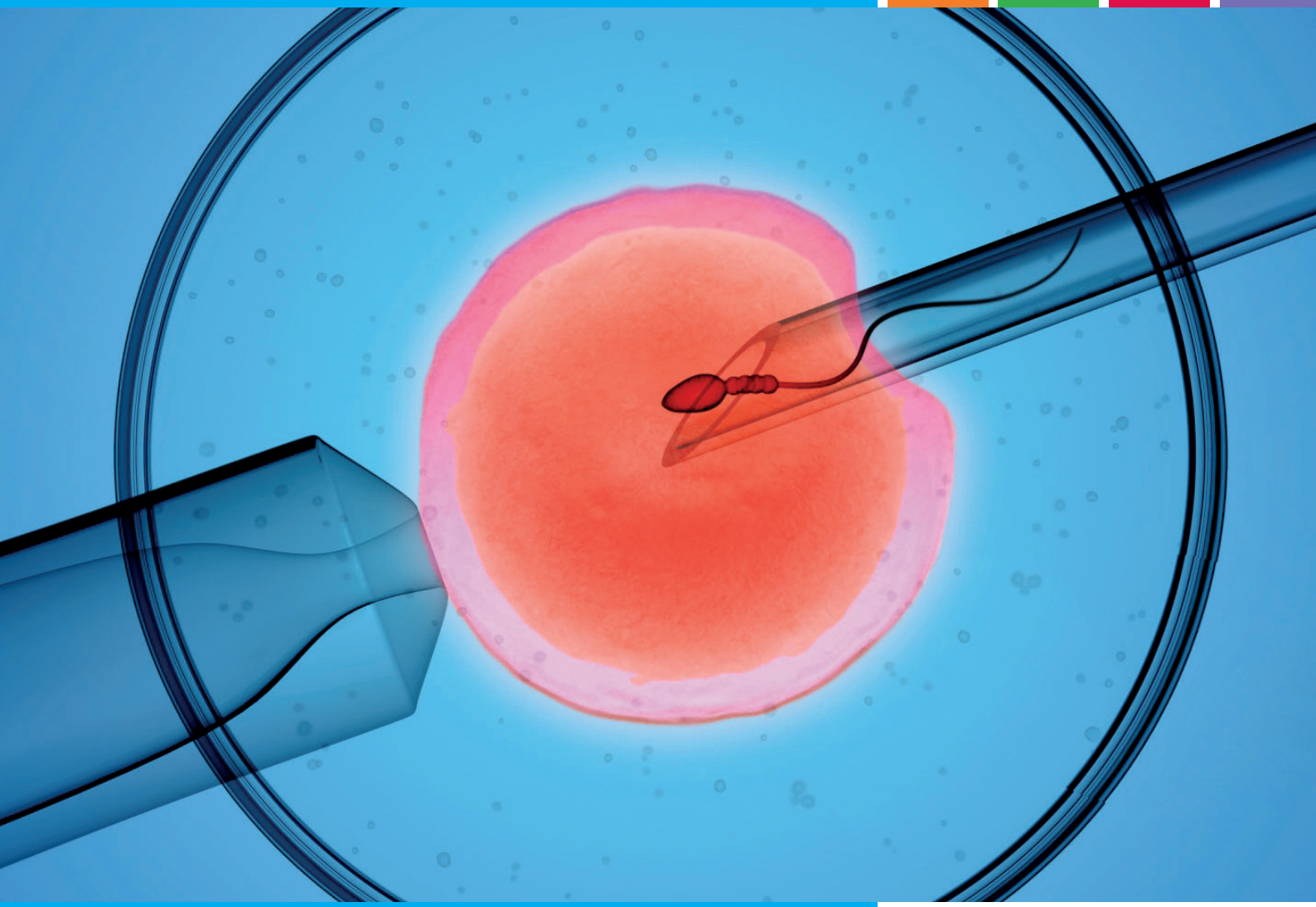
Royal College of Nursing

2020 | International Year of the Nurse and Midwife

Fertility Care and Emotional Wellbeing RCN Guidance

CLINICAL PROFESSIONAL RESOURCE



Royal College of Nursing
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This publication is due for review in November 2022. To provide feedback on its contents or on your experience of using the publication, please email **publications.feedback@rcn.org.uk**

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
This guidance has been developed as a resource for all health care professionals in all areas of fertility care and acknowledges the differences between emotional support and wellbeing, implications counselling and therapeutic counselling.

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Evaluation
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1. Introduction

Fertility care is a well-established aspect of reproductive health care. Health care staff who work in this specialty support individuals and couples to become parents or accept that, even with the advances in technology today, this may not always be possible. The journey to become pregnant can be lengthy, starting in general practice and often encompassing a wide range of services including the more technical and complex care offered by fertility services (whether in the NHS or the independent sector).

Fertility treatment can be a complex pathway, with uncertain outcomes. For those who embark on this journey, it can lead to a range of emotions, sometimes rewarding (but also very challenging).

In 2017 NICE produced a *statement on fertility care (NICE 2017a)*. This explains that:

> "People who are having problems conceiving are offered counselling before, during and after investigation and treatment for their fertility problems."

The rationale is:

> "People experiencing fertility problems should be offered counselling because fertility problems themselves, and the investigation and treatment for fertility problems, can cause emotional stress."

This guidance is focused on the nursing community working in all areas of fertility care and acknowledges the differences between emotional support and wellbeing, implications counselling and therapeutic counselling (these will be explored later in this publication).

Registered nurses, midwives, nursing associates and non-registered health care assistants (HCAs) will all engage with women and their partners throughout the service provision and need to be fully prepared to provide the best support, advice and care they can. Health care assistants play an important role as they are often the first person to be with an individual at various stages of their pathway.

As HCAs are part of the multidisciplinary team, providing hands on care, they contribute to the overall experience and should be able to provide an initial level of emotional support whilst recognising when they need to refer to a registered nurse for further assistance.

At any stage of treatment, a woman may be given unexpected, and/or devastating news and the HCA is often the person she will turn to for support, reassurance or further explanation of what has happened. It is important to recognise the registrant and non-registrant roles in care provision; however, it must be acknowledged that the woman (and her partner) may not make that distinction. The HCA must seek appropriate help with this, speaking to a registered nurse to ensure clarification and offer the appropriate pathway of care.

The Human Fertilisation and Embryology Authority (HFEA), the regulator for fertility services across the UK, has produced a patient support pathway: *Good Emotional Support Practices for Fertility Patients* (HFEA, 2018a). This outlines the key issues and should be read in conjunction with this guidance.

Note about language

The RCN recognises the diversity of those seeking fertility care, however, for convenience of authorship the term women has been used throughout and, where appropriate, woman (and partner).

2. Recognising the need for emotional support

Mind (2019) explains that some signs of stress and distress can often present as irritability, impatience, anxiety, nervousness, fear, worry, loneliness, a lack of concentration, poor appetite, tearfulness and restlessness. Fertility nurses report that many women undergoing treatment may display many of these signs and these may intensify at each stage of their fertility journey. Other signs to look out for include: nail biting, rushing around, lack of eye contact and the appearance of disinterest or disengagement.

As a nurse, midwife or health care assistant, it is important to recognise these signs and manage them appropriately with the woman (and her partner) alongside the fertility treatment. *Guidelines for Nurses* (2017) provide some tools on how to recognise stress in women. These can include asking about:

- sleep patterns
- decision-making ability
- diet
- concentration
- interaction with family and friends
- hobbies and interests.

If a woman reports that several of these points have been affected, then this may be a sign that further intervention is needed.

The HADS (Hospital Anxiety and Depression Scale), a well-established tool used to recognise the need for support (Stern, 2014), is a 14-item scale used in consultation to take a holistic approach to emotional wellbeing for women undergoing fertility care by asking specific questions in relation to anxiety and depression.

Recognising the emotional needs of women (and their partners) is a key part of the role of health care professionals throughout the fertility journey, who will have more opportunity to recognise and support needs. This continuity means that individuals will generally feel more comfortable discussing how they are feeling and coping with those they know better, particularly if they have established a trusting relationship and rapport.

The Human Fertilisation and Embryology Authority (HFEA), the UK's independent regulator of licensed fertility treatment and research using human embryos, aims to ensure that everyone who accesses a fertility clinic, and everyone born as a result of treatment, receives high quality care. One ongoing priority is to improve the emotional experience of care before, during and after treatment or donation. New guidance on patient support was added to the HFEA Code of Practice [portal.hfea.gov.uk/knowledge-base/read-the-code-of-practice/] (guidance notes 2 ,3 and 23) in January 2019. This outlines the expected standard of emotional support and includes a requirement for each licensed UK fertility clinic to have its own patient support policy outlining how the centre 'ensures that women/patients, donors and their partners (where applicable) receive appropriate psychosocial support from all staff they encounter before, during and after treatment' (Guidance note 3). The dedicated patient support page on the Clinic Portal [portal.hfea.gov.uk/knowledge-base/emotional-support-for-patients-resources/] includes resources for clinic staff to help them implement this.

The HFEA's view of support is that emotional wellbeing and support should be embedded in all interactions with women and their partners, with the emphasis on simple, practical improvements which can be adapted to specific groups and resources.

A patient survey by HFEA in 2018 (HFEA, 2018b) showed a mixed picture in terms of the support women and partners received. Most respondents said they could talk to nurses about the emotional side of the experience and could be relied on as a listening ear if needed. The survey identified 'interest shown in you as a person', as one of the top three drivers of satisfaction and improvement of this measure as being 'likely to have the greatest impact on overall satisfaction with the fertility treatment process as a whole.' Respondents spoke positively about emotionally intelligent consultants, 'kind and friendly' nurses, receptionists having a friendly chat with them in the waiting-room and support staff learning women's (and partner's) names, as key factors.

The HFEA Code (2019) states that the standard of care by requiring all clinics to set out a policy outlining how women, donors and their partners will receive appropriate psychosocial support from all staff before, during and after treatment.

The HFEA is actively supporting fertility services to plan and implement their own support policy to reflect local needs by offering clinics a range of resources and training. For more information see: portal.hfea.gov.uk/knowledge-base/emotional-support-for-patients-resources

Continuity of nursing care is an effective way of supporting women. It can facilitate building productive relationships with the woman which will help her feel well supported through the process. Ensure that any time with the woman is used to identify and support emotional wellbeing, whilst it is equally important to use other resources and agencies who may be able to extend that support further. The most effective way to provide care is face-to-face, but when nursing staff experience time constraints they will need to consider how they can provide high quality care, in particular the emotional support required.

Nursing staff are also in a position to be able to empower women to use resources such as:

- peer support groups run by organisations like Fertility Network UK
- online forums and websites such as The Dovecote
- clinic counselling services which can help women manage the emotional demands of treatment.

Electronic resources, such as email and online portals, can also be used effectively allowing women/men to feel that there is always an avenue they can explore. These resources can also help the nursing community to disseminate advice that women (and partners) can access at any time.

As well as helping individuals and couples through the fertility process, it is equally important that employers recognise and support the emotional wellbeing of their workforce, identifying when health care staff may find certain difficult situations challenging and offering appropriate guidance and care.

Support for nursing teams

- Provide peer support forums to discuss difficult issues and reflect on how these are managed and what improvements can be made.
- Hold regular departmental meetings to discuss and improve on practice, with a focus on how to avoid stressful situations. These should be conducted and managed in a positive, blame-free atmosphere, to encourage learning and discourage criticism.
- Offer a stress-free physical environment as this will facilitate good wellbeing, for example, ensure all equipment (such as chairs and computers) is comfortable and accessible.
- Conduct regular appraisals and positive performance conversations to support wellbeing.
- Implement flexible working practices that support the service, as well as individual circumstances – this will enhance the working environment.
- Provide appropriate training to encourage continuing professional development.
- Introduce stress management techniques, for example, mindfulness, massage and yoga sessions.
- Encourage occupational health engagement to have a positive working environment.
- The RCN and NMC also have resources for added support (rcn.org.uk/get-help).

3. Emotional support after confirmation of a pregnancy following fertility treatment

The diagnosis of a longed-for pregnancy after fertility treatment brings a range of mixed emotions and questions. Women and their partners need information about the next steps and should be offered the opportunity to discuss their feelings with appropriately trained staff, immediately after the scan which confirms the pregnancy (RCN, 2017). This is a time for great sensitivity as confirmation of a viable pregnancy is the first step in a journey which can change direction at any time. They will need clear and accurate information to ensure they know where to get further support should the pregnancy continue or not.

The person providing this initial support may be a registered nurse, nursing associate or non-registered health care assistant, and the woman and her partner may not recognise the different expertise available to them. To ensure the best quality care, clear referral pathways must be developed in services to ensure the correct level of support is available as required, and that all health care practitioners understand their role in that pathway.

The time between the diagnosis of the pregnancy and the woman booking for antenatal care can be a time of anxiety as they may have to wait weeks for the first appointment. They should receive information about the booking process in the local area and, to reassure them, the procedure should be explained (this may also be an opportune time to offer counselling). They may expect to be seen immediately and might want to consider screening for fetal abnormalities. Information should be provided about the NHS programme and private providers so they can make an informed choice.

Despite the policy of selective single embryo transfer in the UK (HFEA, 2006) a multiple pregnancy may be diagnosed as the risk of embryo division is higher after IVF. It should not be assumed that this news will be always welcomed. Pre-treatment information and discussion about embryo transfer will mean they are aware of the high risks for mothers and babies, and they may also have concerns about the practical and financial implications of caring for two or more. If triplets or more are diagnosed or suspected at the first scan, they should be referred to a fetal medicine centre to consider an option of multifetal embryo reduction. Counselling should also be offered when there is a multiple pregnancy diagnosis to help prospective parents consider the implications going forward of any decision, especially as a couple may have differing views.

The reality of being pregnant after many years of infertility can be overwhelming, and it is not unknown for women to consider terminating the pregnancy as the actuality of parenting becomes a reality. In these cases, an impartial and objective response from the health care professional is essential and the offer of an appointment with a counsellor a good first step.

4. The impact of repeated cycle failure – being childless not by choice

For many women, the reality of finding out treatment has been unsuccessful is heart-breaking and can have a far-reaching and devastating impact on their life. A survey by the Fertility Network (2016) reported that 'those most in danger of experiencing high levels of distress and suicidal feelings were those who had unsuccessful treatment and who spent longer trying to conceive'. It must be acknowledged that although failed treatment is a regular occurrence in clinics, for a woman, it can signify the end of hopes and dreams and it can feel like a personal failure, so sensitivity and awareness of this loss must be shown to all.

Since fertility treatment can be an all-consuming process, being given the news of another failed fertility cycle can lead to a deterioration in mental health, relationships and overall wellbeing. As a nurse or health care assistant, it is vital to acknowledge that any feelings of sadness, grief or loss being experienced are normal and guide them to access appropriate support and resources, including counselling. Where results are being presented in a clinic setting, it can be helpful for private space or a room to be offered to the woman(and her partner) to enable them to process difficult news before leaving the premises.

For women at the end of their fertility journey, deciding when to stop treatment is incredibly difficult. Information about alternative parenting options is often available in clinics, but it is important that nurses can sensitively signpost women and their partners to other resources about living life without children. This needs to be managed according to the needs of that woman (and partner), particularly as feeling alone and isolated are common following unsuccessful treatment, and they may not yet be ready to hear about alternatives. It is important to always remain sensitive to the fact that their wished-for future as parents (or in completing their family in cases of secondary infertility) not being achieved, can lead to isolation, loss of identity and purpose for a time. Referral to counselling can help people to process their treatment experiences, grieve their losses, reflect on and make decisions about alternative parenting options or plans for a childless future.

Fertility Network UK

A leading patient-focused fertility charity, providing free and impartial support and information for anyone affected by fertility issues including those:

- considering their future fertility
- trying to become parents
- facing the challenges of involuntary childlessness
- successful after fertility problems.

It is the patient voice in the campaign for equitable access to NHS fertility treatment, and Fertility Network UK co-chair the campaign group Fertility Fairness. Their education project raises awareness of the importance of fertility education and highlights practical steps young people can take to help protect their future fertility. fertilitynetworkuk.org/how-we-can-help

5. The role of the counsellor

Fertility care counselling is a distinct professional process which is informed by explicit knowledge and skills. It should not be confused with the provision of support and informed consent for treatment options during treatment.

Implications counselling is the provision of information to ensure that the woman understands the processes and risks associated with undergoing treatments.

Therapeutic counselling is focused on helping individuals to understand their feelings and behaviour and learn how to change, where necessary.

Both strands of counselling are differentiated from the provision of support and informed consent for treatment options or other forms of psychological support provided to women (and their partners) during fertility treatment (RCN, 2017).

Fertility nurses will be engaged in *implications counselling*, for which they must be specifically trained and prepared to carry out appropriately. They will also need to understand that more detailed *therapeutic counselling* should be carried out by a trained/accredited counsellor.

For many people, going through fertility treatment will be one of the most distressing and tumultuous periods in their lives. It is an experience that can deeply affect an individual's sense of self and a feeling of failing to achieve their anticipated 'biological destiny'. This can lead to feeling alone, which subsequently can put a strain on family, partners and general day-to-day living.

Something so apparently easy for others has become 'medicalised' and women may feel a lack of control over their lives. Without the appropriate emotional support before, during and after treatment, can result in an increasing sense of detachment or depersonalisation in different areas of their lives as they try to cope with the stress of trying to create a family.

The 2016 impact study undertaken by Fertility Network UK (Fertility Network UK, 2016) found that women felt they were not always offered counselling at the time when it was most needed and when it could have made a real difference – especially if women were faced with potential bad news which could create increased anxiety. Counselling can help make sense of present difficulties and increase an individual's ability to make choices and initiate changes, for example, by introducing coping strategies.

Most GP surgeries can refer women to IAPT (Improving Access to Psychological Therapies) services to help with anxiety. At initial secondary care contact, the emotional distress associated with fertility investigations is recognised in the NICE Guidelines (2017b), and the British Infertility Counselling Association (BICA) fully support this. However, fertility counselling is not currently offered consistently through the care pathway.

In licensed fertility clinics, therapeutic counselling must be offered and accessible to all women before, during, and after treatment, with a BICA accredited fertility counsellor (or someone working toward their accreditation). Therapeutic counselling offers emotional support and is not to be confused with counselling focused on the implications of a particular treatment plan. However, BICA has identified that provision for therapeutic counselling varies between clinics and may involve additional cost, possibly discouraging uptake.

Counselling should be normalised within the multidisciplinary team and referral pathways known and explained. It is generally offered face to face but should also be offered by telephone (or online) at times when coming into a clinic may be difficult, for example, after a negative result or miscarriage.

Therapeutic counselling can help women understand their feelings of lack of control, grief and loss, relationship tensions, family and social anxiety, decision making about continuing or ending treatment, and to consider adoption or involuntary childlessness.

The British Infertility Counselling Association (BICA) is an organisation of qualified specialist counsellors, working across the UK, who can offer support. **bica.net/about-us/what-is-counselling**

Psychological effects of having problems with fertility

NICE (2017a) is clear that when couples have fertility problems, they should be informed that stress in one or both partners can affect the couple's relationship and is likely to reduce libido and frequency of intercourse, which can contribute to fertility problems. Individuals who experience fertility problems should be:

- informed that they may find it helpful to contact a fertility support group
- offered counselling because fertility problems themselves, and the investigation and treatment of fertility problems, can cause psychological stress.
- offered counselling before, during and after investigation and treatment, irrespective of the outcome of these procedures.

Counselling should be provided by someone who is not directly involved in the management of the individual's and/or couple's fertility care.

6. Emotional support and diversity

All health care staff should demonstrate an understanding of diversity, equality and inclusion. This is critical in ensuring that the best possible women-centred care and emotional support is provided. The welfare of the child assessment for assisted conception needs to be clearly understood by all (HFEA, 2019). Further information can be found in the HFEA Code of Practice 2019 (Guidance Note 29 Treating People Fairly).

Seeking fertility treatment and accessing fertility services can be emotionally and physically exhausting, as well as financially challenging for many. It is essential to recognise and understand diversity in individuals seeking fertility care; this may include same sex couples, single people, men and women seeking fertility preservation, women seeking treatment for medical or social reasons, heterosexual couples, transgender people and those looking to pursue surrogacy arrangements. It is also important to recognise a physical disability and/or learning disability which may impact on an individual's treatment, understanding and outcomes.

Health care staff should also be aware of women and their partners who started their fertility care overseas and may need extra guidance and support in navigating the systems within the UK health and social care services. Similarly, consider culture and language as, again, some individuals may find the services and processes within the UK overwhelming, or they may find the English language a barrier. When this is the case, the woman and her partner should be offered an interpreter – this should also be made available to those with reading, vision or hearing difficulties.

Some individuals may insist that they can interpret for their partner. This is not advised as:

- it can lead to a poor understanding of complex information
- a friend or relative may have a conflict of interest with the woman (health care professionals have no way of knowing about the quality of the interpreting)
- it can result in not accessing emotional support if the English speaking partner does not see the benefit
- some women may feel intimidated or too embarrassed to ask questions – this can lead to a lack of understanding around consent signing and non/poor compliance/errors when taking medications (Elgin, 2018). It can also have a detrimental effect on treatment outcomes, as well as a potential cost implication to the couple.

Providing emotional support for women who do not speak English as their first language can bring different challenges; understanding their cultural issues, use of language and identifying specific issues relevant to them can be key.

The Fertility Network UK (2016) explains that fertility treatments can be isolating and arduous, and that women recognise that the fertility journey is more than a medical process. Getting to know individuals can help with identifying any signs of distress, depression or withdrawal. Counselling, via an interpreter, should be encouraged as they can outline the boundaries of confidentiality while still providing good emotional support.

The use of an interpretation service on a regular basis builds the skills and knowledge of the interpreters. They should be actively encouraged to ask questions if they do not fully understand the information that they are translating as this will improve their knowledge and understanding. Subsequently, this will improve their translation and the quality of the information the women receive. Confidence in the interpreters can build on the relationship of trust between health care providers and the interpretation services. Couples may ask the interpreter questions that they feel they cannot ask the health care professional – the interpreter can then gain permission to ask on their behalf. Women are predominantly used as language interpreters as many of the interventions impact directly on the woman. However, more men are finding it useful to talk about their needs and should be encouraged to ask for, or be offered, a male interpreter if they wish.

As treatment can be traumatic and sometimes isolating for some women, emotional support is a fundamental aspect of care. There are many support groups where free advice and support is offered (see Further support section). It is also important to encourage women to seek support from family, friends and others who may be in a similar position.

Conclusion

The RCN believes that all health care professionals involved in the care of individuals seeking fertility treatment should be able to offer the necessary emotional support needed or be aware when they need to refer on to an appropriately trained health care practitioner.

Key points

- Health care professionals need to recognise each woman's fertility journey is completely individual and there is no 'one size fits all' when it comes to providing emotional support.
- Diversity brings a wealth of knowledge, experience and a range of different perspectives which can be encouraging to women, empowering their decisions and providing essential emotional support.
- All health care professionals providing emotional support to women and their partners need to understand the principles of the 6 Cs at all times. Care, Compassion, Competence, Communication, Courage and Commitment (NHS, 2016).
- Emotional support, counselling and continuity of care are essential skills for nurses, nursing associates and non-registrants to effectively engage with those they are providing care.
- This guidance acknowledges that health care professionals need to be well supported themselves in order to provide high-quality care.

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Further support

The British Infertility Counselling Association (BICA) is an organisation of qualified specialist counsellors, working across the UK, who can offer support.
bica.net/about-us/what-is-counselling

Donor Conception Network - A supportive network of more than 2,000 mainly UK based families with children conceived with donated sperm, eggs or embryos, those considering or undergoing donor conception procedures; and donor conceived people
dcnetwork.org

The Dovecote – enabling and inspiring people facing involuntary childlessness to reconnect with their daily lives and rediscover a passion and purpose.
thedovecoteorg.wordpress.com

Fertility Network UK provides a number of support groups (across the country as well as online) that offer the opportunity to share a story and get advice from others who are also trying to conceive.
fertilitynetworkuk.org/how-we-can-help

Fertility Friends – an online community for women seeking advice for infertility, adoption, parenting after infertility and moving on.
fertilityfriends.co.uk

Gateway Women: Global Childless Friendship Network – a support network for childless women
gateway-women.com

HFEA Clinic Portal - patient support resources
hfea.gov.uk/treatments/explore-all-treatments/getting-emotional-support

HFEA multiple births campaign
https://www.hfea.gov.uk/about-us/our-campaign-to-reduce-multiple-births/

Men's Health Forum – a charity that works to improve men's health services.
menshealthforum.org.uk

MIND - provides advice and support to empower anyone experiencing a mental health problem.
mind.org.uk

More to Life Seminars and support (Fertility Network) – webinar series offering expert opinion and advice on tackling the diverse range of issues that manifest when living without children.
fertilitynetworkuk.org/life-without-children/more-to-life-webinars

Royal College of Nursing
rcn.org.uk/get-help

The Sperm, Egg and Embryo Donation (SEED) Trust. Provides impartial advice, support and information to prospective donors, intended parents and surrogates
seedtrust.org.uk

Stonewall/LGBT – empowering LGBT, offering advice for areas such as legal parenthood, co-parenting, donor insemination and fertility treatment, surrogacy, parental responsibility and family leave/pay.
stonewall.org.uk/lgbt-britain-health

Where a woman and her partner have suffered a loss, further support is available from a range of organisations:

ARC Antenatal Results and Choices
arc-uk.org

Miscarriage Association
miscarriageassociation.org.uk

Multiple Births Foundation
multiplebirths.org.uk

The Ectopic Pregnancy Trust
ectopic.org.uk

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

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