Signs and symptoms
Parastomal hernias are caused because stoma surgery disturbs the muscle structure, making a potential weak point. Over time, the muscles stretch and become weaker. As a result, straining caused by violent coughing, heavy lifting, vigorous exercise, or poor muscle tone allows the abdominal contents, usually the intestine, through the weak spot.

To get a clearer understanding of the problems patients face during diagnosis and treatment of this condition, Salts Healthcare conducted a study to find out more about how people living with a parastomal hernia cope. The findings were presented by Caroline Cowin of Salts Healthcare at the UA AGM last year.

Our survey findings are based on the experiences of over 300 colostomy, ileostomy and urostomy patients who had been diagnosed with a parastomal hernia. They told us about their clinical diagnosis, the type and severity of problems they encountered, how they managed their hernia, what sort of appliances they used, how they rated them, and how they felt about it.

This article focuses on urostomists, but generally the results were similar regardless of ostomy type. Unless otherwise stated, any figures given are for urostomy patients.

Diagnosis
The first thing we established was that over half of the hernia cases in urostomists developed within a year of the original stoma surgery. Another 25% of patients developed a hernia between one and five years after the original surgery.

Interestingly enough, research published last year found that, although half of the group had hernias, only a quarter of them knew they had one. Our study found that the vast majority of hernias are diagnosed by either a hospital consultant or stoma care nurse. GPs only diagnose around 10% of cases. That could mean that around half the people who don’t have a regular review with a stoma care specialist may have an undiagnosed hernia. So we have a common complication of stoma surgery which patients are failing to spot, but stoma care specialists can diagnose on review.

Urostomy Complications
Urostomy patients regularly experience problems with their stoma. Of those who took part in our survey, over half report a mucus discharge, a third experienced urine infections, and a fifth said they had a problem with odour. Less tangible effects, which are harder to observe, were also reported. Just over a third said their stoma was uncomfortable. Over half got a dragging or pulling sensation, and about half said they felt a heaviness around their stoma. These can all be attributed to having a hernia.

The most obvious sign of a parastomal hernia is a bulging round the stoma. Patients reported that the size of their stoma changes as the hernia develops. Over half of urostomists said their stoma had grown by as much as 9mm – the width of a pencil.

When we asked whether having a hernia made it more difficult to put on a pouch, nearly half of the urostomists agreed. Strangely enough, only 21% said that having a hernia had made a difference to how they managed their stoma. This seems to be backed up by the fact that just under half of urostomists continued using the same type of appliance. Of those who changed their appliance, the majority had switched to a convex adhesive.

<table>
<thead>
<tr>
<th>Table 1 Changes in stoma size</th>
<th>Colostomy (74)</th>
<th>Ileostomy (38)</th>
<th>Urostomy (18)</th>
<th>AI (134)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average size at first</td>
<td>34.0%</td>
<td>29.3%</td>
<td>30.0%</td>
<td>31.9%</td>
</tr>
<tr>
<td>Average size changed to</td>
<td>42.1%</td>
<td>35.2%</td>
<td>39.1%</td>
<td>39.4%</td>
</tr>
<tr>
<td>Average change in size</td>
<td>8.16%</td>
<td>5.92%</td>
<td>9.11%</td>
<td>7.51%</td>
</tr>
</tbody>
</table>

^ = Note small sample size
Another main area of concern was the condition of the skin around the stoma. Most urostomists seldom, if ever, reported problems with their skin before developing a hernia. After a hernia developed, the frequency and severity of reported skin problems rose. People said their skin became more sore, red/irritated, and itchy.

The biggest change people told us about was changes in skin thickness. Over 25% of urostomists said they had noticed that the skin around the stoma had become thinner. If the skin is thinner, it’s more likely to be damaged if there’s a leak, or when they change their pouch.

Changes in the size of a stoma and the condition of the surrounding skin can have a noticeable effect on how well a pouch fits. If the pouch doesn’t fit properly, there is an increased risk of having a leak.

Table 2 Leakage timing summary

<table>
<thead>
<tr>
<th></th>
<th>Colostomists (105)</th>
<th>Ileostomists (79)</th>
<th>Urostomists (26)</th>
<th>All (213)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day time only</td>
<td>17%</td>
<td>13%</td>
<td>11%</td>
<td>15%</td>
</tr>
<tr>
<td>Night time only</td>
<td>18% (*)</td>
<td>6%</td>
<td>4%</td>
<td>12%</td>
</tr>
<tr>
<td>Both day and night time</td>
<td>64%</td>
<td>76%</td>
<td>85%</td>
<td>71%</td>
</tr>
</tbody>
</table>

^ note small sample size (*) statistically significant compared to ileostomists

The majority of stomas leak at some time during the day and night, but we found urostomists who reported leakage seemed to have them both during the day and at night.

Leaks during the day seem most likely to happen on a weekly basis or less often. People describe daytime leaks equally as fairly bad or not very bad. Night leaks are slightly less frequent, usually happening monthly or less often, but are likely to be described as bad ones. We don’t know whether this difference in rating of daytime and night leakage is due to factors such as the timing or location of the incidents, but it’s not unreasonable to speculate whether the psychological effect of a night time leak is more distressing because it happens during sleep.

Betty’s story
A urostomy patient living with a parastomal hernia

Age: 70 years
Gender: Female
Weight: About right
Stoma type: Urostomy
Stoma age: 2 years
Appliance type: One piece
Adhesive type: Flat
Change frequency: Once a day
Hernia diagnosis: Stoma Care Nurse

Betty is a composite persona based on research conducted by Salts Healthcare Ltd.

“I've had my stoma since 2009. My hernia was diagnosed about 10 months after my original surgery for bladder cancer.”

“I get a lot of mucus discharge from my stoma. I also feel some discomfort around the stoma. It's like there's something dragging or pulling on it.”

“Before I had the hernia, I rarely had any problems with my skin. It used to get a bit red, itchy, or sore, but it wasn’t very bad. Now I get problems more frequently and they seem to be a bit worse than before. The biggest change I’ve noticed is that the skin seems to be getting thinner. It feels more sore and itchy now, but the skin doesn’t seem to be as red or irritated.”

“I've also noticed that my stoma has changed size. It’s grown about the width of a fat pencil, which makes it more difficult to put on a pouch. I haven’t had to change my appliance, but a number of people I know have started using a convex adhesive.”

“The other problem is leakage. I can get a leak during the day or at night. It happens about once a week during the day, and it can be fairly bad. I get leaks less often at night. It’s only once a month, or so, but it’s bad when it happens.”

“I’m more self-conscious since I found out I had a hernia, but I don’t tend to worry about it. I still manage my stoma the same way. I rarely ask for help, but if I do need it, I’d generally ask the Stoma Care Nurse at the hospital.”

We’d love to hear your views.
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Management
It's interesting to note that despite the fact all the respondents had ordered support garments, just under half the study said they used support belts or girdles to manage their hernia, and only a quarter of urostomists thought it was the best way to manage a hernia. The most popular management technique favoured by urostomists was to be careful, avoid heavy lifting, and don't overdo it.

Finding a mental attitude being classed as a good management technique might be surprising until you delve a little deeper. Although just over half of urostomists agreed that having a hernia had made them more self-conscious, just over 40% said they worried about it. We don't know whether this is because people think a hernia is part of having a stoma, or they don't want to appear concerned. Certainly, this may be something to do with the fact that over half of hernia sufferers rarely, if ever, sought help from a trained stoma specialist once their hernia was diagnosed.

Conclusions
This study has given us information about the diagnosis, effects, and management of parastomal hernias. We know that people generally start developing a parastomal hernia within a year of surgery, many without realising it. We know reviewing patients regularly for the signs and symptoms of a hernia can help reduce management problems. However we don't understand enough about management techniques, and we may be wasting time and money on things that don't work. It's clear we need better understanding of the needs of the patient. It's also important that we develop more appropriate individual management techniques to look after the physical and psychological effects of a hernia.

One way to understand the challenges is for us to try and focus on the individual rather than get lost in the statistics. We have created 'Betty', a 'typical' urostomist suffering with a parastomal hernia. Betty is a fictional character (see page 21), but her story is based on the experiences shared by real urostomists diagnosed with a parastomal hernia. We use Betty as a thumbnail sketch to remind us about what she has to deal with and how she copes. With her help, Betty will keep us on track to deliver better results for her and others who need help and support with a parastomal hernia. Read Betty's story now to see what you have in common and where your story differs.