Royal College of Nursing

Fertility Preservation

Third edition

CLINICAL PROFESSIONAL RESOURCE

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British Fertility Society

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This document has been designed in collaboration with our members to ensure it meets most accessibility standards. However, if this does not fit your requirements, please contact corporate.communications@rcn.org.uk

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Notes

It is recognised that care may be provided by registered nurses and midwives, health care support workers, assistant practitioners, nursing associates and student nurses and midwives, and trainee nursing associates. For ease of reading, the generic terms 'nurse', 'nursing' and 'nurses' are used throughout this document, unless specified.

The RCN recognises and embraces our gender diverse society and encourages this guideline to be used by and/or applied to people who identify as non-binary, transgender or gender fluid.

The RCN also recognises that not all those born female, or male will identify with the same gender nouns, but for ease of reading use the term woman/man/men and where appropriate acknowledge nonbinary terms.

1. Introduction

Fertility preservation involves freezing and storing sperm or eggs (gametes), ovarian reproductive material or embryos for use in a person's future fertility treatment. Techniques for storing gametes and embryos are now well established and progress has also been made with the preservation of ovarian and testicular reproductive material.

It is important that registered nurses and nursing associates understand the reality of what is possible now, what may be available in the future, and to support people to manage fertility should they become infertile due to illness/treatment or through choice for non-medical (social) reasons.

This updated publication provides information for nurses who are supporting and caring for those beginning treatment for potentially life-limiting diseases and where the treatment may adversely affect their ability to have children in the future. This guidance also encompasses those who may wish, for non-medical reasons, to defer having children until later in life, for example members of the armed forces, transgender people, or those considering gender reassignment surgery. Counselling should be available as their needs may be very different, but nonetheless valid.

There are two distinct areas for increasing knowledge and understanding among nurses:

- option 1 – those who require more general information to refer for specialist care
- option 2 – nurses working in fertility services who have roles in fertility preservation.

Nurses working in oncology and haematology, gynaecology, children and young people's services, where medical treatment may affect future fertility, and those working in general practice, are all best placed to provide information about the availability of fertility preservation prior to surgery and/or treatment such as chemotherapy or radiotherapy. These conversations should take account of individual circumstances and include:

- the likely effects of the specific treatment on fertility
- prognosis
- the medical fitness of the patient to engage in the process of fertility preservation
- fertility preservation options (such as freezing sperm, eggs, ovarian reproductive material or embryos).

In addition, nurses need to be aware of the availability of services locally, as well as funding options. All information should be provided in a timely, informed and supportive manner. Any discussions should also include the possibility of posthumous use of stored gametes or embryos.

Key points to consider

- What is fertility preservation and what are the options?
- Documentation of discussions.
- Who are the local contacts?
- What is available locally (NHS/independent sector).
- Who will provide an initial referral?
- Who will provide counselling?
- Who will obtain consent?

In the light of evidence from the National Institute for Health and Care Excellence guideline (NICE, 2017), there is an increasing awareness of the lack of a consistent approach to fertility preservation. This RCN document provides information for nurses and health care professionals engaged with anyone who may have their fertility compromised due to illness or treatment, or who may choose to defer fertility for non-medical reasons.

An inconsistent approach to the commissioning also needs to be acknowledged including funding of fertility services generally and, subsequently, those services focused on preservation of fertility. It is important to consider the nurse's role in developing services, as well as having an understanding of the funding sources and routes available for individual patients.

Generally, funding for fertility preservation following a diagnosis of cancer is provided by commissioners across the UK. Funding for non-cancer conditions is variable, as is funding for duration of storage.

Note for the reader

The term patient is used generically throughout this publication to include men, women, children and young people, and people who consider themselves as non-gender specific.

This publication also acknowledges that regardless of sexuality or sexual orientation, fertility preservation is important for all those who consider themselves heterosexual, gay, lesbian, bisexual or transgender.

An understanding of male and female reproductive anatomy and a comprehension of the physiology involved in reproductive processes is assumed and recommended to enhance the overall understanding of the complexities of preserving fertility.

This document relates to children and young people from birth until their 18th birthday.

"We use the term 'children' to refer to younger children who do not have the maturity and understanding to make important decisions for themselves. We use the term 'young people' to refer to older or more experienced children who are more likely to be able to make these decisions for themselves." (GMC, 2024)

The term 'parents' mean people with parental responsibility and other people who care for or look after children or young people. This might include other family members or adults who live in the same household. "A 'person with parental responsibility' means someone with the rights and responsibilities that parents have in law for their child, including the right to consent to medical treatment for them, up to the age of 18 years in England, Wales and Northern Ireland, and up to 16 years in Scotland."

If there is any doubt about legal parental responsibility, legal advice should be sought.

(Further details are available from the GMC (2024)).

2. Background

Legal and regulation issues

Storage and the use of gametes and embryos falls under the regulatory remit of the Human Fertilisation and Embryology Authority (HFEA), which also provides information about HFEA licensed fertility centres across the UK. The main legislation around fertility preservation is:

- the Human Fertilisation and Embryology Act 1990 (amended) (HFE Act)
- the Human Tissue Act 2004, which includes reference to the use and storage of ovarian and testicular reproductive material.

Storage within NHS units is often time and funding limited. This may need to be clarified for those looking for long-term storage. The patient needs to have sufficient time to consider the implications and provide informed consent before storage and use; this is governed and detailed within the HFEA Code of Practice (HFEA, 2023). However, in emergency situations, where aggressive chemotherapy regimens need to be implemented immediately, patients can consent to storage only and reconsider use once treatment has ended.

It is important to be aware that the retrieval and storage of gametes without consent might be considered an assault, therefore, gametes should not be retrieved from a deceased person unless they have provided consent. There are very limited circumstances where storage may be lawful without consent. The updated HFEA Code of Practice (HFEA, 2023) provides further clarity about this issue. In complex circumstances, advice should be sought from the HFEA on a case-by-case basis.

Non-fertility and fertility settings

There are two distinct groups of nurses involved in supporting fertility preservation (see Appendix 1 for an outline of the recommended process).

Option 1 activity: those who require more general information to refer for specialist care. It is important that nurses who are not working in fertility services feel confident to raise the issue about fertility preservation with patients (or the parents of children) faced with potentially life-limiting diagnoses. Those engaged in such conversations need to understand local pathways and liaise with local specialist services. It is critically important to ensure prompt, appropriate referral to fertility services, preferably at initial diagnosis, to maximise future opportunities. Always check whether a woman may be pregnant already.

Nurses working in non-fertility settings should consider:

- information – what is available locally and nationally (see information on page 7)
- counselling – this must be provided by specialist fertility counsellors who have detailed knowledge and understanding of the contemporary issues in fertility preservation. However, nurses working in non-fertility specialist areas should be able to discuss the information outlined below
- consent – this must be fully informed and meet statutory requirements (HFE Act, 1990) and carried out by those who have been appropriately trained.

Information and action on local fertility services should include:

- locality
- unit or service co-ordinator
- hours of working/where to get support out of hours
- contact names/numbers/emails
- referral process (including emergency and out-of-hours situations)
- cost implications (for example, there may be NHS funding for storage but not for future use of gametes in fertility treatment)
- legal/regulatory requirements
- ensuring fertility is a key issue in the care pathway for all patients whose fertility may be affected
- developing a clear electronic referral system that covers:
  - individual identification, including demographics/social details
  - prognosis and treatment plan (including dates of planned chemo/radiotherapy)
  - the patient's understanding of diagnosis and prognosis
  - the patient's current health, including screening for HIV, hepatitis B and C (HFEA requirement for gamete and embryo storage)
  - a patient's expectations when they are referred and, importantly, the opportunity for fertility counselling (including family members if required)
  - consent to referral, including data sharing.

Option 2 activity: nurses working in specific roles within fertility services

This option refers to those working in fertility services and requires a more complex approach to clinical practice, the commissioning of services and an awareness of local services that will best support an individual's needs.

Patients undergoing treatment, including chemotherapy and radiotherapy, may be at risk of having diminished fertility or may become infertile. Sexual dysfunction for both men and women is a common side effect of some cancer treatments and can be a mechanical cause of infertility. With early intervention, the outcomes (including preservation of sexual function) can be improved. Therefore, it is important to discuss options as early as possible. Patients may have a better opportunity of preserving their gametes if they are referred promptly.

Best practice for referral

- A dedicated expert fertility preservation team (consultant, fertility nurse specialist, counsellor and administrative support).
- Established electronic referral system with a clear referral pathway.
- Flexibility of appointment dates/times.
- Dedicated time and privacy for counselling and communication with patients.
- Access to an independent counsellor (eg, British Infertility Counselling Association (BICA), or a counsellor employed at an HFEA licensed fertility centre).
- Established close working relationship between the referring health care professional/ specialist nurse and the fertility service provider.

From a service-wide perspective this should include:

- collaboration in the development of written patient information, for example, local and national guidelines
- an audit to assess the quality of the service being provided
- regular updates and liaison with those in non-fertility specialty roles
- ensuring non-fertility specialist areas have current operating procedures.

Key issues to consider for those seeking fertility preservation for non-medical reasons

- Counselling is required to ensure informed choice.
- Informed decision making and consent.
- Physically more demanding for women than men and this may influence decision, as the process to collect oocytes (eggs) is more demanding than the collection of sperm in most cases.
- An understanding of the limits of storage.
- The challenges and reality of fertility treatment in particular understanding what is possible within current technology and the possibility of having a baby after treatment.
- Timeframes for treatment and/or storage.
- Cost implications, especially for those seeking fertility preservation for non-medical reasons who will be required to pay. Payment will also be required for the process of preservation and storage. Within current legislation, these individuals can store gametes for up to 55 years providing they re consent every 10 years. This law was updated in July 2022 as previously the limit was restricted to 10 years unless the patient has become, or is likely to become, prematurely infertile, for example, gender reassignment surgery.

3. Information, counselling and informed consent

The importance of accurate and contemporary information for patients undergoing treatment for cancer or a life-limiting illness affecting their fertility, cannot be underestimated. Timely and honest conversations are required at a very difficult time. Services may be provided by the NHS or the independent sector, and will vary across the country. Local knowledge will be an important part of being well prepared to support patients.

It is equally important to consider a range of issues when discussing preservation of fertility with anyone who is considering preservation of their gametes for non-medical reasons. Individual needs will inevitably direct counselling sessions. However, the following points should be helpful for nurses, medical teams and counsellors.

Areas to consider when contemplating fertility preservation

- Inform patient (and the family) of diagnosis, prognosis and individual risk.
- Determine an individual's risk. Factors to include cancer type, prognosis, age and treatment plan.
- Provide risk factor of infertility, with first line treatments and also consider potential for second line (eg, radiotherapy) treatments.
- Current fertility status (existing child/children, reproductive plans prior to diagnosis). Consider, for example, who takes an adolescent male to the clinic for sperm freezing (it may not be comfortable for the parents to do so or for him to have parents present).
- The possible health risks of undergoing fertility treatment.
- Some treatments can cause temporary or permanent infertility and, in women, early menopause.
- The emotional issues and requirement for sperm/egg collection at a time of crisis.
- Timing (for women) – is there enough time for the fertility treatment cycle to be completed before she commences treatment for her condition?
- In some cases, lifesaving treatments may be put on hold (if already pregnant or to allow the patient to conceive) and treatment resumed at a later stage. Fears for health and the hopes of having a baby need to be considered carefully.
- The realistic assisted reproduction options open to them in the future.
- The possibility that they (women) might not respond to fertility treatment and (for men) post-thaw samples may be inadequate.
- Thinking and planning for a future family at a time of uncertainty, including posthumous use.
- The reactions of those close to them, including partner, family and close friends.
- How relationships with family and friends influence their decision making.

- The fear of cancer recurrence after a child is born, and implications for the child/partner.
- The potential disposal of the stored gametes.
- It is essential that adolescent males are provided with preparation information in advance of their sperm banking appointment to ensure they are more comfortable and know what to expect (given that the sample is produced by way of masturbation). Current guidance is that adolescents should be able to decide who accompanies them.

When a person (of reproductive age/prepubescent children) is diagnosed with cancer or an illness that may impact on their ability to reproduce, it is essential to provide an opportunity to discuss fertility preservation. A full assessment in a dedicated fertility centre will be required to provide the patient with an accurate understanding of treatment options. There may also be cultural and/or religious issues to consider, therefore nurses require a sensitive approach to best understand specific individual needs.

The HFEA sets out the requirements that must be met before gametes can be stored. Both patients and nurses should understand the complexities involved (see **www.hfea.gov.uk**). There are specific consent requirements, outlined in the HFE Act (1990) (as amended) and the Human Fertilisation and Embryology (Statutory Storage Period for Gametes and Embryos) Regulations 2009. These relate to storage and use, including issues that may arise where posthumous use is a possibility for a surviving partner. In these circumstances, gametes cannot be stored without consent.

The law requires that the patient is given the opportunity to receive counselling before giving consent. There are many physical and psychological issues that will be raised at this difficult time and these should be explored with a specialist counsellor/psychologist who understands oncology/relevant medical condition and fertility preservation.

When a patient is considering fertility preservation, the partner/family may wish to be involved and it is important that they are given the opportunity to seek counselling and advice on options available. A specialist fertility counsellor can provide this and they can be contacted either through a fertility clinic or a specialist counselling organisation:

British Infertility Counselling Association **bica.net**

British Association of Counselling and Psychotherapy **bacp.co.uk**

When taking consent for storage, all scenarios (including posthumous use) should be discussed. Patients should also be provided with information about the maximum storage period for which they can consent.

Storage time limits

Counselling is required – to ensure informed choice.

- The statutory period which gametes can be stored for all fertility preservation has now been adjusted to 55 years (as of July 2022) providing the individual re-consents every 10 years. The clinic will inform the individual when they are nearing their 10-year mark.
- This change is intended to provide greater flexibility and options for individuals considering fertility preservation for social reasons as well as medical reasons.
- The consent to storage should remain separate from any contractual agreement (costed treatment plan) regarding costs between the patient and the clinic and future use of gametes/embryos.

The specialist counsellor (option 2 activity) requires a specialist knowledge so they can provide the high quality of care needed. This care should cover the following areas.

- A diagnosis of cancer will inevitably affect partners and immediate family members and they may experience a wide range of emotions. It is equally important to provide support and accurate information for the family, as the patient may find it difficult to communicate or share with them. Counselling may be provided within oncology/haematology services; there are also counselling organisations that provide specialist knowledge (eg, BICA or BACP).
- Where there is a high likelihood of death, the question of posthumous use should be explored; clinics and patients should seek medical opinion to comply with the 2009 Regulations (HFEA, 2009) which allow for extended storage beyond 10 years. This will ensure that the surviving spouse is able to use the gametes/embryos long after the death of the patient. Each case must be judged accordingly and it may not be appropriate to have this conversation with some patients.
- Consent to fertility treatment (including surrogacy), as appropriate.
- The cost implications of freezing of gametes should be clarified before considering fertility treatment.
- Further screening will be required if the gametes/embryos are to be used or donated (including in a surrogacy arrangement).

Decision making tool

This is a useful tool to enable decision making, and can be used as part of consultations and/or counselling sessions between health care professionals and patients.
cancerfertilityandme.org.uk

Principles for good quality consent

Consent is always a dynamic and interactive process, based on accurate contemporary understandable information. There should be structured meetings and should involve

a team to ensure a holistic approach to the decision making, and to ensure consent is achieved competently. This should not take place at the first meeting.

- For consent to be valid, it must be voluntary and informed, and the person consenting must have the capacity to make the decision. This means that the decision to either consent or not to consent to treatment must be made by the person themselves, and must not be influenced by nurses, friends or family. The person must be informed of what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments and what will happen if treatment is unsuccessful.
- For consent to be effective, the patient should have received counselling about the implications of the proposed steps. This should include being provided with relevant information on their particular personal and medical circumstances.
- Consent can only be provided by someone with capacity, which means they understand the information given to them and they can use it to make an informed decision. It is the responsibility of the health care professional gaining consent to establish whether or not the patient has capacity (GMC, 2024).
- They should always be informed of the right to vary and/or withdraw consent at any time.
- All such consent must be on a HFEA consent form.
- Nurses should be confident that they have given the information needed to make a considered decision and the essential elements of discussions should be documented in the medical record.

Further details can be found in the HFEA Code of Practice (2023).

Specific information to be declared within the consent includes:

- how long the reproductive material is stored for
- the person's wishes should they become unable to make decisions for themselves or die. This includes whether a partner can use the reproductive material later to create a family and whether the patient wishes to be recorded as the parent of any child born as a result of fertility treatment after death
- if the reproductive material is no longer required, could the tissue be used in research or donated for use in someone else's treatment (if posthumous consent is in place); this excludes those with a diagnosis of a cancer-related illness
- any other conditions the patient may have for the use of their reproductive material.

If no consent to future use is in place and cannot be sought (because the individual is deceased or has permanent mental incapacity), gametes should be allowed to perish. Invasive procedures for retrieving gametes are not covered by the HFE Act, but fall under common law.

The provisions of the Human Tissue Act 2004, which allows next of kin to provide consent to harvesting of other body tissue, do not apply to gametes. If no consent is in place then the gametes must not be procured, stored or used.

There are very limited situations where gametes can be stored without consent (Schedule 3 HFE Act 1990). These apply to people who do not have capacity, are expected to gain/

regain capacity and need medical treatment that is expected to affect their fertility, or are suffering from premature infertility (premature menopause). These provisions will apply to those children deemed not to be Gillick competent (for example, if parents object to storage for a young child), and those 16 years old and above who do not have capacity to consent (GMC, 2020; HFEA, 2023).

If a patient decides to go ahead with fertility preservation and create embryos with their partner, informed consent will be required from both parties. It is important that both partners independently understand the implications of the planned treatment. It is also important that both the patient and partner understand that either can withdraw consent at any time prior to the embryos being used in treatment. Withdrawal of consent must be in writing (using the HFEA withdrawal of consent form) and includes a 'cooling off period'.

The person who fills in the consent form must be the person giving consent, they should not be pre-completed by a health care professional. Only in limited circumstances, stipulated by the HFE Act, can someone else sign on the consenter's behalf. Patients should also be informed of the maximum period of time they can store for, irrespective of the length of time the NHS will fund storage or other contractual arrangements allow for.

Storage is primarily for a patient's own use, however they may also be stored for either research or as donated sperm, eggs or embryos for use by others, such as:

- couples seeking fertility treatment because of inherited disease (for example, haemophilia or Duchenne muscular dystrophy)
- incompatible blood types (for example, if the female partner is Rhesus (Rh) sensitised and the male partner is Rh positive)
- providing treatment for single women or female same sex couples
- surrogacy arrangements for male same sex couples.

Gametes from a person who has cancer would not normally be used in donation.

Informed consent: children and young people

Informed consent involving children and young people is more complex; the principles of ensuring the right information is delivered in a way that they can engage with and understand is particularly important. Children and young people should be included in discussions and consent about preservation of fertility. Age related information should be presented in an appropriate format. It is the specialist fertility team who will ultimately initiate the process and obtain consent. Other health care professionals may be involved, especially when confirming consent from a child or young person. These may include a nurse, counsellor/therapist, paediatric team, social worker, health visitor or school nurse.

Nurses caring for children should be familiar with the specific issues around gaining informed consent from a child/children and young people up to the age of 16, in particular that they meet the Fraser guidelines and Gillick competency criteria (GMC, 2020, HFEA, 2023). The Gillick competency assesses whether they have sufficient intelligence, competence and understanding to fully appreciate what is involved, and then their right to consent or refuse consent stands. The GMC (2020) and HFEA (2023) provide further details of consent with children and young people.

4. Male preservation of fertility

The most effective method of preserving a man's fertility is though sperm freezing (cryopreservation). This process involves the man providing samples of his semen, which are then frozen in liquid nitrogen and stored for future use in the process known as cryopreservation. This can be carried out from around 13 (around puberty). Legally, sperm can be stored for a person for up to 55 years or on a 10-year rolling basis.

Information, counselling and consent are critical elements to this process, and need to take account of individual physical, psychological and psycho-sexual needs, together with aspirations for later life. Easily understood written information, which takes account of language needs, should be available to help men make an informed decision. Semen samples can be discarded if reproductive function is restored/established after successful treatment, or they can be donated for research purposes.

Key considerations for sperm storage

- Counselling about potential sperm quality is important.
- The process involves masturbation and semen analysis. It should be noted that very young boys and unwell men may find masturbation and ejaculation difficult.
- If there is sexual dysfunction/impotence, electro-ejaculation may be required (can be carried out in a specialist fertility centre or a general clinical area with the involvement of a reproductive medicine specialist/andrologist). Surgically retrieved samples require immediate transfer to a HFEA licensed clinic for storage.
- There is a potentially higher risk of genetic damage to sperm following exposure to chemotherapy agents.
- The samples are then treated with a cryopreservation media; the specimen placed in vials or straws and suspended in liquid nitrogen (Levey and Gilbert, 2014).

Resource development in this area is increasing, as is comprehensive educational materials to facilitate discussions. These, alongside the appropriate use of information technology and social media, are all helping to enhance the quality of information available. This is also an area of increasing interest for research with new innovation ongoing (for example, researchers (University of Edinburgh, 2016) have reported freezing reproductive material from the reproductive organs of boys and girls with cancer, which can be reimplanted once they reach adulthood and want to start a family.

In 2020, Goossens et al., reported that more than 1,033 young patients (age three months to 18 years) had undergone testicular tissue retrieval and storage for fertility preservation.

5. Female preservation of fertility

The process of retrieving oocytes or eggs from a woman is more complex than sperm retrieval and involves a surgical procedure to remove eggs from the woman's ovaries.

Fertility preserving options for women

- Egg freezing or cryopreservation is when unfertilised eggs are 'vitrified' and stored. There have been successful cases of oocyte vitrification in adolescent females.
- Embryo freezing, also known as embryo cryopreservation – the most common and successful option for preserving a woman's fertility. Conventional slow freezing or vitrification can be applied.
- Ovarian transposition – a minor surgery to move the ovaries from the area that will receive radiation.
- Ovarian reproductive material freezing – an effective method of enabling a successful pregnancy in women who have had oncology treatment. It is also the only option for younger girls who have not commenced ovulating. However, this carries a risk of xenotransplantation (re-introduction of cancer cells).

Controlled ovarian stimulation and egg retrieval

In a natural menstrual cycle, only a single egg is generally produced, therefore the woman administers daily injections of follicle stimulating hormone over a period of 10-14 days (controlled ovarian stimulation) to stimulate the production of several eggs prior to removal/retrieval under ultrasound guidance.

The ovarian response to medication is monitored by ultrasound and, on occasion, serum estradiol assays. When a number of follicles have reached an appropriate size (≥18mm diameter), a final injection of Gonadotropin Releasing Hormone Agonist (GnRHa) is given to prevent ovarian hyperstimulation and to facilitate egg maturity. This helps the release of the egg from the capsular binding of the follicle 36-40 hours prior to timing of the egg retrieval. GnRH antagonist cycles with agonist triggers are now preferred to reduce the risk of Ovarian Hyper Stimulation Syndrome (OHSS) which is extremely important in fertility preservation.

Egg retrieval is usually carried out under conscious sedation or general anaesthetic. A needle guide is attached to a vaginal ultrasound probe and inserted into the vagina. Using the ultrasound, the ovaries are located, the needle advanced through the guide and the vaginal wall into ovarian reproductive material and each follicle. Gentle suction is applied to remove the follicular fluid and the egg within the follicle (The ESHRE Working Group on Ultrasound in ART, 2019).

After retrieval, the woman may experience some vaginal bleeding and abdominal cramping. As with any invasive procedure there are associated risks (less than 1:1000) such as bleeding, bowel or bladder perforation and risk of infection). The eggs will either be frozen later the same day or mixed with either her partner's sperm or sperm from a donor to achieve fertilisation. Any good quality embryos will be frozen for future use.

There is no 'upper limit' for freezing in the UK (this is at the discretion of the clinic). NHS centres usually have a cut off age of 45 years and requests are considered on a case-by-case basis.

ESHRE (2020) in their recent guidelines outlines four groups of women for possible fertility preservation:

- post-pubertal women diagnosed with cancer undergoing gonadotoxic treatments
- post-pubertal women with benign diseases undergoing gonadotoxic treatments (including surgery) or with conditions from which they will lose their fertility prematurely, eg, Turner syndrome
- transgender patients (assigned females at birth)
- women requesting oocyte cryopreservation for age-related fertility loss.

Anderson et al., (2017) reported on the value for some women of freezing part of an ovary before cancer treatment and other illnesses which might cause a reduction in fertility, reporting that 100 live births have occurred after replacing this ovarian tissue.

The recently published Nuffied report (2020) on egg freezing is clear that accurate data collection is critical so that women are given more accurate information about the chances of having a baby after egg freezing.

6. Considerations in the preservation of fertility in children and young people

Whilst certain medical treatments will affect fertility in the short term, others may have a longer-term effects or may prohibit the possibility of fertility permanently for both children and young people. Some may affect a girl's menstrual cycle, but this does not mean that she will be sub-fertile or infertile. In many cases, young girls will resume a normal menstrual cycle pattern following completion of cancer treatment. However, it is not possible to predict those likely to relapse and subsequently require second line treatments (for example, radiotherapy), which may lead to permanent gonadal damage. This needs to be considered when discussing options.

Fertility is a complex issue to discuss with children and young adults. The best time, place and facilitator for this will vary. Counselling can be offered to them and/or members of the family before, during and after treatment irrespective of treatment outcome. Specialist fertility counsellors may help facilitate a session where the concept is discussed and explored. They may also support the child/young person and/or parents during appointments with the fertility specialists when options are discussed. Studies have shown that those who talk about the options with fertility specialists and fertility counsellors report a better quality of life, and less sense of regret, years after treatment (Mertes, 2015; Peddie et al., 2012).

Information should be provided in a format that uses plain English and which is culturally sensitive and should also be available for parents and family members. It is important to remember that relationships between the patient, their partner/parent and/or the wider family may become strained and, at times, dysfunctional due to stress and anxiety. Consequently, ongoing assessment, support and early specialist interventions can be invaluable in preserving and maintaining relationships during this time.

Tests to ascertain fertility following treatment can be undertaken. A discussion between the medical team and the patient should take place to ensure this is at a time to produce reliable results and gives the information the patient requires that is best for their wellbeing. For young girls who have never been sexually active, consideration should be given to an assessment of ovarian reserve and monitoring ovarian response to stimulation with the use of ultrasound. In those who may be sexually active, it is essential to exclude existing pregnancy prior to commencing fertility treatment.

A young person should be advised and supported to avoid pregnancy during treatment (with contraceptive advice for them and their partner). Some contraceptive methods may reduce fertility for a time following the cessation of its use.

7. Key points

With the diagnosis of a life-limiting disease, (especially those that impact on fertility) lifesaving treatment will always take precedence. However, nurses should discuss the possibility of future infertility with patients of reproductive age or with parents/guardians of children as part of the education and informed consent process before treatments are initiated. This discussion should take place at the time of diagnosis to maximise future reproductive potential and be documented within the patient's records. Nurses should also be up-to-date with all fertility preservation options (local and national) and be familiar with local referral processes to reproductive specialists.

- Nurses have a responsibility to understand fertility preservation and its potential value to those whose fertility may be impaired.
- All services involved in treatment that may adversely affect a patient's future fertility, should have clear processes in place to discuss and enable fertility preservation.
- Nurses and all health care professionals need to understand the legal and regulatory requirements, as well as the ethical, cultural and religious considerations, associated with fertility preservation and treatment.
- Nurses involved in treatment that may adversely affect future fertility should be prepared to have the initial discussion, be familiar with the potential for fertility preservation and understand the importance of early referral to fertility specialists.
- Services should recognise there are two options of activity when advising patients about fertility preservation, that of generalist and specialist.
- All health care professionals involved in areas of care where fertility may be compromised, should have care pathways that include fertility preservation.
- All health care professionals involved in these services should be aware of the process and able to discuss preservation of fertility with patients.
- All service providers should be familiar with local fertility services, networks and referral processes/pathways to ensure an efficient and smooth service.
- Commissioners and funding authorities require contemporary evidence-based information, together with an understanding of local needs, to ensure fertility preservation services are appropriately commissioned.

8. Conclusion

Fertility is an important part of heritage and survival for many women, men and children, but it is not always considered when faced with a life-limiting disease or a long-term medical condition. Even when fertility may be compromised, other priorities often take precedence. Increased survival rates, together with advances in assisted reproduction technologies, offer greater opportunities for people whose fertility has been affected by treatment or for those who have made the decision to delay reproduction (requiring fertility preservation).

Awareness of inequality in access to fertility preservation services and fertility treatment services should also be considered. Health care providers should provide the opportunity for discussion at such a critical time, irrespective of locality, socioeconomic status or parity.

The success of fertility preservation services is reliant on nurses engaging patients in early discussions about its potential, preferably before treatment has commenced. Therefore, nurses need to understand that, despite future fertility not always being a priority for many when facing a critical diagnosis (or medical treatments likely to impact on reproductive function), discussion about fertility preservation should be a key part of care.

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Organisations

British Association of Counselling & Psychotherapy (BACP) **bacp.co.uk**

British Fertility Society (BFS) **britishfertilitysociety.org.uk**

British Infertility Counselling Association (BICA) **bica.net**

Cancer Research UK **cancerresearchuk.org**

Future Fertility Trust **futurefertilitytrustuk.org**

Macmillan **macmillan.org.uk** (for a range of leaflets and CDs for families and partners, for example, Cancer, you and your partner and Cancer and Fertility).

National Cancer Institute **cancer.gov** (for a range of information leaflets).

Royal College of Nursing **rcn.org.uk**

Glossary

Artificial insemination with husband sperm (AIH) – prepared sperm are placed at the entrance of the cervix at the time of ovulation.

Artificial insemination with donor sperm (AID) – similar to AIH but using donated sperm.

Cryopreservation – a process where cells, tissues are preserved by cooling to very low temperatures.

Gamete – a mature male (sperm) or female germ cell (egg).

Gamete intra fallopian transfer (GIFT) – similar to IVF but harvested eggs are placed in the tube with prepared sperm where fertilisation should occur.

Intrauterine insemination (IUI) – drug stimulation is used to promote follicular growth of one to two follicles. Prepared sperm are then transferred into the uterus following the induction of ovulation.

In vitro fertilisation (IVF) – where hormone therapy is used to stimulate the ovaries to produce several eggs. The eggs are then collected and mixed with sperm in a laboratory. If fertilisation is successful, the embryos are allowed to develop for between 2 and 6 days. Then best quality embryo(s) is then transferred back to the woman's womb.

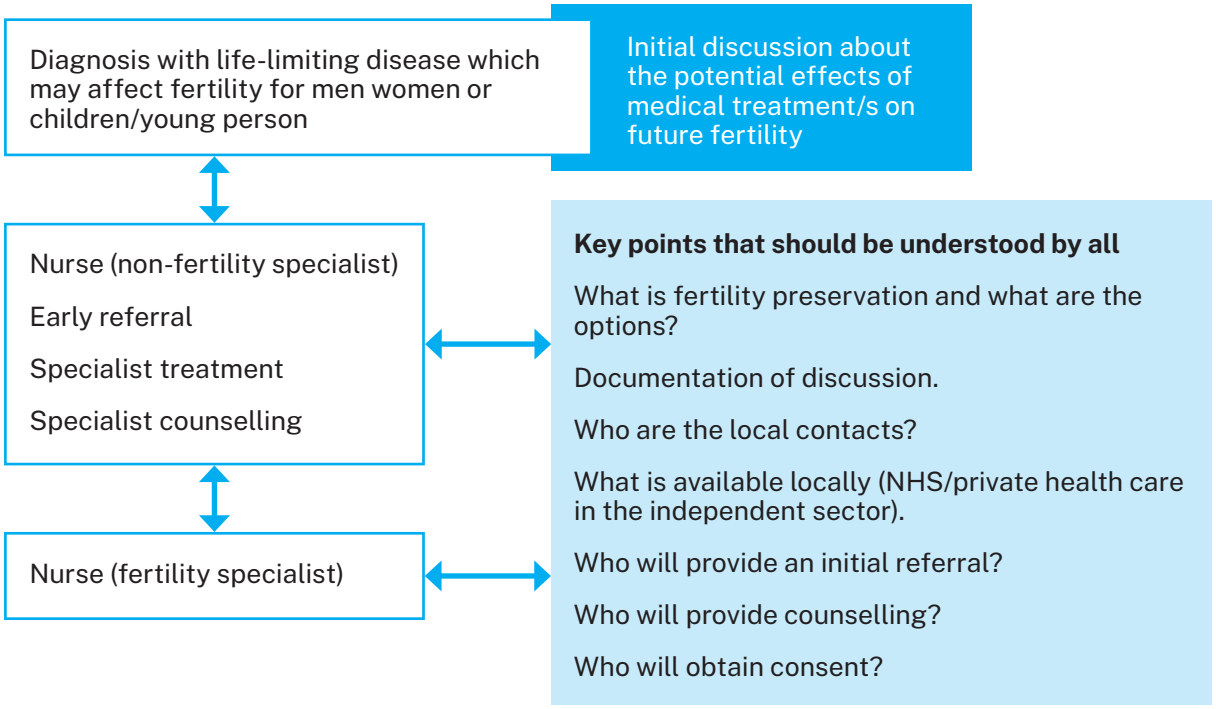
Intracytoplasmic sperm injection (ICSI) – this involves injecting a single sperm into the harvested egg. This is a treatment for male infertility that is frequently used by cancer patients. Where female oocytes (eggs) are vitrified, IVF with ICSI will be required.

Ovulation induction (OI) – drug treatment to establish ovulation in women who do not ovulate regularly.

Surgical sperm retrieval (SSR) – sperm are retrieved from testicular reproductive material and then used to fertilise an egg with ICSI.

Vitrification – a process of converting reproductive material into a glass-like amorphous solid which is free of any crystalline structure (thereby preventing damage to cells from ice formation), either by the quick removal or addition of heat or by mixing with an additive.

Appendix: Fertility preservation



Individual needs will inevitably direct the counselling sessions. However, the following points are useful for nurses, medical teams and counsellors.

- Informing patient (and the family) of diagnosis, prognosis and individual risk.
- Determine individual risk, for example, cancer type, prognosis, age and treatment plan.
- Provide risk factor of infertility with first line treatments, whilst considering potential for second line (radiotherapy) treatments.
- Current fertility status (existing child/children, reproductive plans prior to diagnosis). Consider who takes the younger man to the clinic for sperm freezing, as it may not be comfortable for the parents to do so or for him to have his parents present.
- The possible risks to health of undergoing fertility treatment.
- The emotional issues and requirement for sperm/egg collection at a time of crisis.
- Timing (women): is there enough time for the fertility treatment cycle to be completed before she commences treatment for her condition.
- In some cases, lifesaving treatments may be put on hold (if already pregnant or to allow the patient to conceive), then resumed later. Fears for health versus hopes of having a baby.
- The realistic assisted reproduction options open to them in the future.
- The possibility that the woman might not respond to fertility treatment and, for men, post-thaw samples may be inadequate.
- Thinking and planning for a future family at a time of uncertainty, including posthumous use.
- The reactions of their partner (if in a relationship), family and close friends.
- How relationships with family/friends influence decision making.
- The fear of cancer recurrence after a child is born and implications for the child/partner.
- The potential disposal of the stored gametes.
- Some treatments can cause temporary or permanent infertility and, in women, early menopause.

RCN quality assurance

Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description

Fertility preservation involves freezing and storing sperm or eggs (gametes), ovarian reproductive material or embryos for use in a person's future fertility treatment. This publication provides information for nurses who are supporting and caring for those beginning treatment for potentially life-limiting diseases and where the treatment may adversely affect their ability to have children in the future. This updated guidance also encompasses those who may wish, for non-medical reasons, to defer having children until later in life, for example members of the armed forces, transgender people, or those considering gender reassignment surgery.

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Evaluation

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