



Gamete Donation

A Discussion Paper

**Synod Bioethics Committee
Uniting Church (Queensland Synod)**

While helping people to have children who are biologically and genetically their own is a medical procedure with few, if any, wider social consequences, the transfer of gametes and embryos to non-related hosts changes the possibilities surrounding the family—children and their parents—in ways which can impinge on society in general, as well as on the people directly involved.

Brenda Almond, *Exploring Ethics*, p. 140

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1. Introduction and background

This paper explores the issue of gamete donation. It is hoped that the information provided will promote further discussion from which shared understandings will emerge. Opportunity to provide feedback is given at the end of the paper.

The Bioethics Committee was asked to review the Queensland Synod's current position on a range of assisted reproductive services, including gamete donation. The initial request came from fertility professionals at the Wesley Hospital. Currently, there is significant international reflection on the implications of gamete donation, particularly for donor offspring.

Gamete donation is one facet of the rapidly changing world of reproductive technology. It refers to two forms of assisted reproductive technology (ART). In artificial insemination donated sperm is placed in a woman's reproductive tract. Eggs (oocytes) can also be donated, fertilised in vitro, and placed in a woman's uterus.

Previously, Christian reservations about the use of gamete donation focused on the fact that it involves introducing a third-party into what ought to be an exclusive relationship, but there has also been a wider range of responses in the general community.

Arguments in favour of gamete donation see it as an altruistic, compassionate and caring response to the needs of childless couples. Sperm and eggs can be donated, just as organs and tissues such as blood are. They have little or no value to the giver but enormous benefit to the recipients. Others see gamete donation as an exercise in 'reproductive liberty', whereby couples ought to be free to form families of their own choosing and timing.

Those arguing against gamete donation raise a number of issues beyond the intrusion of a third party into an otherwise exclusive relationship: including, the lack of openness and honesty in the practice; the possibility of identity confusion and genetic bewilderment among donor offspring; loss of biological connection to parents, offspring and siblings; the stigma of

commodification; and issues of power and control over reproduction and relationships.

Views about the benefits of gamete donation have changed dramatically in recent years as donor offspring describe their experiences and voice their concerns. Arguably, as the most vulnerable participants in donor gamete practices, their voice should be given significant weight.

Whether we are discussing in vitro fertilisation, embryo transfer, surrogate motherhood, or donor insemination, we must keep in mind the universal human needs of the people involved and the necessity to preserve those needs. It should be noted that the more complex the method of conception, gestation, and birth, the more complex the psychological implications and emotional reverberations.

Annette Baran & Reuben Pannor, *Lethal Secrets*, p. 165

The most salient emerging ethical concern about gamete donation is that, although intended as a caring response to the grief and pain of infertile couples, it may transfer the burden of grief and loss to the next generation.

Some questions which arise from listening to the experiences of all participants in gamete donation practices are:

- Can practices of gamete donation be transformed to prevent these intergenerational harms?
- Can a practice based on institutional and familial secrecy and deception be transformed if practised with openness and honesty?
- Who will accept responsibility for informing and educating couples and donors about the lifelong implications of gamete donation?
- Who will provide lifelong service to couples, donors and offspring to deal with issues throughout their lifespan?
- Is it ethical to offer such procedures without such support?

Some matters of ethical concern in respect to gamete donation include:

- Openness and honesty
- Experiences of grief and loss
- The value of genetic connection
- Identity loss and confusion
- Commodification of reproduction

- Power and autonomy in reproductive choice
- Effects on extended families and next generations
- The future medical and social importance of genetic identity

While previously the social impact of gamete donation focused on the exclusivity of the marriage relationship, the ethical features of gamete donation are now defined by its impact on a wider set of social relationships—from professionals and their practices, to the couples and donors and their families and extended families and to the wider community.

2. Approaching the ethical issues

Medical ethics and bioethics have focused on issues through the lens of four key principles: autonomy, non-maleficence, beneficence and justice. *Autonomy* focuses on respect for persons and asks, is an individual free to choose for themselves? *Non-maleficence* focuses on the harm principle and asks, is this likely to harm others? *Beneficence* focuses on whether a practice or choice will enhance the well-being of others. Will it do them good? *Justice* focuses on issues of fairness. Will the benefits and risks be distributed equitably, or to those who are most in need, or to those who deserve it?

Principles of medical ethics

Respect for Autonomy

Does this decision or course of action respect a person's capacity to make informed decisions about their own life?

Non-maleficence

Will this decision or course of action cause physical, psychological or social harm?

Beneficence

Will this decision or action promote the wellbeing of individuals or the community?

Justice

Is this decision fair? Does it treat people equally, according to their needs and abilities, whatever their wealth, gender, ethnicity or beliefs?

These principles are relevant to the issue of gamete donation. However, often they are applied to dilemmas confronting individuals, discounting the effects of institutional and cultural practices and impacts on other stakeholders. The issue of autonomy, for example, will be related to the choices confronting an infertile couple and their freedom to choose what they want without interference from others. Clearly, however, maintaining secrecy about a child's origins could severely restrict that child's autonomy to explore their biological connection to others.

Many find a preoccupation with choices confronting individuals or couples too narrow an approach, and applying bioethics to family issues clearly shows why. Clinical decisions do not just impact on an individual couple but also on their offspring and extended family. Rather than seeing ethical dilemmas as focused on isolated individuals, we have come to understand that these individuals are embedded in ever widening circles of concern, from the petrii dish to the wider community.

The core principles of bioethics do not need to be rejected; rather, they need to be placed in the context of the individual and *collective* life stories which shape an ethical situation. The church itself has a collective story, a tradition, which shapes its response. The foundation values of Uniting HealthCare, for example, require us to always consider issues of autonomy, justice, non-maleficence and beneficence in relation to its core commitment to valuing the 'whole person' and 'community'.

Thankfully, just as there are developments in social and technological areas, there are also developments in the way we do ethics. Insights from feminist ethics and applied ethics have drawn our attention to the fact that ethical reflection, particularly on matters involving relationships and families does not only require *intellectual skills*, it also requires *attending* to what is going on, *listening* to the experiences and viewpoints of those concerned and *empathising* with those involved.

In learning morality, we learn who we are, to whom we are connected and what matters enough to care about and care for.

Margaret Urban Walker, *Moral Understandings*, p.201

Peter Isaacs and David Massey (1994) suggest that applied ethics requires 'creating and sustaining relationships which mutually recognise the needs, interests and aspirations of all participants as ends in themselves'. They offer the following framework for exploring ethical issues.

An applied ethics framework

1. *Explore meanings.* (Hermeneutical dimension) First we need to ask questions which will help us to understand the frameworks of all participants, individual and institutional. What are their assumptions, insights and limitations? From the point of view of the various people involved, what is going on here? Not just from my point of view? What meanings does this have for the participants from their point of view.
2. *Appreciate particulars, including constraints on choices.* (Appreciative dimension) The second set of questions we should ask acknowledges the richness, complexity and particularity of others. Do I understand the factors which enable or constrain them; that is, their relative power or powerlessness? Is engagement with others being promoted, or are solutions being advocated from a distance without a fuller, deeper understanding of the situation? Are relationships, practices, individuals, institutions and communities being morally enriched? We ask these questions because not everyone is in a position to choose freely from all the options.
3. *Explore ethical frameworks.* (Appraisive dimension) Only after opening up the context by exploring these two sets of questions can we begin to bring back in the ethical frameworks from our philosophical and religious traditions. Then we can ask what values, principles, and virtues should inform our response? What would be the caring thing to do?. Again, we should seek to understand which moral codes other participants bring to the situation.
4. *Do something about it.* (Transformative dimension) We should not stop our inquiry with an intellectual appraisal. We need to ask ourselves a final set of questions. What can we do about this? What action is possible? What strategies for change are appropriate? What strategies are participants already using to promote their values?

What possibilities are there for informing, educating, mobilising, mediating or, if necessary, resisting?

Based on Peter Isaacs & David Massey, 1994

Whether or not we follow this framework step-by-step, we ought to remain open to these types of questions, returning to them again and again as we seek shared understandings based on appreciation of the experiences and points of view of all relevant stakeholders.

In the past, the issues in gamete donation have been framed mainly by the views of professionals and those considering gamete donation. The Synod Bioethics Committee intentionally set out to include other voices; for example, those involved in counselling couples, couples for whom treatment was not successful, and donor offspring. Some were interviewed in person; others voices were sought out through the literature.

Current policy for UC hospitals in Queensland

In 1985 the Council of Synod approved the following policy for The Wesley Hospital. (At the time, services were provided by the Queensland Fertility Group. These services are now provided by the Wesley IVF Service):

- (i) The programme of the Queensland Fertility Group [as it was then called] shall be confined to treatment of infertile couples within a stable marriage relationship.
- (ii) Only the gametes produced by the partners of that relationship shall be used.
- (iii) Freezing techniques are approved, but only within the limits imposed by the policy statements 1 and 2 above, provided that frozen fertilised ova derived from any one married couple be used only during the reproductive lifetime of that couple and for the treatment of their own infertility.
- (iv) *In the present circumstances, the Board postpones for future consideration any decision on the use of donor gametes until the many implications of such use are clarified further. (Emphasis added)*

In 1989, The Wesley Hospital Board requested amendment of clause (iv) above to allow for gamete donation in some circumstances. In July 1991, the Commission for Community Service resolved to recommend to the

Council of Synod that the use of donor gametes be prohibited. In 2000, in a Synod Bioethics Committee discussion with members of the IVF group at the Wesley Hospital, the Synod policy on IVF was discussed and a lack of congruence between Synod policy and Wesley IVF Group's practice was noted. The Multidisciplinary Ethics Committee of the Wesley Hospital had also recommended in favour of gamete donation. They argued that:

- the Church ought to provide leadership in the discussion of ethical issues such as use of donor gametes in IVF procedures,
- that donor gametes are a means to an end. Whether a childless couple become parents is within the wisdom and the providence of God acting in IVF procedures,
- proper counselling within both the medical and theological perspectives must accompany the contemplation of the use of donor gametes,
- the command to love is the basis of a sound ethic supporting the use of donor gametes,
- in supporting the use of donor gametes the Church has a tremendous opportunity to play a thoughtful part in guiding those responsible for the management of reproductive technology,
- to say 'No' to the question of permitting the use of donor gametes, rather than 'Yes' with a firm set of guidelines and procedures for counselling will potentially remove the substantial influence the Church has been able to exercise on reproductive technology in the past decade or so. There is a risk that clinical units will leave church hospital facilities and the church will relinquish its immense responsibilities in leading our society in the thoughtful use of reproductive technology. This would be a very disappointing and retrograde step.

In May 2000, Dr. Doug Killer of the Wesley Hospital wrote to the Synod Bioethics Committee again suggesting that the whole framework of Assisted Reproductive Technology/IVF policies needed to be reconsidered.

3. Legal situation

It is estimated that about 700 children are born each year in Australia as a result of donor insemination alone. Sperm and egg donation is available in all Australian states. Clinics offer varying degrees of infertility counselling, educational programs and ethics review.

Assisted Reproductive Technology (ART) in Australia is regulated through both legislative and voluntary compliance frameworks. It is regulated by specific legislation in only three States - Victoria, South Australia, and Western Australia.

Victoria - Infertility Treatment Act (1995)

- Offspring from donor procedures have the right to access identifying information about birth origins when they reach 18 years of age. Information is recorded on a central registry managed by the Infertility Treatment Authority. This applies only from the date the Act came into force (1st January 1998) but also applies to offspring born from donors who gave their consent for identifying information to be released prior to this date.

Western Australia - Human Reproductive Technology Act 1991 (WA) and Amendment Act 1996

- Donors must give consent for their sperm to be used for single women
- Offspring from donor materials have no access rights to identifying information but all parties may access non-identifying information at any time.

South Australia - South Australian Reproductive Technology Act (1988)

- Single women and short term de-facto couples who are infertile can access ART in S.A.
- Identifying information about donors of reproductive material is confidential unless the donor agrees to its release. Children born of donated material have access to non-identifying information about the donors once they reach 16 years. Prospective parents receive non-identifying information at the time of donation.
- During 2001 the Council prepared recommendations for the establishment of a Donor Conception Register for SA covering: access to identifying information; non-compulsory retrospective release of identifying information; a voluntary register for existing and future children born from donors who donated prior to proposed legislative changes; regular contact with past donors; and a compulsory central

register for future donors. It is anticipated that this will be considered during 2002.

New South Wales, Queensland, Australian Capital Territory, and Northern Territory have not legislated for reproductive technology practice. They rely on the National Health and Medical Research Council's (NHMRC) recommendations for rulings on reproductive technology issues, with some variations in practice.

ART practices in all states are underpinned by a national system of accreditation by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia, which is in turn founded on guidelines produced by the National Health and Medical Research Council (NHMRC). Currently, the NHMRC is revising its guidelines on the use of reproductive technology in clinical practice and research. The draft of these revisions circulated for public comment has recommended that clinics collect information from donors to 'facilitate the exchange of information between gamete donors, gamete recipients and the persons conceived by gamete donation'. However, there appears to be no mechanism for necessarily communicating this information to those conceived by donation when they turn 18 years of age. There is no Commonwealth legislation covering the regulation of ART clinical practice.

4. History of DI practices

Artificial insemination is the oldest form of assisted reproductive technology. The first pregnancy reported from artificial insemination was in 1790. The first using frozen and stored sperm was in 1953. The procedures have also been extensively used in agriculture. Ironically, meticulous records are kept to preserve information in the agricultural use of artificial insemination but, until recently, not for humans. More than 250,000 individuals have been born by this procedure world-wide (Lewis, p. 384). Again, due to secrecy this can only be estimated.

Historically, most sperm was donated by doctors themselves or medical students who received a small amount of money for their efforts. There is now a wider pool of donors.

A Victorian study has identified that most sperm donors in that state in 1988-1997 were between the ages of 20-29 years (46%) and 30-39 years (37%). The major occupation groups were Student 32%, Professional 23% and Trade or Skilled 17%.

According to the Queensland Fertility Group, the majority of their donors fall into the 18-30 year old group. Over half of their donors are students, though in various courses leading to different occupations. This ratio of students to others has not changed significantly over the last decade.

Some older, perhaps married donors are now recruited through advertising campaigns advocating a humanitarian/compassionate approach (i.e. helping out infertile couples) although the maximum age for donation is 40-45 years.

Apart from issues of storage and screening, donor insemination is low-tech and requires very little medical intervention; thus, the turkey baster's iconic status, although a syringe is more likely to be used. Egg donation, however, is more medical and, thus, more intrusive and costly. Compensation paid to egg donors in the USA is currently around US\$7,000. In the UK, egg donors receive the same compensation as sperm donors—£15. Controversially, *egg sharing* occurs in the UK; that is, in return for a substantial reduction in the costs of their IVF treatment, women undergoing treatment share their 'excess' eggs with women wanting a donated egg. Egg donation makes use of in-vitro fertilisation methods to harvest eggs, fertilise them in a laboratory dish and implant them into the recipient uterus. The first child born as a result of egg donation was born in 1984. Success rates are approximately 20 to 50 per cent (Lewis, p. 388). Advertising in newspapers and in some medical clinics in Australia encourages women to donate eggs, once again appealing on humanitarian and compassionate grounds.

Advertisement in *Village Voice* - New York City, 2002

We're looking for Dreammakers ... become an egg donor

With your help, someone could end up expecting their dream to finally come true. Right now, there are many couples anxiously dreaming of having a baby. For them, anonymous egg donation represents a real chance for successful conception ... perhaps, their only chance.

Women between the ages of 21 and 32 and from all ethnic backgrounds may be eligible to participate in our anonymous egg donor program...

At the completion of the cycle, you will be compensated US\$7,000

Couples (in some cases single women) can select sperm from catalogues which list characteristics of the sperm donor, including blood type, hair and eye colour, skin colour, height, educational background and interests.

Until recently, gamete donation was a matter of concern mainly to prospective parents, donors and professionals. In recent years, the offspring of donor insemination have voiced their views about the procedure. Many are interested in having information about and meeting the person who contributed half of their genetic identity. Others express their grief and sense of loss at having been born as a result, not of sexual intercourse between loving parents, but of an anonymous transaction between strangers. Many parents of DI children have also raised questions in support of their children. Some fathers have written about the emotional effects at their lack of biological connection to their children (Blizzard, 1977). Some DI support groups now strongly oppose donor anonymity.

An increasing number of donors have also said they would like to meet the adults to whom they are biologically related. Some now claim that they donated at a time when they had no real awareness of the significance of family or biological relationships. They only realised when they started their own families that they have many more children. Tragically, some who can no longer have families themselves long for a connection to the persons they helped to create.

Many donor offspring can have hundreds of half-siblings, and this can foster emotional insecurities when seeking out and forming intimate relationships. This sheer weight of numbers also prevents many donors from responding to the desires of offspring for connection, or from telling their own families that they have been donors. Recipient couples who were told that they were simply receiving donated tissue may have made different choices if they had known that their children would have so many siblings. Some countries such as France that allow sperm donation now restrict the number of children conceived from a single donor to two or three. NHMRC guidelines currently being discussed in Australia recommend limiting donations from a single donor to five families;

consequently, the actual number of potential offspring, although no longer in the hundreds, is still potentially large.

[In Queensland] the majority of people using donor gametes (90%) don't tell the children. In Victoria and S.A. there is a register of donors. This is not the case in NSW (yet) or in Queensland. In those other states there is legislation. If Queensland does introduce legislation, QFG hopes that it will be prospective so that the undertakings given to prior donors in relation to anonymity can be honoured.

Heather Pollock, Senior Nurse Coordinator, Queensland Fertility Group

The principle of anonymity was seen as important for maintaining a steady supply of donors. Doctors advised parents to keep the child's origin a secret forever. By law, the child born to a married couple is assumed to be the child of the husband, unless paternity is proved otherwise. Consequently, the birth certificates of all donor offspring are legal fictions. The impact of this veil of secrecy on family relationships can be profound, disrupting the trust fundamental to secure family development. Ironically, this culture of denial and secrecy was being promoted in DI practices at the same time as the wall of secrecy was being dismantled in the field of adoption.

In the world of alternative means of conception, donor insemination is ... the most available, successful, and egalitarian. Breaking the bonds of silence and ending secrecy is necessary ... to address the inherent psychological problems. As we continue headlong down the road of impersonal high-tech procedures ... we need to maintain a strong sense of the importance of the human element and historical connection. In the final analysis these remain fundamental to stable, successful family life.

Annette Baran & Reuben Pannor, *Lethal Secrets*, p xiii

5. Emerging themes and concepts

Altruism and compassion: the public face of gamete donation

Responding to the grief and pain of infertile couples is a powerful motivation for health practitioners and donors alike. Sperm and egg donation is seen as an altruistic, compassionate and responsible act to help

couples when all other procedures have failed. It is presented in the same light as the donation of other tissues or organs. It is no different, it is said, to giving blood. Something of little or no value to the donor—sperm or an excess ovum—the loss of which will cause no significant harm or pain, will bring immense happiness to the recipients. Because the procedures involve the informed consent of husband, wife and donors, with no ongoing relationship between the donor and the couple, it has been argued that the exclusiveness of the marriage relationship is thus preserved.

A central irony of the altruistic view, however, is that while at least some genetic connection is of demonstrable value to recipients, it is imputed to be of little or no value to either donors or offspring. The question is: does this confuse value with significance? While it is true that unused sperm or ova are of little value, there may be considerable significance—informational and cultural—attached to them once used. Gametes not only contribute half the genetic identity of all individuals, they also contain information linking one generation to the next. Traditionally, these links are regulated by strong cultural norms.

The importance of genetic continuity

Gamete donation is rarely the first option for couples experiencing difficulties conceiving a child. Genetic connection is valued so highly that couples will try all other means to have their own children first. Gamete donation is sometimes regarded as a point on a continuum of possibilities somewhere between IVF and adoption. Many fertility specialists see it as the next logical step for couples after they have tried everything else. Added pressure to consider gamete donation comes from the fact that current state laws prevent couples from placing themselves on adoption lists while they are undergoing fertility treatments.

Within the framework of fertility practices, loss of genetic continuity is clearly seen as a significant loss which must be remedied. Until recently, however, the equal importance of genetic continuity to donors and donor offspring has not been acknowledged; in fact, it has often been discounted.

How can genetic heritage be so deeply embedded in our culture and then DI offspring be expected to accept that, for them, it does not matter?

DI adult, Barry Stevens, *Offspring* (Video)

Current experience shows that donor offspring attitudes towards if, when and how to connect with donor parents varies. Some clearly desire to meet their biological parent as soon as they are able; others postpone their decision, prompted by ambivalent feelings or their present life circumstances; for example, study, work, or family commitments. Sometimes the desire is prompted by a narrative milestone, such as starting their own family or the death of one or both of their parents. While attitudes towards and readiness to connect varies, there seems universal agreement that any decision should be the result of an autonomous, informed choice. Without truthful information concerning their birth and the identity of donors, however, they are dependent rather than autonomous individuals. Only with knowledge comes the ability to choose.

Openness and Honesty

The lack of openness and honesty is the most persistent challenge to the notion of gamete donation as an altruistic practice. Few truly altruistic, compassionate and beneficial social practices are surrounded with such secrecy.

Unfortunately, this secrecy is reinforced by a legal fiction. By law, a child is deemed to be the offspring of a married couple unless paternity is proved otherwise. The non-biological father is entitled to have his name on the child's birth certificate. So long as the secret is kept, he need not fear the embarrassment of infertility, the rejection of his child, nor the social stigma of an artificial conception. In the past, he and his partner would have been assured by medical practitioners (on the basis of no evidence) that secrecy was also in the best interests of the child.

As recently as the 1970s, the British Medical Association's advice to women seeking AID was to go home after the treatment and forget it, or even to have sexual intercourse with the infertile husband immediately, so that if a pregnancy is achieved, it would not be absolutely clear that the husband is not, after all, the father of the child. Their pamphlet ends with the words 'No one need ever know'. This seems to be a blatant case of neglecting 'the good of the child'. The child was to be brought up in a cloud of deception.....

Mary Warnock, Making Babies, p. 66

The reasons for not telling children that they were born as a result of gamete donation have included:

- The impact this will have on the child and how they will feel about themselves
- The impact on relationships within the family of unequal genetic connections
- The lack of information about the donor—that there is nothing to tell

Other reasons for keeping the secret from the child include:

- Keeping the secret from the extended family and others; that is, pretending to be a family just like any other
- Ensuring the anonymity of donors out of respect for their privacy
- Ensuring the anonymity of donors to ensure a continuing supply of donors

Some of these justifications presuppose possible negative impacts from gamete donation (mainly for the parents and the child) to which secrecy is a solution. These negative impacts may be internal to the family or external. While some of these negative impacts may be misinformed, irrational or unwarranted, committing to secrecy validates and reinforces them.

Some of the reasons given for maintaining secrecy mirror those which undergirded the closed systems of adoption in the past. After extensively hearing the experiences of birth parents, adoptive parents and adopted persons, hardly anyone now supports secrecy in adoption—though legislative changes lag in certain states and countries. Nevertheless, practices of gamete donation allow these discredited practices to continue.

The position of DI offspring is unique. (At some point, AID became DI. Perhaps it sounds more comfortable if you lose the 'artificial', but both are misnomers: sperm is sold, not donated.) The nearest comparable group is adoptees. But the adopted child is almost certain to know that they are adopted and if their adoptive parents do not tell them, their birth certificate will.

The birth certificate of a DI child, however, yields no clue about their origins: it is a statutorily sanctioned fraud. If an adoptee wishes to try to trace their birth parents, the law supports them and public agencies

will help them. If DI offspring express the same wish, they can expect to meet reactions all the way from helpless sympathy to open hostility.

David Gollancz, DI Offspring from the UK.

In the UK, twenty years ago, Mary Warnock chaired an inquiry into human fertility and reproduction which led to the regulation of fertility clinics. In her report, she expressed the fear that removing the anonymity of donors would lead to the number of donors drying up—a view still widely promoted by some fertility services. She has since changed her mind. She has recognised that not only is there no evidence of a lack of donors, but also that, 'We are much more sensitive now to the idea of genetic inheritance' (*Guardian*, May 14, 2002). She now thinks that donors should be able to be identified by their biological children.

I am convinced that the law could be changed, so that children born with the help of donors would be able to have identifying information about the donor. This would mean that necessarily they would know that they were born with the help of a donor.... The more we know about genes, the more we may crave to know about our genetic parents. It is undermining to any relationship between two people if one knows a salient fact about the other which is not divulged...

If [the child] accidentally discovers the truth, he [sic] may feel diminished.

Mary Warnock, *Making Babies*, p. 66

Some further reasons for telling children that they were born as a result of gamete donation include:

- The child has a right to know
- The child may guess that something is 'different' about themselves
- Someone else may inadvertently or maliciously tell the child
- Keeping the secret will require constant vigilance and possible stress
- Keeping the secret will create stress for the extended family
- If and when the child finds out, they might resent not being told
- Those who have told their children find that their fears have not been borne out
- Donor offspring appreciate being told about their origins
- There may be important medical reasons for allowing offspring to trace their genetic fathers (or mothers)
- Keeping the secret means one must lie to one's child and others

The reasons for openness mainly focus on the needs and interests of the child. The benefits of openness for children can be seen from the literature on adoption. However, openness benefits parents in significant ways. A child vests trust in its caretakers as an emotional inoculation against existential anxieties. When that formative process is overlaid and interwoven with unresolved pain, resentment, anger, loss or secrecy, the individual can become caught in an unresolved web of tension. Keeping secrets is stressful; for example:

- secrets need to be constantly managed
- otherwise innocent inquiries about origins or family connections become emotionally loaded, or
- the child picks up anxieties surrounding birthdays or family occasions
- the use of genetic information in medicine increases the likelihood of a secret being exposed

Being told by authority figures that one must effectively lie to one's children and others can be a substantial challenge to one's character. As one DI mother (in Stevens), put it: 'That is not the kind of person one was brought up to be.'

According to NHMRC proposed guidelines, 'any persons born from the program are entitled to know their genetic parents and siblings and that they [parents] should therefore tell their children about their origins'. No mechanisms are provided, however, to ensure that donor offspring are given that information. Without stronger measures it is unclear whether the number of couples who, in practice, opt for secrecy will change.

Loss

We will....need to exercise care that in seeking to meet the needs of one neighbour in this particular issue of I.V.F. (donor), we do not act without love towards others who are involved.

IVF using donor gametes - the case "for"

For couples

Examining the grief experienced by infertile couples, Australian theologian Andrew Dutney (2001) describes infertility as a 'hopeful space come to nothing'. It is a space of 'banished hope, of eternal loss and perpetual separation'. For many infertile couples the 'experience of infertility commonly includes the loss of life's sequence and structure' causing one to 'to lose confidence in life's orderliness and reliability'.

Adoptive parents also experience this loss of life sequence. However, adoptive parents share the experience of loss and the experience of raising children to whom they are not biologically connected. Parents of donor offspring experience this loss of connection differently. One parent is biologically connected to their child while the other parent adds a loss of this connection to their loss of fertility. Some fathers express feelings of alienation from the rest of their family.

Until recently, few DI parents considered that through filling their 'hopeful space' using donor conception they may have created empty spaces for their children.

For offspring

The wealth of experiences generated from adopted persons and the growing voices of donor offspring give us insights into a range of intergenerational consequences arising out of the pain of infertility. In a culture of secrecy, donor offspring can also experience a loss of life's sequence and structure and a loss of confidence in life's orderliness and reliability.

What level of loss are [we] prepared to place upon ...future generations, so that this generation may have children? The baton of pain is intergenerational.

Jo Rose , Exploring the Caves

The incidence of adopted persons expressing feelings of loss of confidence, orderliness and reliability is well documented. The primary reason given by adopted persons for initiating a process of search and contact is to 'fill in the hole, replace the missing piece, or in some way change their experience in the direction of increased cohesiveness and identity' (Rubin, 1983). Donor offspring are expressing the same need for putting the pieces of the puzzle together. However, they see their fate as fundamentally different from those children whose lack of connection is

the result of tragedy or an unintended consequence of human fallibility. They express frustration that their loss has been the result of a deliberate manipulation of the truth and a premeditated and systemically sanctioned 'treatment' which is effectively an anonymous, contractual arrangement denying them the right to connect with those to whom they are biologically related.

For donors

A sense of loss for donors is perhaps one of the least understood aspects of gamete donation. The possibility of loss is masked by the fact that all donors seemingly made an autonomous and informed decision to participate in the program and they felt that they were helping the community. In recent times, donors have been young and, usually, university students donating regularly in return for payment.

Most of these younger donors experience little to no sense of loss at the time of their donation. Some, however, understand the significance of their donation differently when they create families of their own. A donor can start thinking about the number of offspring he may have fathered who are half-siblings to his own children. Only then might he start to feel a sense of loss, concern and responsibility for their welfare. How would his children feel if they knew? How would parents, siblings and other relations feel about being denied knowledge of these other offspring? The sheer number of possible offspring may weigh against what is humanly possible in terms of contact and responsibility, restricting his freedom and readiness to choose a course of action.

The parent-child relationships awaken in ex-donors a sense of regret, concern, and fear for those other children whom they fathered without any recognition of their fatherhood. Many of them see the person in that period of their lives as irresponsible and immoral.

Annette Baran and Reuben Pannor, *Lethal Secrets*, p. 98

If a donor fails to find a partner with whom to start his own family, has a partner who suffers from infertility problems, or later has problems with fertility himself, a donor may feel a deeper sense of loss for the children who are unknown to him.

One male donor who has not had a family of his own recounts that his mother prays every night for the grandchildren whom she will never meet.

Jo Rose, *Exploring the Caves*

At this point in time, The experiences of egg donors have not been as extensively considered. We might surmise similar emotional effects. However, a situation arising in the UK is instructive. The Human Fertility and Embryology Authority considered banning egg sharing (where a women donates her eggs to another in return for IVF treatment at a reduced cost) after one of the women involved got pregnant and the other did not (*Guardian*, 26 July 1999).

Personhood

The 'self' is defined by where each person speaks from. From her place in the family tree, her place in social space, in the geography of social statuses and functions, in intimate relations with loved ones, and in the space of moral and spiritual orientation within which most important defining relations are lived out. The 'self' knows where it is by recognising landmarks and the way in which it has travelled through them. Every individual lives in a world that depends on the creation of a secure sense of self in order to operate effectively and make complex decisions. One of the most important roles of the family structure is to nurture secure identity formation for the children growing within it (Ryburn, 1994; Snowden, 1998).

For some, the significance of loss in the donor offspring experience is hard to grasp. After all, an infertile and unhappy couple has become a thriving family. How can an offspring feel loss? They are brought into existence by the love of a couple for each other and the altruistic donation of a stranger. They are nurtured in a loving family. Without that donation they would not exist. Can they truly regret their existence? Donors will have opportunities to create their own families if they wish and have only given over what they have in excess and which would have otherwise been wasted. Isn't everyone a winner?

If we see persons as isolated egos, perhaps, but not if we have a richer understanding of the nature of persons. Our sense of self, of who we are, can be said to have both narrative and relational elements. We all have a narrative sense of self. Questions about personal identity can sometimes

by explained by 'show and tell'. We get out the photo album and recount the 'story so far'; in particular, the significant events which have shaped us, our beliefs and attitudes. Pictures of our parents, grandparents, aunts and uncles link us to the past and present. The genealogically-minded map out complex family-trees (or 'orchards' even) showing who we are as parts of a rich and complex story through time. Significant parts of this story are lost to donor offspring.

Another important dimension of personal identity is our social sense of self; that is, our sense of self as securely situated in a web of social relationships—family, school, religious and professional. We relate to each other through a process of reciprocal self-awareness. As selves, we relate to other selves. These others are like me. That is one of the reasons why family life is so important. A 'self' can never be described without reference to those other 'selves' who surround it. This means that in order to have a sense of who we are we must have a coherent narrative, a notion of how we have become who we are and of where we are going (Taylor, 1989). Individual self-understanding is inextricably bound up with our understanding of the meaning of the world, our place within it and our relationships with myriad others, but particularly significant others—relationships that must be based on trust (Horton, 1998). Appreciation of this social dimension of identity is what is missing in contemporary donor conception practice and understanding.

And for those of you who feel that a healthy family relationship can be built around a foundation of deliberate lies, I would wonder what fantasy land you have been living in.

DI Adult Rubin, in Rowland 1992, p 193

The security which comes from knowing where one fits into a network of social relationships is replaced by an atmosphere of insecurity and anxiety whenever questions are raised about one's relatives. Secrecy leaves the source of these anxieties unknown to the offspring, and possibly other members of the extended family as well.

Given an atmosphere of openness and truthfulness, it is likely that families created by donation can create new stories and new sets of social relationships that mutually address the needs of all those involved. How much an individual's narrative and social sense of self can be re-shaped is, at this stage, an unknown question. Some would say this makes DI families something of a social experiment, and no one ought to be forced grow up as

a guinea pig in a social experiment. Nevertheless, we do know from the adoption experience that the problems that come with growing up in families we are not biological related to are not insurmountable. But the virtues of honour, respect, love and joy which allow such families to flourish require honesty and openness.

People can experience narrative disruption for many reasons—illness, job loss, accident, tragedy, financial loss, and marital breakdown. Severe ongoing trauma results for some individuals, whilst others remake and refashion their stories and relationships with considerable success. We don't really know enough about this for us to be able to 'bottle' and sell solutions. Yet, arguably, one key to successful re-storying seems to be the amount of control one has over one's own story. The less power an individual has over their story, and the more it is controlled by powerful others the more likely it is that they will experience negative impacts on their well-being—hopelessness, apathy, self-destructiveness, and a loss of self-esteem.

The major issue in so far as the child is concerned is the quality of the family life into which he or she enters - the relationships which are established and maintained between all of the members of that family. If sufficient care is exercised to try to ensure that these really are loving relationships, the child's identity will be assured.

In vitro fertilisation using donor gametes - the case "for"

Accepting what advocates of gamete donation say about the importance of the quality of relationships to the health of the child, it is not hard to see that while honesty and openness may test those relationships, secrecy can only undermine them.

The very desire to maintain a narrative of family and connection which drives couples to seek out gamete donation also affects the personhood of donors and offspring. The desire to piece the jigsaw together and to connect is strong, even though it may not be uniform or universal. The level of emotional involvement in seeking to redress these lost stories and connections will vary with an individual's current age, circumstances and needs. If acted upon it will be a powerful expression of both personal autonomy and negotiated responsibility—best understood not as a moral dilemma, but a moral opportunity.

Confusing identities

For couples

For the majority of couples bearing children is the expected outcome of a permanent relationship. This is both biologically and culturally determined. The biological loss felt by a couple is compounded by society's expectations about family creation. It is not difficult to understand and identify with a couple who find that they have fertility problems. The infertile partner feels the pain of being unable to fulfil a function that has previously been taken for granted, or even prudently and responsibly guarded against. This personal biological loss may be compounded by guilt over a failure to provide offspring in the relationship. The fertile partner in the relationship may feel anger resentment and powerlessness at being denied the ability to procreate because of their partner's infertility.

Perhaps the couple have been through all that IVF has to offer and now find themselves drawn to the option of either sperm or egg donation. In the case of sperm donation, the male partner may regard this option as only fair - why should his partner be 'punished' for his failure to procreate? It would at least allow her the opportunity to physically bear her own children. He may feel that being a social father is better than not being a father at all. Within a culture of secrecy no one need ever know how the family was created. Unfortunately, he may also feel a strong sense of loss at the intrusion of a third party into his relationship with his partner. This third party is unknown but is always physically present in the child. His potential sense of loss and alienation in this scenario is often hidden or ignored. The father of David Gollancz, a UK donor offspring, describes how he both emotionally and literally used to find himself walking three steps behind his wife and children (in Stevens).

When their situation is no longer a secret they must deal with the fact that their child has two fathers. Sometimes they take on a new public identity, that of the so-called 'social father.' Or they may hear people thoughtlessly refer to their child's biological father as their 'real father'.

We can expect the experience of mothers who receive donated eggs to be somewhat different, as pregnancy gives them an opportunity to have a biological, if not genetic, connection with their child.

For donor offspring

Donor offspring are not individuals existing in the vacuum of a nuclear family. They are children, grandchildren, nieces, nephews, aunts, uncles, and cousins to large numbers of people through both their family of upbringing and their unknown biological father. Donor offspring are also *not* biologically connected to a large number of people whom they already know and who in turn may or may not know that they are donor offspring.

We are interdependent beings—not just independent beings with choices. The creation of a life (a personal life) can't be just contained in married relationships. Other relationships are involved as well as the quality of those relationships.

Dr Jayne Clapton, committee member

Not surprisingly, one of the issues confronting donor offspring who know of their status is genetic bewilderment. Knowledge of half their genetic identity is unknown and, often, unknowable. Increasingly, genetic identity is becoming a routine key to medical diagnosis and treatment. Without knowledge of genetic origins donor offspring will be at a disadvantage. Most people take for granted that they look like others in their family or extended family and thus make some sense of their body-selves. Donor offspring, however, have a blank space for one-half of their mirror-self. It an experienced shared with adopted persons.

While friends, other family members and, it seems, society at large takes for granted the point that most family members 'look like one another' to greater or lesser extents, adopted persons often feel conspicuously excluded from such tangible evidence of familial affiliations and belonging.

Jon Telfer, 2000, p. 2

According to Barry Stevens (himself a donor offspring), life is like a great novel with several critical chapters missing. Thus, donor offspring are unable to understand or have control over their own story. As each individual grows they look to the people around them for information about

who they are. They do this through verbal interaction with their parents and extended family and friends. They also take non-verbal cues through the interaction of adults around them and through constantly seeking reassurance about their physical selves from those who look most like them. For donor offspring these important identity landmarks are either missing or replaced by false ones. False assumptions about biological connectedness to one parent are borne by the offspring and communicated to family, relations and even health professionals.

The possibilities for identity confusion are likely to be more critical for offspring of egg donation. Currently, in Queensland, egg donations are altruistic donations from near relatives. Indeed, there is some feeling in the community that such altruistic donations from a close relative are more desirable than anonymous donation. Perhaps, this again underlines the high value put on genetic connection even by prospective recipients. While using gametes from near relatives does preserve some genetic connection to an infertile partner, it would seem that, in a climate of openness and honesty, this approach *prima facie* has the potential to further confuse the offspring's social sense of self. Internationally, near relatives who have donated eggs include sisters, mothers and grandmothers.

For donors

Identity confusion for donors arises when they create their own families, and they discover the significance of biological connectedness. Rather than donating tissue, they may come to understand that they have relinquished a biological connection.

The donor is the biological parent of a child but, through a contractual obligation, usually has little or no contact with the child. Anonymity becomes a more or less permanent feature of their identity, sometimes making it difficult, if not impossible, to be completely honest, even with significant others. While reconnecting with one or several offspring may be manageable and certainly has parallels with the experiences of birth parents elsewhere (in adoption, for example), there are no models for making sense of how one ought to relate to potentially three or four hundred offspring and what one's responsibilities in such a situation ought to look like. What if in the future the child needs life-saving medical treatment, or subsequent hereditary medical conditions are discovered by the donor later in life?

Still others are concerned that they must admit to themselves and to others that, rather than being altruistic donors, they did it out of self-interest, for the money.

Commodification

An important source of identity confusion for donor offspring surrounds the process of conception itself. It is clear that some individuals experience feelings of being a product rather than a person.

I got my barcode because I thought I was the product of technology...because I've been bought and sold.

Paul, a DI Offspring, describing his tattoo, in Rose, *Exploring the Caves*

While donor insemination has historically been a low-tech procedure, the capacity to store frozen sperm and eggs and the necessity to screen them in a post-AIDS world, has led to increasing commercialisation. Egg donation also requires high-tech treatment to harvest, fertilise in vitro, and implant in a recipient. Concerns have been expressed about the commodification of human fertility and how this impacts upon offspring. Procreative industries can take on the same characteristics as other industries, and economic factors may distort fertility practices and affect equitable access to services. The intersection of power and privilege tends to be reproduced in institutional practices.

- Who benefits from procreative industries and who loses?
- Why is the concept of 'donation' so important?
- What is the relative power and powerlessness of donors, recipients and professionals?
- Does the child see itself as a product of a procedure or transaction?
- What is the psychological impact of the labelling of these techniques as 'artificial'?

Donors and recipients are able to make choices regarding their participation in gamete donation. Indeed, the concept of 'donation' itself attempts to downplay the fact that a transaction takes place. Central to this transaction is not the provision of services, but the transfer of

gamete material capable of creating an individual life. The donor is given compensation for the inconvenience they are put through, and in the USA values range from \$50 for a sperm donation to \$7,000 for an egg donation. (Egg donation also carries more risks due to the use of medication and invasive procedures.) Proposed AHEC guidelines stipulate that any compensation should never be at a level that would form an inducement. It could be argued, however, that any level of compensation could form an inducement depending on the donor's circumstances. For this reason, many services will use only altruistic donors.

To avoid the connotation that the transaction has anything to do with selling children, the donated material is disengaged from its connection with an individual life. It is always seen as merely a component or human tissue. De-personalisation allows the transaction to occur, but it remains as a residual feature in the identities and relationships formed from it.

This subtext of commodification is interpreted in different ways by the donors themselves.

In adoption you are dealing with a baby. In DI, I see the sperm and eggs as components in baby-making, like the wheels are components of a car. Giving up sperm is not like giving up a baby.

Donor-conceived adult William, 18yrs in
Guardian Unlimited Observer(2002)

For DI offspring, feelings of commodification are exacerbated by the knowledge of how they were created. They know that they were deliberately created by an unknown male masturbating into a tube, that this male was contracted to have no concern about the individuals created by relinquishing his genetic material, and that this practice was deliberately encouraged in order to provide children for infertile couples. This has led some donor offspring to liken themselves to commodities exchanged in the market place.

The offspring is the commodity.... The mother is the master, the child is the servant and the husband only the window dressing.

Anne, a DI offspring in Rose, *Exploring the Caves*

Offspring self-esteem can also be seriously affected by the knowledge that they may have hundreds of half-siblings each, the result of using the same donor for hundreds of inseminations. This undermines all claims to their being 'special', 'wanted' or 'unique'. The fact that any desire to establish contact with their biological father has been thwarted by a contractual arrangement does nothing to lessen the sense of commodification.

Sadly, treating children like objects is a feature of many types of families and is not restricted to families created DI or IVF practices. Usually, we assign responsibility for such callousness squarely on the parents. Unfortunately, whatever parents intentions are, they can find themselves caught up in the justificatory rhetoric of gamete donation practices, with its concern about the 'supply' of donors, 'compensation' and the need to 'advertise' for donors.

It's...seen as purely a medical therapy...they're given doses, dosages of sperm as if this was a drug, it's not a drug, it's the essence of somebody.

Bill Cordray, *Who Am I?* ABC 4 Corners (Video)

Forgetting the children - unheard voices

Studies into genetic continuity in physical traits and characteristics have been helpful in understanding the bewilderment experiences of adopted persons and the stolen generations. In the case of donor-conceived adults the intentionality involved with the loss is reported to be a compounding factor (Ruben 1983). Barrett (1997) writes that children conceived through gamete donation react in different ways to the lack of knowledge about their genetic heritage. Some have little interest; others want all the information and sometimes need help grieving when little information is available. Many offspring will experience all of these emotions throughout their lifespan.

A heightened sense of abandonment is noted by many DI offspring. Ariel (in Cordray, 2001) comments on the fact that her biological father (donor) had no intention of doing anything other than abandoning her before she was even conceived. She compares this to the stories of many birth parents in adoption whose heart-rending circumstances eventually broke their resolve to keep their child. The intentionality of such abandonment

appears to intensify this issue for the offspring as, according to Glazer (1999), 'adults had a choice and chose to separate them from their heritages.' Fostering this lack of accountability in the name of compassion is simply confusing.

An alternative argument speculates that there should be fewer problems for donor offspring than for adopted persons because they have a biological connection, in the majority of cases, to one parent (Blyth, 1998). However, it seems that the majority also grow up erroneously believing that they are biologically related to both parents. Gaining sufficient insight into this area is problematic for a number of reasons; including, the dubious ethics of researching the fate of children who are ignorant of their origins; the impact such research would have on family dynamics; and whether the issue ought to be a matter of maths (statistics) or morality. Ought we not focus our responsibilities on those who claim to be suffering as a result of these practices, whatever their number?

I feel that in a way it's like abandonment, because [my biological father] has given 50% of him away, just as though I'm nothing...it's me, he's created a person out of this. It's not just nothing.

Priscilla, a donor offspring in Rose, *Exploring the Caves*

Some adult donor offspring experience feelings of being a product rather than a person.

In my mind.....Donor insemination is a big machine, somewhat like a conveyor belt for luggage at airports.....one at a time each couple goes forward and picks up a baby from the conveyer belt and leaves'. 'It's the mass production of human beings.

Geraldine - a donor offspring in Rose, *Exploring the Caves*,

Donor offspring Joanna Rose (2001) asserts that, 'It is perhaps not surprising that the sense of being a commodity is so strongly articulated when an individual is conceived by people with no specific interest or affection for each other, often mediated through a financial exchange.' The affection between the recipient mother and father can strongly counter such commodification, as it was a primary motivating factor in creating the family. However, should that couple later separate, the emotional effects are likely to be more problematic. In fact, the

separation of the parents is sometimes the occasion when children learn of their donor offspring status.

Power/Control

At the heart of gamete donation practices are imbalances of power between professional and patients. While this imbalance is a part of all professional relationships, it is heightened in the context of the emotional roller-coaster that the experience of IVF treatment is for many couples. Traditionally, this imbalance of power is addressed by giving decision-making power to the patient.

Many couples facing decisions with respect to gamete donation have experienced considerable financial and health disadvantages through participating unsuccessfully in IVF programs. Some professionals interviewed by the Committee argued that gamete donation should be offered as the next option for infertile couples, 'when all other procedures to effect the reproduction of a child have failed or are inappropriate.' There is a danger, however, that the momentum of a culture of reproductive medicine may subvert patient decision-making. From the point of view of reproductive medicine, the techniques employed are similar, but couples may be better served by appreciating the qualitative differences between creating a family using one's own genetic materials and creating a family using the genetic materials of strangers. Arguably, decisions about gamete donation ought to be disengaged from their previous treatments. Counselling is universally recommended, but it should never be seen as only a prelude to an inevitable treatment. Couples must be given space to explore the implications of forming a family that is not genetically their own and the different psychological challenges that this entails. They must be exposed to a wide range of views, including not only other parents but also donors and offspring. While in the professional-client setting the choices will remain theirs, little will be gained by not exploring the fundamentally different set of responsibilities that might be entailed by choosing to use the genetic materials of either strangers or close relatives. The involvement of a wider range of professionals to assist couples at this point might lower the perception of any potential conflict of interest on the part of fertility professionals.

Regaining power over one's decision-making requires giving closer attention to the quality, context and kind of information one receives. All participants—parents, donors and professionals—could benefit from a moral 'space' where they sort through who they are, what and who they care about, and who and what they are willing to be responsible for. There also needs to be a temporal dimension to this 'space'. The medical profession often exits the process at conception or birth, but for the parents and offspring decisions affect them all their life.

That 'moral space' would be enriched by the participation of adult donor offspring. The position of donor offspring in this moral space is paradoxical. It may be argued that they owe their very existence to gamete donation procedures, and they should be grateful. Gratitude is certainly a virtue; however, it is only so when freely given. Demanding a sense of gratitude, however, would be dis-empowering. Moreover, having opened the door to reactive attitudes which underpin our moral obligations (such as gratitude), we would not then be entitled to factor out the expression of others such as, for example, regret. While a donor offspring's interests may be predicated upon their existence, and thus the mode of their conception, they may still express their regrets about the way in which it was done, particularly if it has resulted in the kinds of confusions and losses outlined above. Perhaps, this suggests that the establishment of relationships with adult donor offspring may be as important as counselling would be for charting the responsibilities which any decision to use gamete donation might entail.

Infertility - charting responsibilities

From the preceding discussion, it is clear that the ethical challenges of gamete donation are not exhausted by considering our responsibilities to infertile couples. There is a rich constellation of responsibilities to chart and navigate, responsibilities relating to not only intending parents, but also donors, offspring, extended families and professionals. Acknowledging this, we must return to the core issue: how ought we to respond compassionately to the grief and pain of infertile couples?

Male infertility is due to low sperm count or sperm that cannot swim or are abnormal in structure. Female infertility can be due to irregular menstruation, blocked fallopian tubes, fibroid tumours, endometriosis, or a misshapen uterus may prevent implantation of a fertilised ovum, and

secretions in the vagina a cervix may inactivate or immobilise sperm. Oocytes may fail to release a sperm-attracting biochemical. Sometimes medical tests can reveal no cause.

R. Lewis, *Human Genetics: Concepts and Applications*, p. 383

The current view, accepted in the practice of reproductive medicine, is that infertility is a disease which can in some circumstances be treated. The possibilities for treating fertility problems have greatly advanced with the introduction and development of in-vitro fertilisation techniques. However, while many of these conditions are now to a degree treatable, infertility has always had both biological and social dimensions. Physiologically, infertility is an individual problem, but an infertile marriage is a social problem; that is, infertility arises as an unintended consequence of a prior social commitment with psychological and moral dimensions of trust, loyalty and responsibility.

Gamete donation seems an easy way to maximise those social responsibilities, while working around physiological limitations. However, the fact that one member of the relationship is infertile and the other is not disrupts the foundation of reciprocity on which trust, loyalty and responsibility are negotiated; put simply, a lot more is being asked of one partner than the other. Also, as outlined above, expecting to see gamete donation as a simple extension of the trusts, loyalties and responsibilities negotiated by the couple themselves, would seem to entail a significant pre-meditated foreclosing of intergenerational responsibilities. If we are provisionally willing to accept that we have some responsibility to respond to the loss and pain experienced by couples with treatable infertility problems, ought we not also accept some responsibility for ensuring that we do not, in the process, create equivalent losses of the next generation?

There is another social dimension to infertility. The physiological causes of infertility are often age-related; therefore, current infertility rates are partly a consequence of life-style decisions to delay creating a family for a variety of social reasons. Social responsibility would entail a commitment to educate couples as early as possible to this dimension of the problem. The church is ideally situated to do this, through its marriage preparation programs.

The need for more and more reproductive technology because of increasing problems in having children starts at the wrong end. ... Instead of working

at the curative end, if we began with the preventative, ... [we] could put serious money into affordable high-quality childcare so that women who wanted them could have their babies younger. We need a society that promotes reproductive health rather than expensive technological fixes.

Hilary and Steven Rose, *Guardian*, July 3, 2003

For many couples and individuals, choosing not to create a family is a conscious choice, not an illness. We ought not to make family creation a means to an end. While it can lead to happiness, parenthood must be sought as an end in itself and not a means to another end. While family creation is integral to community well-being, there seems no reason for it to be mandated. It is here that the traditional concept of a 'vocation', a conscious choosing or acceptance of a role which contributes to the well-being of a community is worth recalling. Both creating a family and not creating a family can be responsible undertakings.

In the past, childlessness was viewed as social tragedy. There seems little to commend this view, either by current community standards or theologically. However, neither this fact, nor what has been said about vocation, should blind us to the fact that, for many, infertility remains a personal tragedy, not sought after, nor seen as a calling.

There is an expectation that married couples will have children, and the trauma of childlessness is very great for some. What should the church's response to this situation be - how does the church exercise love towards them? If there are procedures available which may give them the possibility of having children, is it the loving thing to do to encourage this?

IVF using donor gametes - the case "for"

Creating families and reproductive liberty

There is no doubt that reproductive medicine has restored to many couples choices that have previously been denied to them by biological limitation, and this is to be celebrated. However, as well as restoring choices, it has also created new ones. These same techniques allow us to exercise choice in new ways over areas of our lives which were not thought possible in the past. By removing physiological limitations from the equation, reproductive medicine not only corrects biological deficits, it gives us the capacity to

work around them to the extent that the technologies themselves challenge social mores about who is entitled to become a parent. Further impetus for change comes from other changing values; in particular, changing attitudes to marriage and families based on our experiences with a wide-range of current child-rearing practices: extended families, nuclear families, single-parent families, and so-called 'blended' families, to name but a few.

Note: The discussion of who ought to be considered for fertility treatment will be covered by a future discussion paper. Provisionally, we can claim, that the gamete donation issues raised here apply equally to married couples, de- facto couples and singles.

Proponents of so-called 'reproductive liberty', assert that in a liberal democracy there is a right to parent. The values of liberalism it is argued, entitle individuals and families to non-interference by the state in their reproductive choices (Robertson). The right to create a family at the time of one's own choosing and by the means of one's own choosing should only be limited by demonstrable harms. The state may involve itself in the protecting the interests of the child but not to any further extent than is applied to families in general.

The right to form a family is an important value. We can understand it as a strong limitation on the state to interfere with freedoms in the private sphere. However, to see it merely as an extension of our individual rights, rather than of our communal responsibilities, would seem to have unintended consequences when applied to a domain such as reproductive medicine, which is by its nature a social enterprise. Narrowing application of reproductive liberty to the choices of couples and individuals would also severely restrict the application of an avowedly universal principle to the narrow context of liberal societies. The right to family, as a universal right, is clearly meant to be exercised in a variety of cultural settings, and applied to a wide variety of families, rather than restricted to one particular individualised view of the family.

The concept of reproductive liberty defines the limits of the law, but not our moral responsibilities. Reproductive liberty only begs that question: are all forms of family creation socially responsible? It does not itself provide an answer to this question. The church accepts the responsibility of participating in a liberal society; its ethical stance strongly supports the idea that one takes into account whether one's actions potentially harm

others. It also takes seriously the communal dimensions of both faith and morality, seeking to negotiate responsibilities both in the present and, through respect for its traditions, across time. In terms of the values of Uniting HealthCare, concern for the whole person is balanced with the value of community.

6. Responding in faith

There is no doubt that family has played, and continues to play, a central role in Christian life. In the Jewish tradition, procreation was not only important to individual continuity but also to the perpetuation of the faith. Various practices such as concubinage seem remote from contemporary values, yet for a time were favourably viewed. Even in the Gospels, we find that Jesus portrays family allegiance as a potential stumbling-block to discipleship. Paul advocated a strong position regarding marriage and family, but did not participate himself. Far from suggesting that 'anything goes', this historical perspective confirms that Christian life is founded on faith in a living God, expressed in changing social and cultural contexts. The family is a fundamentally worldly setting in which both personal and social development occurs. (Consider our changed views on the role of women and domestic violence, for example.) There is no blue-print for family in the tradition, no stipulated form or narrative. Families are not formed by faith, rather they are informed by faith. Family is a setting in which faith is practiced and which can be transformed by which the grace and presence of God .

For individuals and couples, the desire to create a family becomes an intersecting point between personal and cultural expectations and the Christian story of faith. What responsibilities are to be negotiated at this crossroad?

Australian theologian Andrew Dutney, in his provocatively titled book, *Playing God: Ethics and Faith*, argues that the common understanding of the term 'playing God' as an accusation must be turned on its head.

Though we usually have in mind the biomedical heroes when we talk about playing God, it is in fact almost always ordinary people like you and me who are required to 'make the decision' that will determine our destinies and those for whom we might be responsible. The decisions are ours. The risks

are ours. The responsibility for the outcome is ours—like it or not. We are playing God because we must.

Andrew Dutney, *Playing God: Ethics and Faith*, p. 153

While advanced technologies solve many of our problems, they also help create a culture of risk, which requires us to take on new responsibilities. The automobile is a clear example. It has created new opportunities and benefits, but also new challenges to our health and safety. New technologies always bring such a mixture of benefit, risk and responsibility. It is through addressing our responsibilities that we go beyond technological determinism on the one hand, or nay-saying, doomsday thinking on the other.

Perhaps, these responsibilities are best negotiated by paying closer attention to the impact of our decisions on our relationships with each other and with God. When we ask, in its many sophisticated or unsophisticated ways, 'What would Jesus do?', are we looking for a word, or a teaching? Perhaps, we are also asking how will choosing one way or the other affect my ongoing relationship with God? Will that relationship be enriched or impoverished by my choices? How will my choices draw on and promote faith, hope and love?

Decision-making in the context of risk is a necessary part of reproductive responsibility. Dutney argues that we must remain open to the fundamental attitude of hospitality which informs our initial desire to create a family. In modern times, family creation is usually the outcome of a conscious decision. It is possible that such a decision may be over-managed, or be undertaken for dubious or selfish reasons. However, for most couples it is the expression of a basic moral impulse—to make room for an 'other'. A process of extending concern beyond the self begins. Individuals prepare to commit themselves—emotionally, economically, and socially—to caring for a child through concrete practices of hospitality: preparing and painting a room, taking lessons and reading books about birthing and baby care, and saving money to meet the babies needs. Couples are extending hospitality to another, drawing on Godly virtues of faith, hope and love. When the expected guest does not arrive, or looks like never arriving, it is devastating. As Dutney says, infertility is a 'hopeful space come to nothing'. That nothingness is a threat to our being, and our relationship to the ground of being—our God.

As couples seek alternative ways of extending godly hospitality, whether through reproductive technologies or adoption, that fundamental orientation to the other, to the expected child, should remain paramount. Reproductive responsibility should be child-centred, continuing to draw on the same resources of faith, hope and love which provided the primary motivation to parent. The devastating blow of infertility brings with it the danger of isolation, not only from those who have created families, but from other relationships which can nurture and sustain a couple in faith, hope and love. Ironically, at a time of great vulnerability, couples quickly find that alternative modes of conception are considerably less private than they expected.

When it comes to playing God with fertility, when it comes to medicalised contraception, conception and assisted reproductive technologies, the primary ethical issues are personal. But they are not personal in the privatised, individualistic way that we have come to think of personal things. They are personal in the social, political, communal way that real persons actually experience bodily life.

Andrew Dutney, *Playing God: Ethics and Faith*, p. 175

By their nature, problems with fertility are personal, private matters. However, it is important to never lose sight of the fundamentally social nature of families and the corresponding implied burden of social responsibility.

If gametes are to be regarded as being no more than raw material for the medical manufacture of children, a whole dimension of human reproduction is lost—in particular the network of kinship relations that provides the key to an understanding of society's culture and practices.

Apart from parents, then, children are linked to a wider kinship network of grandparents, siblings, cousins, aunts and others—a network of connections that constitutes the social space within which they find their original identities. To break the genetic link is to remove that important network of relationships.

Brenda Almond, *Exploring Ethics*, p. 142

7. Recommendations

Healthcare of the whole person in community

In recent decades, the health profession has declared that healthcare should address the needs of the whole person. The World Health Organisation in 1958 made its now well-known statement that 'Health is physical, emotional and social well-being, and not simply the absence of disease or infirmity.'

The Christian understanding the human person is of an indivisible unity of body mind and spirit. That understanding goes further to seeing each person not just in terms of their individual existence, but in terms of the rich context of relationships in which they live.

Of six 'foundational values' articulated by Uniting HealthCare, the first two are 'the whole person' and 'community'.

Healthcare according to such an understanding and value base, should seek the harmonious functioning of a unified person within a community of persons. It cannot therefore view an issue like IVF as simply the treatment of the physical limitation of infertility in isolation from consideration of the ongoing consequences for a resultant child, the parents, and indeed for a range of other people whose lives may be affected by this activity.

Ian Peers, Synod Bioethics Committee

Having attended to the voices of some of the stakeholders in gamete donation, how ought we to respond? Clearly, there are still significant concerns about the effects of both past and present gamete donation practices on donor offspring which need to be addressed. The following suggestions are put forward as a focus for discussion and comment.

Until recently, it seems clear that gamete donation practices have proceeded with little concern for their impact on the next generation and have responded only to the articulated needs of potential recipients. Given the reported continuing high rates of secrecy where gamete donation is

practiced and disclosure of donor identity is not required, it is not clear that current practices adequately inform potential recipients of these issues, or that leaving that decision entirely in the hands of the parents themselves is in the child's best interests.

Institutionally assisting socially irresponsible practice is of serious concern. Wherever people have sought to make gamete donation practices more ethical, by focusing on the interests of the child, it has led to significant curtailment in its scope and increased advocacy of openness. Whether an open system where genetic information is shared and the number of potential half-siblings is strictly limited will fully meet the needs of all participants is not clear. It is clear, however, that to encourage practices which do not prevent the possibility of secrets or the creation of hundreds of siblings is not in the best interests of the child. Wherever the interests of children require protection there is justification for regulation.

Unless there are fundamental changes in the way gamete donation is practised it is unlikely that it will meet the ethical concerns raised in this discussion paper. It is clear, therefore, that greater attention will need to be directed to addressing the needs of infertile couples through means other than reproductive intervention using donated gametes. Given that some of the causes of infertility are social, some of this support, counselling and information should be provided to couples as they enter into permanent relationships.

The ethical concerns raised above may be summarised as follows:

- The creation of a family by gamete donation is qualitatively different from creating a family by other reproductive techniques. As such, it should not be offered as the next step on a continuum of reproductive services. Couples will be best served by being given space to thoroughly explore and understand the nature and implications of these differences and their possible emotional effects.
- Though legal, falsification of birth certificates does not meet the basic requirements of truthfulness.

- When combined with a culture of secrecy, falsifying a birth certificate clearly diminishes the ability of donor offspring to exercise their own informed choices about contacting individuals to whom they are biologically related.
- As well as not respecting their personal autonomy, secrecy can, in some circumstances, entail direct harms to offspring at a time when genetic information is routinely used to diagnose and treat illnesses.
- Secrecy undermines the trust essential to family life, isolates individuals within the family, and reduces opportunities to nurture faith, hope and love in core relationships.
- The contractual nature of arrangements which undergird current practice (for example, allowing secrecy and compensating donors) introduces elements of commodification which can negatively impact on the self-esteem of donor offspring. These arrangements also replace the covenantal nature of professional-client relationships with a market-like transaction.
- Restricting gamete donation to altruistic known donors is likely to exacerbate, rather than solve, issues of identity confusion experienced by many donor offspring. The culture of secrecy prevents wider research on these impacts.
- The church needs to form deeper, more nurturing connections with those experiencing the pain, loss and grief of infertility. Their experiences remind us that we are all at times vulnerable and dependent, and that although some suffering is unavoidable, we can share that suffering and seek to support each other in faith, hope and love.
- The church also needs to re-affirm its commitment to address all forms of avoidable suffering where to do so does not lead to harming others. This means that the church remains committed to using reproductive technologies appropriately to assist conception. It also means that the church must accept some responsibility for informing couples of the avoidable, social causes of infertility and opening a space for them to explore the significance of that for their lives.

These points are the Committee's summary of its inquiries to this point in time. They are not policies of the Uniting Church. The Committee welcomes feedback on the issues raised in this discussion paper from the general public, church members and those affected by gamete donation. A response form appears below.

Acknowledgements

Synod Bioethics Committee (Queensland)

Present Committee members: Rev. Marjorie Neil (Chair), Rev Ian Peers (Secretary) , Rev Dr Doug Brandon, Dr Jayne Clapton, Ms Michelle Cook, Mrs Lyndall Dial, Rev. Brian Gilbert, Rev. Ann Hewson, Rev. Helen Prior.

Past Committee Members who contributed: Dr Libby Dutney, Mrs Caroline Holmes, Rev Doug Jones, Rev Linda McWilliam, Mr James Matthews, Rev. Noel Park, Dr Eva Popper.

DISCUSSION PAPER - RESPONSE FORM

The Uniting Church Bioethics Committee (Qld) values your comments on this discussion paper.

1. Which sections of the paper do you see as most important?
2. Are there any sections of the paper which are not clear or need more explaining?
3. Are there any other factors which you believe should be considered by the report?
4. In the light of the paper, and the present UC policy (as on p. 7), what recommendation do you think the church should address regarding the use of donor gametes? (Note: The issues of access and eligibility for all IVF practices is the subject of another discussion paper).

Your details Name: Address: Phone: Email:	Please send your response to Rev. Marjorie Neil Chair, UC Synod Bioethics Committee GPO Box 674 Brisbane 4001
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(An expanded list of resources is available from the committee, upon request)