

Endometriosis

It can exist where?

**You mean its not only about my
reproductive organs?**

Extra-pelvic disease:

What is it?

Why is it important to know?

How do I advocate for myself?

Q: What is endometriosis?

A: Endometriosis is a condition where tissue similar to the lining of the uterus (the endometrial stroma and glands, which should only be located inside the uterus) is found elsewhere in the body.

(Kennedy S, et al. ESHRE guideline for the diagnosis and treatment of endometriosis. Human Reprod 2005;20(10):2698-2704.)

Q: Where does endometriosis come from?

A: The origin is unknown. There are many theories but no single one can explain all disease throughout the body. It is possible more than one origin and 'type' of the disease exists.

Q: How common is it?

A: Estimate 1 in every 10 female-gendered individuals have endometriosis.

(Rogers PA, et al. Priorities for endometriosis research: recommendations from an international consensus workshop. *Reprod Sci* 2009;16(4):335-46. Endometriosis.org/endometriosis 12/03/2017).

Every individual is unique.






There are a variety of things that impact how and what a person feels. Some of these include where and what type of lesions a person has.

These are a few things that impact what activities a person is unable to do when the disease is active.

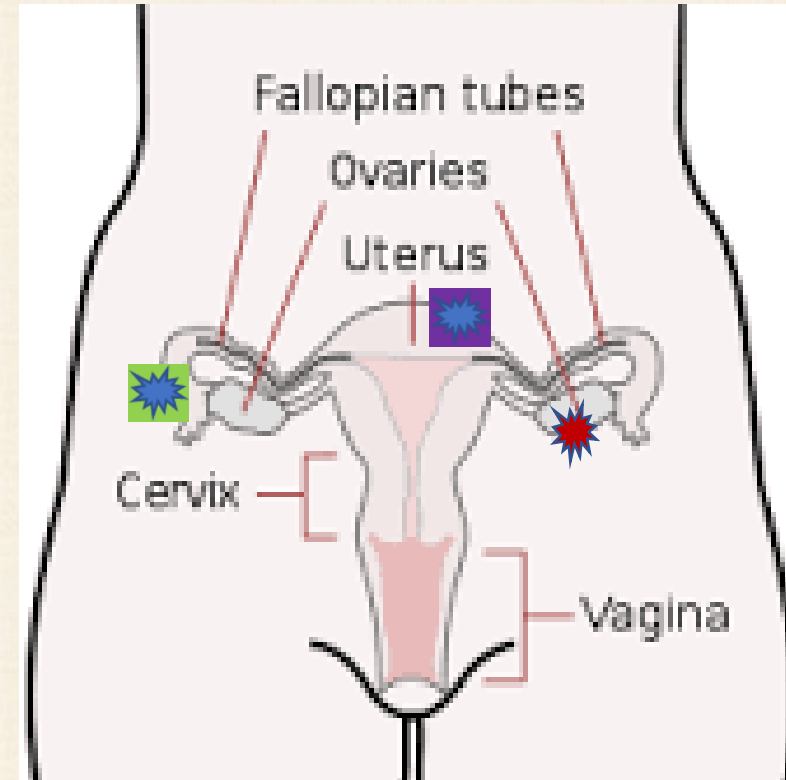
Q: Where is it located?

**A: Endometriosis lesions can be found
anywhere in the pelvic cavity: front view**

(endometriosis.org/endometriosis. 12/03/2017)

-  ovaries (endometrioma)
-  fallopian tubes
-  pelvic side-wall (peritoneum)
-  the cul-de-sac (not pictured)
(the Pouch of Douglas)
(the rectal-vaginal septum)
-  outer surface of the uterus

uterosacral ligaments, (not pictured)








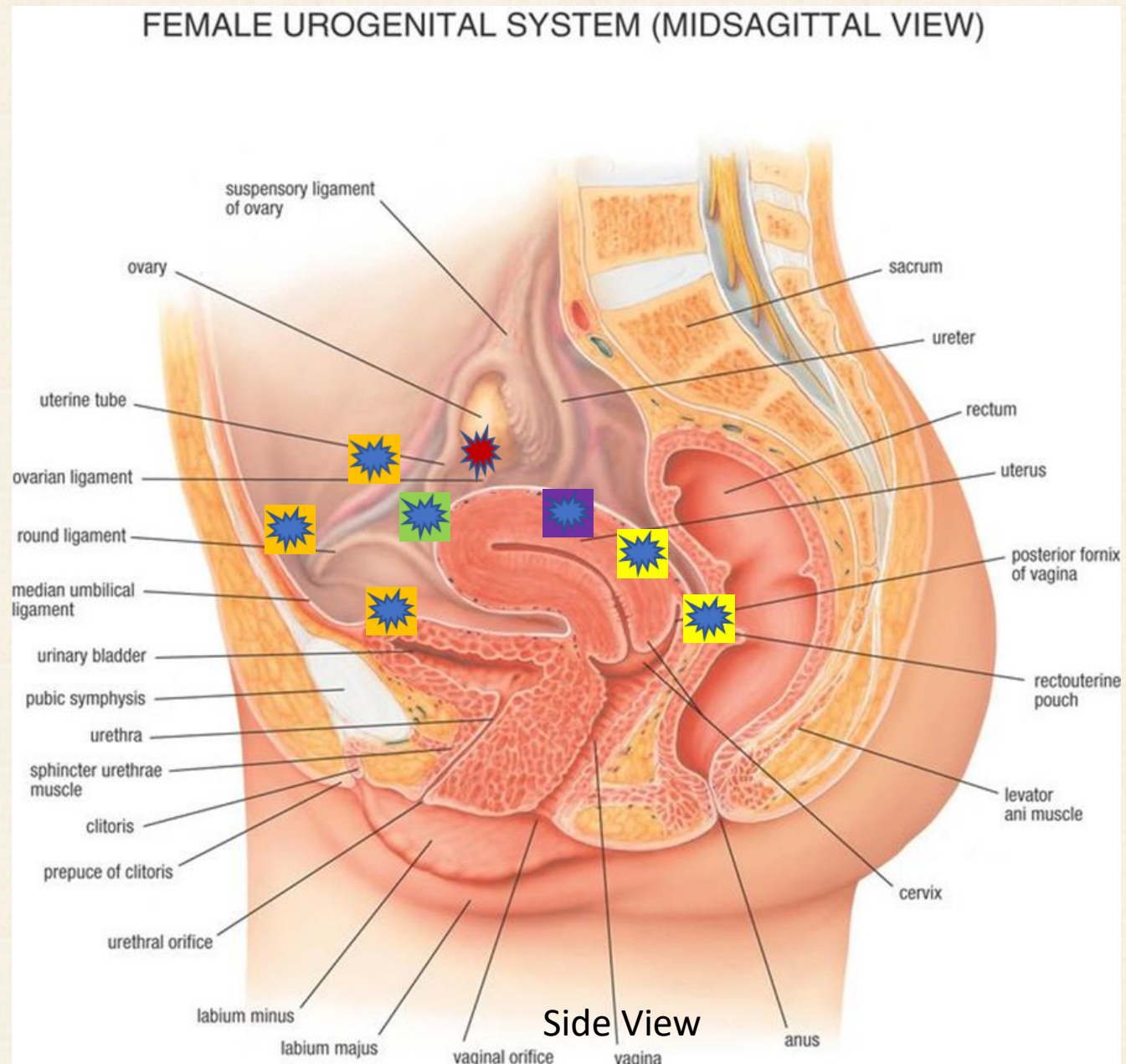
Front View

https://en.wikipedia.org/wiki/Female_reproductive_system

Q: Where is it located? (side view)

A: Endometriosis lesions can be found anywhere in the pelvic cavity:
(endometriosis.org/endometriosis. 12/03/2017)

-  ovaries (endometrioma)
-  fallopian tubes
-  pelvic side-wall (peritoneum)
-  the cul-de-sac
(the Pouch of Douglas)
(the rectal-vaginal septum)
-  outer surface of the uterus
- uterosacral ligaments
(not pictured)



What is 'normal' menses?

- Onset menses:** Age 12-13 years (slightly earlier for non-white females).
No menstruation by age 15 yrs - seek consultation.
- Normal cycle range:** 21-45 days between menses (first two years). By third year 21-34 days.
'Average' cycle length 28 days but there is a large range of 'normal'.
- Number of bleed days:** 2-7 days.
- Blood Loss w/ menses:** Average menstrual product use of 3-6 pads or tampons per day.
Need to change sanitary device more frequently than every 1-2 hours,
or result in routine soiling of bed linens – seek consultation.
30-80mL blood loss is normal (2-6Tbps. or 1-2.7fl.oz. or 1/2 -1/3C.)

“Menstruation in Girls and Adolescents: Using the Menstrual Cycle as a Vital Signs”. Committee on Adolescent Health Care. The American College of Obstetricians and Gynecologists. Number 651, Dec 2015. <https://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Adolescent-Health-Care/Menstruation-in-Girls-and-Adolescents-Using-the-Menstrual-Cycle-as-a-Vital-Sign> (Accessed Dec 12, 2017)

What is 'abnormal' menses?

- If menstruation routinely impacts the ability to participate in:
 - daily activities
 - social events
 - attendance at school or work
- Menstrual bleeding > 7 days.
- Regular heavy flow; change sanitary device > every 1-2 hours.
(>6Tbps or 1/3 C)

Q: What is 'extra-pelvic' disease?

A: All endometriosis outside the reproductive organs.

Q: Where can 'extra-pelvic disease occur?

A: Endometriosis has been identified in every major organ of the body, in ALL 11 systems of the body.

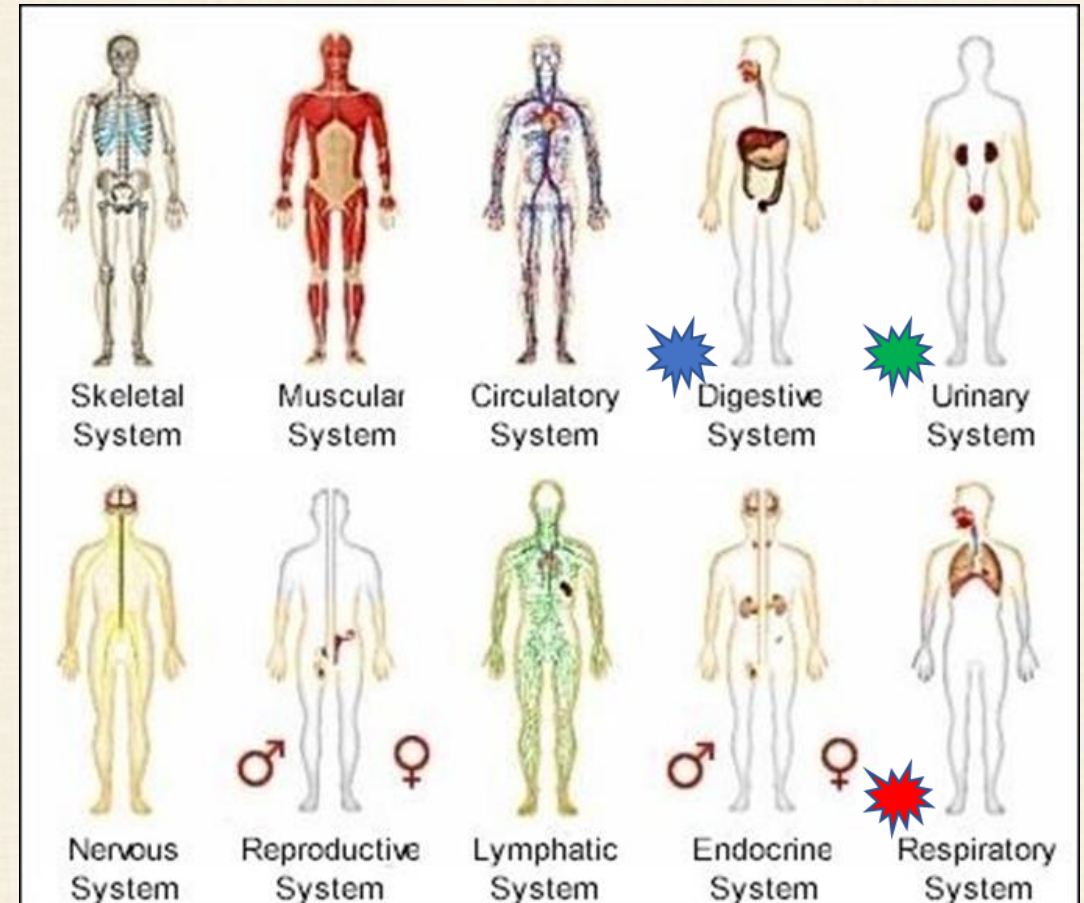
The majority of extra-pelvic disease is found in these 4 systems:

 Digestive

 Urinary

 Respiratory

Skin (Cutaneous) (not seen)



Note: The Integumentary System
(Skin, Scar, Cutaneous is not listed.)

<https://www.pinterest.com/pin/324329610637510208/>

It very infrequently involves the nerves, blood vessels, musculoskeletal and areas like nose and tear ducts. These are very, very rarely reported.

How common is extrapelvic disease?



1 in 10 female-gendered persons have endometriosis

If 100 female-gendered persons were in a room....
10 will have endometriosis...
2 of the 10 will (also) have..
extra-pelvic disease.

For every 100 women with endometriosis...
20 will (also) have extra-pelvic disease.

.....about 20%

References:

Ruffo G, Scopelliti F, Manzoni A, Sartori A, Rossini R et al. Long-Term Outcome after Resections for Deep Infiltrating Endometriosis: A Single-Center Experience after 900 cases. Biomed Res Intl. 2014.

Matalliotakis M, Goulielmos GNB, Kalogiannidis I, Koumantakis G, Matalliotakis I et al. Extra pelvic endometriosis: Retrospective analysis on 200 cases in two different countries. Eur J Obstet Gynecol Reprod Biol. 2017;217:34-37.

■ 1:5 women with Endometriosis have disease which involved areas outside the 'pelvic' organs



Endometriosis has been found in all **11** systems of the body. But most disease is found in these 4 systems:

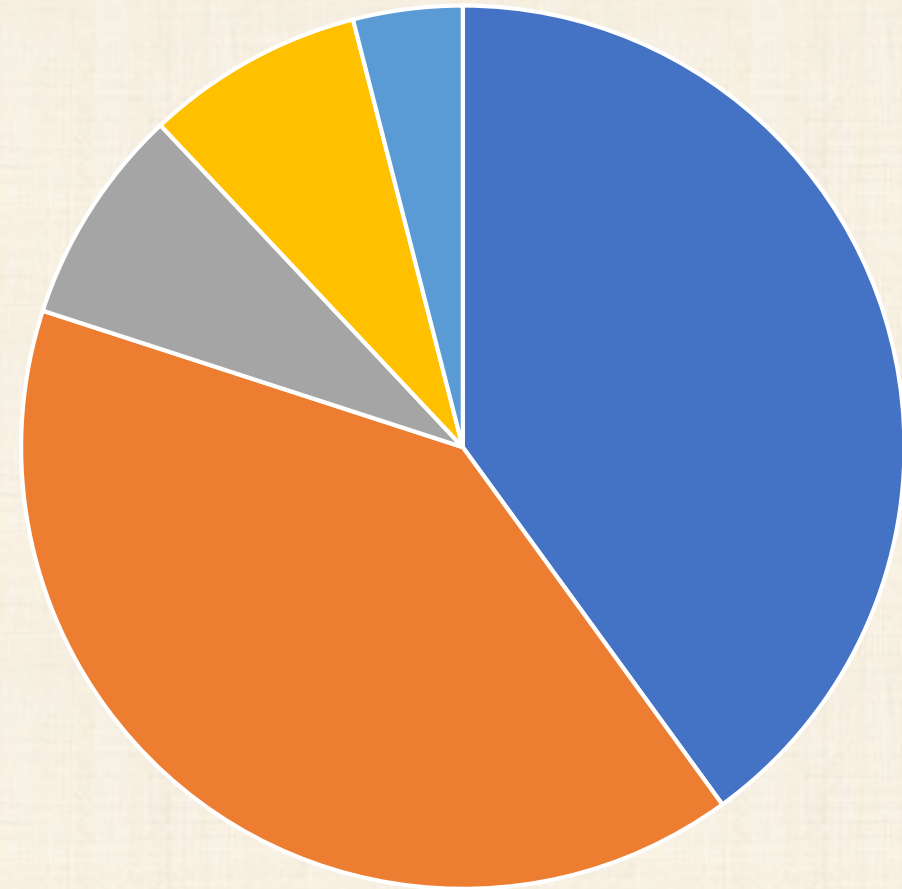
- Digestive
- Urinary
- Respiratory
- Skin and Scar
- Other*

Other* includes all 'rarer' locations of disease collectively. (ex: nerve, blood vessel, muscles, bones, nose, tear ducts...)

The pie chart shows the probabilities of a female-gendered person with extra-pelvic endometriosis – and likelihood of disease within each systems.

- 40% probability each of **Digestive** or **Urinary**
- 8% probability each of **Respiratory** or **Skin/Scar**
- 4% probability of '**Other**'

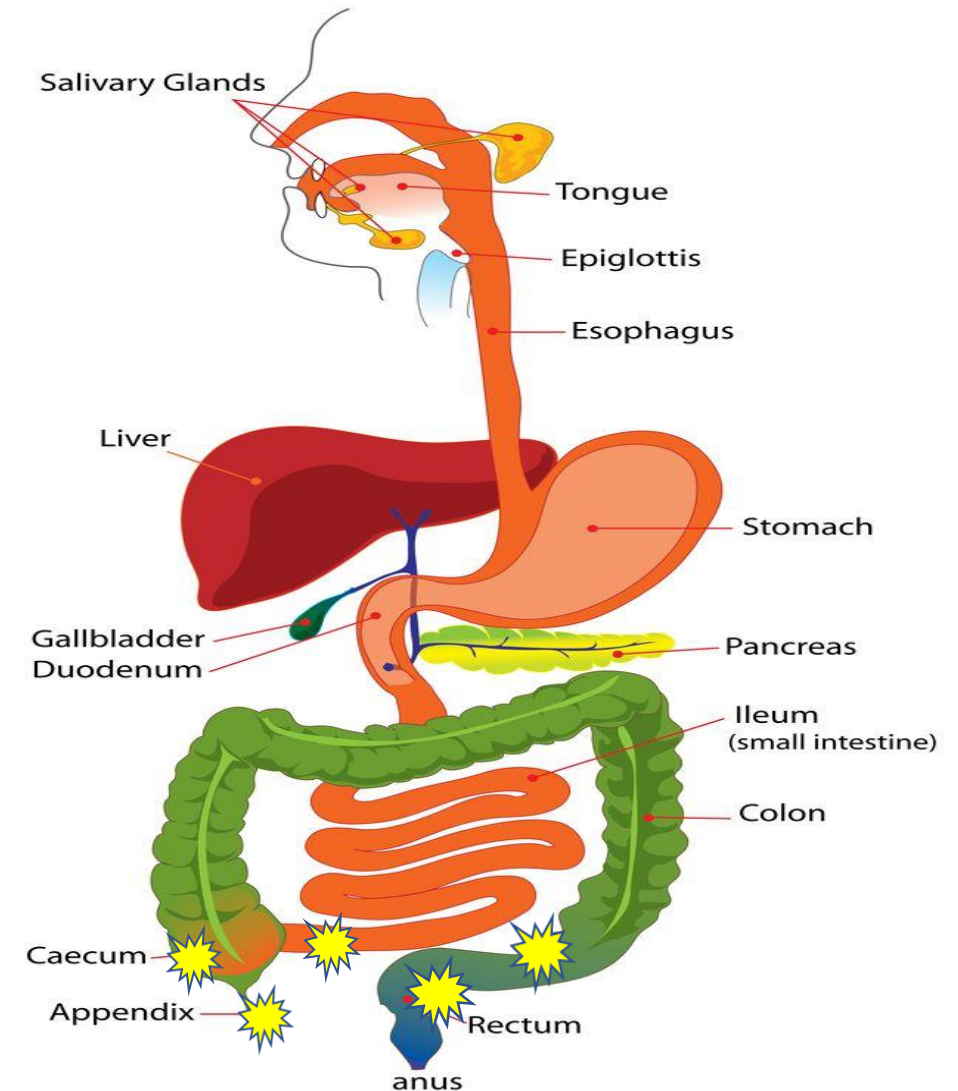
The distribution of extra-pelvic disease in the 1 of every 5 women with endometriosis



- Digestive System
- Urinary System
- Respiratory System
- Skin and Scars
- Other (Collectively nerves, muscles, nose and other remote areas)

Endometriosis of the Digestive System

- An estimated **11-12%** of female-gendered persons are affected.*
- Disease can be found in any part of the digestive system.
- The majority is found in the large intestine and very end of the small intestine. ✨
- Most to lesser frequented areas are:
 - Rectum/Sigmoid Colon
 - Cecum
 - Ileum (the end portion)
 - Appendix



*Matalliotakis m, Goulielmos GNB, Kalogiannidis I, Koumantakis G, Matalliotakis I et al. Extra-pelvic endometriosis: Retrospective analysis on 200 cases in two different countries. Eur J Obstet Gynecol Reprod Biol. 2017;217:34-37.

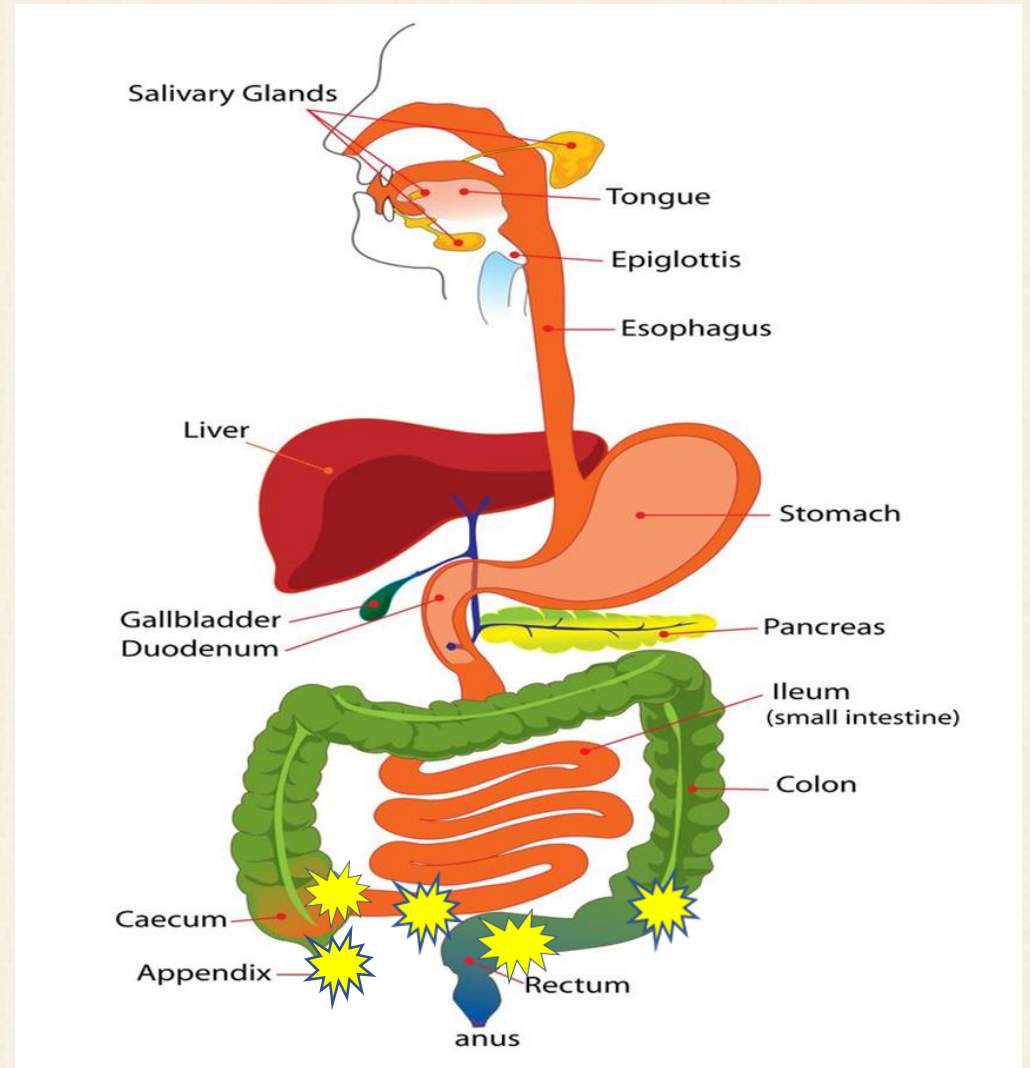
Endometriosis of the Digestive System

Symptoms may include:*

nausea and/or vomiting
back pain
pain with bowel movements
blood in stools
painful contractions after meals
diarrhea and/or constipation



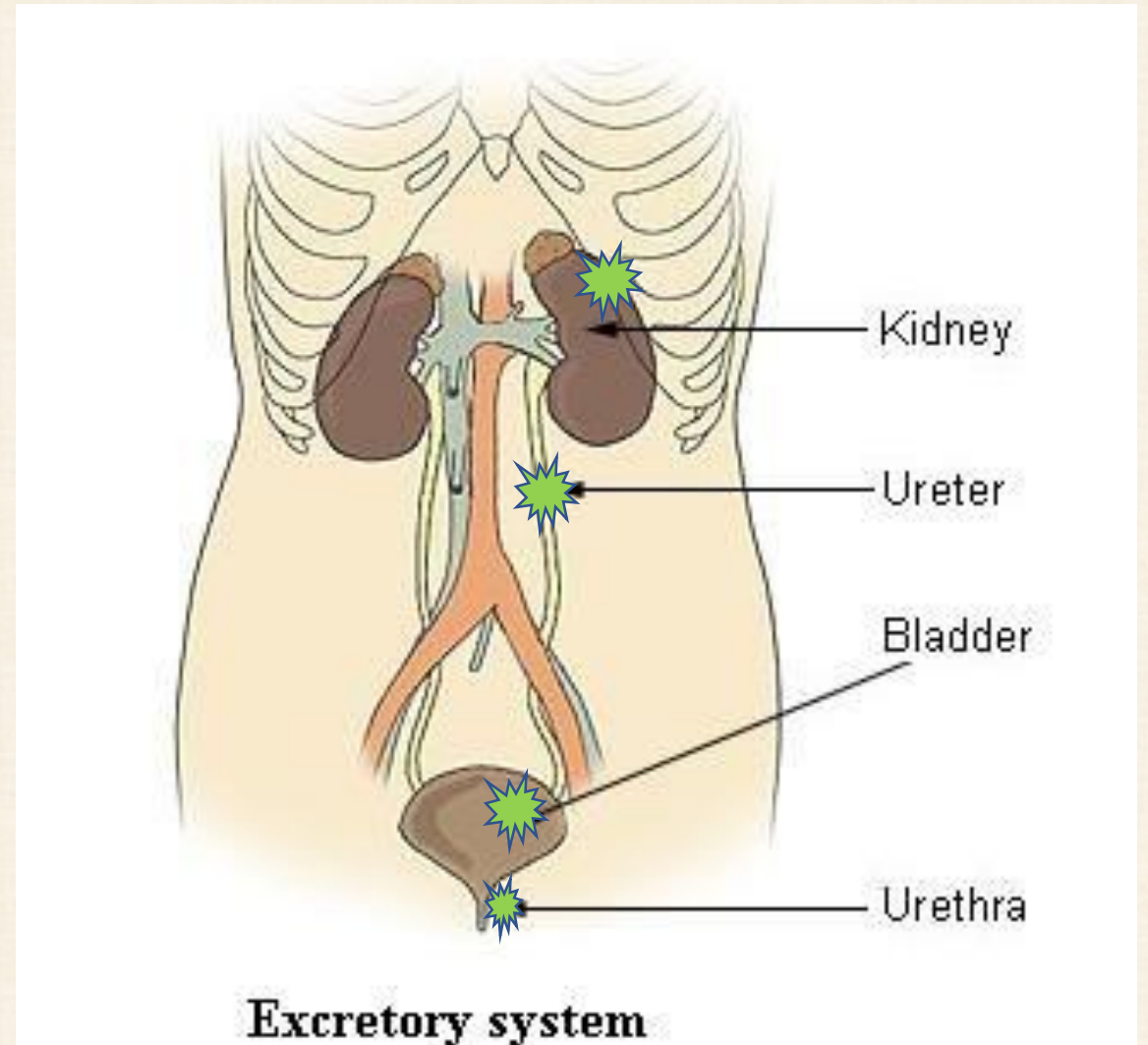
(diarrhea occurs most often with menses and constipation occurs between menses cycles but also may not occur)



*Matalliotakis m, Goulielmos GNB, Kalogiannidis I, Koumantakis G, Matalliotakis I et al. Extra-pelvic endometriosis: Retrospective analysis on 200 cases in two different countries. Eur J Obstet Gynecol Reprod Biol. 2017;217:34-37.

Endometriosis of the Urinary System

- The urinary system is comprised of the:
 - Kidneys (2)
 - Ureters (2)
 - Bladder
 - Urethra
- Occurs in about **1-12%** of all women with endometriosis. *
- The bladder is most commonly involved (**85%**).
- A very small frequency the ureter(s) are involved.
- Even less frequently the kidney(s) or urethra is involved.



* Maccagnano C, Pelluchi F, Rocchini L, Ghezzi M, Scattoni V et al. Diagnosis and Treatment of Bladder Endometriosis: State of the Art. Urol Int. 2012;89:249-258.

Endometriosis of the Urinary System

Symptoms may include:*

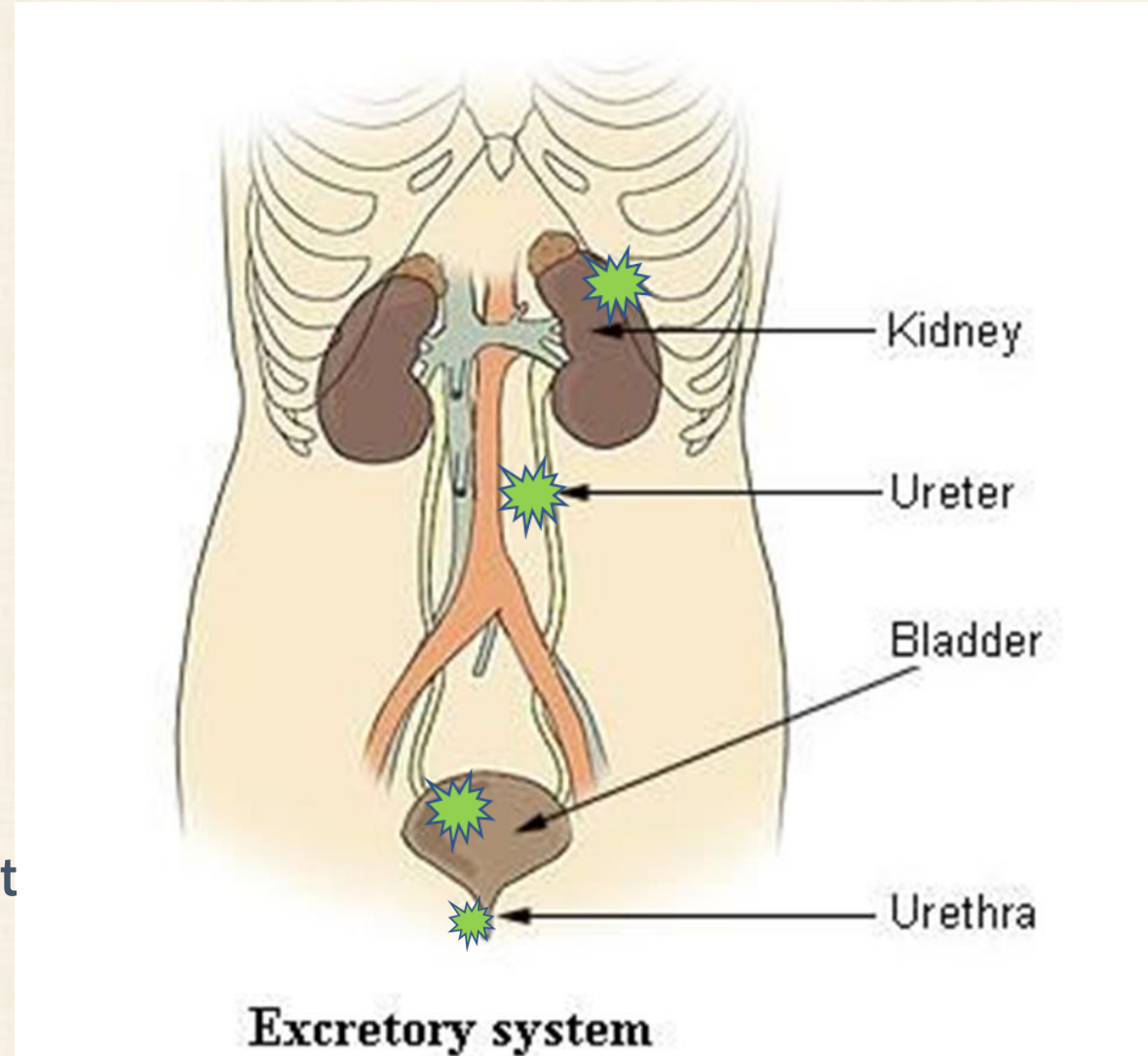
Pain around the pubic bones or groin on either side, especially when urinate.



Difficult to start or maintain a stream of urine (and may be painful)

Blood in the urine.

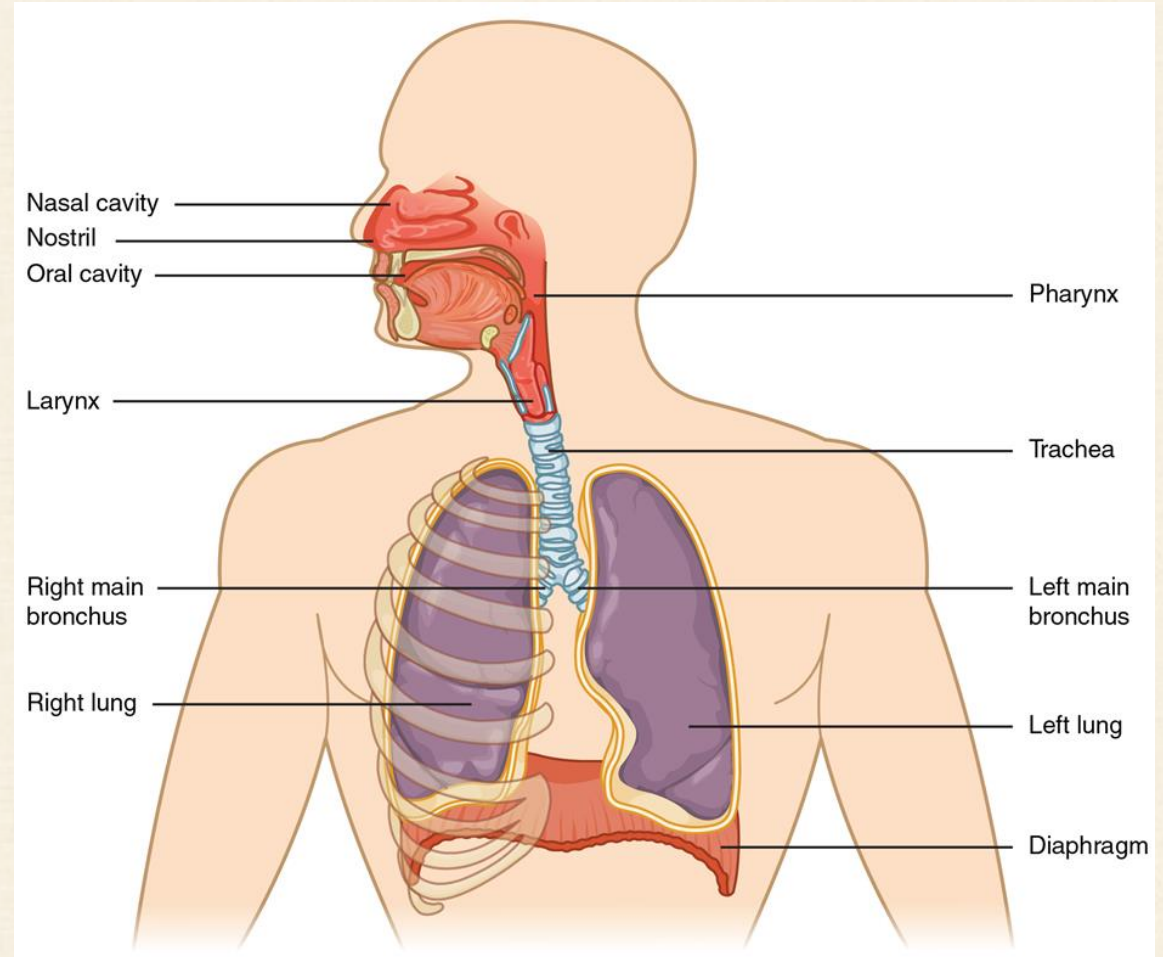
Lower back pain or dull ache when attempt to urinate or leading up to the need to urinate.



*Maccagnano C, Pelluchi F, Rocchini L, Ghezzi M, Scattoni V et al. Diagnosis and Treatment of Bladder Endometriosis: State of the Art. Urol Int. 2012;89:249-258.

Endometriosis of the Respiratory System

- The Respiratory System is divided into two sections: Upper and Lower.
- The Lower Respiratory System (our focus) is composed of:
 - Diaphragm
 - Lungs
 - Bronchi
 - (and branches into each lung)
 - Pleura layers
 - (not labeled (yellow))It surrounds each lung and diaphragm.




<https://humananatomyly.com/wp-content/uploads/2017/07/labeled-picks-of-the-human-respiratory-system-organs-and-structures-of-the-respiratory-system-c2b7-anatomy-and-1.jpg>

Wendy Bingham, DPT
Dec 6, 2017

Endometriosis of the Respiratory System

Endometriosis in any of these structures is referred to as 'Thoracic Endometriosis'.

About 2.5-5.6% sufferers of endometriosis experience lesions of the Respiratory System. *

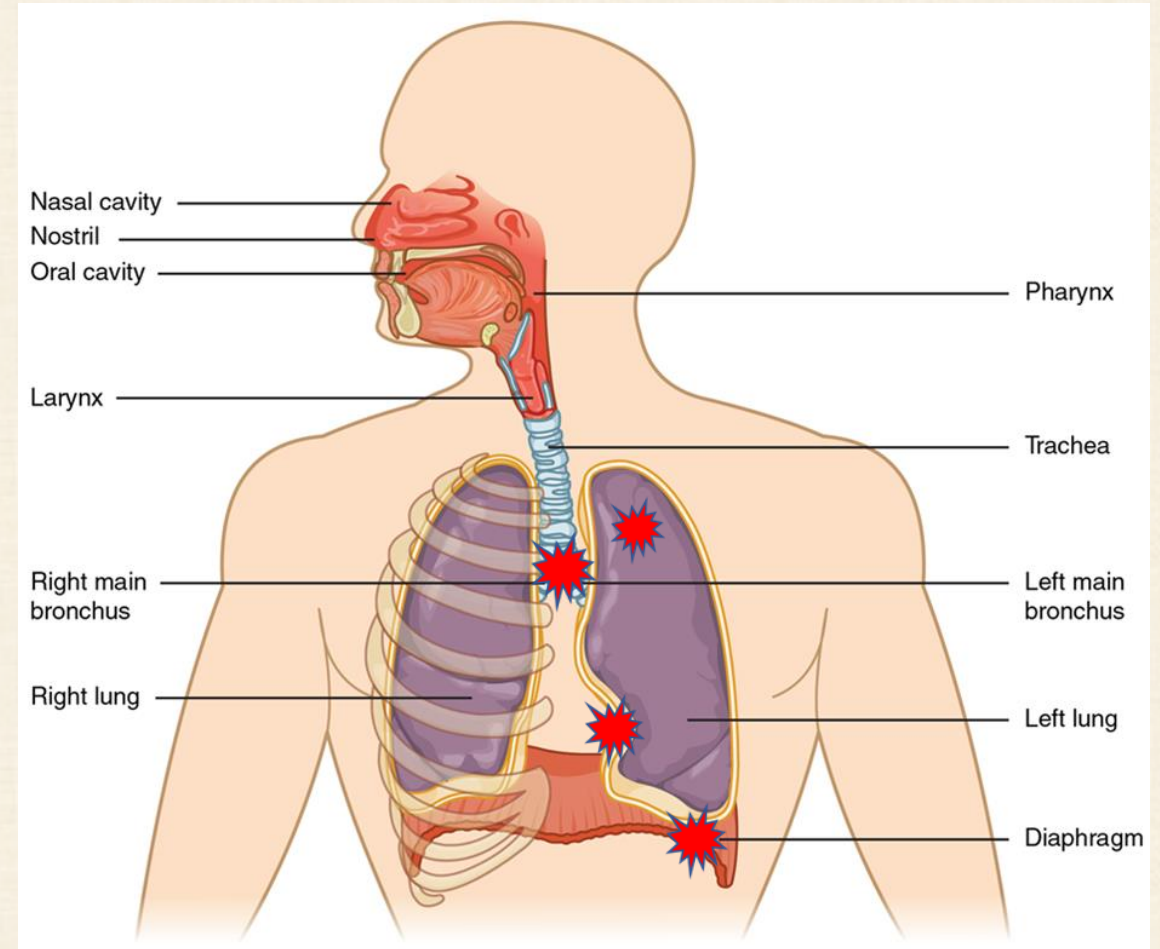
Endometriosis may be located on/in any of these structures. In order of most to least common locations: 

Diaphragm

Pleura

Lung Parenchyma

Bronchi and its smaller branches



Endometriosis of the Respiratory System

Lesions: Right is most common, up to 95% ^{*1}
Left and both sides less common ^{*2}

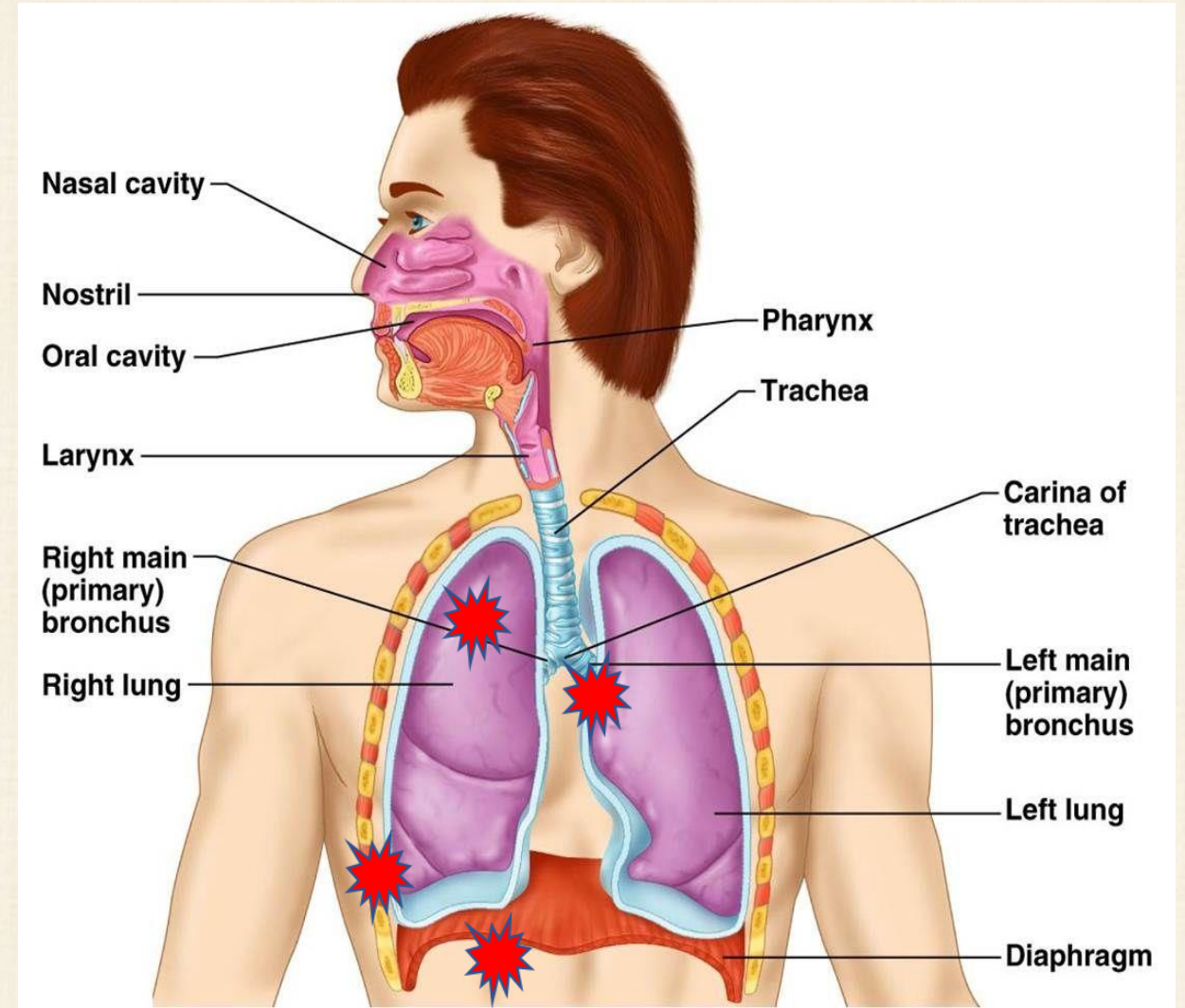
Most common presentation of 'Thoracic Endometriosis':

recurrent chest, shoulder tip, neck and/or jaw pains that....

frequently recur and coincide with your menses.

¹* Azizad-Pinto P, Clark D Thoracic Endometriosis case report and review of the literature. The Permanente Journal. 2014;18(3):61-65

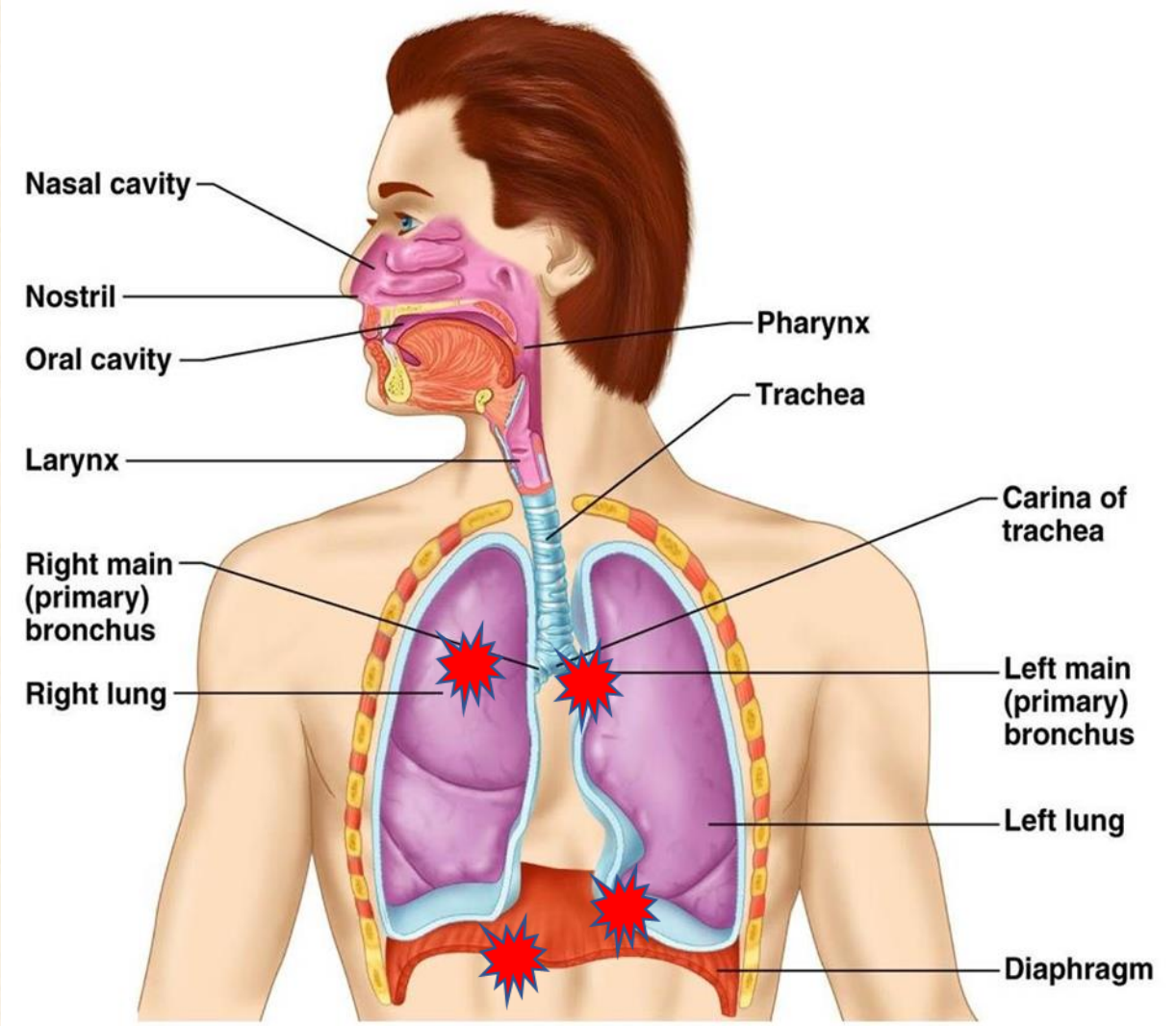
²* Joseph J, Sahn SA. Thoracic endometriosis syndrome: new observations from an analysis of 110 cases. Am J Med. 1996;100(2):164-70



Endometriosis of the Respiratory System

Symptoms may include: *

- Shortness of Breath
 - Increased effort to breath in
 - Heartburn
 - Pain behind breast bone, ribs, shoulder, neck, arm, scapula
 - Pressure
- (squeezed or front-back or one side)



*Joseph J, Sahn SA. Thoracic endometriosis syndrome: new observations from an analysis of 110 cases. Am J Med. 1996;100(2):164-70

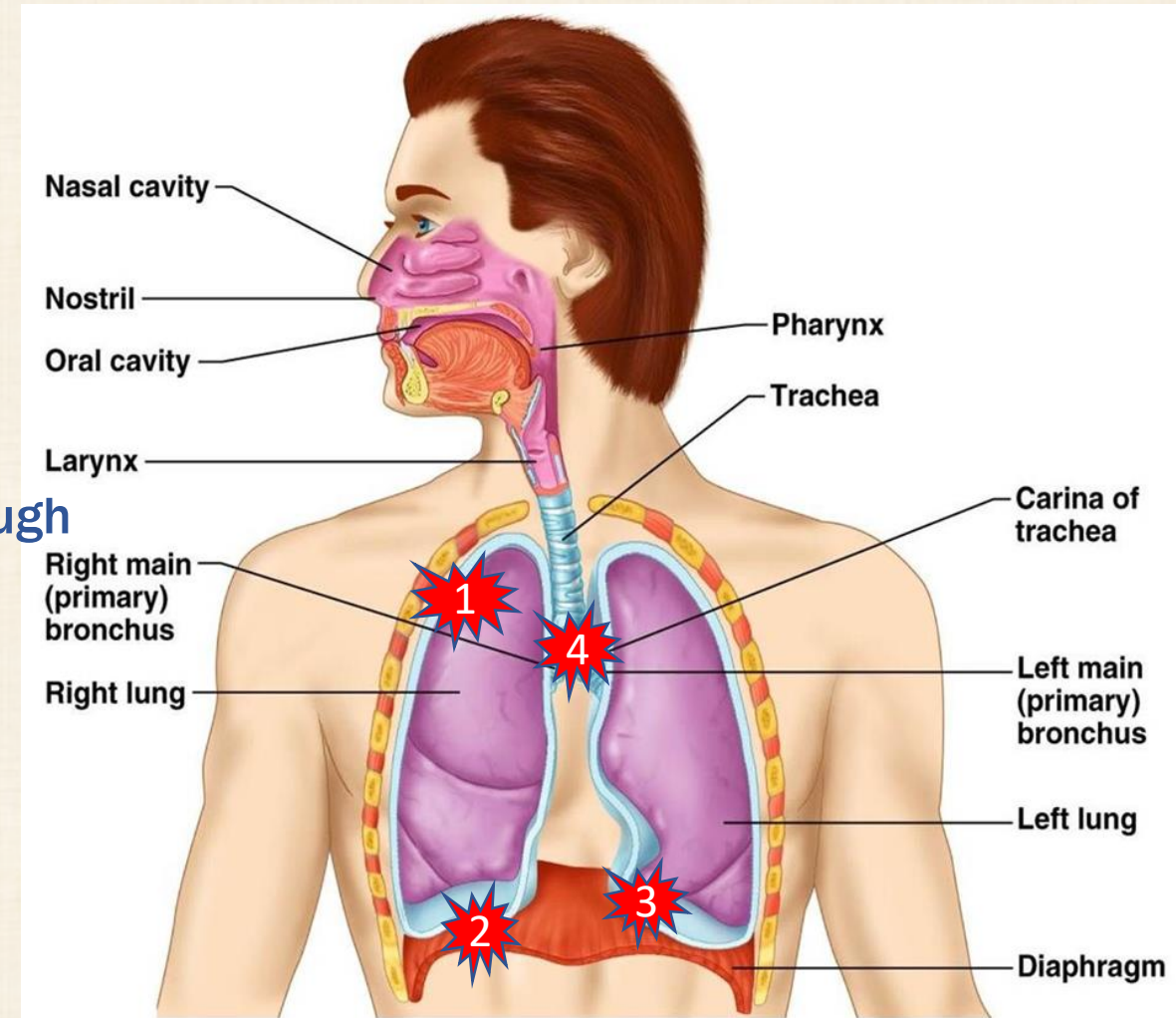
Endometriosis of the Respiratory System

A very small portion of sufferers may develop more complications. These include:*

Develop an air leak causing the lung to collapse (pneumothorax)

- 1** A lesion on the outside of the lung or inside near air exchange areas ruptures.
- 2** A lesion of the diaphragm may penetrate through the diaphragm, creating a hole for air to pass through
- 3** Accumulation of fluid and blood in the chest cavity (outside the lung, inside the chest wall)
- 4** Develop coughing of blood or blood-tinged sputum (up to 15mL/1 Tbsp) during time of menses.

It is very important to document and describe your symptoms and locations very carefully.



<http://anatomybody-charts.us/wp-content/uploads/2016/03/the-respiratory-system-diagram-quiz-the-respiratory-system-diagram.jpg>

*Joseph J, Sahn SA. Thoracic endometriosis syndrome: new observations from an analysis of 110 cases. Am J Med. 1996;100(2):164-70

Skin and Scar Endometriosis

Very Rare. Occurs in 1-5% of all persons with endometriosis.*

Involves the Epidermis, Dermis, Fascia and sometimes abdominal wall muscle

Usually a single lesions. Most often found:

- belly button (umbilicus)
- prior surgical scars
- abdominal wall (muscle below skin layers)

Very rarely, found in the arms and legs.

Lesions may: swell with hormone changes
become tender to pressure
may be discolored
may bleed



Figure 1 umbilical cutaneous endometriosis, clinical presentation. Multiple 5-6 mm reddish-blue dome shaped papules within the umbilicus.

<http://raredisorders.imedpub.com/articles-images/rare-disorders-diagnosis-therapy-cutaneous-endometriosis-3-1-5-g001.png>

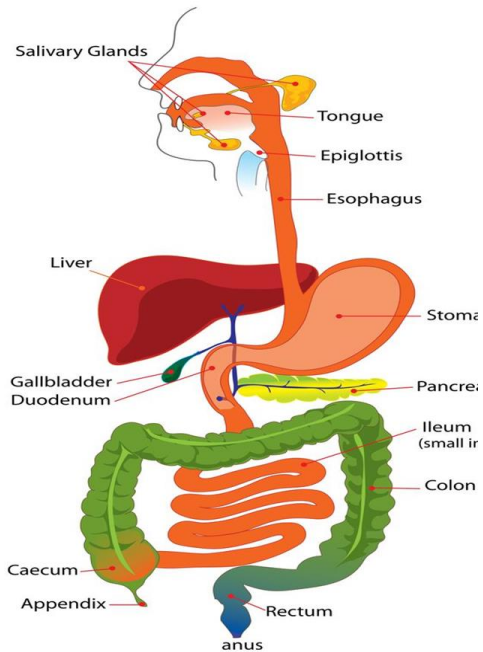


FIGURE 1 – Endometrioma near the scar of cesarean section, with emphasis on color

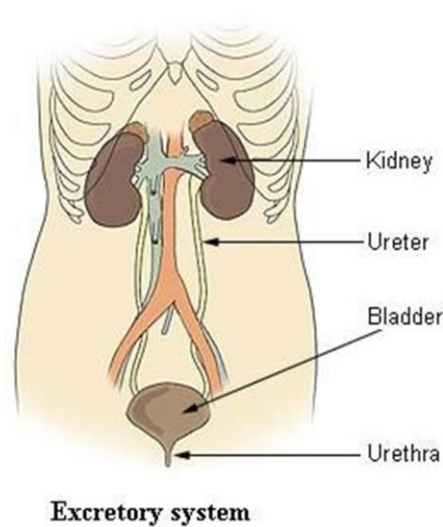
Summary

Endometriosis outside of the reproductive organs is known as 'extra-pelvic' disease.

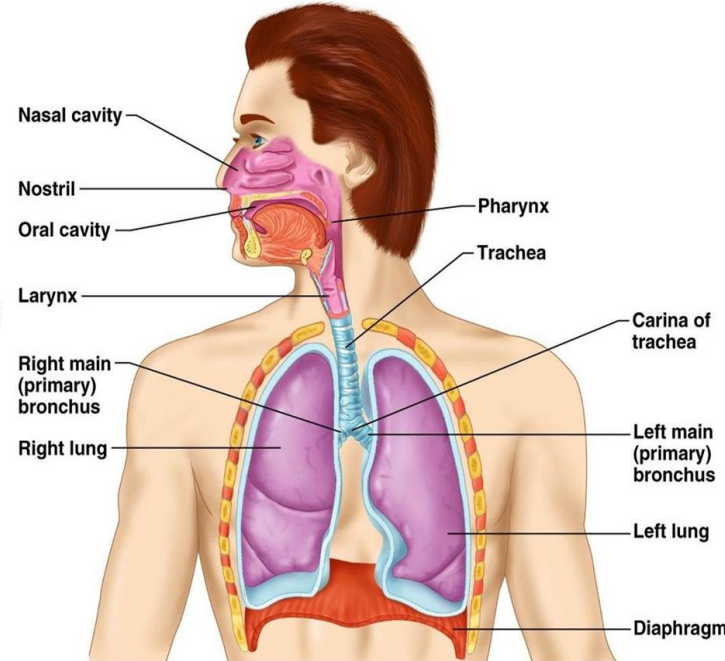
Found in all 11 systems of the body. Majority occurs in 4 systems:



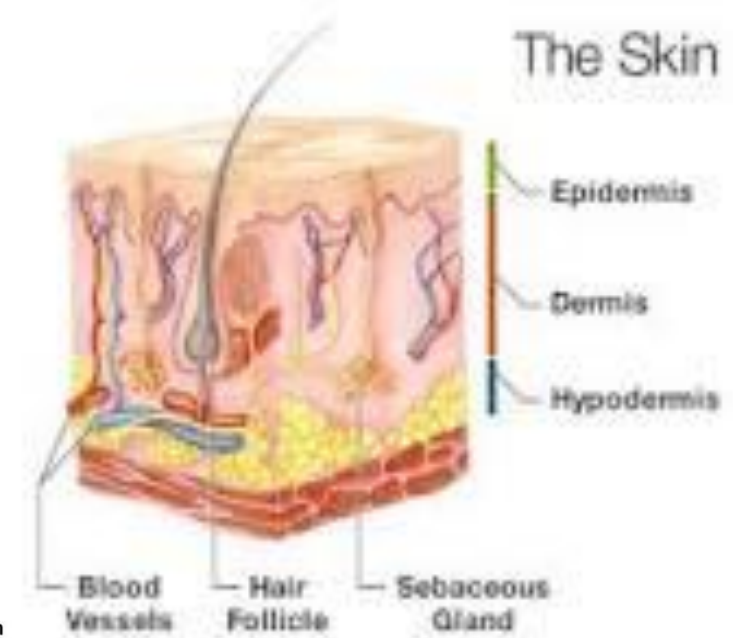
Digestive System



Urinary System



Respiratory System



Skin/Scar

The anatomy, location(s) of lesions and symptomology were stated for each of these systems. Endometriosis occurs in the 7 other systems of the body but very, rarely occur.

How can I advocate for myself?

Use a calendar and body diagrams. (Google Images-download). Document at least 3 continuous months.

What do I record?

- (1) If have a menstrual cycle: **day of your cycle symptoms occur** (ex: Dec 5th day 11 of cycle).
If No menstrual cycle - still important to record. (hormone use, lack of a uterus, menopause)

You do not need to have a menses for active endometriosis.

(2) Pain: 0-10/10

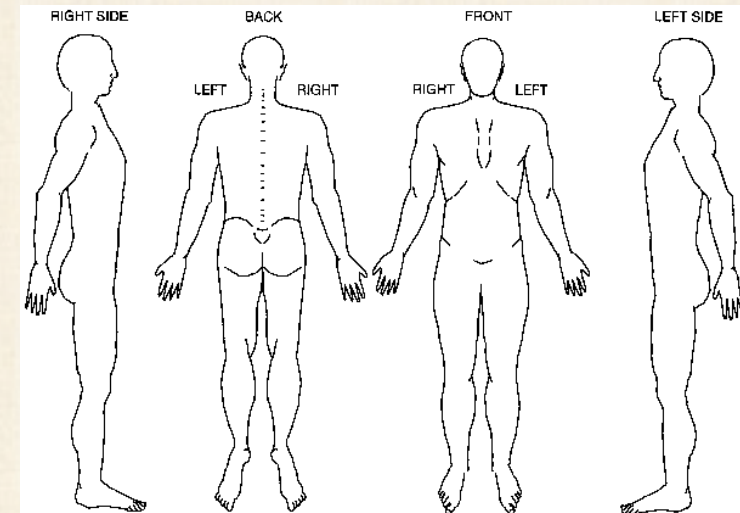
(3) Location: Body Part

diffuse: **shade** specific (x) travels (↗)

(4) Symptom Descriptions:

Sharp * Dull ● Ache # Burn ☀ Throb @ Numb ?

(symbols and colors are helpful)



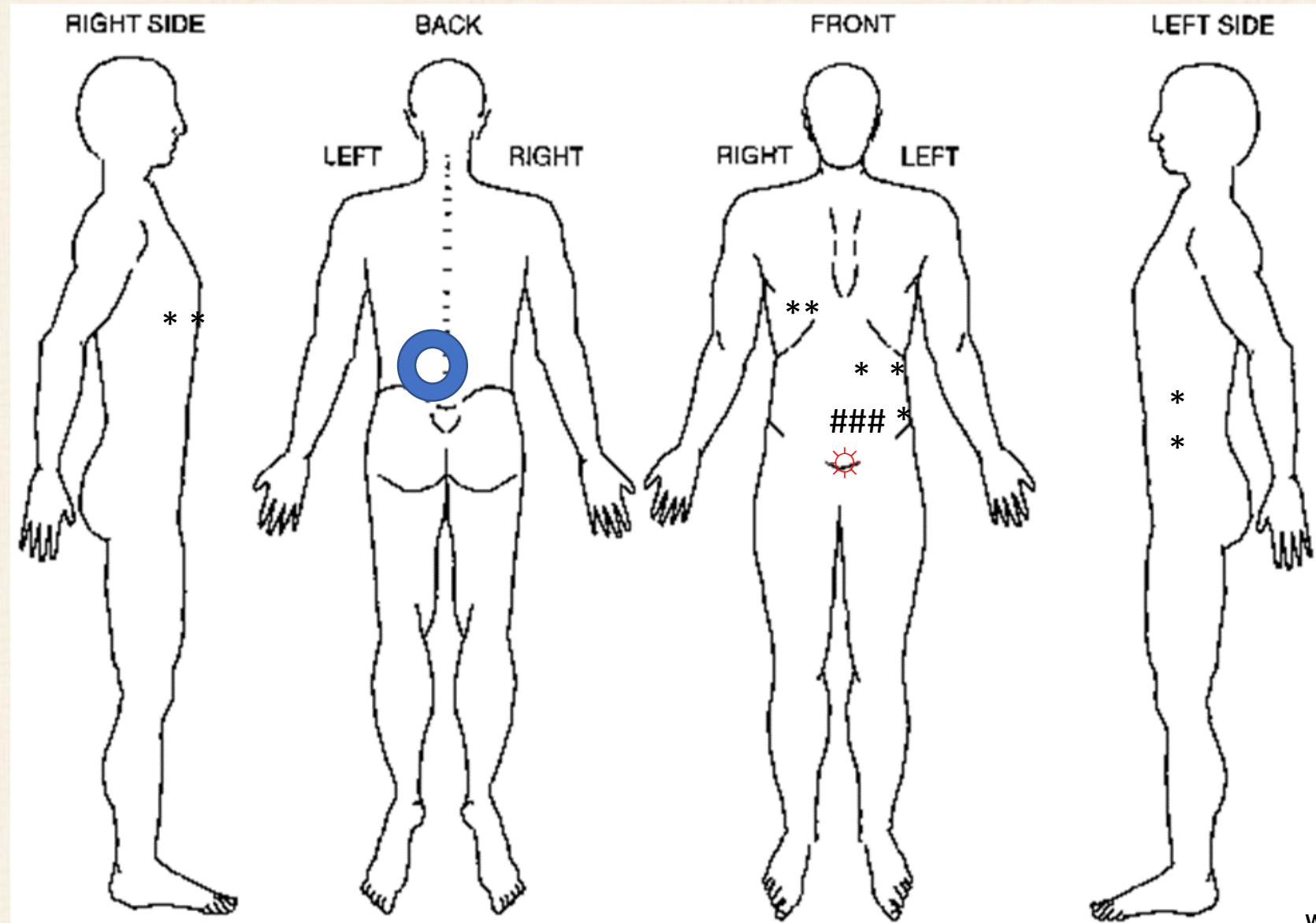
Jane Doe
Dec. 5, 2017
Day 11 menses

Pain 5/10 (moderate)

Notes: An hour after meals stomach cramps increased and made me sweating and feel weak.

☀ when urinating

* * happen
'whenever, no matter what I am doing, usually last a minute or less.



Additional things to consider...

Some symptoms may be related to other components of your daily routine and activities.

(1) Do the symptoms travel? (Start in one place and end in another)

(2) Does eating affect my symptoms?

Does eating certain items in my diet affect my symptoms?

(ex. Gluten and dairy products are common irritants that increase inflammation and make some people feel worse).

(3) Is there anything that helps relieve my symptoms?

(Ice Packs, Heating Pad, Soak in a Tub, over-the-counter or prescription pain medications, etc.)

(4) If I change positions does this affect my symptoms?

(5) Are they better or worse in what positions and activities?

**This concludes the slide
presentation of
extra-pelvic endometriosis**