



endometriosis uk

the leading UK charity that supports women living with endometriosis

Endometriosis Diagnosis Survey 2011:

Jan 10th – Feb 4th 2011

Summary Findings

- On average it takes over 7.5 years to diagnose endometriosis
- Women wait nearly 2 years before visiting their GP about their symptoms
- GPs then took on average 4 years to refer the patient to a specialist
- It then takes a further 1 year 9 months to get a formal diagnosis
- Over 50% of participants waited more than 6 years for a diagnosis
- Less than 20% of those who responded received a diagnosis within two years
- One third of respondents waited at least 10 years, and 15% waited for over 15 years, to be diagnosed.

Reason for the Survey

Endometriosis is the second most common gynaecological condition, and is estimated to affect around 2 million women in the UK - around one in ten, though some health bodies suggest that this figure is much higher (possibly as many as one in every five women).

The condition can cause extreme pain and can therefore be debilitating for sufferers, but as symptoms vary greatly and often mimic symptoms of other diseases, it can be difficult to diagnose. Extreme fatigue is also very common.

Whilst there is no cure, once diagnosed, the condition – and the painful symptoms – can be treated, with different options available depending on the patient's circumstances.

Our 2005 survey (Pain Survey, TNS 2005), showed that in the UK it took 11 years to get a formal diagnosis of endometriosis (via laparoscopy) from the onset of symptoms. Feedback and input from our members and supporters indicated that difficulties and delays still existed. This survey has therefore enabled us to see how much or how little has changed since 2005.

What is Endometriosis?

Endometriosis (pronounced *end - oh - mee - tree - oh - sis*) is a condition where cells like the ones in the lining of the womb are found elsewhere in the body. Every month, hormones cause the cells in the womb lining to build up, then break down and bleed – this bleeding is then released from the body as a period.

Endometriosis cells react in the same way, but as the cells are outside of the womb, the internal bleeding, unlike a period, has no way of leaving the body. This leads to inflammation, pain, and the formation of scar tissue (adhesions). These adhesions can cause organs to stick together.

Endometrial tissue can also be found in the ovary, where it can form cysts, called 'chocolate cysts' because of their appearance.

- Endometriosis is not an infection.
- Endometriosis is not contagious.
- Endometriosis is not cancer.

Endometriosis can be found in almost any organ in the body though it is most frequently found in the pelvic area, around the womb, ovaries, bladder and bowel. The only place that endometriosis has not been found is the spleen. Whilst it is a very common condition, the symptoms experienced by each sufferer can vary greatly, often because of where the endometriosis occurs in the body. The most common symptoms are severe pain just before or during your period, heavy or irregular periods, painful bowel movements, fatigue, and pain during or after sex. Fertility may also be affected.

The only definitive way to diagnose endometriosis is through a surgical procedure called a laparoscopy, which involves a general anaesthetic and a camera being inserted through a small cut in the abdomen. Endometriosis may be suspected through other methods, e.g. ultra-sound or MRI scans, but visual confirmation is required.

Survey Details

- Number of Respondents: 2956
- Cleaned data: n=2890
(Note: Lines of data where one result gave a negative figure were removed before analysis and extremes were also taken out)
- Average age of respondents: 32.5 years
- Conducted via SurveyMonkey and promoted on Endometriosis UK website, Facebook page, Twitter and the Charity's e-newsletter
- Questions asked:
 1. What age are you now?
 2. What age were you when you first experienced symptoms?
 3. What age were you when you first went to your GP about these symptoms?
 4. What age were you when your GP referred you to a specialist/gynaecologist?
 5. What age were you when you received your diagnosis of endometriosis?

Final Diagnosis Overall Breakdown by years to diagnosis

No of Years	Responses	%	Percentages
0-1	225	7.79	}
1-2	348	12.04	19.83 }
2-3	300	10.38	} 48.17
3-4	179	6.19	28.34 }
4-5	175	6.06	}
5-6	165	5.71	}
6-7	158	5.47	}
7-8	150	5.19	}
8-9	124	4.29	18.96 }
9-10	116	4.01	}
10-11	137	4.74	}
11-12	98	3.39	}
12-13	93	3.22	} 51.83
13-14	69	2.39	}
14-15	90	3.11	32.87 }
15-16	60	2.08	}
16-17	50	1.73	}
17-18	58	2.01	}
18-19	49	1.70	}
19-20	49	1.70	}
20years +	197	6.82	}

n.= 2890

TOTAL Averages	From symptoms to diagnosis	From symptoms to GP	From GP to specialist	From specialist to diagnosis
	7.60	1.86	4.01	1.73

Average results for women whose diagnosis took 10 years or more	From symptoms to diagnosis	From Symptoms to GP	From GP to specialist	From specialist to diagnosis
	15.7	4.10	9.58	3.87

For further information, please visit www.endometriosis-uk.org to find more details on the specific aspects of the condition, its treatments or other ways that Endometriosis UK works to support anyone affected by endometriosis. Endometriosis UK is funded by membership subscriptions and fundraising contributions.

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