

What psychosocial support should you get from your fertility clinic?

> Patient version of the ESHRE Guideline: Routine psychosocial care in infertility and medically assisted reproduction.

Version 2015

Introduction

This booklet is for you if:

- You have been assessed for infertility
- You are starting or undergoing fertility treatment (MAR, ART; IUI, IVF, ICSI)

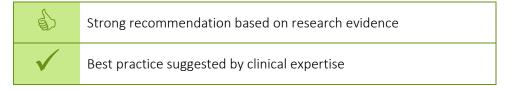
This booklet is intended for patients, but may also be useful for their family members or caregivers.

The booklet contains:

10 things you should expect from your fertility staff and clinic. 10 tips for patients undergoing fertility treatment.

This booklet and the information presented are entirely based on the ESHRE Guideline: Routine psychosocial care in infertility and medically assisted reproduction – A guide for fertility staff. All the information and recommendations in the guideline are based on the best available evidence from research. When there is insufficient evidence from research, a group of experts have formulated recommendations based on their clinical expertise.

We have added the following symbols to explain the strength of the recommendations



More information is available at the last pages of this booklet. The entire guideline is available on the website of ESHRE (www.eshre.eu/guidelines)

ESHRE guideline: Routine psychosocial care in infertility and medically assisted reproduction

The diagnosis of infertility and fertility treatments can have a significant impact on you and your partner (if you have one).

We believe it is important to ensure that you have a healthy experience of your infertility diagnosis and treatment. We have written recommendations for fertility staff on how to optimise routine psychosocial care at fertility clinics, and thereby improve your treatment experience and quality of life. The guideline only discusses care that should be routinely provided to all patients. Some patients may experience significant psychosocial problems during diagnosis or treatment and may require specialized support such as infertility counselling or psychotherapy. These will not be discussed in this guideline.

The guideline aims to inform clinicians on the (psychosocial) needs of indivduals and couples undergoing fertility treatment and how psychosocial care should be organised to address these needs.

The overall conclusions of the guideline are:

- Patients have clear preferences about the psychosocial care they receive at fertility clinics. Fertility staff should be aware of these preferences and consider addressing them.
- The needs of patients vary across treatment stages and therefore psychosocial support should be tailored accordingly. Fertility staff must be informed about the specific needs that patients experience at different treatment stages.
- Some patients are more vulnerable to the demands of treatment and therefore need additional psychosocial support. Fertility staff must be aware of specific patient characteristics that indicate a risk of experiencing increased needs or problems before, during, or after fertility treatment.
- The most effective way to start incorporating psychosocial care in routine fertility care is by improving information at clinics.

10 things you should expect from your fertility staff and clinic.

Based on studies investigating what patients find important when evaluating their fertility staff and clinic, we formulated recommendations for the staff and the clinic.

| Based on these recommendations, patients should expect: | | | |
|---|--|---|--|
| 1 | staff to show understanding and pay attention to the emotional impact of infertility. | 6 | |
| 2 | that both partners are involved in the treatment process. | 6 | |
| 3 | to be involved in decision-making. | 6 | |
| 4 | minimal waiting times, not to be hurried in medical consultations, and to be followed by the same physician. | 6 | |
| (5) | fertility staff to be competent and to receive personalized care. | 6 | |
| 6 | to be in a clinic specialized to infertility care. | 6 | |
| (7) | to have access to specialized psychosocial care (if needed) before, during, and after IVF treatment. | 6 | |
| 8 | to receive written treatment-relevant information that is understandable and personally relevant. | 6 | |
| 9 | to be given explanations about treatment results and treatment options. | 6 | |
| 10 | to receive information about psychosocial care options (e.g., contact details of support groups, online support options, access to infertility counselling, or psychotherapy). | 6 | |

Based on the section: "Which aspects and components of psychosocial care are important to patients" of the ESHRE guideline Routine psychosocial care in infertility and medically assisted reproduction – A guide for fertility staff.

10 tips for patients undergoing fertility treatment.

Based on the recommendations of the guideline, we have written concise and pragmatic advice for patients starting, undergoing or ending fertility treatment. The goal of these tips is to help you to get the best care and support at your clinic, and therefore to have a healthy experience of the diagnosis and treatment of infertility.

Be open and honest to fertility staff regarding your lifestyle behaviours (for example smoking, alcohol use, diet, eating disorders) and ask advice on improving your chances of getting pregnant/fathering a child.

Studies have shown that a considerable number of patients have lifestyle behaviours that may negatively affect their general and reproductive health, and that patients do not fully these. The guideline recommends that fertility staff consider providing you with information about lifestyle. They should also support you in changing your lifestyle to improve your general health and chance of treatment success.

Ask fertility staff about assessing your risk of developing emotional diffciulties during treatment.

The guideline recommends fertility staff to offer you the opportunity to have your psychosocial needs assessed and to inform you about your emotional adjustment before the start of treatment. The aim is to ascertain if you have emotional difficulties and, if yes, to provide you with additional support, for example, seeing a counsellor or a psychologist, or having contact with other patients.



If you have a partner, undergo all treatment procedures together

The guideline recommends fertility staff to actively involve both partners of the couple in the diagnosis and treatment process. Therefore, if possible, take your partner to the clinic.



Be aware that men and women experience infertility and fertility treatments differently.

Several studies indicate that men and women experience infertility differently. Women report higher levels of depression and stress before treatment. Men are more stoic so that they can support their partner, but report feeling more isolated during treatment. Furthermore, in couples, the way one partner reacts to infertility is associated with how the other partner reacts. Expecting differences between you and your partner may help you in coping with treatment and understanding and talking to each other.



Ask for written information on medical procedures.

Studies have shown that preparatory information about medical procedures promotes compliance with treatment, decreases infertility-specific anxiety and stress and increases patient knowledge. Therefore, the guideline recommends fertility staff to provide you with preparatory information about medical procedures.

Be aware that you will experience different emotions during your fertility treatment

Studies have shown that most patients experience different emotions during a fertility treatment cycle. Patients report being optimistic during the hormonal stimulation period. They always experience more anxiety before important medical procedures such as collecting the oocytes and transferring the embryos. At these moments, women may also experience physical fatigue but they also feel closer to their partner. Anxiety and stress are higher during the two-week waiting period to know if a pregnancy was achieved. Those patients who have a negative pregnancy test can experience intense sadness and depression. You will probably experience some of these emotions during treatment. Be reassured that these feeings are common.

Expect an impact of treatment on your work

Studies have shown that during an IVF/ICSI cycle, 6 in 10 patients report missing work. On average, patients miss 23 hours of work per IVF cycle. You can ask for more information about the impact of treatment on your work and how you can best handle this.



Be involved in decisions regarding your treatment

The guideline recommends fertility staff to discuss treatment options with patients and to support them in making their choices. In addition, fertility staff should offer patients the opportunity to discuss and clarify their treatment related concerns. If you have questions, or you need more information, do not hesitate to ask. No question is too silly!

) If you experience psychosocial problems, ask fertility staff to refer you for additional support.

The guideline recommends fertility staff to provide routine psychosocial care and to refer patients at risk of experiencing severe psychosocial problems to infertility counselling or psychotherapy. Do not hesitate to discuss psychosocial issues with your team.

When ending fertility treatment (succesfull or unsuccesfull), ask for an appointment with your doctor.

The guideline recommends fertility staff to offer patients the opportunity to discuss their worries about a pregnancy achieved with fertility treatment or to discuss the consequences of ending unsuccessful treatment. When you are ending treatment, because you or your partner became pregnant, you may want to discuss your worries concerning the pregnancy and the health of the baby. If you stop treatment without achieving pregnancy, you may have questions about additional options, or concerns about coping with being childless. In either case, you may benefit from an appointment with your doctor. Your doctor may discuss the next steps with you and help you to get additional support, if needed.

About this booklet

This booklet aims to involve patients in healthcare improvement, either by learning about the current expected standard of care, or by enabling patients to make informed decisions on their health, supported by the best available evidence.

How this booklet was developed

This booklet was written by Dr Nathalie Vermeulen (methodological expert), and revised by a patient representative from Infertility Network UK and Dr Sofia Gameiro (psychologist and chair of the Guideline Development Group). All the information provided is based on the recommendations for fertility staff, summarized in the ESHRE guideline: Routine psychosocial care in infertility and medically assisted reproduction – A guide for fertility staff.

Who developed the ESHRE guideline?

The ESHRE guideline: Routine psychosocial care in infertility and medically assisted reproduction – A guide for fertility staff, was developed by a guideline development group of psychologists, 2 medical doctors, a midwife, a literature methodological expert and a patient representative.

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More information

More detailed information on each of the topics in the patient version can be found in the clinicians' edition of the guideline on the ESHRE website (www.eshre.eu/guidelines).

For more detailed information or support, you can contact your doctor or a patient organisation.

In most European countries, national patient organisations provide support and information to couples faced with infertility and their families.

Most of these patient organisations have a website were you can find:

- information on infertility and fertility treatments,
- real life stories,
- information on how to get in contact with other couples,
- specific (national) information on fertility treatments and clinics.

For contact details of national patient organisations, you can ask your doctor, or contact Fertility Europe (www.fertilityeurope.eu)

Disclaimer

The European Society of Human Reproduction and Embryology (ESHRE) developed the current information booklet for patients based on the clinical practice guideline. The aim of clinical practice guidelines is to aid healthcare professionals in everyday clinical decision about appropriate and effective care of their patients.

This booklet is in no way intended to replace, dictate or fully define evaluation and treatment by a qualified physician. It is intended solely as an aid for patients seeking general information on issues in reproductive medicine.

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