



Treating
Your
Endometriosis

The 'Treating Your Endometriosis' Survey 2008

*Helping Us All Gain A Greater
Understanding of Endometriosis.*

Shelley Ross

Author of [Treating Your Endometriosis](#)

A survey by Endometriosis Sufferers for Endometriosis Sufferers

Discover the remedies fellow sufferers recommend, what lifestyle changes help...

And the triggers to avoid.

***Disclaimer:** All material in this report is provided for information only and may not be construed as medical advice or instruction. No action or inaction should be taken based solely on the contents of the survey findings. Instead readers should consult their physician or other qualified health professionals on any matter relating to health and well-being. Readers who fail to consult with appropriate health authorities assume the risk of any injuries. The publisher is not responsible for errors or omissions. Reference herein to any specific commercial product, process, or service by trade name, trademark, manufacturer, or otherwise does not necessarily constitute or imply its endorsement, recommendation, or favoring by the publisher.*

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Survey Summary

An invitation to complete The Treating Your Endometriosis Survey 2008 was sent to a total of 3972 newsletter subscribers in March 2008. Of these people around 624 are considered to be 'very active' subscribers based on email newsletter opening rates.

The survey ran between the 4th March and the 11th March 2008 and a total of 274 people completed the survey, which is 6.9% of the total number contacted, but 44% of the estimated 'very active' group.

The aim of the survey was to identify the respondents' experience with Endometriosis, to gather their thoughts on both treatments and remedies and what their overwhelming area of concern was.

The high level summary of all the results are:

The respondents were mainly females aged between 26 - 45, with 94% of the respondents having had Endometriosis formally diagnosed.

32% of the respondents had suffered with Endometriosis for over 10 years, with "Pain before and during menstruation" being the most common symptom.

47% of respondents reported no known effect on fertility as a result of their Endometriosis and 58% answered 'no' when asked if there was a hereditary link to their condition.

When given a list of common Endometriosis drugs/medical treatments to rate in terms of effectiveness (1 being 'not effective' and 5 being 'very effective'), 5 treatments scored above average and 4 scored below average. GnRH Agonists (i.e. Lupron, Zoladex) were rated as the most effective medication with an average score of 3.4.

A selection of natural products for Endometriosis was also rated in terms of effectiveness (1 being 'not effective' and 5 being 'very effective'), 7 products scored above average and 4 scored below average. Heat pads were rated the most effective with an average score of 3.4, followed by Naturopathic treatments with 3.2.

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The responses relating to managing Endometriosis symptoms through diet were interesting. The majority of survey respondents (34%) said that they are mostly careful about what they eat. However a further 32% don't manage their Endometriosis symptoms with careful diet choices.

From the responses there are a number of common trigger foods that can make symptoms flare up. The top three trigger foods and beverages were identified as:

- Dairy products
- Caffeine
- Alcohol

When asked which products, services or information the respondents found most helpful in coping with Endometriosis symptoms 21% of respondents said information provided in the Treating Your Endometriosis newsletter, blog, email and downloadable book.

Note: these results should be viewed in context as it was the "Treating Your Endometriosis" newsletter subscribers who were asked to complete the survey.

When asked to rate certain products, if made available, which would be most useful, the respondents chose 'Pain Elimination Methods for Endometriosis Sufferers' and the second choice was a 'Monthly Endometriosis newsletter with recipes, natural remedies & tips'.

The top three tips for dealing with Endometriosis symptoms were as follows:

- 1.** Educate yourself about your condition
- 2.** Avoid 'trigger' foods and eat a nutritious diet with minimal processed foods
- Joint 3.** Remove stress from your life and learn to relax
- Joint 3.** Find a doctor/surgeon/consultant who is experienced in dealing with endometriosis - ask for referrals

The final question dealt with the respondents biggest concern. There were many different questions, but the one asked the most was 'How does endometriosis start and where does it come from?'

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The Survey Results in Detail:

The questions and answers are detailed below with the answers displayed in both text and graph form (where applicable), along with a brief explanation of the findings.

Where open-ended free form questions were asked, only the most common answers have been included in the survey. The remaining details can be found in the appendices.

Please feel free to pass a copy of this survey onto anyone you feel may be interested in the information.

Alternatively send them to the following website where they can sign up for a free newsletter and get a complimentary copy of the Survey Report:

<http://www.treatendometriosis.com>

Thank you again to all those who took part in The Treating Your Endometriosis Survey 2008, your input has been invaluable.

Shelley Ross

Shelley Ross

Author: [Treating Your Endometriosis](#)

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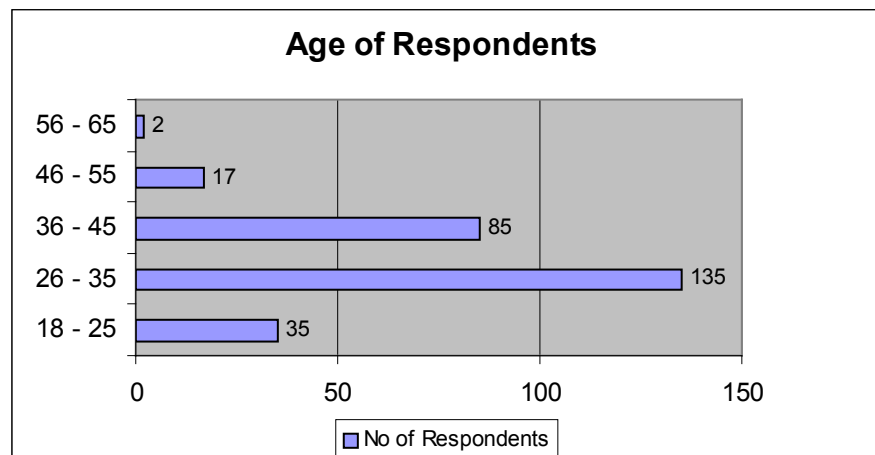
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1. The first question asked was to determine the respondents age.

Age	No of Respondents	Percentage
18 - 25	35	13%
26 - 35	135	49%
36 - 45	85	31%
46 - 55	17	6%
56 - 65	2	1%
66+	0	0%



What Does This Mean:

The results show that the majority of Endometriosis sufferers are aged between 26 and 45. There could be a number of reasons for this result:

1. That there are more people in this age group subscribed to The Treating Your Endometriosis Newsletter.
2. People within this age group who are subscribed to Treating Your Endometriosis Newsletter are more likely to answer surveys.
3. Endometriosis can occur at any age after puberty, however it is commonly diagnosed in women between the ages of 20 and 40, which ties in with the survey results. This could be because Endometriosis can be easily misdiagnosed leading to patients suffering for many years before receiving their diagnosis.

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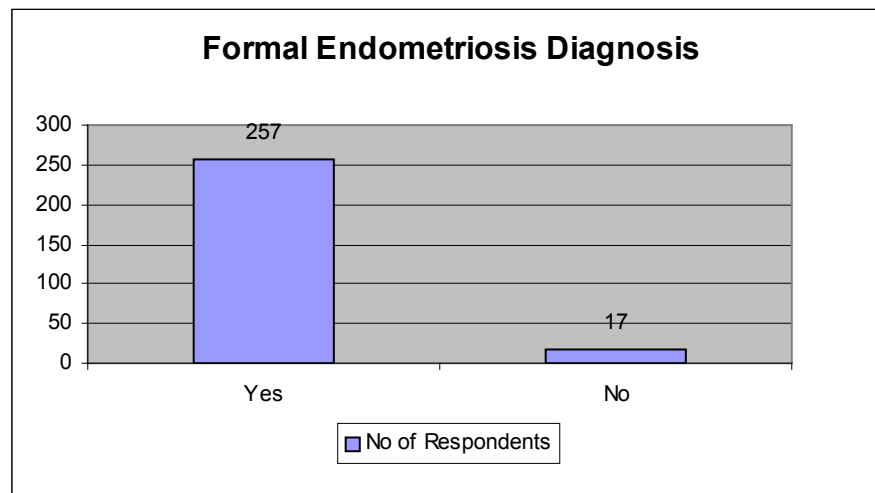
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2. The second question determined how many women have had their Endometriosis formally diagnosed.

	<u>No of Respondents</u>	<u>Percentage</u>
Yes (diagnosed)	257	94%
No (not diagnosed)	17	6%



What Does This Mean:

The vast majority of survey respondents have had Endometriosis formally diagnosed.

This is an encouraging result as Endometriosis is often misdiagnosed and women suffer for many years before finding out the cause of their symptoms.

These results don't show how long women had their symptoms for before finally receiving an Endometriosis diagnosis.

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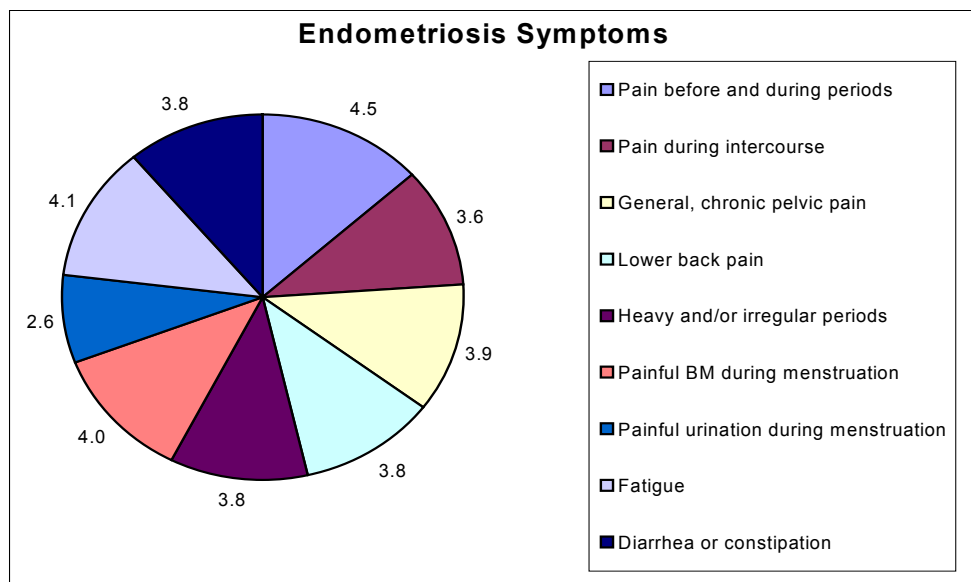
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3. In Question 3 respondents were asked to rate the following Endometriosis symptoms according to frequency of occurrence with 1 being 'rarely' experienced and 5 being experienced 'most frequently'.

Rating

Pain before and during periods	4.5
Pain during intercourse	3.6
General, chronic pelvic pain	3.9
Lower back pain	3.8
Heavy and/or irregular periods	3.8
Painful Bowel Movements during menstruation	4.0
Painful urination during menstruation	2.6
Fatigue	4.1
Diarrhea or constipation	3.8



What Does This Mean:

Pain before and during periods is the most frequent, followed closely by fatigue and painful bowel movements during menstruation. These symptoms are similar to those associated with other conditions like IBS or Pelvic Inflammatory Disease, which can contribute to difficulties in getting Endometriosis diagnosed.

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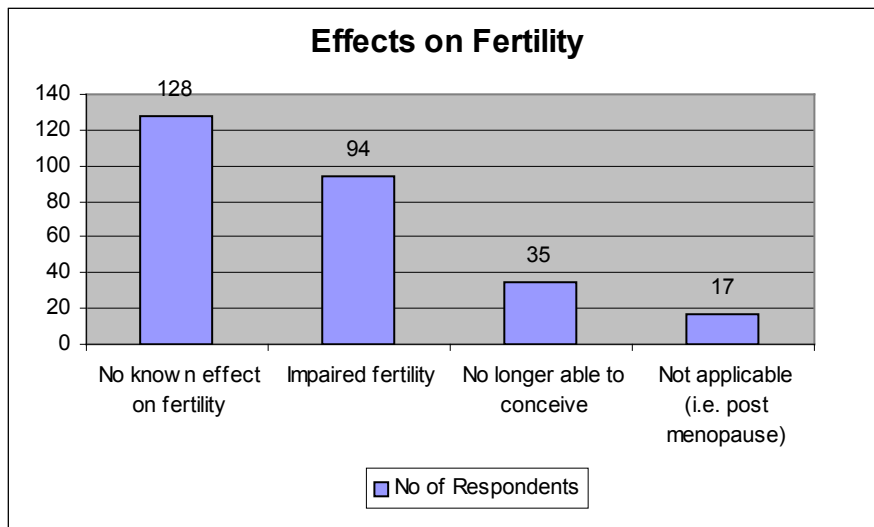
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4. **One of the complications of Endometriosis is the impact it can have on fertility. This question asked respondents to assess the impact Endometriosis has had on their fertility.**

	<u>No of Respondents</u>	<u>Percentage</u>
No known effect on fertility	128	47%
Impaired fertility	94	34%
No longer able to conceive	35	13%
Not applicable (i.e. post menopause)	17	6%



What Does This Mean:

For those women for whom fertility is likely to be a concern the numbers are evenly split between those who have no known effect on fertility and those who have impaired fertility or are now infertile as a result of Endometriosis.

Unfortunately due to the hormonal nature of Endometriosis many treatments suppress fertility to relieve symptoms. For women wanting to become pregnant the limited treatment options currently available are reduced even further.

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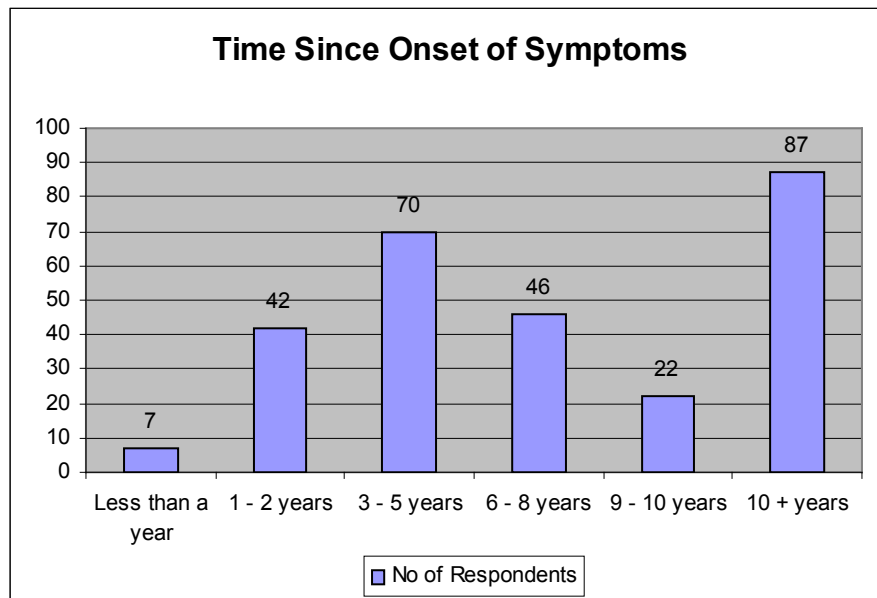
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5. Question 5 asked respondents to select how long they have been suffering with Endometriosis symptoms.

	<u>No of Respondents</u>	<u>Percentage</u>
Less than a year	7	3%
1 - 2 years	42	15%
3 - 5 years	70	26%
6 - 8 years	46	17%
9 - 10 years	22	8%
10 + years	87	32%



What Does This Mean:

With a majority of respondents (32%) reporting ongoing symptoms of Endometriosis for over 10 years it is clear that sufferers have to discover methods that reduce symptoms for the long term, as the condition is often a lifelong problem.

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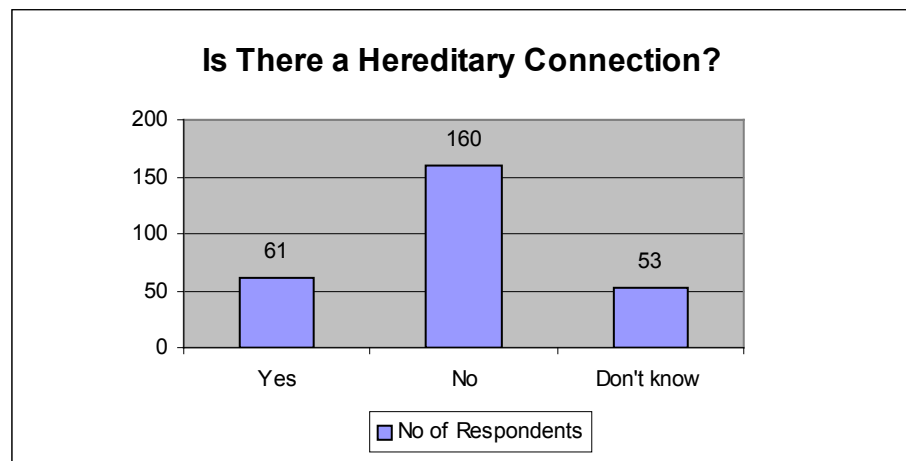
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6. In question 6 respondents were asked about hereditary links that may exist, with the question 'Have any other members of your close family been diagnosed with Endometriosis? I.E. your mother, sister, grandmother or daughter?'

	No of Respondents	Percentage
Yes	61	22%
No	160	58%
Don't know	53	19%



What Does This Mean:

A hereditary link is one of the theories regarding the cause of Endometriosis.

But as you can see from the results the majority of women (58%) responded with 'No' when asked whether close a female relative suffered with Endometriosis.

However, 22% of women do have a close family member also with Endometriosis, so for these women it could indicate a hereditary link or possibly a shared environmental link.

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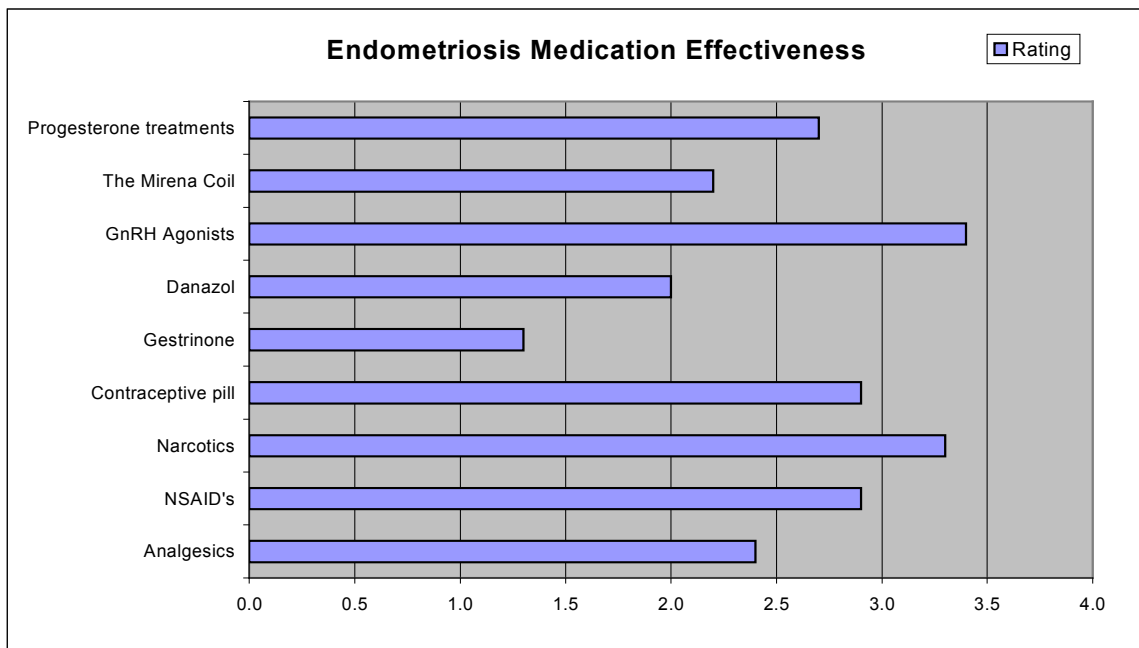
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7. Question 7 asked the respondents to rate the medications listed below in terms of effectiveness with 1 being 'not effective' and 5 being 'very effective'.

Rating

Analgesics (i.e. aspirin and paracetamol)	2.4
NSAID's (i.e. nurofen, volteren etc)	2.9
Narcotics (i.e. codeine)	3.3
Contraceptive pill	2.9
Gestrinone	1.3
Danazol	2.0
Gonadotrophin Releasing Hormone (GnRH) Agonists (i.e. Lupron)	3.4
The Mirena Coil	2.2
Progesterone treatments (i.e. Duphaston, Provera, Depo-provera)	2.7



What Does This Mean:

Of the 9 medical treatment options listed 4 failed to score over 2.5, meaning that in this survey, they failed reach an average score for their effectiveness. Of the 5 medications that did score above average, GnRH Agonists (e.g. Lupron) were considered to be the most effective (3.4 out of 5)

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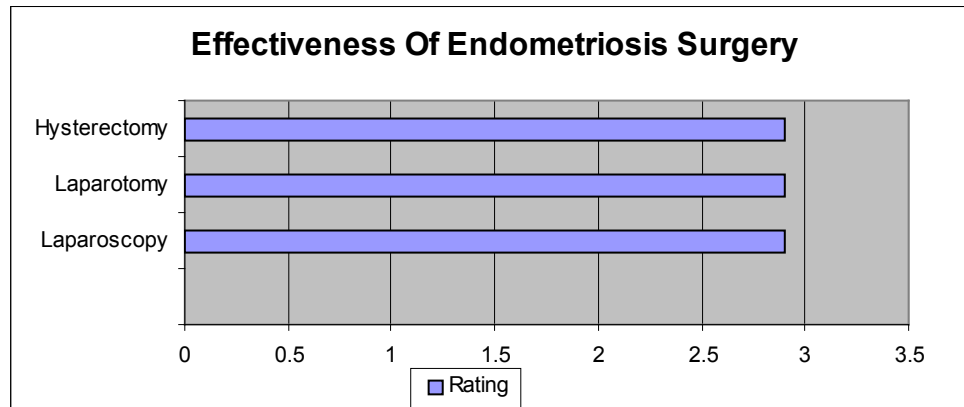
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8. Respondents were asked whether they had undergone any surgery for Endometriosis by rating it's effectiveness in terms of symptom relief, with 1 being 'not effective' and 5 being 'very effective'. If they hadn't had surgery they were requested to go to Question 10.

	<u>Rating</u>
Laparoscopy	2.9
Laparotomy	2.9
Hysterectomy	2.9



What Does This Mean:

While the three different forms of surgical treatment for Endometriosis all scored the same in terms of effectiveness, the results are not very encouraging as they are only just above average.

From this result it could be concluded that surgery does not provide the whole solution to managing Endometriosis symptoms.

This assumption is backed up by the answers to question 9 below.

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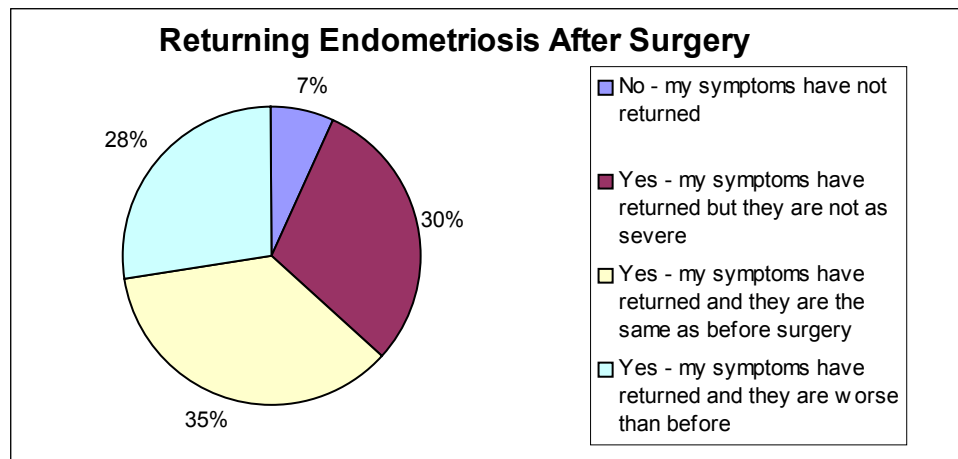
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9. Following on from Question 8, those respondents who had undergone surgery were asked if their Endometriosis symptoms had returned and to assess the severity of the returning symptoms.

	<u>No of Respondents</u>	<u>Percentage</u>
No - my symptoms have not returned	16	7%
Yes - my symptoms have returned but they are not as severe	69	30%
Yes - my symptoms have returned and they are the same as before surgery	83	36%
Yes - my symptoms have returned and they are worse than before	64	28%



What Does This Mean:

With 78% of respondents having returning symptoms after surgery explains the low ratings surgical treatment achieved in question 8.

From question 9's results it is apparent that surgical treatment is not effective for many sufferers and that women choosing to undergo surgical treatments should be made aware of the high possibility of symptoms returning. In just over a quarter of cases the symptoms returning worse than they were before surgery.

It would be prudent for sufferers to fully explore other medical and alternative treatments before opting for surgery.

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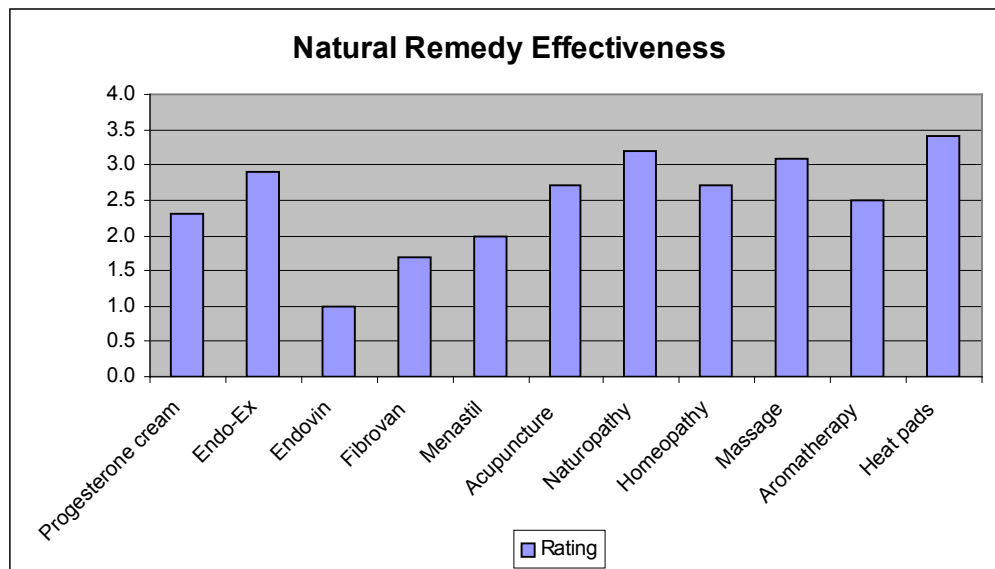
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10. Question 10 asked the respondents to rate the natural products listed below in terms of effectiveness with 1 being 'not effective' and 5 being 'very effective'.

	<u>Rating</u>
Progesterone cream	2.3
Endo-Ex	2.9
Endovin	1.0
Fibrovan	1.7
Menastil	2.0
Acupuncture	2.7
Naturopathy	3.2
Homeopathy	2.7
Massage	3.1
Aromatherapy	2.5
Heat pads	3.4



What Does This Mean:

Heat pads and Naturopathy scored the highest for effectiveness, outstripping the surgical options and on a par with Endometriosis medications. This indicated that natural options are potentially more or just as effective as surgical and medical treatments. They also tend to come with less side effects.

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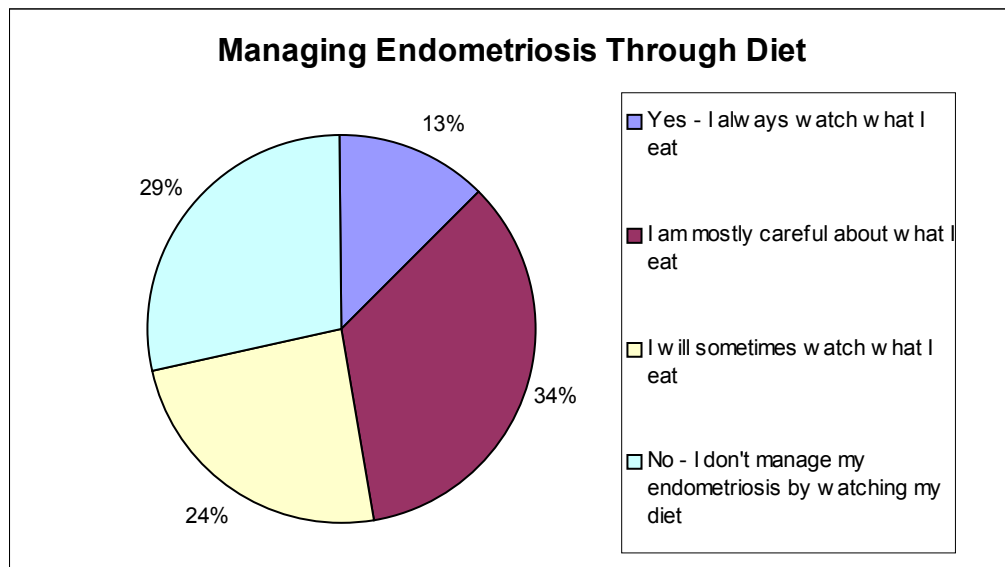
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11. Question 11 was asked to determine if Endometriosis sufferers managed their symptoms by watching their diet and avoiding items they know will cause symptoms to flare-up? Respondents were asked to select the option that was most applicable.

	<u>No of Respondents</u>	<u>Percentage</u>
Yes - I always watch what I eat	35	13%
I am mostly careful about what I eat	94	34%
I will sometimes watch what I eat	66	24%
No - I don't manage my endometriosis by watching my diet	78	29%



What Does This Mean:

The majority of sufferers either don't or only sometimes watch what they eat and manage their symptoms through diet.

This question, when considered in conjunction with question 12 suggests that many women could be experiencing an increased level of symptom relief if they maintained an Endometriosis 'friendly' diet.

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12. Question 12 asked respondents to list the top three 'trigger' foods or beverages they have identified as having a worsening effect on their Endometriosis symptoms.

<u>Endometriosis Triggers</u>	<u>No of Respondents</u>
Dairy products	31
Caffeine	23
Alcohol	21
Wheat products (gluten)	20
Red meat	16
Sugar/Sweet foods	16
Breads	15
Fried or fatty foods	15
Coffee	14
Chocolate	13
Spicy foods	11
Soda/carbonated drinks	10
Phytoestrogen foods (I.e soy)	8
Processed foods	6
Fast/Junk foods	6
Pasta	4
Yeast (including marmite)	3
Salty foods	3
Citrus fruits	3
Carbohydrates	3

What Does This Mean:

These items above are commonly ones that are suggested as items to avoid for Endometriosis sufferers. So, although the majority of respondents said they didn't or only sometimes watched what they ate (see question 11) most appear to be aware of the items that effect their symptoms and should be avoided.

A full list of trigger foods from respondents can be found in the Appendices at the end of the report.

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13. Question 13 asked respondents whether there were any particular products, services or information that they have found helpful in managing or reducing Endometriosis symptoms.

No of Respondents

Treating Your Endometriosis newsletter	58
Internet Research	31
Books	15
Endometriosisassn.org	9
Doctor/Consultant	9
NZ Endo Foundation	7
Endo Ex	6
Newsletters	6
Mary Lou Ballweg books	5
Information from Doctors/Gynecologist	5
Evening Primrose	4
Birth control pills	4
Endometriosis support groups	4
Endometriosis-uk.org	4
Acupuncture	3
Endometriosis: Natural & Medical Solutions by Kaz Cooke and Ruth Trickey	3
Heat pads	3
Living Well with Endometriosis: What Your Doctor Doesn't Tell You...That You Need to Know by Kerry-ann Morris	3
Endometriosisissurgeon.com	3
Webmd.com	3

What Does This Mean:

Nearly a quarter of all respondents named The Treating Your Endometriosis newsletter and downloadable book as the most helpful resources.

However, these results should be viewed in context, as the survey was completed solely by subscribers to the Treating Your Endometriosis Newsletter.

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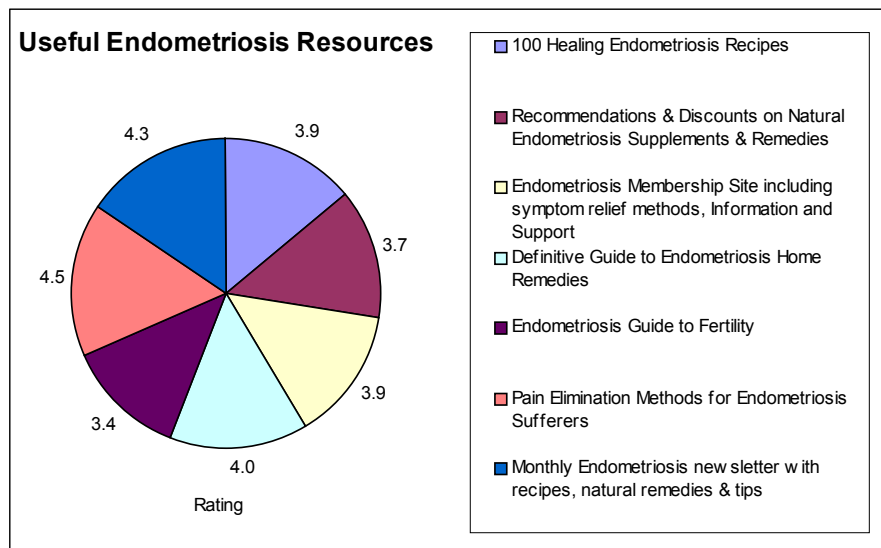
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14. In an effort to discover what information Endometriosis sufferers needed the most, respondents were asked to rate the suggestions below from 1 to 5 (1 being 'not useful' and 5 being 'very useful')

	<u>Rating</u>
100 Healing Endometriosis Recipes	3.9
Recommendations & Discounts on Natural Endometriosis Supplements & Remedies	3.7
Endometriosis Membership Site including symptom relief methods, Information and Support	3.9
Definitive Guide to Endometriosis Home Remedies	4.0
Endometriosis Guide to Fertility	3.4
Pain Elimination Methods for Endometriosis Sufferers	4.5
Monthly Endometriosis newsletter with recipes, natural remedies & tips	4.3



What Does This Mean:

The information that Endometriosis sufferers would find most helpful would be 'Pain Elimination Methods for Endometriosis Sufferers', with the least helpful being a guide to Fertility.

Given the pain experience by many sufferers the top result was expected, however it was surprising to find that an Endometriosis Guide to Fertility scored the least favorable result. From this it could be concluded that for many sufferers relieving the pain is the main focus of their treatment, rather than preserving or enhancing fertility.

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15. In Question 15, respondents were asked to provide the best tip they would give someone who has been newly diagnosed with Endometriosis.

The answers were grouped, where applicable and the following is a summary of the answers with 6 of more recommendations. The remaining tips can be found in the Appendices.

No of Respondents

Educate yourself about your condition	57
Avoid 'trigger' foods and eat a nutritious diet with minimal processed foods	57
Remove stress from your life and learn to relax	33
Find a doctor/surgeon/consultant who is experienced in dealing with endometriosis - ask for referrals	33
Exercise is a good pain reliever	26
Join a support group or forum to stay in touch with other women with endometriosis	25
Remain positive and don't give up	22
Use a hot water bottle or heat pad on your abdomen to ease the pain	16
Listen to your body - only you know how you feel.	15
Don't feel alone - lots of women suffer with endometriosis	10
Educate your family and friends about Endo so they know what you're going through and can be more understanding when you're in pain	10
Involve your partner with your medical appointments. This way they will have a greater understanding of your condition.	10
Don't give up in trying to find a specialist that works for you	9
Try Natural and Herbal remedies before medication and surgery	8
If you suspect endometriosis raise it with your doctor straight away	7
Having a supportive spouse and family can make all the difference	6
If a treatment isn't working, don't give up, try something else	6
Remember not to let endometriosis take over your life - make an effort with your appearance and clothes to give yourself confidence and to feel sexy	6
Take BCP to control endometriosis	6

What Does This Mean:

For the majority of women their best tips are to educate yourself about your condition and to avoid trigger foods and eat an Endometriosis “friendly” diet. With no medical cure for Endometriosis, knowing as much as possible about the condition will enable women to make informed choices about which treatments they choose to follow.

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16. The final question of the survey asked respondents to enter the ONE question they would like answered about Endometriosis:

The answers were grouped, where applicable, and the following is a summary of the questions asked by 4 or more people. The remaining questions can be found in the Appendices.

No of Respondents

How does endometriosis start and where does it come from?	45
Is there or will there be a cure?	36
How can I control the pain?	21
How to control fatigue/ lack of energy?	15
How can I get pregnant?	9
Why some people get it and others don't?	7
Why is endometriosis often misdiagnosed for years?	7
How does it effect fertility?	7
How to stop endometriosis returning after laser surgery?	6
How to prevent Endometriosis?	6
How can I increase fertility?	6
Will it ever go away on its own?	5
Why don't doctors know more about endometriosis?	5
What is the best treatment for endometriosis	5
Can I get pregnant?	5
What are the symptoms of endometriosis?	4
Is it progressive / does it get worse?	4
Does it come back?	4
Does endometriosis effect a baby's development/cause pregnancy complications?	4
Can Endometriosis occur after a hysterectomy?	4

What Does This Mean:

Perhaps not surprisingly the most important question that 45 people (or 16% of the survey respondents) want to know is how Endometriosis starts and where it comes from. This is not surprising, as despite research, the medical community is unsure why some women develop Endometriosis and others don't

This is closely followed by whether there will ever be a cure, which no doubt ties in with the 3rd most popular question regarding pain relief.

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Appendix i

Question 12 – Full list of trigger foods:

Endometriosis Triggers No of Respondents

Dairy products	31
Caffeine	23
Alcohol	21
Wheat products (gluten)	20
Red meat	16
Sugar/Sweet foods	16
Breads	15
Fried or fatty foods	15
Coffee	14
Chocolate	13
Spicy foods	11
Soda/carbonated drinks	10
Phytoestrogen foods (I.e soy)	8
Processed foods	6
Fast/Junk foods	6
Pasta	4
Yeast (including marmite)	3
Salty foods	3
Citrus fruits	3
Carbohydrates	3
Cauliflower	2
Beans	2
Broccoli	2
Tea	2
Cold/frozen foods	2
Potatoes	2
Rice	2
Food high in prostagladins I.e. beef, peanuts etc	1
Cabbage	1
Artificial preservatives	1

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Artificial sweeteners	1
Green peppers	1
Apple juice	1
Cereals	1
Red colored foods	1
Hot drinks	1
Chemicals I.e. glue, cleaning products etc	1

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Appendix ii

Question 13 – Full list of helpful Endometriosis Resources

<u>Endometriosis Resources</u>	<u>No of Respondents</u>
Treating Your Endometriosis newsletter58	
Internet Research	31
Books	15
Endometriosisassn.org	9
Doctor/Consultant	9
NZ Endo Foundation	7
Endo Ex	6
Newsletters	6
Mary Lou Ballweg books	5
Information from Doctors/Gynecologist5	
Evening Primrose	4
Birth control pills	4
Endometriosis support groups	4
Endometriosis-uk.org	4
Acupuncture	3
Endometriosis: Natural & Medical Solutions	
by Kaz Cooke and Ruth Trickey	3
Heat pads	3
Living Well with Endometriosis: What Your Doctor	
Doesn't Tell You...That You Need to Know by Kerry-ann Morris	3
Endometriosisurgeon.com	3
Webmd.com	3
Endometriosis: A Natural Approach - by Jo Mears	2
Massaging your abdomen in the morning with (cod liver) oil	2
Vitamin C high dose/1mg a day	2
Endoknow.com - currently not working	2
Endo-resolved.com	2
Endometriosiszone.org	2
Pain relief meds (including Percocet & acetametaphine)	2
Endometriosis - Healing through Diet and Nutrition by Dian Mills	2
Take a warm bath	2
Hot water bottle on lower stomach to ease pain	2
Hystersisters.com	2
Taking regular exercise	2
Reflexology	2

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Consulting a Naturopath	2
Women's Bodies, Women's Wisdom by Dr Christine Northrup	2
Dual Action' body cleanse	1
Wild Yam root	1
Endometriosis In the Uk	1
B-Complex with calcium, effective at eliminating endo growth	1
Raspberry leaf tea at night	1
Avoid dairy	1
Avoid products containing wheat	1
Milk thistle	1
Vitamin E 300iu per day	1
Avoid processed foods	1
Avoid stress	1
Hormone Balance Made Simple by Dr John Lee	1
Chasteberry capsules	1
Coping with Endometriosis: A Practical Guide by Robert Philips	1
Cyproterone (hormone treatment)	1
Dong Quai	1
Drink warm boiled water	1
Echinacea for immune system support	1
Benefiber® for improved bowel function	1
Endofem (herbal product)	1
Pain diary to track symptoms	1
Endometriosis.org	1
Endosisters.org	1
Endocenter.org	1
Eat organic foods	1
Iron supplements	1
Vitamin B6	1
Cranberry extract	1
Stay hydrated	1
Become a vegan	1
Drcook.com	1
Add flax seeds to your foods and take flaxseed capsules	1
Johnleemd.com	1
Pure Encapsulations - Indole-3-carbinol 400mg	1
Natural Progesterone oil	1
Avoid gluten, dairy, additives, preservatives or processed foods	1
Avoid xenoestrogens in plastic, makeup etc	1

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Having the support and understanding of loved ones	1
What Doctors Don't Tell You wddty.com	1
Marilynglenville.com	1
Vitamin and Dietary supplements	1
mymonthlycycles.com to keep track of menstrual cycle and pain	1
The Oxford Clinic (Christchurch, NZ)	1
Taking Omega 3 supplements	1
SHE Trust	1
ivillage.co.uk	1
Renewed Balance progesterone cream	1
Homeopathy	1
Sitting on a cloth soaked in hot water	1
Endometriosis - A New Zealand Guide by Andrea Molloy	1
Realsavvymoms.com	1
Avoid sodas/carbonated drinks	1
Eat more vegetables	1
Holistic therapy	1
Castor oil packs	1
Womentowomen.com	1
Take up yoga	1
Chinese herbs	1
Obgyn.net	1
Endometriosisupport.com	1
Flora-Q 2 for improved digestion (Probiotics)	1
Endo Care Seminar (NZ)	1
Ginger Green Tea herbal infusion	1
Eat Right 4 Your Type by Dr. D'Adamo	1
The ABC's Of Superfoods, Unlocking Natures Mysteris	1

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Appendix iii

Question 15 – Full list of Endometriosis Coping Tips

<u>Endometriosis Coping Tips</u>	<u>No of Respondents</u>
Educate yourself about your condition	57
Avoid 'trigger' foods and eat a nutritious diet with minimal processed foods	57
Remove stress from your life and learn to relax	33
Find a doctor/surgeon/consultant who is experienced in dealing with endometriosis - ask for referrals	33
Exercise is a good pain reliever	26
Join a support group or forum to stay in touch with other women with endometriosis	25
Remain positive and don't give up	22
Use a hot water bottle or heat pads on your abdomen to ease the pain	16
Listen to your body - only you know how you feel.	15
Don't feel alone - lots of women suffer with endometriosis	10
Educate your family and friends about Endo so they know what you're going through and can be more understanding when you're in pain	10
Involve your partner with your medical appointments. This way they will have a greater understanding of your condition.	10
Don't give up in trying to find a specialist that works for you	9
Try Natural and Herbal remedies before medication and surgery	8
If you suspect endometriosis raise it with your doctor straight away	7
Having a supportive spouse and family can make all the difference	6
If a treatment isn't working, don't give up, try something else	6
Remember not to let endometriosis take over your life - make an effort with your appearance and clothes to give yourself confidence and to feel sexy	6
Take BCP to control endometriosis	6
Try acupuncture	5
Keep a diary of your symptoms to show your doctor/consultant together with meds taken so your condition can be effectively monitored	5
Take pain meds as soon as pain starts	5
Take warm baths or showers to ease the pain (try adding lavender)	5
Have surgery to remove endometrial implants	5
Try alternative therapies alongside traditional medical or surgical options	4
Try massages	4

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Natural cures work just as well, if not better than medicines	4
Try reflexology	4
Don't be pushed into a hysterectomy by the medical profession	3
Take Omega 3 (fish oils)	3
Take Endo-Ex daily	3
Purchase Treating Your Endometriosis and sign up for Shelley's newsletter	3
Take up Yoga	3
Try breathing exercises to help relax and control pain	3
Take flaxseed	3
Don't give up in trying to find a treatment that works for you	3
Don't suffer in silence - seek second opinions if your doctor doesn't offer much help	3
Tell your employer about your condition and that you're likely to have days off. This reduces the stress when you have to call in sick (again).	2
If you want to have children, start as early as possible to give yourself the best chance of conceiving	2
Take vitamin supplements	2
Try Agnus Castus to balance hormones	2
Boost your immune system	2
Avoid caffeine	2
Visit a naturopath or homeopath for guidance	2
Taking personal heat pads /thermo pads when you go out is great for unexpected pain as you can stick them to your skin under your clothes	2
Getting pregnant will stop symptoms	2
Avoid Wheat based products	2
Avoid hormone drugs - find hormone supporters instead	2
It gets easier	2
Drink Warm Drinks	2
Relax with a good book	2
Reduce or eliminate caffeine	1
Eat regularly to keep your energy levels up	1
When in pain roll up a pillow and lie on it. This places pressure on the lower abdomen and relieves the pain	1
Write down any questions you have before you go to the doctor and take notes of the answers during your appointment.	1
Take Tramadol for pain	1
Take Co codamol for pain	1
Take Flurbiprofen for pain	1
Try ginseng	1

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Have a laparoscopy for infertility	1
If you're young and want children, have a laparoscopy to remove endometriosis and follow it by taking Lupron or BCP to keep endometriosis at bay until you're ready to have children	1
If you have to have (or choose to have) a hysterectomy try and keep your ovaries as they are important for general health and strong bones	1
Try Chinese therapies	1
Take Evening Primrose oil daily	1
Avoid constipation as this makes symptoms worse	1
Try pilates	1
Keep your weight at a suitable level for your height and age	1
Take the two weeks on/two weeks off approach by Naturopath Phil Vanderzeil - Week one and two of splurging (drinking, eating etc) Week one starts on the first day of bleeding and weeks three and four of being really good to your body - making sure you're eating protein at every meal. Meals to be natural and simply prepared.	1
Apply castor oil packs	1
Avoid Xenoestrogens (found in plastics and meat)	1
Contact your doctor if symptoms change or worsen	1
Ibuprofen is an effective pain reliever	1
Full body cleansing	1
Drink Kombucha tea	1
Drink plenty of water so your body stays hydrated	1
Avoid Lupron Depot	1
The information on drcook.com is very useful	1
Aromatherapy is effective in reducing pain	1
Give up smoking	1
Take NSAID's before your period is due to keep pain at bay	1
Get a Tens machine to use at home	1
Get tested for Lyme disease as this can impact the immune system and may make symptoms worse or non-responsive to treatment	1
Try belly dancing to encourage blood flow to the stomach area	1
Treatments can take time to work so give it time for symptoms to improve before moving onto another treatment.	1
If you can, go private	1
Endometrial Ablation (surgical removal of endometrial tissue) reduces heavy menstrual bleeding	1
Pain management tapes and CD's	1
Get medical Insurance	1

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Don't get pushed into treatment	1
Take natural progesterone to manage estrogen levels	1
Take Pamprin	1
Formulate a pain management program	1
Insist on regular checks	1
Avoid Lupron - it encouraged mood swings	1
Make the most of pain free days	1
Carry out a liver cleanse to help break down the extra estrogen	1
Good quality sleep	1
Chamomile tea	1

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Appendix iv

Question 16 – Full list of questions asked

<u>Questions Asked</u>	<u>No of Respondents</u>
How does endometriosis start and where does it come from?	45
Is there or will there be a cure?	36
How can I control the pain?	21
How to control fatigue/ lack of energy?	15
How can I get pregnant?	9
Why some people get it and others don't?	7
Why is endometriosis often misdiagnosed for years?	7
How does it effect fertility?	7
How to stop endometriosis returning after laser surgery?	6
How to prevent Endometriosis?	6
How can I increase fertility?	6
Will it ever go away on its own?	5
Why don't doctors know more about endometriosis?	5
What is the best treatment for endometriosis	5
Can I get pregnant?	5
What are the symptoms of endometriosis?	4
Is it progressive / does it get worse?	4
Does it come back?	4
Does endometriosis effect a babies development/ cause pregnancy complications?	4
Can Endometriosis occur after a hysterectomy?	4
Why aren't governments doing more?	3
Is there an age that endometriosis stops?	3
What diet reduces endometriosis?	2
How to prevent further growth other than Birth Control Pill/ hormones?	2
How to cope with pain during bowel movements?	2
Does the pain get easier?	2
Can it be diagnosed or spotted through follow up tests without a laproscopy?	2
Am I at risk of other complications because of Endometriosis's effect on the body?	2
Why isn't there more that can be done naturally?	1
Why is endometriosis so hard to treat?	1
Why have I put on weight and have mood swings?	1

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Why isn't there more treatment centers?	1
Where can I go to talk to people about this?	1
What natural or home remedies are there?	1
What is vesicular endometriosis?	1
What are the different types of endometriosis I.e. adenomyosis?	1
Is there is link to thyroid problems?	1
Do food or hormones trigger it?	1
Is it common to also have back pain?	1
Is endometriosis related to trauma?	1
How to treat bladder endometriosis?	1
How to stop it spreading after survey?	1
How to live with endometriosis?	1
How to control bloating?	1
How much money is going into research?	1
How effective is Lupron in helping women remain fertile?	1
How does endometriosis spread to the abdomen?	1
How do you know it's endometriosis and not something more serious?	1
How do you know if your infertility is due to endometriosis?	1
How do I naturally stop my periods?	1
How can you get your sex drive back?	1
How can you control the growth of endometriosis cysts?	1
How can we make people take the condition seriously?	1
How can I reduce the pain during sex?	1
How can I preserve my fertility?	1
How can I help my liver to help my endometriosis?	1
Does it cause night sweats?	1
Does it cause lack of feeling and swelling in the vagina?	1
Does exercise really help? If so what kind?	1
Does endometriosis effect the digestive system?	1
Does acupuncture increase fertility?	1
Do prenatal vitamins make endometriosis worse?	1
Do endometriosis medication cause osteoporosis and what can be done to counter it?	1
Can it effect Crohn's disease?	1
Can I conceive after surgery?	1
Can Endometriosis turn cancerous?	1
Can endometriosis cause urinary/ bladder infections?	1
Can endometriosis cause blockages in the fallopian tubes?	1
Best remedy for endometriosis in the bowels?	1
Are there proven treatments for endometriosis that will permanently heal it?	1
Are there links with cancer?	1

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Are there herbs or vitamins to prevent getting endometriosis?	1
Are there any promising new treatments?	1
Are there any good doctors in South Carolina?	1
Are there any environmental links to endometriosis?	1
Are there any drugs in phase ii or phase iii trials for endometriosis?	1
Are birth Control Pills effective for severe endometriosis?	1
Are Agnus Castus and Milk Thistle effective treatments?	1

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