



PATIENT PERSPECTIVES ON LIVING WITH ENDOMETRIOSIS

Before choosing one or more topics please take a moment to answer the following questions. We will use this information to write a short introduction to your story:

- Name
- Age
- Place of residence
- Occupation, hobbies, family, children, spouse, volunteer work etc.

Example: *My name's Cassy, I'm in my mid-30s, I live in rural Texas, I'm a stay-at-home mom to my three children, and I love hiking.*

If you would rather remain anonymous then feel free to use a penname. Age, place of residence and the other personal information you provide can be as specific or as vague as you'd prefer. This information is useful as it will provide a backdrop to your perspective, which will help the reader to relate to your experiences.

Now select one or more of the following topics (or come up with your own topic):

1. Journey to diagnosis
2. The symptoms of endometriosis
3. The impact of endometriosis
4. Endometriosis and infertility
5. Finding an excision specialist
6. Effective and ineffective treatments
7. Surgery experiences
8. Accessing optimal treatment
9. Surgery survival guide
10. Life after endometriosis
11. Tips from patient to patient

In the next pages you'll find a set of questions per topic to help guide you when writing/recording your patient perspective (you can choose to focus on just a small number of these questions if you'd prefer). If you'd rather use your own structure, that's also fine – these pointers are just here to help. The most important thing is to write or tell your story as you have experienced it, focusing on the details that were most poignant to you.

1. Journey to diagnosis

- Start from the very beginning... how did it all start? When did you first think something was wrong? When and how did you first start searching for an answer? Did those around you take you seriously? If not, what explanation were you given for your difficulties? What tests did you undergo? How long did the process take? How did you feel when you were finally diagnosed (or perhaps you are still in this process)?
- For some women the diagnosis may have come out of the blue as an unexpected discovery during another surgery or during a routine exam – if so, how did this feel?
- What were your hopes/fears when you first heard you had endometriosis? Did you understand what it was? Did you already know about the disease? Were those around you understanding when you received the news?
- For those with a diagnostic delay – what impact has this had on you? Do you think had you been diagnosed earlier things would have turned out differently? What would you say to doctors to help them diagnose their patients sooner? What advice would you give to other women who are currently seeking a diagnosis?

2. The symptoms of endometriosis

- When did your symptoms start? At what age? Can you describe how it felt? How did they affect you and what did you and/or others do about them?
- Did your symptoms change over time? If so, how? Did the strategies to deal with your symptoms adapt as your symptoms worsened/changed?
- Were those around you understanding of your symptoms?
- By symptoms we don't just mean pain but also any other symptoms related to the disease (or related conditions) – frequent bouts of illness, fatigue, bowel obstructions... bladder and bowel issues, the side-effects of the medications and so on.
- In the case of multiple sources of pain (endometriosis, adenomyosis, and adhesions, for example), could you distinguish between these different types of pain?

3. The impact of endometriosis

- How has this disease affected your life and the life of those around you? Has it stopped you from doing the things you wanted to do (school, career, starting a family, leisure, hobbies...)?
- What did you miss out on due to having endometriosis?
- For those who have had relief from surgery or other treatments, what difference has this made to your quality of life – have you been able to 'catch up' on the things you missed?
- Have you gained anything from having this disease (this might sound odd... but this could be support, new friendships, a different perspective on life)?

4. Endometriosis and infertility

- Has endometriosis and/or adenomyosis (or the treatments for these conditions) impacted upon your fertility?
- Perhaps you are a young woman and you do not yet know whether you will have difficulties conceiving or not but would like to share about your hopes and fears in this regard?
- Perhaps you have not had problems conceiving but were pressured into moving plans for children forward or told you would never conceive yet you did anyway – what impact has this had on you?

- For those who have faced infertility or the loss of your reproductive organs, what has this meant to you? Have others been understanding of this loss?
- For those who have undergone infertility treatments in relation to endometriosis, what was this experience like for you? Was it successful?
- Have you adopted or fostered children or are you in the process of doing this? Can you describe how this process has been for you? How did you reach this decision? Was it easy or challenging?
- Coming to terms with unwanted childlessness: can you write about this process? Do you feel understood by the wider community about this side of your illness?

5. Finding an excision specialist

- For those who have had excision surgery, how did you hear about this special type of surgery and how did you go about searching for a specialist? What questions did you ask before going ahead and how did you decide your surgeon was the right one for you? Was it a good decision or do you regret it? Did it involve traveling far for treatment and/or financial hardship?
- For those who are still in this process – what are your hopes and what are your fears?
- For those who have had excision surgery, what difference has this surgery made to your life?
- Do you wish you had opted for excision earlier?
- What tips would you offer other women to help them find a good surgery to provide optimal treatment as early as possible?
- How did your local OBGYN/GP respond when you said you would go elsewhere for treatment? Did they refer you to your specialist? Were they supportive of your decision and did they provide support after your surgery?

6. Effective and ineffective treatments

- What treatments have you undergone until now? (surgical, medical, and/or alternative)
- Which were effective and which were not?
- Did some treatments help but only for a short while?
- Did some make your symptoms worse?
- Did you experience any side effects or complications from the treatments you underwent?
- Are there any treatments you have tried which you regret undergoing?
- Have you made other lifestyle changes to help manage your symptoms? If so, which and have they helped?

7. Surgery experiences

- Prior to surgery: were you well prepared? What were your thoughts/concerns/hopes about the surgery? Did you feel your surgeon prepared you well and answered all your questions or did you feel rushed at the pre-op appointment or left uninformed? Did he/she explain what he was going to do or was this unclear? Was the information you were given accurate?
- How was the bowel prep (if you underwent this) – do you have any tips for others undergoing this procedure?
- How did you feel on the day of surgery? How did you feel when you came round? How was your hospital stay?

- What happened during your surgery? What type of surgery was it (traditional laparoscopy, robotic laparoscopy, mini-laparotomy, laparotomy... etc.)? How long was it? How long was your hospital stay?
- Did you have any complications from the surgery? Did you have much pain post-op and was this managed? Did the surgery create any new problems?
- How was the long-term recovery? How long until you felt back to normal again? Was it easy returning to normal activities again? How about the emotional side (for example in the case of hysterectomy)? How did you adjust to this?
- At what point did you find out about the result of the surgery? Did the surgery help? If you had persistent problems, did your surgeon help or was he/she dismissive? Were the results of surgery as expected?
- Specific experiences: bowel resection, removal of diaphragmatic/thoracic disease, adhesiolysis/2nd look surgery, having a stent due to ureter resection/damage.
- How did those around you respond to your surgery – were they understanding during your recovery?

8. Accessing optimal treatment

- What difficulties did you encounter in accessing optimal treatment?
- Was it hard on you financially?
- Did you have issues with insurance coverage?
- Was there a specialist available in your local area/country or did you need to travel to get specialist treatment?
- Was your local doctor supportive of you going to a specialist?
- Did you have to travel far, and if so did you do this alone or with a friend/family member? What issues did this present?
- Are you still having difficulties in accessing optimal care? If so, what difficulties? In your view, what needs to change in this regard to make it easier for women like you to get the care they need?

9. Surgery survival guide

- What tips would you give to other patients who are preparing for surgery?
- How much time to take off?
- What to take with them to the hospital?
- What questions to ask at the pre-op?
- How to prepare for the bowel prep?
- How to deal with the post-op recovery as best as possible?
- Tips when traveling out of state/abroad for surgery?
- Tips following bowel surgery?
- Tips following bladder surgery?
- Tips following thoracic surgery?
- Are there things you would have done differently with your own surgery had you known better?

10. Life after endometriosis

- For those who are cured of endometriosis (i.e. the disease was successfully removed during excision surgery with no recurrence), how is life now? Are you completely better? Or do you still have problems, and if so what kind of problems?
- What are the things you can do now that you couldn't before?

- Do you believe you are 'cured' – what is your personal perspective on this question?

11. Tips from patient to patient

- What tips would you offer to other women in the same boat to help them on their journey to symptom relief? i.e. getting diagnosed, being taken seriously, coping with the symptoms, explaining to others about this disease, and getting the best of treatment.
- Do you have any words of encouragement to help motivate others not to give up? What has kept you going through the tough times? What was the best thing you did to help yourself during this journey? How have you overcome the biggest challenges of this disease?

Thanks for your help!