific training relating to infertility, reproductive technology and the implications of these for participants, and possess an accredited professional counselling qualification. This 'step-by-step' approach is suggested to give sufficient time to set up appropriate training courses and for treatment centre staff to obtain this training. While the short, specialist training courses are likely to be newly established, it is expected that the general counselling qualification would be based on existing counselling courses.

***Recommendation 16.*** **A strategy of short, medium and longer term arrangements for the training of infertility counsellors should be implemented.**

***Recommendation 17.*** **In the short term (within two years) specialist training courses should be arranged as necessary to supplement and develop the knowledge and skills of treatment centre staff.**

***Recommendation 18.*** **In the mid-term (up to five years) treatment centres which do not have a professionally trained counsellor as a member of staff should encourage their counsellors (who have previously completed the short specialist training course) to obtain a general professional counselling qualification.**

[8] See Appendix 4 for a description of the structure and content of what these short specialist courses might offer.

***Recommendation 19.*** **Long term arrangements for training should be fully implemented by the beginning of the sixth year. This would require infertility counsellors to be in possession of a general professional counselling qualification and evidence of having successfully completed a short specialist training course.**

## Training Courses

2.28 The short specialist training courses should involve class work, discussions and observation in an infertility clinic. Training for those who possess medical and nursing qualifications will concentrate on developing communication, counselling and interpersonal skills and on gaining insight into the interpersonal relationships in families; for those who possess social work and counselling qualifications emphasis will be placed on the issues directly related to the treatment of infertility. The course should total a minimum of 10 days study linked to a programme of distance learning; it is not expected that the time taken to complete study will exceed three months.

2.29 Training should be provided through accredited centres and will require validation of the course content, staffing and training facilities.[9]

2.30 A certificate showing satisfactory completion of the training course should be given to the trainee.

2.31 The specialist training courses should be established as soon as possible.

2.32 The longer, general counselling course will not necessarily refer to infertility treatment or gamete donation but will cover general counselling skills with particular emphasis on child development and parent/child communication. A number of these courses already exist and it is recommended that the Authority considers how best to identify appropriate professional counselling courses.

***Recommendation 20.*** **Arrangements should be made for the identification and accreditation of training centres and courses which will provide specialist and general counselling training.**

***Recommendation 21.*** **Treatment centres should bear the costs of staff training but central support should be considered for establishing the specialist training courses required.**

## The Monitoring of Counselling Services

2.33 The monitoring of the counselling service provided in infertility centres should be treated as equally important as the other activities of the treatment centre during inspections by the Authority.[10]

**Recommendation 22. An assessment of counselling provision should take place when the other activities of treatment centres are being inspected by the Authority.**

2.34 As regulated infertility counselling is being introduced arrangements should be made to review progress in the implementation of the proposed training and counselling activities. The Authority is required to assess the availability of counselling as part of its inspection of licensed infertility centres; the proposed review is intended to complement this by concentrating on the *conduct* and *content* of training and counselling. The need for a review of these activities is particularly important in order to inform the Authority of suggested changes should these be required. The Committee considers that this specialist review should be undertaken by a small group consisting of members possessing an established expertise in the provision of counselling. An annual report should be made available to the Authority during the five years following publication of the Authority's first code of practice; this will coincide with the proposed period for full training

[9] See Appendix 4 for a description of the structure and content of what these short specialist courses might offer.

[10] A suggested list of topics for evaluation is given in Appendix 5.

implementation. Reports should be biennial thereafter.

**Recommendation 23. A specialist review of the conduct and content of counselling and relevant training should be undertaken annually during the first five years and biennially thereafter.**

# 3 The Counselling Needs of People Seeking Regulated Infertility Treatments

## Provisions of the Act

3.1 Before receiving treatment services involving donated gametes or the creation or handling of embryos outside the body, the Act requires that individuals and couples being treated for infertility must be given a 'suitable opportunity to receive proper counselling'. This counselling may take various forms depending on its timing and the type of treatment being offered.

3.2 Where a couple seeks treatment regulated by the Act, counselling must be available to both partners. The counselling of couples should be made available in a form which allows both partners to be seen together and separately.

3.3 The structure and content of counselling will be influenced by the anticipated relationship between the adult(s) seeking treatment and the child. It is assumed that treatment will be provided mainly for heterosexual couples; this does not preclude the provision of services regulated by the Act to others, but the wording of the Act [see Section 13(5)] means that the welfare of the child, including that child's need for a father, must be addressed in this, as in every other, case.

## The Conduct of Counselling

3.4 The presentation, ease of access and conduct of counselling at the treatment centre should reinforce the view in every way possible that the need for counselling in this context is both usual and normal. Counselling is available because of the stressful and complex situation created by the issues surrounding infertility and for the long term consequences for the couple and for the child conceived in this way; it is not made available because of any particular failure of the patient to cope, or because of the presence of abnormal reactions to infertility or the desire for a child.

3.5 Most people seeking infertility treatment will have experienced stress in relation to their inability to achieve a pregnancy. They may have undergone tests over a period of time accompanied by discomfort, embarrassment and frustration before concluding that they are unable to have a child of their own without the help of major medical intervention. While waiting for treatment their uncertainty will continue with the knowledge that even with treatment, they may fail to achieve a pregnancy. In addition, some may face severe financial hardship as a result of their quest for treatment. The realisation that they will never be able to produce their own genetic offspring will be an added burden. It is in this context that decisions are often made which, while aimed at dealing with shorter term needs, contain within them profound longer term implications. The counselling process in such a situation needs to be conducted with considerable sensitivity and skill.

> ***Recommendation 24.*** **The availability of counselling should be presented as a usual and routine component of the infertility treatment being offered.**

## Information counselling

3.6 Counselling is not synonymous with the giving of information but well presented information is fundamental to counselling. Information about the diagnosis of infertility, the nature and purpose of the treatment or procedure recommended, together with any associated risks and complications and an indication of the success and failure rates linked to these procedures should be honestly and sensitively presented. The issues requiring 'effective consent'[11] also need to be identified clearly. Before giving this consent, patients must be informed that such consent can subsequently be varied or withdrawn. In the

[11] See Appendix 1.

case of patients who do not speak English, every effort should be made to ensure that information is understood; where necessary counselling should be offered in their own language or through an interpreter.

3.7 The first time this information is presented to those seeking treatment is likely to be a time of stress for them. Even if presented in what the information-giver believes to be a simple and uncomplicated way, such information is often only partially understood. For this reason it is important that carefully prepared written information designed for those seeking treatment is made available for reading in their own time.

## Implications counselling

3.8 The skills of the counsellor should be used to enable careful consideration of the personal implications and meanings of this information for the couple or individual seeking treatment. The implications for current or future family relationships will also need to be addressed.

3.9 Because of the perceived stigma often associated with infertility some people may not want others to know about their own or their partner's infertility. The reasons underlying this desire for secrecy and its possible implications will need to be explored together with how it will affect their ability and willingness to be open and honest with their children.

3.10 If the use of donor gametes is contemplated, implications counselling is of particular importance. Donor procedures enable childlessness to be overcome but the underlying infertility remains and the implications of this for the couple and the potential child need careful consideration.

3.11 The Warnock Report recommended that the parents of children resulting from regulated infertility treatments should be encouraged to be open and honest with their child(ren) about their genetic origins. It is important for couples to have an opportunity to discuss the implications of withholding or sharing this information with their children. Couples will need guidance about when and how such information is best provided.[12] It is of the utmost importance that potential parents are given an opportunity to consider these matters together before donor gametes are used.

> ***Recommendation 25.*** **Couples should be encouraged to be open and honest with their child(ren) about the circumstances of the child's conception. They should be provided with appropriate written material to help them in this task.**

3.12 Time for reflection, to assimilate the information provided and for an opportunity to frame their own questions is also important for those seeking treatment. If a decision is made that treatment should take place, sufficient time should be allowed for reflection before treatment begins. Such a delay also ensures that the decision made to proceed is arrived at in the absence of pressure generated by the stresses associated with first time attendance at the treatment centre.

> **Recommendation 26. After counselling, sufficient time for reflection should be made available before treatment is commenced.**

## Support Counselling

3.13 The uncertainties and trauma of treatment and the failure to achieve a pregnancy will impose considerable pressure upon individuals and upon their relationships with others. The treatment centre team should be sensitive to this pressure and be prepared to help those affected to appreciate that the feelings and emotions they are experiencing are a normal reaction. Such people require support, and an opportunity to consult a counsellor should be offered to all patients who fail to achieve a pregnancy. In addition women who become pregnant but whose pregnancy is not viable, as well as women who experience a multiple pregnancy, have special needs and may require additional counselling support. The decision to terminate treatment can be particularly difficult to make and to accept. People experiencing failure to achieve a pregnancy and who need skilled support may find it difficult to ask for help.

[12] See Appendix 2 and Appendix 3.

This suggests that counsellors will sometimes need to be proactive in the support they provide. The treatment team should also appreciate the value of a support group for such patients. The counsellor should assist in the formation of self-help groups among those seeking or undergoing similar treatment.[13]

## The Decision to Withhold Treatment

3.14 While not a requirement of the Act, the Committee wishes to encourage the availability of counselling for those who are denied treatment on medical or social grounds.

> ***Recommendation 27.*** **Counselling should be made available to individuals and couples where treatment is not possible or a decision is made not to provide it.**

3.15 Consideration of the welfare of the child born as a result of, or affected by, the regulated infertility treatments introduces a complex but essential dimension to counselling. People already experiencing some stress and understandably preoccupied with their own needs may find it difficult to consider the welfare of a child, especially one not yet conceived. It may be particularly difficult for the potential parent to accept that a child's needs and welfare might not always be consistent with their own desires.

3.16 In addition to helping potential parents to consider the implications of treatment for existing or future children, the counsellor needs to make a judgement about the welfare of the child(ren) in order to contribute to the decision of the treatment centre team as to whether or not treatment should be offered. Maintaining a perspective which embraces the interests of both adults and children while directly addressing the needs of one or the other in the counselling setting requires skills of a high order. The counselling process should help adults seeking treatment to understand that society, while being concerned and compassionate and recognising the right to seek treatment, also has a responsibility to children born as a result of, or affected by, that treatment. Whilst recognising that fertile couples are not subject to such judgements, the provision of a treatment service which has important implications for the society in which it takes place must carry within it accountability to that society.

3.17 Decisions about the welfare of the child born as a result of treatment and any other child affected is an important and complex area of the Act. In our view it will be impossible to separate the process of counselling from consideration of the welfare of the child. Counselling skills have a special contribution to make to the decision-making process, the responsibility for which ultimately rests with the clinician. There are, however, other sources of factual information and procedural matters which should be explored if this issue is to be addressed adequately.

3.18 At the very least, treatment centres should seek relevant information from G.P.s, should set out any exclusion criteria in advance to those seeking treatment, and establish a decision-making process which includes counsellors. Special attention should also be given to how this matter may be addressed adequately in relation to couples or individuals from overseas seeking treatment here.

3.19 We are conscious that it is not within our remit to address the welfare of the child fully although we cannot discuss counselling without making reference to it. We are also aware of a major body of knowledge which should inform proper consideration of this issue and recommend that the Authority takes this into account when developing the code of practice for treatment centres.

> ***Recommendation 28.*** **In making decisions about the welfare of children, the HFEA should ensure that treatment centres establish procedures for information-gathering and decision-making in which the special contribution of the counsellor is recognised.**

> ***Recommendation 29.*** **The HFEA should give guidance in the code of practice to assist treatment centres in considering the welfare of children**

[13] See Recommendations 9 and 10 and para.2.16ff.

**affected by the treatment they provide. The HFEA is also asked to consider how this issue might adequately be addressed in relation to those from overseas seeking treatment.**

3.18 The provision of a counselling service for those refused treatment, those for whom treatment has been discontinued and those for whom treatment has precipitated or revealed other underlying problems, introduces a counselling role which may go beyond that directly linked to infertility treatment. This identifies the importance of delineating clearly the limitation of the counselling that can be offered in the treatment centre. It also reinforces the recommendation that centres should have an agreed procedure for the referral to other specialist agencies of those individuals and couples who may need help not available directly in the treatment centre or who may require longer term counselling.

# 4 The Gamete Donor

4.1 The provisions of the Act require that gamete or embryo donors, prior to the giving of 'effective' consent for the use of their gametes must be given a suitable opportunity to receive proper counselling about the implications of their proposed action. Donors must also be provided with relevant information, and reminded of the possible uses of their gametes: for the treatment of others or for research either immediately or after a period of storage. 'Effective' consent is consent given to a written description of this use and this can be varied or withdrawn at any time the donor wishes provided the agreed use of any gametes or resulting embryo has not already taken place.[14]

4.2 Section 13(7)(a) of the Act also requires that 'suitable procedures are maintained for determining the persons providing gametes or from whom embryos are taken'. This implies that some assessment of the donor must take place to ensure that persons contributing to the genetic make-up of the resulting child are suitable. Assessment on physical grounds, despite difficulties in predicting possible future illness, requires genetic knowledge and careful assessment. An assessment of psychological and emotional suitability is equally important. The determination of psychological suitability requires skilled assessment. A procedure whereby the gametes of evidently unsuitable donors are not obtained should be the minimum objective.

> ***Recommendation 30.*** **Counselling of donors should take place in order to assess their psychological suitability.**

4.3 The welfare of the donor should also be considered during the selection process. It is important that persons approached to donate gametes or embryos are not in a situation where they may feel themselves to be under an obligation to comply with the wishes of the person making the approach. This could be the case where potential donors are also patients receiving treatment under the care of the person making the approach.

> ***Recommendation 31.*** **Care should be taken to ensure that potential donors do not feel themselves to be under undue obligation to comply with the request to donate their gametes. The Committee notes that the Act allows the donor to review the terms of consent and stresses the importance of this provision.**

4.4 Donor recruitment policy will affect counselling strategy and content and the Committee believes that greater emphasis should be given to recruiting donors who have children of their own, and who, with the knowledge and agreement of other family members, are willing to cooperate . Such donors are more likely to have an understanding of the implications of gamete donation for themselves, for their own families, for the potential parents making use of the donated gametes and for the child yet to be born.

> ***Recommendation 32.*** **Greater consideration should be given to the recruitment of donors who have children of their own.**

> ***Recommendation 33.*** **Where applicable, donors should be encouraged to obtain consent from their partner before donating their gametes.**

4.5 While the overall responsibility for the procedures governing the selection of donors remains with the 'person responsible' as defined by the Act, the counsellor should contribute to the decisions surrounding the selection of donors. Selection should be reviewed if major changes relevant to the donor's role as a donor

[14] See Schedule 3 of the Act.

become known, or where a break between donations takes place.

***Recommendation 34.*** **The procedures governing the selection of donors is the responsibility of the 'person responsible' as defined by the Act but the advice and opinion of the counsellor should be sought. Selection should be reviewed if changes in the donor's personal circumstances occur.**

4.6 Donors should be provided with relevant information about the procedures involved in donation and the uses to be made of his/her gametes. To facilitate this understanding, donors should be provided with written as well as oral information. When giving their consent donors must be informed such consent can subsequently be varied or withdrawn.

4.7 The Act requires that an opportunity must be provided for careful consideration of the implications of donation, both for the donor and for his/her present or future family. Little is known about the effect of gamete donation on donors because of the secrecy which has generally surrounded this activity. However, donors are known to occasionally regret their action which suggests that care is needed in their selection and preparation. Other donors view their donation with great responsibility, an attitude all donors should be encouraged to emulate as they think about the outcome of their donation. Implications counselling by a trained counsellor must be made available to all prospective donors before donation and should be available after donation.

***Recommendation 35.*** **Implications counselling must routinely be made available to donors of gametes or embryos before donation and should be available after donation.**

4.8 Because of the need for a careful consideration of the implications of donation, a reasonable time for reflection should elapse between counselling and the obtaining of gametes from the donor.

4.9 The donation of gametes or embryos by individuals or couples who are already undergoing regulated infertility treatment can pose particular problems as they both contain the potential for causing stress. The complexity of the implications inherent in treatment can be further complicated by the addition of the implications inherent in donation. Because of this, it is the view of the Committee that persons undergoing infertility treatment should be separately counselled for treatment and for donation of gametes or embryos. A reasonable time interval should be allowed between consent and the obtaining of gametes to allow for a period of quiet reflection in the absence of immediate treatment pressures.

***Recommendation 36.*** **Persons undergoing infertility treatment should be counselled on a separate occasion if they are considering gamete donation.**

***Recommendation 37.*** **After counselling, sufficient time for reflection should be allowed to elapse before obtaining gametes or embryos from the donor.**

4.10 Prospective donors who are discovered on investigation to be unsuitable as donors, perhaps because of some previously unknown disability, can suffer stress. Support counselling should be available for such persons.

***Recommendation 38.*** **Support counselling should be available for prospective donors who are found to be unsuitable.**

4.11 During counselling of the potential donor, the implications of anonymity both for the donor and for the future child, should be explored. It will be necessary for the donor to provide identifying information for recording in the central register, but the donor should be assured that this information will be held in confidence. The only exception indicated in the Act is where identity can be revealed in the interests of justice.[15] This procedure is in accord with the Act but the Committee believes that donors should be encouraged to volunteer further information about themselves, including their reasons for agreeing to donate gametes, which could be passed on to the child if a

[15] See Sections 34 and 35 of the Act.

request was made. This information may help, in part, to meet the need of the child for knowledge of his/her genetic origins.

***Recommendation 39.*** **Donors should be encouraged to volunteer additional information about themselves which could be passed on to the recipient parents and the child.**

# 5 The Child

5.1 In the Act, specific mention is made of the need to take into account the welfare of any child resulting from regulated treatment services, or any child(ren) who may be affected by the birth.[16] This focus on the welfare of the child should permeate all the counselling to be provided even though the child has yet to be conceived. In addition persons born 'in consequence of treatment services' may, after the age of 18 years (or in some cases earlier) receive counselling in their own right concerning the provision of information relating to their genetic origins.[17]

5.2 The Act also requires the Authority to include procedures in their code of practice for treatment centres which relate directly to the welfare of children.[18] In drawing attention to this the Lord Chancellor stressed the importance '...which the Government attaches to the welfare of children in this context'. It is hoped the code of practice will give due consideration to the evidence supporting the importance of genetic and biographical information to young people. The destructive potential of the tension caused by secrecy in the family is also well documented and the code of practice should draw attention to the implications of this issue. Counsellors will need to help potential parents to understand the value and importance of openness and honesty and to consider how they might handle these issues sensitively with children.

5.3 Introducing the government sponsored amendment about the welfare of children during the debate in the House of Lords, the Lord Chancellor described a fundamental principle of English law which was most recently stated in the Children Act 1989; that the welfare of the child is of 'paramount consideration'. In doing so he drew attention to 'the wide range of circumstances and meanings which the concept of welfare involves'. These include adequate standards of financial and material security and physical care. More important, however, are '...stability and security, loving and understanding care and guidance, the warm and compassionate relationships that are essential for the full development of the child's own character, personality and talents'. In this context it must be remembered that 'the child' includes not only the progeny resulting from successful treatment but any other child who may be affected by the birth.

5.4 The skills of the counsellor should be used to explore issues relevant to the welfare of children and to contribute information and opinion to the decisions about providing treatment regulated by the Act. Issues such as the general health and age of the potential parent(s) are relevant as an indication of their life-expectancy and capacity to care adequately for a child throughout his or her childhood. There may be other information about lifestyle, previous denial of child custody or a history of removal of a child from the family home which could contra-indicate treatment. As the decision to provide treatment or accept gamete donation involves consideration of both non-medical and medical issues, the treatment centre team should consider how best such decisions might be reached. Unless the decision comes before a court, whether or not to provide treatment is the responsibility of the medical practitioner but the advice and opinion of the counsellor should contribute to that decision.

5.5 During implications counselling, prospective parents will need to consider the implications of the child's conception from the child's point of view. These implications are even more complex and important if donor gametes have been used. Prospective parents need to consider the child's need for information about his/her genetic origins. Knowledge about relationships in other forms of

[16] See Section 13(5).
[17] See Section 31.
[18] See Sections 13 and 25 of the Act.

social parenting can offer useful parallel insights for such counselling. Written material should be available for both children and parents to facilitate the skilled communication of such matters.[19]

5.6 Parents should be able to contact the treatment centre for advice concerning guidance about relevant issues which arise as their children grow up. In certain cases, referral to a specialist agency might be necessary.

***Recommendation 40.*** **Counselling support should be available for parents who request guidance about relevant issues as their child(ren) grow up.**

5.7 Some children who were themselves conceived following use of the regulated infertility procedures, siblings who are affected by the presence of such a child or children whose parents are known to have been donors, may find it helpful to talk with someone outside their immediate family about family-related issues associated with gamete donation which may be of concern to them. This may be particularly important during the child's adolescence. Such children should have access to an infertility counsellor.

***Recommendation 41.*** **Children who wish to discuss issues associated with gamete or embryo donation should have access to an infertility counsellor.**

5.8 The Act makes provision for persons born in consequence of treatment services to be given certain limited information about their genetic origins when they are of sufficient age. Persons requesting information 'must be given a suitable opportunity to receive proper counselling about the implications of compliance with the request'.[20] Some information held by the Authority will not be made available. Counselling in this situation may prove to be very difficult and is likely to be focussed upon the distress and frustration flowing from a refusal to provide this available information. The limited provision of information to young adults born as a consequence of regulated infertility treatment is a source of concern to the Committee. It would appear to be inconsistent with a proper concern about the welfare of the child.[21] There is a considerable body of research evidence and received practice wisdom deriving from psychiatry, psychology and social work which demonstrates the importance of openness and honesty in family relationships. The development of personal identity (and the contributing role of information about genetic origins which most of us take so much for granted) is important to the healthy development and maturity of these relationships. The Committee believes the importance of this matter must not be underestimated and urges the Authority to keep it under active review. Counselling in these circumstances should be provided by a trained counsellor specialising in family relationships. It is recognised that counsellors will be working in a new practice area but they will be able to draw on the considerable counselling experience of others who have helped adults learn about their genetic origins.

***Recommendation 42.*** **The counselling of persons requesting information from the Authority about their genetic origins should be undertaken by a counsellor specialising in family relationships.**

***Recommendation 43.*** **Information to be made available to young persons born as a consequence of regulated infertility treatment should be kept under review by the Authority.**

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[19] See para. 2.5ff and Appendix 3.
[20] See Section 31.
[21] See Sections 13 and 25 of the Act.

# 6 Recommendations

The following recommendations accompanied by explanatory text appear in Sections 2 – 5:-

## The Organisation of Infertility Counselling

**Recommendation 1.** The Committee recommends that 'proper counselling' required by the Act should contain four components and should be made available by treatment centres. These components are: information counselling; implications counselling; support counselling and therapeutic counselling.

**Recommendation 2.** The Authority should set minimum standards for the provision of written material over a range of issues which should be available to prospective parents and donors, and for young people conceived by the use of donor gametes.

**Recommendation 3.** Written material should be made available to General Practitioners and others who may be expected to provide information to people enquiring about regulated infertility treatments.

**Recommendation 4.** Written material should be updated regularly and provided in languages other than English as necessary.

**Recommendation 5.** The Authority should consider the appropriate source of financial support for producing and distributing relevant written material.

**Recommendation 6.** Sufficient time should be allocated for counselling when offering regulated infertility treatments.

**Recommendation 7.** Counselling should take place in comfortable and relaxing surroundings where the discussion is unlikely to be disturbed.

**Recommendation 8.** Implications counselling must be provided by a trained infertility counsellor.

**Recommendation 9.** Treatment centres should recognise that support counselling may be needed throughout the treatment process.

**Recommendation 10.** Treatment centres should encourage the development and operation of patient support groups.

**Recommendation 11.** The counselling arrangements in treatment centres should be capable of assessing and differentiating between (a) those patients with extensive and complex needs for counselling, but who nevertheless fall within the bounds of normal reaction to their situation and (b) those patients having major and deep-seated problems not specifically deriving from infertility.

**Recommendation 12.** Treatment centres should make arrangements for referring patients in Recommendation 11, category (b) to appropriate specialist help.

**Recommendation 13.** While counselling must be available before regulated infertility treatment or gamete/embryo donation takes place, it should also be available during and on completion of such treatment.

**Recommendation 14.** The financial costs of counselling should be regarded as part of the overall treatment budget.

**Recommendation 15.** All treatment centres should employ at least one person trained in infertility counselling and others according to HFEA recommendations.

**Recommendation 16.** A strategy of short, medium and longer term arrangements for the training of infertility counsellors should be implemented.

**Recommendation 17.** In the short term (within two years) specialist training courses should be arranged as necessary to supplement and

develop the knowledge and skills of treatment centre staff.

**Recommendation 18**. In the mid-term (up to five years) treatment centres which do not have a professionally trained counsellor as a member of staff should encourage their counsellors (who have previously completed the short specialist training course) to obtain a general professional counselling qualification.

**Recommendation 19**. Long term arrangements for training should be fully implemented by the beginning of the sixth year. This would require infertility counsellors to be in possession of a general professional counselling qualification and evidence of having successfully completed a short specialist training course.

**Recommendation 20**. Arrangements should be made for the identification and accreditation of training centres and courses which will provide specialist and general counselling training.

**Recommendation 21**. Treatment centres should bear the costs of staff training but central support should be considered for establishing the specialist training courses required.

**Recommendation 22**. An assessment of counselling provision should take place when the other activities of treatment centres are being inspected by the Authority.

**Recommendation 23**. A specialist review of the conduct and content of counselling and relevant training should be undertaken annually during the first five years and biennially thereafter.

## Counselling Needs of People Seeking Treatment

**Recommendation 24**. The availability of counselling should be presented as a usual and routine component of the infertility treatment being offered.

**Recommendation 25**. Couples should be encouraged to be open and honest with their child(ren) about the circumstances of the child's conception. They should be provided with appropriate written material to help them in this task.

**Recommendation 26**. After counselling, sufficient time for reflection should be made available before treatment is commenced.

**Recommendation 27**. Counselling should be made available to individuals and couples where treatment is not possible or a decision is made not to provide it.

**Recommendation 28**. In making decisions about the welfare of children, the HFEA should ensure that treatment centres establish procedures for information-gathering and decision-making in which the special contribution of the counsellor is recognised.

**Recommendation 29**. The HFEA should give guidance in the code of practice to assist treatment centres in considering the welfare of children affected by the treatments they provide. The HFEA is also asked to consider how this issue might adequately be addressed in relation to those from overseas seeking treatment.

## The Gamete Donor

**Recommendation 30**. Counselling of donors should take place in order to assess their psychological suitability.

**Recommendation 31**. Care should be taken to ensure that potential donors do not feel themselves to be under undue obligation to comply with the request to donate their gametes. The Committee notes that the Act allows the donor to review the terms of consent and stresses the importance of this provision.

**Recommendation 32**. Greater consideration should be given to the recruitment of donors who have children of their own.

**Recommendation 33**. Where applicable, donors should be encouraged to obtain consent from their partner before donating their gametes.

**Recommendation 34**. The procedures governing the selection of donors is the responsibility of the 'person responsible' as defined by the Act but the advice and opinion of the counsellor should be sought. Selection should be reviewed if changes in the donor's personal circumstances occur.

**Recommendation 35**. Implications counselling must routinely be made available to donors of gametes or embryos before donation and should be available after donation.

**Recommendation 36**. Persons undergoing infertility treatment should be counselled on a separate occasion if they are considering gamete donation.

**Recommendation 37**. After counselling, sufficient time for reflection should be allowed to elapse before obtaining gametes or embryos from the donor.

**Recommendation 38**. Support counselling should be available for prospective donors who are found to be unsuitable.

**Recommendation 39.** Donors should be encouraged to volunteer additional information about themselves which could be passed on to the recipient parents and the child.

## The Child

**Recommendation 40**. Counselling support should be available for parents who request guidance about relevant issues as their child(ren) grow up.

**Recommendation 41**. Children who wish to discuss issues associated with gamete or embryo donation should have access to an infertility counsellor.

**Recommendation 42**. The counselling of persons requesting information from the Authority about their genetic origins should be undertaken by a counsellor specialising in family relationships.

**Recommendation 43**. Information to be made available to young persons born as a consequence of regulated infertility treatment should be kept under review by the Authority.

# Appendix 1: References to Counselling in the H.F. & E. Act 1990

The Committee considers the following references are directly or indirectly relevant to counselling; their explicit and implicit implications are discussed in the body of the report.

## Licence Conditions

Section 12 – General Conditions

c) That the provisions of Schedule 3 to this Act shall be complied with. (Schedule 3 includes a provision for counselling – see below).

d) That proper records shall be maintained in such form as the Authority may specify in directions,

g) That the Authority shall be provided, in such form and at such intervals as it may specify in directions, with such copies of or extracts from the records, or such other information, as the directions may specify.

Section 13 – Conditions for Licences for Treatment

2) Such information shall be recorded as the Authority may specify in directions about the following:- a) the persons for whom services are provided in pursuance of the licence; b) the services provided for them; c) the persons whose gametes are kept or used for the purposes of services provided in pursuance of the licence or whose gametes have been used in bringing about the creation of embryos so kept or used; d) any child appearing to the person responsible to have been born as a result of treatment in pursuance of the licence.

3) The records maintained in pursuance of the licence shall include any information recorded in pursuance of subsection 2) above and any consent of a person whose consent is required under Schedule 3 to this Act.

4) No information shall be removed from any records maintained in pursuance of the licence before the expiry of such period as may be specified in directions for records of the class in question.

5) A woman will not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth.

6) A woman shall not be provided with any treatment services involving:- a) the use of any gametes of any person, if that person's consent is required under paragraph 5 of Schedule 3 to this Act for the use in question; b) the use of any embryo the creation of which was brought about *in vitro*; or c) the use of any embryo taken from a woman, if the consent of the woman from whom it was taken is required under paragraph 7 of that Schedule for the use in question, unless the woman being treated and, where she is being treated together with a man, the man has been given a suitable opportunity to receive proper counselling about the implications of taking the proposed steps, and has been provided with such relevant information as is proper.

Section 16 – Grant of Licence

1) ...a licence may be granted to any person by a licence committee if the requirements of subsection 2) below are met...

2) The requirements include- c) that the licence committee is satisfied that the character, qualifications and experience of that individual are such as are required for the supervision of the activities and that the individual will discharge the duty under section 17 of this Act.

Section 17 – The Person Responsible

1) It shall be the duty of the individual under whose supervision the activities authorised by a licence are carried on to secure:- a) that the other persons to whom the licence applies are of such character and are so qualified by training and experience, as to be suitable persons to participate in the activities authorised by the licence;...d) that suitable practices are used in the course of the activities.

Section 24 – Directions as to Particular Matters

1) If in the case of any information about persons for whom treatment services were provided, the person responsible does not know that any child was born following treatment, the period specified in directions by virtue of section 13 (14) of this Act shall not expire less than 50 years after the information was first recorded.

Section 25 – Code of Practice

1) The Authority shall maintain a code of practice giving guidance about the proper conduct of activities carried on in the pursuance of a licence under this Act and the proper discharge of the functions of the person responsible and other persons to whom the licence applies.

2) The guidance given by the code shall include guidance for those providing treatment services about the account to be taken of the welfare of children who may be born as a result of treatment services (including a child's need for a father), and of other children who may be affected by such births.

Section 27 – Meaning of 'Mother'

1) The woman who is carrying or has carried a child as a result of the placing in her of an embryo or of sperm and eggs, and no other woman, is to be treated as the mother of the child.

Section 28 – Meaning of 'Father'

2) ....the other party to the marriage shall be treated as the father of the child unless it is shown that he did not consent to the placing in her of the embryo or the sperm and eggs or to her insemination (as the case may be).

Section 29 – Effect of Sections 27 and 28

1) Where by virtue of section 27 or 28 of this Act a person is to be treated as the mother or father of a child, that person is to be treated in law as the mother or, as the case may be, father of the child for all purposes.

Section 31 – The Register of Information

1) The Authority shall keep a register which shall contain any information obtained by the Authority which falls within subsection 2) below.

2) Information falls within this subsection if it relates to:– a) the provision of treatment services for any identifiable individual; or b) the keeping or using of the gametes of any identifiable individual or of an embryo taken from any identifiable woman, or if it shows that any identifiable individual was, or may have been, born in consequence of treatment services.

3) A person who has attained the age of eighteen ('the applicant') may by notice to the Authority require the Authority to comply with a request under subsection 4) below, and the Authority shall do so if:- a) the information contained in the register shows that the applicant was, or may have been, born in consequence of treatment services; and b) the applicant has been given a suitable opportunity to receive proper counselling about the implications of compliance with the request.

4) The applicant may request the Authority to give the applicant notice stating whether or not the information contained in the register shows that a person other than the parent of the applicant would or might, but for sections 27 to 29 of this Act, be a parent of the applicant and, if it does show that:- a) giving the applicant so much of that information as relates to the person concerned as the Authority is required by regulations to give (but no other information); or b) stating whether or not that information shows that, but for sections 27 to 29 of this Act, the applicant, and a person specified in the request as a person whom the applicant proposes to marry, would or might be related.

5) Regulations cannot require the Authority to give any information as to the identity of a person whose gametes have been used or from whom an embryo has been taken if a person to whom a licence applied was provided with the information at a time when the Authority could not have been required to give information of the kind in question.

6) A person who has not attained the age of eighteen ('the minor') may by notice to the Authority specifying another person ('the intended spouse') as a person whom the minor proposes to marry require the Authority to comply with a request under subsection 7) below and the Authority shall do so if:- a) the information contained in the register shows that the minor was, or may have been, born in consequence of treatment services; and b) the minor has been given a suitable opportunity to receive proper counselling about the implications of compliance with the request.

7) The minor may request the Authority to give the minor notice stating whether or not the information contained in the register shows that, but for sections 27 to 29 of this Act, the minor and the intended spouse would or might be related.

Section 34 – Disclosure of Information

1) Where in any proceeding before a court the question whether a person is or is not the parent of a child by virtue of sections 27 to 29 of this Act falls to be determined, the court may on the application of any party to the proceedings make an order requiring the Authority:- a) to disclose whether or not any information relevant to that question is contained in the register kept in pursuance of section 31 of this Act; and b) if it is, to disclose so much of it as is specified in the order, but such an order may not require the Authority to disclose any information falling within section 31(2)(b) of this Act.

2) The court must not make an order under subsection 1) above unless it is satisfied that the interests of justice require it to do so taking into account – ...b) the welfare of the child, if under 18 years old, and with any other person under that age who may be affected by the disclosure.

Section 35 - Disclosure in interests of justice: congenital disabilities etc

1) Where for the purpose of instituting proceedings under section 1 of the Congenital Disabilities (Civil Liability) Act 1976 (civil liability to child born disabled) it is necessary to identify a person who would or might be the parent of a child but for sections 27 to 29 of this Act, the court may, on the application of the child, make an order requiring the Authority to disclose any information contained in the register kept in pursuance of section 31 of this Act identifying that person.

## Schedule 3: Consents to Use of Gametes or Embryos

Paragraph 1 – Consent

1) A consent under this Schedule must be given in writing and, in this Schedule, 'effective consent' means a consent under this Schedule which has not been withdrawn.

Paragraph 3 – Procedures for Giving Consent

1) Before a person gives consent under this Schedule:- a) he must be given a suitable opportunity to receive proper counselling about the implications of taking the proposed steps; and b) he must be provided with such relevant information as is proper.

2) Before a person gives consent under this Schedule he must be informed of the effects of paragraph 4 below.

Paragraph 4 – Variation and Withdrawal of Consent

1) The terms of any consent under this Schedule may from time to time be varied, and the consent may be withdrawn, by notice given by the person who gave the consent to the person keeping the gametes or embryo to which the consent is relevant.

2) The terms of any consent to the use of any embryo cannot be varied, and such consent cannot be withdrawn, once the embryo has been used:- a) in providing treatment services; or b) for the purposes of any project of research.

# Appendix 2: Summary Content of Counselling

This guide to the content of counselling assumes that certain preconditions which are recommended in the body of this report have been met. That is, suitable accommodation for counselling is provided (i.e. in the treatment centre, and in comfortable and relaxing surroundings where the discussion is unlikely to be disturbed); that adequate time is allocated, and that counselling is regarded as a normal and constituent part of the treatment process.

What follows should not be interpreted as a 'check-list' of topics but treated as a guide designed to ensure consideration of a number of topics believed to be important. The content of counselling will depend on the unique situation presented by the individual or couple concerned and so cannot be rigidly predetermined. Nevertheless, certain general areas must be addressed.

## Information counselling for those seeking treatment

The 'person responsible' under the Act must ensure that persons seeking regulated treatment are given information about, and understand:-

- the diagnosis;
- the nature and purpose of the treatment or procedure recommended;
- the risks and complications associated with such treatment;
- alternative treatments or procedures available and their potential risks;
- the chances of success and failure of the procedure;
- rights and duties contained in relevant legislation including maternity and paternity, parental rights, birth registration, and the rights of any resulting child or other child(ren) who may be affected.

Patients should understand that their consent to treatment has to be given in writing and that this consent can subsequently be varied or withdrawn.

## Implications counselling for those seeking treatment

Relevant written information should be given to the persons seeking treatment prior to the counselling session so that the discussion can focus on the reactions to this information.

The discussion should be semi-structured and focussed on relevant topics but the sequence and time allocated to each topic should remain flexible. The following areas should be addressed:-

- the impact of infertility on the affected person;
- the impact of infertility on the couple and their relationship;
- consideration of other ways of dealing with childnessness (including the option of remaining child-free);
- the mutuality of the decision to seek treatment;
- response to the possibility of failure of a given technique;
- potential reactions to failure to achieve a pregnancy;
- possible termination of treatment.

## The possible use of donor gametes

When treatment might involve the use of donor gametes the following points should also be considered by the infertile person and his/her partner:-

- readiness to relinquish genetic parenthood;
- reactions by other family members to the inclusion of genetic material not their own into their family;
- feelings about the donor;
- feelings about the potential baby/child/young adult;
- implications for the child's grandparents and other relatives;
- implications of donor assisted conception from the child's point of view;
- feelings about openness and sharing

knowledge of the child's conception with the child;
- ways of handling information about the donor;
- implications of current legislation relating to the rights and duties of the parents, donor, child, and the treatment centre;
- the right of young persons to seek information from the Authority in the context of consanguinity.

## Information counselling for donors of gametes or embryos

Prospective donors of gametes or embryos will require information about:-

- selection procedures for donors;
- procedures involved in the collection of gametes/embryos;
- the risks and complications associated with such procedures;
- the use to which donated gametes/embryos may be put;
- information recording procedures and content;
- the legal position of the donor, including the possibility of the disclosure of identifying information; the recipient couple; the child and the treatment team.

Donors must be told that their consent to donate is required in writing and that this consent can subsequently be varied or withdrawn providing agreed use has not already taken place.

## Implications counselling for donors of gametes or embryos

Relevant written information should be given to donors prior to the counselling session so that the discussion can focus on the meaning and consequences of donation rather than on the practical aspects of donation. The following areas should be addressed:-

- motivation for donation;
- the uses of gametes/embryos;
- feelings about the potential child;
- feelings about the recipient parents;
- the possibility of their own childlessness;
- feelings about relinquishing knowledge of, and responsibility for, a genetically linked child;
- implications of donor assisted conception from the child's point of view;
- feelings about the child becoming aware of his/her donor assisted conception;
- storage of confidential, identifying information by the treatment centre and the Authority;
- provision of personal information to the recipient parents and the child;
- acknowledgement to significant others of their donation;
- implications for present and future kin (parents, spouse, children).

## Counselling for young persons seeking information held by the Authority

Relevant written material should be made available prior to the counselling session so that discussion can focus on the implications associated with the information being sought. The following areas should be addressed:-

- motivation for seeking the information;
- the applicant's reaction to awareness of his/her donor assisted conception;
- the applicant's expectations in seeking information;
- possible consequences of this information for the applicant, his/her kin and his/her partner.

# Appendix 3: Written Material Required

It is recommended that the H.F.& E. Authority make arrangements for the production of leaflets containing information describing various aspects of the regulated infertility service associated with counselling. These are:-

i) *Providing advice about infertility*
How to inform newly diagnosed individuals of their infertility. Designed for G.P.s and others likely to be providing such information and containing advice concerning the management of stress this news may cause.

ii) *Infertility treatments*
A description of the different types and possible causes of infertility together with a description of available treatments. This brief introduction to infertility treatments would be designed for use by those learning of their infertility and will include information about the specialist services available.

iii) *Semen donation*
A description of the procedures and implications for those contemplating sperm donation, and their families.

iv) *Egg and embryo donation*
A description of the procedures and implications for those contemplating egg/ embryo donation, and their families.

v) *Information for younger children*
Designed to be seen by younger children (under 10 years of age) but provided by parents who wish to discuss assisted conception with their child.

vi) *Information for older children*
Designed to be seen by the older child (10 years and over) whose parents wish to have the topic of assisted conception discussed.

vii) *How to tell your child about gamete donation*
Designed for use by parents and others responsible for these children describing why and how to approach possible discussions about assisted conception with the child. This will include reference to the implications of secrecy as well as the process and genetic implications of gamete donation.

viii) *Approaching the Authority for information*
Information about the enquirer's legal rights and the procedures to be followed when seeking information from the Authority.

# Appendix 4: Suggested Content of Short Training Courses for Infertility Counselling

We have recommended that specialist training should be arranged as necessary to supplement and develop the knowledge and skills of treatment centre staff (Recommendation 17). There is a need to provide specialist training for two identifiable groups of trainees; those who already possess medical/scientific/nursing experience and orientation and those who approach the subject predominantly from a social science/psychological perspective. A mixture of these approaches to infertility and infertility treatment to meet individual interests and requirements may most appropriately be presented as a series of training modules. Within each module there could be two levels, one introducing basic information and concepts on the assumption of minimal knowledge and the other providing more advanced training for those already possessing some knowledge of the subject matter. In addition, each module could contain a mixture of academic or classroom teaching and skills learning with the mix varying according to the subject of the module. Five modules have been identified:-

## Module 1: Medical

Reproductive health care.
Infertility and medically assisted conception.
Backgound, availability and outcomes of these treatments.
Relevant scientific research and developments.

## Module 2: Law, Ethics, Management

(a) Legal, ethical and management issues in medical services.
Accountability, confidentiality, record keeping etc.
Ethical principles (eg WHO) within medical practice and research.

(b) The Human Fertilisation and Embryology Act 1990.
Legislation, regulations, directions, code of practice.

## Module 3: Psychosocial Issues in Infertility and Assisted Conception

(a) Introduction to the literature.
Marital and sexual relationships; treatments and therapies.
Loss, grief, life crises, post-traumatic stress.

(b) Skills development.
Bereavement counselling.
Stress management.

## Module 4: Family Studies

(a) Introduction to family research.
Kinship, parenting, child development.
Alternative family structures; adoption, foster-care, reconstituted families, child-free life-style.

(b) Family law.
Various but with particular reference to the welfare of the child.

Training packs are available which contain inter-disciplinary child-care teaching for social workers, medical and legal practitioners.

## Module 5: Counselling: Theory and Skills

Introduction to models and theories (eg.Egan, Heron, Rogers).
Basic concepts in counselling.

This module aims to develop skills using experiential, face-to-face and group learning techniques.

## Three Days of Practical Observation

A. For medical, scientific, nursing staff.

*Either* one day in a different clinic to observe how counselling skills are used and two days in a non-medical counselling agency specialising in families and children;
*or* three days in a non-medical setting with

(perhaps) a day in a child guidance centre, a day with a health visitor working with children under 5 years and a day with an IVF family or with a childless couple seeking or experiencing infertility treatment.

B. For non-medical staff.

Three days in an infertility treatment centre; out-patient, in-patient, laboratory etc.;
*Note:* The three days are intended as observational visits and are not intended to be an opportunity for practising counselling skills. The experience and impressions gained during these observation visits will be used to demonstrate the link between practice and theory.

## Conclusion

This outline is based on a *minimum* training period of 10 days containing seven days of classroom work and three days practical observation. This will need to be accompanied by the completion of prepared readings. The total training period would not be expected to exceed three months. It should also be noted that this short period of specialist training is meant as a supplement to (rather than a substitute for) the much longer period of training required to obtain a professional counselling qualification.

The proposed short specialist training will benefit from a combination of distance learning techniques and face-to-face and group teaching. There will be a need for each trainee to have a personal tutor to ensure that the mix of modules and levels is appropriate and that a continuous monitoring of progress is possible.

Assessment of courses as a whole (perhaps for the purpose of accreditation) could be undertaken jointly by an established validating body such as the Central Council for Education and Training in Social Work (CCETSW) with representatives from appropriate professional bodies such as the RCOG, RCGP, RCN, RCM, the British Infertility Counselling Association (BICA) and the British Association of Social Workers (BASW).

# Appendix 5: Monitoring and Evaluation of Counselling

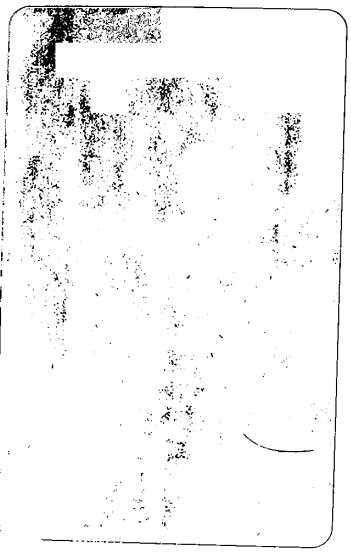
In the context of licensing and regulation of services, the Authority will need to consider how to ensure that an appropriate and adequate counselling service is maintained. This raises questions about monitoring and evaluation. The Authority might wish to consider consulting with the sources of expertise and experience in this field in the Social Services Inspectorate (SSI) and the Central Council for Training and Education in Social Work (CCETSW). Experienced counselling practitioners should be involved in the monitoring process.

Monitoring and evaluation should be based on relevant statistical and other factual information provided by the treatment centre. It is suggested this could include:-

- number of staff and staffing structure;
- number of counsellors;
- qualifications of counsellors;
- presence and quality of a training programme for counsellors;
- size of the budget for the training of counsellors;
- arrangements for the employment/provision of counsellors;
- provision of written information to patients/donors;
- number of patients referred to the treatment centre;
- number of patients seen by the counsellor;
- number of patients referred to specialist agencies following a problem identified during counselling;
- number of patients withdrawing from treatment after counselling.

Analysis of this information would identify areas for further exploration and discussion during follow-up contact with the treatment centre. Included in visits to centres should be an inspection of counselling facilities, a sample reading of counselling records and detailed discussion of work with individual counsellors. In treatment centres with training/observational facilities there might be an opportunity to observe counselling practice given the normal conventions of consent and confidentiality. The role of counselling from the perspective of other team members would also provide useful information. The Authority should, in addition, consider how the views of patients may contribute to the monitoring process.

Counsellors have an important role to play in ensuring that the welfare of the child born following use of the regulated infertility services (or otherwise affected by the use of such services) is taken into account. It is logical, therefore, that this requirement of the Human Fertilisation and Embryology Act receives appropriate emphasis in the monitoring and evaluation of counselling.



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