

# Parastomal hernia: improving quality of life, restoring confidence and reducing the fear. The importance of the role of the stoma nurse specialist

## ABSTRACT

This article provides an overview of qualitative comments regarding parastomal hernia (PSH) taken from a survey of ostomy patients in the UK in 2018. This article also considers the importance of the role of the stoma nurse specialist in improving quality of life (QoL), reducing fear, and restoring confidence in patients with a stoma and/or a PSH.

**Keywords** Parastomal hernia, exercise, education, quality of life, stoma nurse

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## INTRODUCTION

A parastomal hernia (PSH) is a common complication after stoma surgery. The true incidence is not known, but prevalence is estimated to be approximately 25–30% at 12 months post-surgery<sup>1</sup> and 50% or higher after 2 years, and many clinicians feel that PSH may be inevitable in time<sup>1-5</sup>. In general, there is a lack of quality research about the history, risk factors and causes of PSH and a lack of consensus about prevention and treatment<sup>3</sup>, although clinical trials, in particular the CIPHER study, are underway to address this issue.

Although not conclusive, key risk factors for PSH development are generally considered as male gender, age (over 60), surgical complications/technique, having an end colostomy, previous steroid or chemotherapy treatment, obesity (BMI >25), smoking, COPD/respiratory condition and weak abdominal muscles<sup>6-10</sup>. Previous studies show a trend towards physical inactivity after stoma formation, with the fear of a PSH being a major deterrent to living an active life<sup>11</sup>. Other studies (by the author of this paper) showed that 40% of patients reported becoming less physically active after stoma surgery but, in those with a diagnosed PSH, this increased significantly to 53%<sup>12,13</sup>.

Comments from patients from these studies concluded that 'making the hernia' worse or a lack of advice about living with a PSH were significant factors in reduced quality of life (QoL) and physical inactivity<sup>13</sup>. Patients generally (confirmed by comments below) report feeling fearful and unsure of activities they can safely do to reduce their risk of developing a PSH, and are unclear of what to do when they have a diagnosis of PSH, leading to a sense of fear and vulnerability. Patients often anecdotally report being told not to do abdominal exercises, to be cautious of exercise and lifting, and to 'be careful' in case they develop a PSH, further compounding the issue and leading to a cycle of fear, activity avoidance and reduced QoL.

## QUALITATIVE PATIENT COMMENTS

Survey responses were gathered from 1,500 people with stomas in the UK in 2018. The following comments are taken directly from the survey comments:

*I'm scared to do too much exercise as it makes my stoma/hernia sore and I don't know how much I can push myself.*

*Personally, I wish I had been advised about hernias and how to prevent them from the beginning, prevention being better than cure.*

*I'd love to know do's and don'ts of exercise with a hernia.*

*I think more information is needed in this area. Both with reference to abdominal exercises, and also how to engage in more vigorous activities safely.*

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*The most I was told was no heavy lifting for 6 weeks, nothing more than a full kettle. But after that? Who knows... after care should include visits to physios with stoma knowledge and experience.*

*I am scared to do exercise in case I get a hernia.*

*It would be good to be advised on what exercises one should or shouldn't do in order to improve one's health/strength or avoid injury/hernia.*

*Too often patients are not being advised of do's and don'ts after a hernia repair resulting in a hernia returning, physical rehabilitation after surgery should be standard practice.*

*I would like to know how to strengthen my stomach muscles without risking provoking a serious hernia.*

*I am VERY angry that I was given NO information on how to prevent or minimize a hernia until I insisted. I only found out about how I could help myself by referring to the internet. Unfortunately, too late to support my ever-growing hernia.*

*I worry about getting hernia, it is difficult to know when exercise is too much*

These comments, which are representative of the most common responses, indicate a common theme of fear and misinformation, and a palpable desire for better advice about PSH and safe exercise/rehabilitation after stoma surgery. These comments, together with findings from other studies<sup>11</sup>, show a clear trend towards 'fear avoidance'<sup>14</sup> in patients with stomas, but more particularly those diagnosed with a PSH.

## HOW CAN THE STOMA NURSE SPECIALIST HELP?

The stoma nurse specialist is in a unique position to be able to re-educate and support, reducing patients' feelings of anxiety and fear, ultimately improving confidence, activity levels and QoL<sup>15</sup>. In this section we suggest three ways this can be done:

- Using a person-centred approach.
- Using strength-based language.
- Implementing an appropriate therapeutic rehabilitation exercise programme

Providing clear, evidence-based advice about PSH (reduction of risk as well as PSH management), in line with clinical guidelines published by the Association of Stoma Care Nurses (ASCN) UK<sup>6</sup> is without question. Modifiable risk factors, as stated in the ASCN guidelines, can be sensitively discussed with patients, in particular weight loss and smoking cessation. This advice should also include the introduction of – or signposting to – an appropriate therapeutic rehabilitation programme before or after surgery. This could be in the form of booklets, online videos, appropriate cancer or stoma rehabilitation classes or 1:1 instruction. Stoma nurses should ensure educational materials are made available such as those produced by charities (Ileostomy Association and Macmillan) and stoma bag manufacturers, and those highlighted in the ASCN clinical guidelines. Ideally, they should also be able to demonstrate suitable exercises to their patients. However, the way in which

this advice and information is delivered, and the language used, may have a profound effect on how a patient feels about PSH<sup>16</sup>. It's important that patients don't feel guilt or shame, nor that they somehow caused their hernia.

### Person-centred approach

A person-centred approach takes a holistic view of a patient, considering not only their medical condition, but their psychological and social needs as well as personal preferences, hobbies and interests<sup>17,18</sup>. It places any medical condition or disability in the context of the whole person. This is important when discussing PSH with a patient. Consider the effect that unintentionally cautious advice may have on the person.

In this case study example, Patient A (a 75-year-old man with a colostomy) had been told to avoid playing golf in case it made his PSH worse. This advice was given quickly in the clinic, almost as a throw away comment and was given with kindness and in good faith but had the effect of being devastating. Golf was Patient A's life. He was the chairman of the golf club and had played his whole life. He had even chosen to buy a house backing onto the golf course. It was his vital lifeline for his social life and his mental and physical wellbeing. To be told not to play ever again was confusing and damaging for his physical and mental wellbeing.

Instead, a person-centred approach would have meant providing modifications to enable him to play golf more safely, for example doing abdominal core exercises, showing the correct technique when lifting his clubs, using a buggy on the course, and wearing of support garments if he felt it was helpful.

### Strength-based language

Strength-based language emphasises people's strengths, abilities and opportunities, instead of their challenges, conditions or perceived deficiencies<sup>16</sup>. It focuses on providing advice about what someone can do, rather than the things they should avoid (Figure 1). However, it is easy to fall into unintentional negative language when attempting to provide caring, cautious advice.

When discussing PSH with a patient, using 'strength-based' language would mean using positive language and focussing on patient-centred modifications, emphasising things they CAN do rather than things they CAN'T. This enables patients, giving them the confidence to self-manage their PSH, empowering them and reducing their fear.

This simple change can make a fundamental difference to the way in which a patient adapts to life with a stoma or PSH, and could be the key to them moving out of the 'fear avoidance' cycle, reducing fear and improving QoL.

### Therapeutic rehabilitation exercise programme

Finally, the implementation of an appropriate therapeutic exercise-based rehabilitation programme can be a powerful tool to help patients restore confidence in their body, reduce fear, and improve QoL<sup>19-21</sup>.

This recommendation is in line with UK ASCN clinical guidelines<sup>6</sup>. These guidelines state that appropriate ‘core’ exercises can be commenced as soon as 3–4 days post-surgery. If possible, they can also be implemented BEFORE surgery as a form of ‘prehabilitation’. Suitable exercises are illustrated in the UK ASCN clinical guidelines. Other suitable programmes and exercises could be sourced from hospital physiotherapists, stoma charities or stoma bag manufacturers. The me+recovery programme from ConvaTec<sup>22</sup> is a three-phase programme, approved by ASCN, the Royal College of Nursing and the Association of Coloproctology GB and Ireland. It provides a range of exercises suitable for anyone at any stage of surgical recovery.

Through such simple exercise programmes, patients can regain normal movement patterns, improve core and pelvic floor function and control, and learn to move with more confidence<sup>20</sup>. Core abdominal exercises can give people a sense of control and stability and can be key in living with both a stoma and/or PSH. Suitable core abdominal exercises for people with a stoma involve simple tightening of the deep core and pelvic floor muscles and movements such as pelvic tilts and knee rolls whilst lying on their back. These exercises have their foundation in clinical Pilates and are similar to post-natal exercises. The goal is to gain control, connection and function of the deep core muscles and pelvis. Figure 2 shows how this foundation phase is important for all, restoring function, confidence, movement and physical fitness.

A suitable therapeutic exercise rehabilitation programme should include a range of rehabilitation exercises that can be done immediately post-surgery. It should also have options to progress as the patient improves and regains condition. This also helps with motivation and engagement. It should also offer a wide range of adaptations and modifications for patients who wish to exercise in a chair, when standing, or on a bed<sup>19-21</sup>.

In line with person-centred care, each patient should also have the opportunity to choose the exercises that they feel are most appropriate for their physical condition, goals and lifestyle. The programme should therefore be presented in a positive way where the patient feels they have a choice, and they feel empowered and motivated.

## CONCLUSION

PSH may well be inevitable for many patients and the reality of living with a stoma and PSH can be difficult to cope with. Once diagnosed with PSH, many patients become less active, fearful and have reduced QoL.

An appropriate therapeutic exercise programme can be a powerful tool in rebuilding self-confidence and physical strength and should be encouraged and introduced to all patients. Appropriate core abdominal exercises – such as in the me+recovery programme – are safe for stoma patients to potentially reduce their risk of PSH and also for those who have already developed a PSH.

The stoma care nurse specialist is in a unique position to have a significant influence on how a patient adapts and copes with life with a stoma and/or a PSH. Using a person-centred approach and strength-based language, along with providing evidence-based advice and introduction of a therapeutic exercise programme, it is possible to reduce fear, increase confidence, and improve QoL for the stoma patient.

## CONFLICT OF INTEREST

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What you say...	What the patient hears...
You must avoid lifting	Lifting anything will damage me = FEAR
You have high risk of a hernia	That sounds bad (what’s a hernia anyway?) = FEAR
Wear this support garment	I need to rely on something rather than my own body/muscles = DISABLEMENT
Be careful with exercise	I better not move (ever again) = FEAR and DISABLEMENT
<b>INSTEAD SAY.....</b>	
When lifting, do it like this..	I can lift safely without hurting myself = ENABLEMENT
You can reduce your risk of a hernia by...	I have skills and knowledge to help myself = EQUIPPED and ENABLED
Do abdominal exercises to strengthen your own muscles	I can rely on my own body/muscles to support me = EQUIPPED and ENABLED
It’s really important to exercise and here’s how....	Exercise is important for my health and I know how to do it safely and appropriately = EMPOWERED

Figure 1. Some examples of strength-based language (created by the author)



Figure 2. The foundation phase of the me+recovery programme from ConvaTec<sup>22</sup>

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