PUTTING THE FOCUS ON ENDOMETRIOSIS

UNDERSTANDING THE IMPACT OF COMPLEX CHRONIC DISEASES BEYOND DIABETES AND HYPERTENSION
WHAT IS ENDOMETRIOSIS?

ENDOMETRIOSIS IS A CHRONIC, DEBILITATING DISEASE IN WOMEN¹

Endometriosis happens when tissue lining the uterus grows elsewhere in the body and continues to grow and bleed as it normally does during the menstrual cycle.

Scar tissue and inflammation can result, causing pain and other complications, including fertility problems.

SYMPTOMS OF ENDOMETRIOSIS MAY INCLUDE*:

- Chronic and intense pelvic pain during and outside of menstruation¹
- Painful sex¹
- Heavy menstrual bleeding¹

*This list is not all-inclusive.

In one cross-sectional study of 638 participants who reported overall symptom severity at diagnosis²†:

- 54.5% of women reported severe symptoms
- 37.2% reported moderate symptoms
- 8.3% reported mild symptoms

†Results from an online, cross-sectional survey conducted from August 6, 2012 through September 14, 2012. Respondents aged 18 to 54 years who reported a physician’s diagnosis/suspicion of endometriosis within the previous 10 years were included.
WHO GETS ENDOMETRIOSIS?

ENDOMETRIOSIS AFFECTS WOMEN DURING THEIR REPRODUCTIVE YEARS

6%-10% of women of reproductive age are affected by endometriosis.³

- In addition to employees who have endometriosis, some employees may have covered family members, including wives or daughters, with the disease.

An estimated 4.1 million women age 18-49 years in the United States are diagnosed with endometriosis.⁴*

- Most often diagnosed in women in their 30s and 40s¹
- Average time to endometriosis diagnosis is up to 6-10 years⁵,⁶

Studies suggest there is a family component to endometriosis.⁷,⁸

- A member who has a first-degree relative with endometriosis may be ~7-10x more likely to develop endometriosis.

*Number derived from an online, cross-sectional survey that used 3 panels in which 48,020 women aged 18 to 49 years responded between August 6, 2012 through September 14, 2012, of whom 6.1% reported a diagnosis of endometriosis. The authors used sampling weights from US population statistics to estimate that 4.1 million had diagnosed endometriosis.

ENDOMETRIOSIS AND INFERTILITY

38% of women with infertility have endometriosis³

HOW MANY OF YOUR EMPLOYEES AND THEIR FAMILY MEMBERS DOES ENDOMETRIOSIS AFFECT?
ENDOMETRIOSIS CAN BE A LONG, PAIN-FILLED JOURNEY FOR MANY WOMEN

This diagram is for illustrative purposes only and may not represent a typical patient’s journey or every patient’s experience.

Onset of symptoms

Primary care physician #1
- Prescribed OC #1 for pain management.

Age 16

Age 17

Age 18

Age 19

Age 20

Age 21

Age 22

Age 23

Age 24

Age 25

Age 26

Age 27

Age 28

Age 29

Age 30

Age 31

Age 32

Age 33

Age 34

Age 35

OB/GYN #1
- Pain severity increases. Prescribed NSAID for pain management.

OB/GYN #2

ED visit #1

Pain severity increases. Prescribed OC #2 and NSAID for pain management.

OB/GYN #3
- Diagnosed with endometriosis. Prescribed OC #3 and short-term course of opioids for pain management.

Laparoscopy #1

Laparoscopy #2
- Excision of endometrial tissue. Continues on opioid PRN.

OB/GYN #3
- Prescribed opioid PRN for pain management.

OB/GYN #4
- Pain persists. Returns to OB/GYN to explore other treatment options.

Pregnancy
- Symptom relief.

OB/GYN #4

OB/GYN #2
- Pain returns. Prescribed progestin (depot injection) for pain management.

OB/GYN #3

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## HOW IS ENDOMETRIOSIS TREATED?

**THERE ARE A VARIETY OF PHARMACOLOGICAL AND SURGICAL OPTIONS TO MANAGE ENDOMETRIOSIS**

Physicians use their clinical expertise to determine the appropriate course of treatment for patients with endometriosis.⁹

**Opioids** may be prescribed to some patients to help them manage their pain.¹⁰

Endometriosis treatment options include:

### PHARMACOLOGICAL⁹,¹⁰

- **NSAIDs** (Oral)
- **Progestin** (Depot Injection)
- **Contraceptives** (Oral/IUD)*
- **GnRH Agonist** (Depot injection/nasal)
- **Opioids†** (Oral)
- **Modified Testosterone** (Oral)

### SURGICAL⁹,¹⁰

- **Laparoscopy**
- **Laparotomy**
- **Hysterectomy**

*Oral contraceptives are more frequently used, but the use of IUDs can be employed anywhere along the treatment path.
† Although less common, opioids are sometimes used for pain management.

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IUD=intrauterine device.
WHAT IS THE IMPACT OF ENDOMETRIOSIS ON YOUR MEMBERS?

WOMEN OFTEN SEEK MULTIPLE MEDICAL AND SURGICAL TREATMENTS IN SEARCH OF PAIN RELIEF

According to a survey of 1160 women with surgically diagnosed endometriosis:

• **45.5%** reported **3 or more medical treatments** during their lifetime
  – The number of treatments received ranged from 1 to 11
  – Medications used most often and for the longest duration were **analgesics** and **oral contraceptives**

• **41.5%** reported **3 or more surgical procedures** during their lifetime
  – The number of surgical procedures performed ranged from 1 to 17
  – 75.4% received a **laparoscopy**, which is used to confirm endometriosis

OVER 70% OF PATIENTS WITH ENDOMETRIOSIS ARE UNABLE TO RELIEVE THEIR PAIN DESPITE ATTEMPTS TO MANAGE IT

*According to an international multicenter survey of patients treated in tertiary care centers.*
PAIN RELIEVERS—BOTH OPIOIDS AND NSAIDS—ARE COMMONLY USED BY WOMEN WITH ENDOMETRIOSIS

A retrospective claims analysis examined the incremental direct and indirect healthcare costs of women with endometriosis who underwent endometriosis-related surgical procedures (n=124,530) compared with those who did not get surgery (n=37,106).

Baseline characteristics showed that pain medication was commonly used by women at some point during the year prior to surgery.

Among women in the surgery cohort

- 94.8% used opioid pain relievers
- 76.6% used NSAID pain relievers

Among women in the non-surgery cohort

- 76.2% used opioid pain relievers
- 64.9% used NSAID pain relievers

WHAT IS THE IMPACT OF ENDOMETRIOSIS ON YOUR MEMBERS? (CONT’D)

ENDOMETRIOSIS IMPACTS ALL ASPECTS OF A WOMAN’S LIFE

In an international, multicenter, cross-sectional study of 931 women with endometriosis treated in tertiary care centers who completed an HRQoL questionnaire:

- 51% reported their work being affected
- 50% reported their relationship being affected
- 16% reported their education being affected

HRQoL=health-related quality of life; NSAID=nonsteroidal anti-inflammatory drug.
WHAT ARE THE HEALTH RISKS IN MEMBERS WITH ENDOMETRIOSIS?

ENDOMETRIOSIS IS ASSOCIATED WITH MULTIPLE COMORBIDITIES

One study showed that women with endometriosis self-reported more comorbidities than those without endometriosis.

**ODDS RATIO OF SELECT COMORBIDITIES (95% CI)**

<table>
<thead>
<tr>
<th>Immune system diseases</th>
<th>4.9X</th>
<th>Ulcerative colitis (3.6-6.6)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4.1X</td>
<td>Crohn’s disease (3.0-5.6)</td>
</tr>
<tr>
<td></td>
<td>3.4X</td>
<td>Celiac disease (2.5-4.5)</td>
</tr>
<tr>
<td></td>
<td>3.3X</td>
<td>Multiple sclerosis (2.3-4.8)</td>
</tr>
<tr>
<td></td>
<td>1.9X</td>
<td>Psoriasis (1.6-2.4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancers</th>
<th>4.1X</th>
<th>Ovarian cancer (2.8-6.1)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.8X</td>
<td>Breast cancer (1.9-4.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Heart conditions</th>
<th>2.8X</th>
<th>High triglycerides (2.4-3.3)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.2X</td>
<td>High cholesterol (1.9-2.5)</td>
</tr>
<tr>
<td></td>
<td>1.9X</td>
<td>Hypertension (1.6-2.1)</td>
</tr>
</tbody>
</table>

| Mental health conditions | 2.0X | Depression (1.8-2.2) |

Additionally, women 40 years of age and younger with endometriosis may have 3X greater risk of coronary heart disease.14†

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*An online, cross-sectional study of 48,020 women aged 18 to 49 years examined the prevalence and symptoms of endometriosis in which 2922 reported being diagnosed with endometriosis. Women completed an online survey that, in addition to having questions pertaining to endometriosis-related symptoms, asked respondents to select all comorbidities that applied to them from a list of 23. Data were collected between August 2012 and September 2012.

†RR 3.08; 95% CI, 2.02-4.70. The Nurses’ Health Study II prospectively examined the association between endometriosis and coronary heart disease over a 20-year period (1989-2009) in 116,430 female patients in the United States. When compared to women without endometriosis, women with endometriosis had a higher risk of myocardial infarction (MI), angina, and coronary artery bypass graft (CABG)/angioplasty/stent.
WHAT ARE THE COSTS ASSOCIATED WITH ENDOMETRIOSIS?

ENDOMETRIOSIS IS A COSTLY BURDEN

Based on a prospective, questionnaire-based survey of 909 women with endometriosis across 12 tertiary care centers in 10 countries who had at least one tertiary–care–center-specific contact related to endometriosis-associated symptoms in 2008.

ENDOMETRIOSIS IS ASSOCIATED WITH HIGHER HEALTHCARE UTILIZATION

A retrospective claims analysis found that compared to women without endometriosis, women with endometriosis in the year immediately before and after diagnosis had, on average:

- ~205% more hospitalizations
- ~72% more ED visits
- ~13% more outpatient visits

*Data source: Truven Health MarketScan claims database (2000-2010). Data from a 10-year retrospective claims analysis of healthcare utilization and costs of women with endometriosis compared with those without (N=75,140) showed that women with endometriosis had 205% more hospitalizations in the years immediately before and after diagnosis (3229 vs 3077 one year prediagnosis and 14,902 vs 2877 one year post diagnosis [P<0.05]); 72% more ED visits in the years immediately before and after diagnosis (9901 vs 5695 one year prediagnosis and 9651 vs 5652 one year post diagnosis [P<0.05]); and, 13% more outpatient visits in the years immediately before and after diagnosis (36,800 vs 32,583 one year prediagnosis and 36,902 vs 32,704 one year post diagnosis [P<0.05]).
WHAT ARE THE COSTS ASSOCIATED WITH ENDOMETRIOSIS? (CONT’D)

CERTAIN COMORBIDITIES SIGNIFICANTLY INCREASED HEALTHCARE COSTS\textsuperscript{17}*†

Based on a retrospective, matched cohort study of 54,070 women aged 18 to 49 years with endometriosis that examined the impact of certain comorbidities on healthcare spending 12 months before and after an index date.

<table>
<thead>
<tr>
<th>COMORBIDITIES</th>
<th>INCREASED PER-PATIENT HEALTHCARE SPENDING FOR PATIENTS WITH COMORBIDITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>BREAST CANCER</td>
<td>$54,453</td>
</tr>
<tr>
<td>OVARIAN CANCER</td>
<td>$19,881</td>
</tr>
<tr>
<td>PREGNANCY COMPLICATIONS</td>
<td>$7728</td>
</tr>
<tr>
<td>SLE/RA/SJOGREN’S/MS</td>
<td>$5073</td>
</tr>
<tr>
<td>INFERTILITY</td>
<td>$4630</td>
</tr>
<tr>
<td>UTERINE FIBROIDS</td>
<td>$4007</td>
</tr>
<tr>
<td>OVARIAN CYSTS</td>
<td>$3866</td>
</tr>
<tr>
<td>HEADACHE/MIGRAINE</td>
<td>$373</td>
</tr>
</tbody>
</table>

\textsuperscript{MS=\text{multiple sclerosis}; RA=\text{rheumatoid arthritis}; SLE=\text{systemic lupus erythematosus.}}

*Total spending amounts in 2015 USD.
†Data source: Clinformatics\textsuperscript{TM} DataMart (OptumInsight) de-identified commercial insurance claims database. Claims and enrollment records drawn from January 1, 2006 through December 31, 2015.
HOW DOES ENDOMETRIOSIS AFFECT ABSENCE AND PERFORMANCE?

ENDOMETRIOSIS RESULTS IN SUBSTANTIAL HOURS OF LOST PRODUCTIVITY PER WEEK

48% of women had to reduce the number of hours they worked per week due to endometriosis, based on a multinational, international, questionnaire-based, cross-sectional study of 931 women with endometriosis who completed an HRQoL questionnaire.12

Women reported an average of **6.4 to 10.8 hours of work lost** (both absenteeism and presenteeism) per week due to endometriosis.6

WOMEN WITH HIGHER LEVELS OF PATIENT-REPORTED SEVERITY OF ENDOMETRIOSIS SYMPTOMS LOST EVEN MORE HOURS IN EMPLOYMENT PRODUCTIVITY18

Based on a cross-sectional, web-based survey of 5879 women with endometriosis, of which 810 were employed, reported a significant association between symptoms and the hours of lost employment.

<table>
<thead>
<tr>
<th>REPORTED SYMPTOMS</th>
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</tr>
</thead>
<tbody>
<tr>
<td>SEVERE</td>
<td>15.8 TOTAL LOST EMPLOYMENT PRODUCTIVITY 11.6 DUE TO PRESENTEEISM 4.2 DUE TO ABSENTEEISM</td>
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<td>MODERATE</td>
<td>9.6 TOTAL LOST EMPLOYMENT PRODUCTIVITY 8.2 DUE TO PRESENTEEISM 1.5 DUE TO ABSENTEEISM</td>
</tr>
<tr>
<td>MILD</td>
<td>1.9 TOTAL LOST EMPLOYMENT PRODUCTIVITY 1.8 DUE TO PRESENTEEISM 0.1 DUE TO ABSENTEEISM</td>
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</table>
WHAT DO MEMBERS WITH ENDOMETRIOSIS NEED TO DO?

TAKE ACTION—RECOGNIZE SYMPTOMS AND SEEK APPROPRIATE CARE FROM A GYNECOLOGIST

Women with endometriosis often spend years in the healthcare system searching for relief due to the challenges of diagnosing the disease. Early intervention can get these women on the path to treatment sooner.

Average time to endometriosis diagnosis is up to 6-10 years, and it can be longer for younger women.\(^5,6\)

- In 2 cross-sectional, self-reported surveys of women with endometriosis, **younger patients often experience a longer delay in diagnosis** than older patients.\(^2,19\)

Most women saw **up to 4 physicians before diagnosis**.\(^{19*}\)

Seeing a gynecologist first resulted in visiting fewer **physicians overall** compared with those who saw a generalist or another specialist first.\(^{19*}\)

**63%** of women surveyed said **1 or more physicians told them nothing was wrong**.\(^{19*}\)

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*Results from a 1998 cross-sectional, self-reported survey of 4334 women with surgically diagnosed endometriosis, which examined the time from onset of symptoms to diagnosis. Women completed a 10-page survey developed by the Endometriosis Association, which included questions on pain, infertility, bleeding, and nongynecological symptoms.*

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MEMBERS NEED EDUCATION AND ACCESS TO CARE FROM GYNECOLOGISTS WHO CAN HELP THEM GET **PROPERLY DIAGNOSED AND MANAGE THEIR DISEASE**
WHAT SHOULD AN EMPLOYER DO?

BE SURE YOUR MEMBERS AFFECTED BY ENDOMETRIOSIS HAVE ACCESS TO THE SUPPORT, EDUCATION, AND CARE THEY NEED

STEP 1: Talk to your benefits partners about the right plan design for your members to ensure access to appropriate care

- Promote preventive care benefits for women, including annual gynecological exams
- Ensure access to healthcare providers and services for endometriosis diagnosis
  - For example, physical exams, ultrasounds, and laparoscopies
- Medication, especially for pain management, may be needed to help manage endometriosis
- Some members will require medical procedures, such as laparoscopies and hysterectomies, to treat endometriosis
- Additional support and education may be needed, such as guidance from infertility specialists and other healthcare professionals

STEP 2: Provide your members with appropriate educational resources

- Raise awareness of endometriosis symptoms among undiagnosed women
- Help those with endometriosis better manage their condition
WHAT RESOURCES CAN YOU PROVIDE TO YOUR EMPLOYEES?

DISTRIBUTE EDUCATIONAL RESOURCES THAT SUPPORT AND EMPOWER WOMEN WITH ENDOMETRIOSIS

Brochures and videos you can provide to your employees.

Endometriosis Awareness Advertisement

Mechanism of Disease Video

"Speak Endo" With Your Gynecologist

Surprising Endometriosis Statistics

Endometriosis Patient Testimonial Videos

Are You Ready to Speak Endometriosis Fact Sheet
ENDOMETRIOSIS IS A CHRONIC, DEBILITATING DISEASE THAT MAY BE AFFECTING EMPLOYEE PERFORMANCE IN YOUR ORGANIZATION

References


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