ENGAGe
ESGO | European Network of Gynaecological Cancer Advocacy Groups

WHAT SHOULD YOU ASK THE DOCTOR?

Useful information before, during, and after your meeting with your doctor(s)

CONTENTS

GETTING READY

- ☐ Make sure you can explain your symptoms and situation well (How do you feel? Are you in pain? Where do you feel pain?).
- ☐ Brainstorm your questions in advance and write them down.

AT THE MEETING

- ☐ Take a friend, partner, or family member with you (two people will take in more information than one).
- ☐ Write notes during the conversation or ask permission to record it with your phone.
- ☐ Talk about your symptoms and pain—don't presume what you feel is 'normal'.
- ☐ Repeat the doctor's words in your own words ("so, if I understand you…"). This is the best way to be sure you have understood.
- ☐ Talk openly and honestly about your concerns. Your feelings and those of your loved ones matter!
- ☐ Ask for extra time to think before making any important decisions.
- ☐ Ask about a patient organization that can help in your patient journey and find out where you can read more about the disease and treatments.

DARE TO ASK

Ask for an explanation about anything you don't understand, for example, medical terms.

- ☐ What choices or options do I have? What are the pros and cons? How will the pros and cons affect me? What about in the long term?
- ☐ Do I have the possibility of surgery?
- ☐ What are the next treatment steps?
- ☐ What are the treatment risks?
- ☐ What happens if I choose not to have this treatment?
- ☐ Has the doctor discussed / will the doctor discuss my case with colleagues? Will I have an onco team*? Do I have to participate in it? If not, how will I be informed about the decision? When is it?
- ☐ How often do you treat this type of cancer?
- ☐ What are the consequences for my future? (For example, concerning: health, sexual life, work, sports, femininity, fertility, quality of life..)
- ☐ Can I have more information / links / brochures so I can read more at home?
- ☐ Can I have copies of my lab / test / scan / results? What about online access?

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* *The onco team (oncology team) is a group of healthcare professionals from different fields who discuss patient cases to plan and determine the best treatments. A team may be made up of, for example, gynaecologists, oncologists, surgeons, radiologists, psychologists, geneticists, oncology nurses, nurse coordinators, and more.*

AFTER THE MEETING

☐ Talk about the information you've received with your partner / parents / friend / (adult) children. Give them reading material; they will also have questions.

☐ If you think you need a second opinion, ask for it. But first check with your health insurance about coverage.

MAKING DECISIONS

☐ Listen to your intuition. Never take a decision that you don't fully support.

☐ Only you can decide about your life, and so only you can decide about your treatment. The specialist will make a decision for you only if you request it.

GENERAL QUESTIONS

☐ Is my cancer curable?

☐ What is my prognosis?

☐ Is it hereditary?

☐ Will I recover from this treatment?

☐ When will I know if I am cured or not?

☐ What happens if or when the cancer comes back?

☐ What are the treatment options for recurrent cancer?

☐ What will my quality of life be like? In the short term and the long term?

☐ Can I work, work out, travel, or visit family during the treatment?

☐ What is the follow-up plan?

☐ Am I being attended by a multidisciplinary team?

☐ Who will my supervising specialist be?

☐ Should I refer to a dietician for special nutrition advice?

☐ Is this covered by health insurance?

☐ Is there a specialist I could ask questions regarding hereditary issues?

☐ Is there social / psychological assistance available for extra help regarding issues I am facing (or expect to face)?

☐ Is this covered by health insurance?

☐ How do I tell my children about my disease?

☐ Can I have sexual intercourse again? When? Will it be different?

☐ How can scar tissue affect my organs and my quality of life?

☐ Do all patients have scar tissue after treatment?

☐ What can I do to keep in shape during treatment?

☐ What can I do to get my physical condition back after treatment?

☐ What do you know about biological / complementary treatments?

SURGERY

- ☐ Is surgery the only option?
- ☐ How often does this hospital perform these operations?
- ☐ Will you be the surgeon?
- ☐ How often have you performed this surgery before?
- ☐ What are the risks and benefits?
- ☐ What complications can occur? For the short term and long term?
- ☐ How long will I need to stay in hospital?
- ☐ How can I prepare for the surgery?
- ☐ Will I need extra help in my household?
- ☐ How long will my recovery take?
- ☐ Will it affect my fertility / hormonal status / sexual life?

CHEMOTHERAPY

☐ How can I prepare for chemotherapy?

☐ Why do I need chemotherapy (before or after) surgery?

☐ What are the side effects? Short term and long term?

☐ Will it make me sick?

☐ Will I fully recover from chemotherapy?

☐ Will it affect my fertility / hormonal status / sexual life?

☐ Will I lose my hair? Is there any way to prevent this?

☐ Should I take any extra precautions while having chemo treatments?

☐ Can I continue to take care of my children / my household?

☐ Can I continue to work?

☐ Are there any alternatives?

☐ Are there different types of chemotherapies? What are the pros and cons?

☐ Do you choose a specific chemo drug that is tailored to my tumour genetic profile?

☐ Do all women with my type of cancer need chemotherapy?

☐ Do I have to finish all the chemotherapy sessions, even if it weakens me?

☐ What if my body can't handle this type of chemo?

☐ Can I take vitamins or any other nutritional supplements before and during treatment?

RADIOTHERAPY

☐ Why do I need radiotherapy (before / after surgery)?

☐ What are the side effects? Short term or long term?

☐ Will it affect my fertility / hormonal status / sexual life?

☐ How can I prepare for radiotherapy?

☐ Will I fully recover?

☐ Does it hurt?

☐ What is the difference between normal radiotherapy and brachytherapy?

☐ How and when will you know the therapy has been successful?

☐ Do all women with my type of cancer need radiotherapy?

☐ Can I continue to take care of my children / my household?

☐ Can I continue to work?

BIOLOGICAL THERAPIES, MONOCLONAL ANTIBODIES, AND IMMUNOTHERAPIES

☐ What is biological therapy?
☐ What is the difference between immunotherapy and monoclonal therapy?
☐ Are any biological therapies suitable for my cancer type?
☐ What side effects should I expect in the short term and long term?
☐ Will it cure me?
☐ Will I fully recover afterwards?
☐ Will it affect my fertility / hormonal status / sexual life?
☐ Has this treatment been proven to be effective?
☐ Can I continue to take care of my children / my household?
☐ Can I continue to work?
☐ What are the risks?
☐ How often have you performed this therapy in this hospital?
☐ Can I take vitamins or other nutritional supplements before and during treatment?

CLINICAL TRIALS

☐ What is a clinical trial?
☐ Are there any clinical trials for my disease?
☐ Is this hospital taking part in a clinical trial that would suit me?
☐ Can you help me find a clinical trial that would include me?
☐ Will I be able to keep taking the medicine once the trial is over?
☐ Will I be informed about the results of the trial?
☐ Can I decide to leave the trial whenever I want to?
☐ How risky is it?

DIET AND NUTRITION

☐ Can I be referred to a dietician?

☐ Is this covered by insurance?

☐ What should I eat before / during treatment or chemo / radiotherapy?

☐ Do I need to eat extra protein?

☐ What should I eat after my treatment to regain strength?

☐ What should I eat while in remission to keep me healthy?

☐ Is sugar / alcohol / (processed) meat bad for a cancer patient?

☐ Should I eat organic food?

FOOD SUPPLEMENTS / ORTHOMOLECULAR MEDICINE

- ☐ What is your opinion about food supplements / orthomolecular medicine*?
- ☐ Should I refer to an orthomolecular specialist?
- ☐ Can I take food supplements?
- ☐ Can food supplements support my health / treatment?
- ☐ Is it covered by insurance?

QUESTIONS RELATED TO PSYCHOLOGICAL / MENTAL HEALTH

- ☐ Is there a patient organisation I can talk to?
- ☐ Can I meet with fellow patients somehow?
- ☐ Can I be referred to psychologist?
- ☐ Is visiting a psychologist covered by insurance?

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* *Orthomolecular medicine is a field that focuses on treating patients with vitamins, minerals and trace elements.*

Linda Snoep, ovarian cancer survivor, Olijf Netherland, ENGAGe member:

"During my treatment for ovarian cancer (stage 3C), I changed from a patient—more or less paralysed by fear—who thought the doctor always knows best, to a patient who started to understand she has a choice and that she should be in charge of her own decisions. This wasn't easy, because nobody taught me how to do this, but in the end, being the director of my own life changed me into a self-confident patient with less fear and much more acceptance of the challenges of my disease."

Kim Hulscher, cervical cancer survivor, Olijf Netherlands, ENGAGe member:

"When I was diagnosed with cervical cancer in 2013, I had absolutely no idea what to expect or even what to ask at my doctor's appointments. I didn't know there was such a thing as late effects and I also wasn't told about it. So I ended up with an unpleasant surprise after my treatments. I would've really appreciated it if this tool would've been available for me back then. So I could've asked these questions, e.g., about possible late effects. I'm glad we are able to help other women now who are in the same situation as I was back then."

Prof. Dr. Murat Gultekin, gynaecological oncologist, onco-surgeon, Turkey, ESGO-ENGAGe Co-Chair:

"This brochure showed me how little information we share with our patients when we start several therapies. I hope these questions and answers will be routinely evaluated by physicians before they start any type of treatment with their patients. It is the patient's right to ask and learn before they decide; it is our responsibility to explain and to respect their concerns."

Icó Tóth, cervical cancer survivor, Mallow Flower Foundation, Hungary, ESGO-ENGAGe Co-chair:

"We must ask! We must ask for our lives. Sometimes we need to be our own manager in the disease, and all information is crucial because we don't know which piece can send us in the right direction. Asking is not easy when we are the patient. Sometimes we need help for this, and not just to ask, but to understand the answers. With ENGAGe, we hope this brochure will help you ask questions and also to focus on the answers! Never be afraid to ask—there is no bad or stupid question!"

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Contact information of ENGAGE

Webpage: https://engage.esgo.org/
Email: engage@esgo.org
Facebook: https://www.facebook.com/groups/155472521534076/about/

ENGAGe recommends contacting your local patient association!

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