Catamenial Pneumothorax

Survey of Women who experienced 1 or more Lung Collapses confirmed via Medical Imaging - April 2016

Author: Julie Lawrence, MPH
Survey Information

- Self reported data
- Online survey with multiple choice and free form comments sections as appropriate
- Distributed to two Facebook support groups for women who suffer from Catamenial Pneumothorax and Thoracic Endometriosis
- Survey responders were asked to complete the survey ONLY if they had experienced at least 1 lung collapse confirmed by medical imaging (Xray or CT scan).

*60 women started the survey and completed the first section on demographics, however, there are 13 women who did not complete the remaining sections regarding detailed imaging findings & surgical findings.

As of April 29, 2016, there are 47 women who have completed the diagnosis, surgery, medication, & subsequent questions.
Patient Demographics

Note: Only those who had at least one lung collapse confirmed via imaging tests (Xray and/or CT scan) were requested to complete this survey.

- **47 survey responders** for all questions regarding diagnosis, surgeries, etc.
  - Note: 60 survey responders for demographics, however 13 skipped all subsequent questions/sections
- Average age - 37 years
- Country
  - USA - 33 patients
  - United Kingdom - 10 patients
  - Canada - 5 patients
  - Australia - 3 patients
  - Denmark - 2 patients
  - Italy - 1 patient
  - Malaysia - 1 patient
  - Netherlands - 1 patient
  - Portugal - 1 patient
  - Singapore - 1 patient
  - South Africa - 1 patient
  - Sweden - 1 patient

Q4 Have you been diagnosed with at least 1 lung collapse from imaging tests (Xray, CT)? Check all that apply.

- Right Lung collapse(s)...
  - 88.14%
- Left Lung collapse(s)...
  - 22.03%
Symptoms of Lung Collapse
# Executive Summary of Lung Collapse Symptoms

(Note that “n” = the number of responders)

## Breathing Symptoms During Lung Collapse - 48 Responders

1. **Shortness of Breath** - 79.17% of responders (n=38)
2. **Fluttery feeling in lung** - 62.50% of responders (n=30)
3. **Rasping, crackling sensation in lung** - 60.42% of responders (n=29)

## Chest Pain During Lung Collapse - 48 Responders

**Top 3 Locations of Chest Pain (47 Responders)**

1. **Right Upper Quadrant of chest** - 85.11% of responders (n=40)
2. **Collarbone** - 45.81% of responders (n=22)
3. **Sternum** - 29.79% of responders (n=14)

**Top 3 Chest Pain Symptoms (48 Responders)**

1. **Internal air movement when changing position** - 79.17% of responders (n=38)
2. **Sharp and stabbing chest pain** - 64.58% of responders (n=31)
3. **Pressure in chest** - 64.58% of responders (n=31)

## Back Pain Symptoms During Lung Collapse - 47 Responders

**Top 3 Locations of Back Pain**

1. **Right upper back** - 70.21% of responders (n=33)
2. **Right mid back** - 55.32% of responders (n=26)
3. **Left upper back** - 17.02% of responders (n=8)

**Top 3 Back Pain Symptoms**

1. **Sharp and stabbing back pain** - 74.47% of responders (n=35)
2. **Dull ache/ pressure in back** - 38.30% of responders (n=18)
3. **Tightness** - 36.17% of responders (n=17)

## Shoulder Pain Symptoms During Lung Collapse - 44 Responders

**Top 3 Locations of Shoulder Pain**

1. **Right Shoulder Blade** - 68.18% of responders (n=30)
2. **Right front of shoulder** - 40.91% of responders (n=18)
3. **Right shoulder tip** - 36.36% of responders (n=16)

**Top 3 Shoulder Pain Symptoms**

1. **Sharp & stabbing in shoulder** - 68.18% of responders (n=30)
2. **Pressure in shoulder** - 36.36% of responders (n=16)
3. **Dull ache in shoulder** - 34.09% of responders (n=15)

## Lower Rib Symptoms During Lung Collapse - 39 Responders

**Top 3 Symptoms**

1. **Pressure near lower ribs** - 53.85% of responders (n=21)
2. **Internal air movement sensation when changing position** - 51.28% of responders (n=20)
3. **Sharp & Stabbing pain near lower ribs** - 46.15% of responders (n=18)
## EXECUTIVE SUMMARY OF LUNG COLLAPSE SYMPTOMS

### NECK PAIN DURING LUNG COLLAPSE - 31 RESPONDERS

<table>
<thead>
<tr>
<th>Top 3 Locations of Neck Pain (31 Responders)</th>
<th>Top 3 Neck Pain Symptoms (30 Responders)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Right side of neck - 64.52% of responders (n= 20)</td>
<td>1. Dull ache in neck - 53.33% of responders (n= 16)</td>
</tr>
<tr>
<td>2. Back of neck - 32.26% of responders (n= 10)</td>
<td>2. Tightness in neck - 36.67% of responders (n= 11)</td>
</tr>
<tr>
<td>3. Left side of neck - 25.81% of responders (n= 8)</td>
<td>3. Pressure in neck - 36.67% of responders (n=11)</td>
</tr>
</tbody>
</table>

### THROAT OR VOCAL SYMPTOMS DURING LUNG COLLAPSE - 28 RESPONDERS

<table>
<thead>
<tr>
<th>Top 3 Symptoms</th>
<th>1. Sensation as though something stuck in throat - 50% of responders (n= 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Hoarseness - 42.86% of responders (n= 12)</td>
</tr>
<tr>
<td></td>
<td>3. Change in pitch of voice - 35.71% of responders (n = 10)</td>
</tr>
</tbody>
</table>

*Note: Only those who had at least one lung collapse confirmed via imaging tests (Xray and/or CT scan) were requested to complete this survey.*

Source: Detailed Analysis of Catamenial Pneumothorax Survey as of April 2016  
Author: Julie Lawrence, MPH
Symptoms of Lung Collapse
Detailed Analysis
Chest Symptoms during Lung Collapse

Q5 Please indicate Location of Chest symptoms experienced during a lung collapse.

Answered: 47  Skipped: 13

Right upper quadrant of chest: 85.11%
Collarbone: 46.81%
Sternum: 29.79%
Left upper quadrant of chest: 19.15%

Pain that increases when changing position:

Internal air movement sensation when changing positions: 79.17%
Sharpen and Stabbing: 64.58%
Pressure: 64.58%
Tightness: 60.42%
Crackling: 58.33%
Gurgling: 47.92%
Dull ache: 37.50%
Pulling: 20.83%
Burning: 10.42%
Stinging: 6.25%

COMMENT ANALYSIS

Shoulder Blade Pain Right Lung Rib Cage Chest Sitting Lying Bending Breath Air Lung Chest Collapse
Lower Rib Symptoms During Lung Collapse

Q7 Please indicate location of lower rib pain symptoms experienced during a lung collapse.

Answered: 39  Skipped: 23

- Right lower rib: 92.31%
- Left lower rib: 15.38%

Q8 Please elaborate on nature of lower rib symptoms experienced during a lung collapse.

Answered: 39  Skipped: 23

- Pressure: 53.85%
- Internal air movement sensation when changing positions: 51.28%
- Sharp and stabbing: 46.15%
- Pain that increases when changing position: 43.59%

- Dull ache: 35.90%
- Tightness: 33.33%
- Gurgling: 30.77%
- Crackling: 25.64%
- Pulling: 17.95%
- Burning: 12.82%
- Stinging: 5.13%
Back Pain Symptoms During Lung Collapse

Q10 Please elaborate on nature of back pain symptoms experienced during a lung collapse.

- Sharp and stabbing: 74.47%
- Bull ache: 38.30%
- Pressure: 38.30%
- Tightness: 36.17%
- Internal air movement sensation when changing positions: 31.91%
- Pain that increases when changing position: 31.91%

Q9 Please indicate location of back pain symptoms experienced during a lung collapse.

- Right upper back: 70.21%
- Right mid back: 55.32%
- Left upper back: 17.02%
- Left mid back: 17.02%
- Right lower back: 12.77%
- Left lower back: 4.26%
Shoulder Pain Symptoms During Lung Collapse

Q11 Please indicate location of shoulder pain symptoms experienced during a lung collapse.

- Right shoulder blade: 68.18%
- Right front of shoulder: 40.91%
- Right shoulder tip: 36.36%
- Left shoulder blade: 18.18%
- Left front of shoulder: 13.64%
- Left shoulder tip: 13.64%

Q12 Please elaborate on nature of shoulder pain symptoms experienced during a lung collapse.

- Sharp and stabbing: 68.18%
- Pressure: 36.36%
- Dull ache: 34.09%
- Tightness: 29.55%
- Pain that increases when changing position: 29.55%
- Burning: 27.27%
- Pulling: 20.45%
- Stinging: 11.36%
Neck Pain Symptoms During Lung Collapse

Q13 Please indicate location of neck pain symptoms experienced during a lung collapse.

Answered: 31  Skipped: 29

- Right side of neck: 64.52%
- Back of neck: 32.26%
- Left side of neck: 25.81%
- Front of neck: 25.81%

Pain that increases when changing position

Q14 Please elaborate on nature of neck pain symptoms experienced during a lung collapse.

Answered: 30  Skipped: 30

- Dull ache: 53.33%
- Tightness: 36.67%
- Pressure: 36.67%
- Sharp and stabbing: 30.00%
- Burning: 20.00%
- Pulling: 20.00%
- Stinging: 6.67%
Breathing & Throat Symptoms During Lung Collapse

Q15 What breathing symptoms do you experience during a lung collapse?

- Shortness of breath: 79.17%
- Fluttering feeling in lung: 62.50%
- Rasping, crackling sensation: 60.42%
- Dry cough off and on: 37.50%
- Dry cough upon changing positions: 25.00%
- Dry cough constant: 16.67%

Q16 What throat, vocal symptoms do you experience during a lung collapse?

- Sensation as though something stuck in throat: 50.00%
- Hoarseness: 42.86%
- Change in pitch of voice: 35.71%
- Sensation of air in throat: 25.00%
- Difficulty/pain while swallowing food: 14.29%
- Difficulty/pain while swallowing liquid: 14.29%
Lymph Node Symptoms During Lung Collapse

Q17 Do lymph nodes become painful or swollen during a lung collapse?

Answered: 44  Skipped: 16

No: 88.64%
Yes - Please elaborate in...
11.36%
Diagnosis of Lung Collapse
Executive Summary - Lung Collapse Diagnosis

- Hemothorax (accumulation of blood between linings of lung) is less common than Pneumothorax (accumulation of air outside of lung). (6 out of 47 (13%) indicated Hemothorax).

- Pneumoperitoneum (free air in the peritoneal cavity below the diaphragm) is usually not present.  
  11 out of 38 (29%) had a pneumoperitoneum

- Apical Lung Collapse (Top of lung) is the most common location of initial collapses
  34 out of 42 (81%) were apical lung collapses for initial collapse

- Location of collapse did not change for the majority of responders from first collapse to subsequent collapses.
  27 out of 38 (71%) had subsequent collapses in the same location as initial collapses.
  If the subsequent collapse did change location, the most common finding was to suffer an apical collapse initially, with a basilar collapse following (10 out of 38; 26%)

- Having only one collapse is NOT common (only 3 out of 47; 6%).
  2-4 collapses: 21 out of 47 (44.68%)
  5-9 collapses: 12 out of 47 (25.531%)
  10+ collapses: 11 out of 47 (23.40%)

- During menstruation (incl. 24-48 hrs prior) and ovulation is the most common time for collapses (70%)
  12 out of 46 (26%) suffered collapses not only during menstruation or ovulation, but also at times outside of menstruation & ovulation
  2 out of 45 (4%) suffered collapses only outside of menstruation and ovulation.

- For collapses that occurred outside of menstruation & ovulation, hormonal state during this time ranged from:
  7 out of 14 (54%) were on continuous birth control pill when collapse occurred.
  5 out of 14 (38%) were in medically induced menopause (such as Lupron, Danazol) when collapse occurred.
  1 out of 14 both ovaries removed; and 1 out of 14 one ovary removed

- For collapses outside of menstruation and ovulation*, almost half had a pattern (41%).
  10 out of 17* (59%) no pattern.
  7 out of 17* (41%) followed a pattern (either same time of month, monthly, or same number of weeks apart).

Key Take-Aways

Having only one collapse is NOT common.

While menstruation, ovulation are more common times for collapses to occur. They can and do occur outside of those times, & often follow a pattern in timing.

Collapses outside of menstruation and ovulation happened most commonly while on continuous birth control pill and secondarily while in medically induced menopause from Lupron, Danazol, etc.

Key Questions to Consider

Should continuous birth control and Lupron, Danazol and other medical menopause medications be the first line of defense against further collapses, as many ob-gyn providers believe?
Lung Collapse Diagnosis

Q18: How was lung collapse diagnosed? Check all that apply.

- X-ray: n = 47 (100.00%)
- CT Scan: n = 24 (51.06%)
- Other: n = 2 (4.26%)
  Comments indicate ultrasound

Q19: What type of lung collapse was diagnosed? Please check all that apply.

- Pneumothorax (Lung collapse): n = 46 (97.87%)
- Hemothorax (accumulation of blood between membranes lining the lung): n = 6 (12.77%)
- Other - Please elaborate in...: n = 1 (2.13%)
  Comments indicate that one was a pneumothorax and other was hemothorax
Lung Collapse Diagnosis

Q20 Was a pneumoperitoneum (free air in the peritoneal cavity below the diaphragm) present upon imaging?
Answered: 38 Skipped: 22

- No, n = 27, 71.05%
- Yes, n = 11, 28.95%

Q21 Where was lung collapse occurring during INITIAL collapse?
Answered: 42 Skipped: 11

- Apical lung collapse (top of lung to partially down lung), n = 34, 80.95%
- Basilar lung collapse (bottom of lung, above diaphragm), n = 5, 11.90%
- Other - Please specify below, n = 3, 7.14%
Comments: not sure, unknown
Lung Collapse Diagnosis

- **47 survey responders**

- **Average age at time of initial confirmed collapse:** 34 years

- **Average number of collapses confirmed from medical imaging:**
  - 6.48 average number of collapses
  - 1 collapse: 3 responders (6.38%)
  - 2-4 collapses: 21 responders (44.68%)
  - 5-9 collapses: 12 responders (25.53%)
  - 10+ collapses: 11 responders (23.40%)
Lung Collapse Diagnosis

Q25 Did your lung collapses occur in a pattern?

- Only during menstruation: n = 19 (41.30%)
- Have occurred during menstruation, ovulation, and outside of those times: n = 12 (26.09%)
- Only during menstruation and ovulation: n = 7 (15.22%)
- Other. Please specify below: n = 5 (10.87%)

Majority of comments state: 24-48 hours prior to start of menses.

Q26 If a lung collapse occurred outside of menstruation and ovulation, please elaborate on your hormonal state at time of collapse: (If more than one apply, please check all that apply).

- On continuous birth control pill: n = 7 (53.85%)
- Medically induced menopause (Lupron, Danazol, etc.): n = 5 (38.46%)
- Surgical menopause - both ovaries removed: n = 1 (7.69%)
- Natural menopause: n = 1 (7.69%)

Answered: 46 Skipped: 14

Answered: 13 Skipped: 46
Lung Collapse Diagnosis

**Q27 If lung collapse(s) occurred outside of menstruation and ovulation, was there a pattern?**

- No pattern: 58.82% (n = 10)
- Not monthly, but always at same time of a given month (beginning of month, mid month, or end of month): 23.53% (n = 4)
- Monthly (but with no period): 11.76% (n = 2)
- Always the same number of weeks apart: 5.88% (n = 1)

**Q28 Do lung collapses tend to occur at a specific time of day?**

- No pattern: 80.00% (n = 32)
- Evening: 10.00% (n = 4)
- Afternoon: 7.50% (n = 3)
- Morning: 2.50% (n = 1)
Surgical Treatments
Surgical Treatments

**VATS surgery Statistics:**
- 42 women had at least 1 VATS Surgery
- 1.59 average number of VATS surgeries
- 1 VATS: 23 responders (54.76%)
- 2 VATS: 16 responders (38.10%)
- 3 VATS: 2 responders (4.76%)
- 4+ VATS: 1 responder (2.38%)

**Thoracotomy Surgery Statistics:**
- 15 women had at least 1 Thoracotomy
- 1.33 average number of Thoracotomies
- 1 Thoracotomy: 11 responders (73.33%)
- 2 Thoracotomies: 3 responders (20.0%)
- 3 Thoracotomies: 1 responder (4.76%)
- 4+ VATS: 1 responder (6.67%)
Surgical Treatments

- **Chest tubes (pigtail catheter, Heimlich Valve) (not related to surgery):**
  - 38 women had at least 1 chest tube
  - 3.16 average number of chest tubes
  - 1 Chest Tube: 12 responders (31.58%)
  - 2 Chest Tubes: 8 responders (21.05%)
  - 3 Chest Tubes: 9 responders (23.68%)
  - 4 Chest Tubes: 1 responder (2.63%)
  - 5+ Chest Tubes: 8 responders (21.05%)

- **Talc Pleurodesis**
  - n = 10

- **Excision of abnormal tissue from lung**
  - Chemical pleurodesis with talc through tube (not in surgery)

- **Tal 5 Surgical Treatments that FAILED to prevent recurrent lung collapse:**
  - Mechanical pleurodesis: 25 out of 36 women (69%)
  - Bleb removal/repair: 17 out of 36 women (47%)
  - Talc pleurodesis: 10 out of 36 women (28%)
  - Lung wedge resection: 8 out of 36 women (22%)
  - Diaphragm hole repair: 6 out of 36 women (17%)
Top 5 Surgical Treatments that SUCCEEDED in preventing further collapses:

- **Talc pleurodesis**: 12 out of 30 women (40%)
- **Mechanical pleurodesis**: 9 out of 30 women (30%)
- **Mesh on diaphragm**: 7 out of 30 women (23%)
- **Diaphragm hole repair**: 6 out of 30 women (20%)
- **Lung wedge resection**: 6 out of 30 women (20%)
### Success Rate of Preventing Further Collapses by Procedure

*Note: Often 2 or more procedures were done in one surgery, so this data is not reliable to draw definitive conclusions about a procedure in isolation.*

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Numerator: # indicated procedure prevented further collapses</th>
<th>Denominator: Total # who indicated they had this procedure</th>
<th>Procedure-Specific Success Rate in preventing collapses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mesh on Diaphragm</td>
<td>7</td>
<td>10</td>
<td>70.00%</td>
</tr>
<tr>
<td>Diaphragm Plication</td>
<td>2</td>
<td>3</td>
<td>66.67%</td>
</tr>
<tr>
<td>Chest wall abnormal tissue excision</td>
<td>3</td>
<td>5</td>
<td>60.00%</td>
</tr>
<tr>
<td>Diaphragm abnormal tissue excision</td>
<td>4</td>
<td>7</td>
<td>57.14%</td>
</tr>
<tr>
<td>Talc pleurodesis in surgery</td>
<td>12</td>
<td>22</td>
<td>54.55%</td>
</tr>
<tr>
<td>Diaphragm hole repair</td>
<td>6</td>
<td>12</td>
<td>50.00%</td>
</tr>
<tr>
<td>Excision of abnormal tissue from lung</td>
<td>5</td>
<td>10</td>
<td>50.00%</td>
</tr>
<tr>
<td>Total pleurectomy</td>
<td>4</td>
<td>8</td>
<td>50.00%</td>
</tr>
<tr>
<td>Lung wedge resection</td>
<td>6</td>
<td>14</td>
<td>42.86%</td>
</tr>
<tr>
<td>Apical pleurectomy</td>
<td>3</td>
<td>8</td>
<td>37.50%</td>
</tr>
<tr>
<td>Talc pleurodesis (tube) (not in surgery)</td>
<td>2</td>
<td>6</td>
<td>33.33%</td>
</tr>
<tr>
<td>Mechanical pleurodesis</td>
<td>9</td>
<td>34</td>
<td>26.47%</td>
</tr>
<tr>
<td>Lobectomy</td>
<td>1</td>
<td>4</td>
<td>25.00%</td>
</tr>
<tr>
<td>Bleb removal/repair</td>
<td>4</td>
<td>21</td>
<td>19.05%</td>
</tr>
</tbody>
</table>
Surgical Treatments

Q35 Did you try GYNECOLOGICAL surgery to prevent recurrent lung collapses? Please check all that apply.
Answered: 17  Skipped: 46

- Laporoscopy (for removal of pelvic endometriosis) n = 12 70.59%
- Removal of uterus n = 6 35.29%
- Removal of both ovaries n = 5 29.41%
- Tubal ligation n = 2 11.76%
- Removal of one ovary n = 2 11.76%
- Laporotomy (for removal of pelvic endometriosis) n = 1 5.88%

Q36 Did the gynecological surgery indicated above prevent recurrent lung collapses for you?
Answered: 20  Skipped: 43

- No n = 14 70.00%
- Yes n = 6 30.00%
Surgical Treatments

Q37 If you had gynecological surgery, can you clarify if you were on any hormonal medication/hormone replacement treatment that could have affected your estrogen levels after your gynecological surgery above?

Answered: 14  Skipped: 49

- I was NOT on estrogen or progesterone medications after my gynecological surgery. **n = 9 (64.29%)**
- I was on medication containing estrogen after my gynecological surgery. **n = 3 (21.43%)**
- I was on medication containing progesterone after my gynecological surgery. **n = 1 (7.14%)**
- I was on medication containing both estrogen and progesterone after my gynecological surgery. **n = 1 (7.14%)**
Surgical Treatments

Q38 How long have you been collapse free?

Answered: 46  Skipped: 17

<table>
<thead>
<tr>
<th>Time Frame</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 year</td>
<td>25</td>
<td>54.35%</td>
</tr>
<tr>
<td>1-2 Years</td>
<td>8</td>
<td>17.39%</td>
</tr>
<tr>
<td>3-4 Years</td>
<td>6</td>
<td>13.04%</td>
</tr>
<tr>
<td>5-6 Years</td>
<td>3</td>
<td>6.52%</td>
</tr>
<tr>
<td>11+ Years</td>
<td>3</td>
<td>6.52%</td>
</tr>
<tr>
<td>9-10 Years</td>
<td>1</td>
<td>2.17%</td>
</tr>
<tr>
<td>7-8 Years</td>
<td>1</td>
<td>2.17%</td>
</tr>
</tbody>
</table>

Q39 In this period of time of being collapse-free, are you having regular periods (menstruation/ovulation)?

Answered: 45  Skipped: 18

<table>
<thead>
<tr>
<th>Response</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
<td>33.33%</td>
</tr>
<tr>
<td>No (if no, please indicate)</td>
<td>30</td>
<td>66.67%</td>
</tr>
</tbody>
</table>
Surgical Findings of Lung
Surgical Findings of Lung

Lesion, focal sub pleural fibrosis with Ossetia metaplasia and sub pleural ventriloquial emphysema (no I never smoked) Lower lobe: sub pleural ventriloquist emphysema, Inflamed tissue
Surgical Findings of Lung

Q42 Were any thoracic lymph nodes removed during surgery?
Answered: 37  Skipped: 26

Yes  n = 2

No  n = 35

Q43 Were any imaging tests effective in diagnosing lung abnormality? Please check all that apply.
Answered: 20  Skipped: 43

X-ray  n = 11

CT Scan  n = 16

MRI  n = 3

Other  n = 1
Surgical Findings of Lung

Q44 During surgery, how was lung abnormality treated? Please check all that apply.

Answered: 29  Skipped: 34

- Bleb removal and repair: n = 22, 75.86%
- Wedge resection: n = 11, 37.93%
- Biopsy only: n = 4, 13.79%
- Lobectomy: n = 3, 10.34%
- Other: n = 1, 3.45%
Surgical Findings of Pleural Surface
Surgical Findings of Pleural Surface

Q45 Was an abnormality found on: (Please check all that apply)

- No clear indication of parietal or visceral pleura, only chest wall involvement: n = 6 (54.55%)
- Parietal pleural: n = 4 (36.36%)
- Visceral pleura: n = 1 (9.09%)

Q46 Was pleural surface abnormality identified from pathology report as: (Please check all that apply)

- Endometrial tissue: n = 8 (72.73%)
- Other: n = 3 (27.27%)
Surgical Findings of Pleural Surface

**Q47** Were any imaging tests effective in diagnosing pleural surface/chest wall abnormality? (Please check all that apply)

- **CT Scan**
  - $n = 9$
  - 90.00%
- **X-ray**
  - $n = 6$
  - 60.00%
- **MRI**
  - $n = 2$
  - 20.00%
- **Other**
  - $n = 2$
  - 0.00%

**Q48** During surgery, how was pleural surface/chest wall abnormality treated? Please check all that apply.

- **Excision of abnormality**
  - $n = 6$
  - 50.00%
- **Biopsy only**
  - $n = 5$
  - 41.67%
- **Cauterization of abnormality**
  - $n = 2$
  - 16.67%
- **Other (specify below)**
  - $n = 2$
  - 16.67%
Surgical Findings of Diaphragm
Surgical Findings of Diaphragm

Appearance of Abnormality of Diaphragm from Comments:

- White scar tissue/ fibrous nodule. Right hemidiaphragm showed extensive scarring, fibrosis. Thinning of diaphragm with visible endometriomas underneath (bluish).
- No glands or stroma present but lesions were Hormonally Receptive per surgeon.
- Black powder burn.
- Fleshy nodule.
- Blue discolorations.
- Blue discolorations as well as red irritated looking sores. Explication was performed during first surgery so no path report. For 2nd thoracic surgery, excision was performed of entire plicated area as well as new area white dotted appearance on diaphragm behind liver. This path report showed positive for endometriosis of diaphragm.
- Blue/purple
Surgical Findings of Diaphragm

Q51 Were any holes (fenestrations) of the diaphragm identified?

- Yes - more than 1 hole: n = 16 (51.61%)
- No: n = 13 (41.94%)
- Yes - 1 hole / fenestration: n = 2 (6.45%)

Q52 Were any imaging tests effective in diagnosing diaphragm abnormality? Please check all that apply.

- CT Scan: n = 2 (50.00%)
- X-ray: n = 1 (25.00%)
- MRI: n = 1 (25.00%)
- Other: n = 0 (0.00%)
Surgical Findings of Diaphragm

Q53 During thoracic surgery, how was diaphragm abnormality treated?

- Repair of hole with suture/staple: n = 8, 42.11%
- Excision and repair of: n = 4, 21.05%
- Talc administered near diaphragm: n = 4, 21.05%
- Mesh placed on diaphragm: n = 4, 21.05%
- Diaphragm plication: n = 3, 15.79%
- Other (specify below): n = 3, 15.79%
- Biopsy only: n = 1, 5.26%
- Cauterization of abnormal...: n = 1, 5.26%

Answered: 19, Skipped: 44
Multiple Thoracic Surgeries & Recurrence
Multiple Thoracic Surgeries & Recurrence

Q54 If you had more than one thoracic surgery: in the subsequent surgery, was there a recurrence of lung, diaphragm or pleural abnormalities? Please check all that apply.
Answered: 23

Not applicable... n = 10 43.48%
Bleb on lung n = 6 26.09%
Hole/fenestration in diaphragm n = 6 26.09%
Endometrial tissue on diaphragm n = 5 21.74%
Abnormal tissue on lung n = 4 17.39%
Abnormal tissue on diaphragm n = 4 17.39%
Endometrial tissue on lung n = 2 8.70%
Endometrial tissue on chest wall n = 2 8.70%
Abnormal tissue on chest wall n = 2 8.70%
Thymus tissue on lung

Q55 If you answered yes to an abnormal finding in your SUBSEQUENT thoracic surgery, please confirm the length of time from the INITIAL surgery to the SUBSEQUENT surgery.
Answered: 14

Less than 1 year n = 9 64.29%
1-2 years n = 3 21.43%
5-6 years n = 1 7.14%
7-8 years n = 1 7.14%
9-10 years
11+ years
Multiple Thoracic Surgeries & Recurrence

Comments indicated:
- Nerve damage to arm, breast area
- Shoulder pain
- Scar tissue pain
- Central sternum pain
- Numbness, tingling on right side of body
- Ongoing tightness and pain when breathing deeply affecting right upper back
- Periodic chest pain, tightness
- Pleurisy, Infections, Collapse, Pneumonia, Pulmonary embolism
- Occasional abnormal heart beat
- Nerve pain from intercostal damage
- Horner syndrome

Q56 Have you had complications or health issues from thoracic surgery? If yes, please elaborate in Comments box.

Answered: 35  Skipped: 28

Yes  n = 16

No  n = 19
Multiple Thoracic Surgeries & Recurrence

Q57 If you answered yes to complications or health issues from thoracic surgery, please confirm the length of time post surgery that the complications arose.

- Within 2 weeks of surgery: n = 9 (52.94%)
- 3-4 months post surgery: n = 3 (17.65%)
- 4-6 weeks post surgery: n = 2 (11.76%)
- 7-12 weeks post surgery: n = 1 (5.88%)
- 1-2 years post surgery: n = 1 (5.88%)
- 5-6 years post surgery: n = 1 (5.88%)
- 7-12 months post surgery
- 3-4 years post surgery
- 7-8 years post surgery
- 9-18 years post surgery
- 11+ years post surgery
Medications to Prevent Lung Collapses
### Medications to Prevent Lung Collapses

**Q58 What medications have you tried to prevent lung collapses BUT recurrent lung collapse still experienced during course of medication (i.e., Medication FAILED to prevent lung collapse)? Please check all that apply.**

**Answered: 24  Skipped: 39**

<table>
<thead>
<tr>
<th>Medication</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth control pill no breaks</td>
<td>15 (62.50%)</td>
</tr>
<tr>
<td>Lupron 3 month injection</td>
<td>5 (20.83%)</td>
</tr>
<tr>
<td>Lupron 1 month injection</td>
<td>4 (16.67%)</td>
</tr>
<tr>
<td>Mirena Coil</td>
<td>4 (16.67%)</td>
</tr>
<tr>
<td>Birth control pill w/ breaks</td>
<td>15 (62.50%)</td>
</tr>
<tr>
<td>Progesterone only</td>
<td>3 (12.50%)</td>
</tr>
<tr>
<td>Visanne</td>
<td>3 (12.50%)</td>
</tr>
<tr>
<td>Zoladex</td>
<td>3 (12.50%)</td>
</tr>
<tr>
<td>Depo provera</td>
<td>2 (8.33%)</td>
</tr>
<tr>
<td>Letrazole (Femara)</td>
<td>2 (8.33%)</td>
</tr>
<tr>
<td>Danazol</td>
<td>1 (4.17%)</td>
</tr>
<tr>
<td>Synarel</td>
<td>1 (4.17%)</td>
</tr>
<tr>
<td>Anastrozole (Arimidex)</td>
<td>1 (4.17%)</td>
</tr>
</tbody>
</table>

**Comments indicated:**
- Zarah
- Norethidrone made worse
- Lo Ovral
- Nexplanon Implant
- Lo Loestrin Fe
- Emoquette
- Naferilin nasal spray
- Goserilin
- Cerazette
- Necon
- Aviane
- Yaz
- Mirena coil
- Provera
- Gynera
Medications to Prevent Lung Collapses

Comments indicated:
- Zarah
- Migrogestin
- Lupron 1 month
- Lutera
- Cerazette
History of Pelvic Endometriosis
Fertility after Thoracic Surgery/Lung Collapses
Fertility after Thoracic Surgery/Lung Collapses

Comments indicated:
• IVF
• IVF with donor egg
• Clomiphene
Fertility after Thoracic Surgery/Lung Collapses

n = 9

Comments indicated:
• Difficulty breathing during labor
• 2nd collapse 3 months postpartum
• Asthma attacks increased during pregnancy
History of other Diseases/Conditions
History of Other Diseases/Conditions

Q65: Have you been diagnosed with any of the below? Please feel free to add other conditions not listed in the Comments box.

Answered: 24  Skipped: 3

- **Asthma**: n = 11 (45.83%)
- **Pleurisy (prior to IFL)**: n = 5 (20.83%)
- **Hypothyroidism (or Hashimoto)**: n = 5 (20.83%)
- **Pleural effusion (pr...)**: n = 4 (16.67%)
- **Costochondritis**: n = 3 (12.50%)
- **Emphysema**: n = 3 (12.50%)
- **Deep vein thrombosis...**: n = 2 (8.33%)
- **Hyperthyroidism**: n = 2 (8.33%)
- **Pericardial Endometriosis**: n = 1 (4.17%)
- **Pulmonary embolism (BE)**: n = 1 (4.17%)
- **Thoracic outlet syndrome**: n = 1 (4.17%)
- **Polycystic Ovary Syndrome**: n = 1 (4.17%)
- **Postural Orthostatic...**: n = 1 (4.17%)