Advancing Stoma Care Services

ASCS CASE STUDIES

By Natasha Rolls

Abstract

This document includes 3 anonymous case studies observed by Natasha Rolls on those receiving stoma care.

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Case study one

Introduction

64-year-old male, married, no children working in IT.

Diagnosed through bowel cancer screening program with an ultra-low rectal cancer, stage T3 N1 M0. He will need oncological therapy (chemo-rad) to down- stage the tumour and then extra elevator abdominal perineal excision (ELAPE). The operation is curative in intent.

Consultation

Referred as a routine by consultant and colorectal CNS for pre-op consultation with Stoma Care, as he will have a permanent colostomy.

Several calls made to this gentleman, answer machine messages left but no response, we have time as he will have oncology treatment prior to surgery so will keep trying to make contact with him.

Noted on hospital system that he is attending for a pre-op appointment so we join that consultation to introduce ourselves and suggest an appointment with us. Gentleman is very adamant that he does not want a stoma. He states that he is hopeful that his oncology treatment will be all that is needed, which demonstrates the lack of understanding and compromises the Informed consent process. I make contact with the consultant and we arrange a joint appointment to discuss with this gentleman and explain again the oncology treatment is to shrink the tumour but the surgery would be the definitive treatment with curative intent.

I give him the literature and a brief un-complex chat about living with a stoma. Lots of reassurance given that life is possible and can be good with a stoma, that we will give him space for his oncology and once he has a date for surgery, we will invite for an outpatient- one hour, to discuss stoma formation and living well with stoma.

He attends with his wife and it becomes immediately clear that much of his reluctance and aversion is shared with her. She is unable to look at any pictures or products and makes audible sounds of disgust. He is able to look at pictures and I suggest he speak to a patient who has already had surgery, to which she says they don't want to do that. I suggest we draw the consultation to close but should rearrange when they have had time to think about the prospect of his surgery, I reiterate again that his surgery is his best chance of survival and that once he cured he can live well with a permanent colostomy.

I text him the details of a patient, on our list, who is happy to talk to others and arrange another outpatients for two days' time, I suggest that he attends alone for this appointment.

He attends, this time alone, and at this point he is very tearful. He hasn't called the other patient and I suggest we do this together so he agrees and we call and we arrange a time for them to talk. The rest of the pre-op chat is calmer; he does look at products and admits that they are not so bad. We talk about his greatest fears which are being able to travel, being able to go to work, and sexual intercourse; we addressed these one by one. I agree that things will be different but not worse. I then offer to talk to his wife if that would help. He asked me to call her then, which I do she is withdrawn at first but warms up through the call and I see him visibly relax. Surgery is scheduled for the next week so I site and encourage him to practice with pouches.

We see him again on the morning of surgery he has no further questions for us, but he obviously terrified, his wife is not present at this consultation, but the team will call her postop.

Post-Op Recovery

Day one post-op

seen the on the ward, he has not yet looked at his stoma and does not want to do so. I suggest he places his hand over the bag to feel the stoma, that it is not alien but he in fact part of him and advise that the longer he puts off looking the bigger barrier this will become for him. He holds his hand over the pouch and stoma and relaxes a little. I change the pouch for him stoma is healthy, pink and warm, spouted at skin level in the pre-marked spot, abdomen is soft, uniform and regular. Advise that he may feel or hear flatus as the first indication that the bowel is becoming active and that this is a positive sign.

Day two post-op

I note that opiate use is high so suggest to the F1 stool softeners, the junior doctor is reluctant as has been advised to prescribe laxatives to lower GI patients with caution, but I explained that there is no anastomosis, so no risk of stimulant perforation and the risk of his constipation is high and stool softeners are safe, so laxido is prescribed.

This time the patient looks at his stoma as I perform a teaching pouch change, he looks first through the bag and then again when the bag is off, clearly much less disturbed by the appearance of the stoma and appears more relaxed for the first time. Encouraged him to touch the stoma, which he does.

He's very tearful but admits he feels relieved that it's not as bad as he thought. I return that afternoon as he does a supervised change. We talk about him increasing his oral fluids, the appropriate diet choices to stimulate activity and that he should mobilise. I also provide him with a valley cushion so that he can take this home, it will aid sitting to ease the pain around his perineum.

Day three post-op

Today the stoma is active of stool which is a new step for the patient to acknowledge and deal with. We talk about closed bags instead of drainable as the stool is soft and thick. He doesn't want to use the closed bags yet but is given both, form our free issue stock, so that he can make a decision himself. He performs an independent change, lots of praise given and he is clearly very happy with his achievement. He's wearing a flat drainable one piece bag, selected as per clinical need and I have talked about the range of pouches available and that we can re-visit his choices throughout his journey but we will always offer those with greatest clinical benefit to suit his requirements. (closed bags are more cost-effective if changing more frequently daily and our advised for colostomy users.)

Day four postop

When I arrive, he has already changed the pouch himself and he's clearly very impressed with himself. So we take this consultation time instead to discuss how he feels about going home, and in particular how his wife may be feeling, trying to establish his particular concerns and what support he wants from us.

He expresses that he thinks his wife may need to learn to care for his stoma; we explored why he felt this and what benefit this may bring. We discussed this; the impact on his relationship as partners versus carers etc. and he decided that he should be self-caring. He agreed that once recovered this is not a medicalised procedure and he wants to present to her as well and coping. I also discussed that

much of her reluctance was fear, so whilst not learning to care for his stoma for him it may be beneficial for her to see the stoma or a picture of the stoma to dispel some of her anxieties. He agreed and would take a picture at his next change then she can choose whether to look or not. Plans are being made for discharge so stock given (from our free issue supply) and a home visit for one week booked. Our contact details have also been provided.

Further Recovery

Following week see by community colleague (company nurse on honorary contract with the trust, funded by Sponsorship Company) one week post discharge at home. All contact notes shared and full handover provided to ensure seamless, patient centred care.

Patient managing so well feeling relieved and positive, order placed now for closed bags and adhesive remover spray. He is changing 2 to 3 times daily output is good, advised choice of delivery companies or chemist and registered with his chosen delivery company, time for questions which he asked. Future ordering process explained including recommended volumes and order frequency.

Outpatient appointment for clinic local to him made for one month, his wife not present at this consultation as she was at work but as discussed with my colleague, it was offered that his wife could call me if she had any questions or concerns, considering that she may find talking to someone she had already met easier. That day his wife called, she was tearful, and I asked her about her specific fears or anxieties particularly related to the stoma. She said that she worries that he is 'weaker and now vulnerable'. Reassure her that this is not the case, the cancer and surgery recovery has made him vulnerable, and he will take time to get back to full fitness, but the stoma will allow, not hinder, this. Reiterated that she cannot hurt him, that he is the same person, but has lived through a life changing event, and is changed by this, but will discover a new way of being with her help and support. Encouraged her to acknowledge that she has also lived through this trauma and will feel changed because of it but they can support each other. I suggested I could refer for formal counselling but at this stage she declined, although promised me she would give it some thought for them both. I also suggested that she might look at the picture of his stoma to dispel her fear and she considered that she might. Reassured her that she can call us to if needed, but she is doing well, and his prognosis looks promising from his pathology and surgical outcomes.

Current Status

This gentleman is now two years post ELAPE and all is surveillance is good. They are both back at work. They go on holidays and are intimate and close. We see this gentleman annually to check his product usage and any concerns he may have with the stoma

Case study 2

Introduction

34-year-old female, mother of two; aged six and eight, emergency de-functioning loop ileostomy for Crohn's disease.

Patient not seen preoperatively as presented as an emergency, although has previously seen a stoma nurse many years ago when resident elsewhere, as her Crohn's diagnosis has been long-term, she therefore has some awareness and is actually very positive about having a stoma as she struggled with her symptoms for so long, she was not sited pre-op.

Post-op Recovery

Day two postop:

Surgery performed over the weekend and referred by the ward team.

Patient awake but in pain and distracted and admits she's unable to concentrate or look at her stoma, pouch changed for her.

Stoma spouted above skin level, but in a deep crease and low on her right abdomen under an abdominal fold, on a soft variable and inward profiled abdomen. Output watery, faecal, fluid, with the bag already demonstrating signs of seepage.

Volumes not accurately recorded so instigated a fluid balance chart and accurate fluid measurement and recording. Applied a convex high output system with drainable bag, directed team to high output guidelines, written by the Stoma Care team, which have been through trust governance and have been adopted as best practice in the trust. Suggested commencing loperamide orally and IV fluid replacement titrated to losses (as per guidelines). Urine output moderate, pale yellow with adequate volumes, permitted to eat and drink so suggestions for safe diet made (low fibre/residue, small volumes eaten frequently), and to consume isotonic fluids. Reassurance that we will see her again tomorrow. Patient tells me that she just needs to get home to see her children. This is her priority.

Day three post-op:

2nd visit feeling less distracted so wanted to participate in a pouch change, lots of reassurance needed as stoma active throughout the change but she was very determined to complete this.

Check drug chart and discover loperamide capsules have been prescribed, these are less effective in a patient with an ileostomy as designed to dissolve in colon, so changed to the tablet form and discussed with the team about increasing the dose.

Also gave her a Colostomy UK colouring book for her children, when they visit and 2 cuddly toy rabbits which have stomas to aid their understanding and acceptance and make it easier for her to discuss with them.

Day 4 postop:

Patient changed pouch under supervision, stoma output still high 1.4 to 1.6 L in 24 hours. Discussed again diet to aid physical thickening and slow gut transit, hospital menu challenging so we looked together at what she might choose to select the best choice. Loperamide tablets have been taken but timings are challenging as the drug rounds are not coinciding with mealtimes, so suggested to the ward staff that she permitted to self-administer so that these can then be taken 20 minutes pre-meals which enables these to be more effective.

Patient managing well physically but presents as increasingly distressed, feeling a strong need to be home with her children. This distress may be impacting and influencing her higher output. Arrange to take her downstairs to the café to meet them and her husband later that day.

Day five postop:

Patient changing the bag herself, output at one to 1.2 L in 24 hours, drainable bag given in order that she is confident and competent with these ready for discharge. Remains desperate to get home, medical team reluctant as output still higher than desired, bloods within normal range and psychological impact of inpatient stay reiterated. Suggested stoma team can call tomorrow to offer safety net, check volumes and condition and required advice, so discharge home arranged.

Day six postop:

Video call (Dr Dr) made at 11 am, she had emptied once overnight and twice by this morning, which is in line with expected volumes, feels output is thickening still passing good volumes of urine and no symptoms of dehydration. Looks well and alert.

Presenting as much more positive in affect and tells me she feels like she can, at last, start to get better now she is home, home visit arranged for next week, and feedback given to surgical team.

Day nine postop:

Home visit- output now thickened and emptying 4 to 5 times in 24 hours, advised to begin to reduce her loperamide and titrate it to her output. Advised to ensure diet is low fibre for at least the next few weeks, she can build up to a normal diet gradually and we will support her with this.
Stoma size changed so template adjusted, and alternative deep convex bag applied as slight seepage still noted. Peristomal skin intact and healthy. DET 0

Discussed ordering and registering with the delivery company of her choice, explained future ordering including recommended volumes of product and order frequency. Discussed troubleshooting and red flags as to when to cease south management and seek help.

Further Recovery

2 weeks outpatient offered instead of one month, at a clinic local to her, but advised if managing well we can do this as a video or telephone call and we would then see in person at one month.

Phone call at two weeks continues to manage well and is feeling well so we'll see in clinic at the 1-month point.

One month outpatient, continues to manage well, has found that low dose loperamide helps at times, especially first thing in the morning but titrates this herself. Consultant informed so the team can monitor. Pouches appropriate and manages a wear time of 48hrs consistently. We will see as per pathway in 3 months.

Current Status

This patient continues to have periodic episodes of higher output, she admits this is when she strays with her diet or if she's had a few glasses of wine more than normal. She calls us to alert us to this episode but then with our support and advice self manages. We have liaised with the GP and hospital team to ensure she has regular bloods. especially U's and E's to check renal function, and more recently we have referred for dietician input to ensure she has not nutritionally compromised. We have also liaised closely with our IBD colleagues. Her priority is her family and being there for them, but she knows when to seek help and to stay safe.

Case study three:

Introduction

Through our recent prescribing product, we are alerted to many patients who have self-managed for years without seeing Stoma Care services, these are the so-called ‘lost ostomates’.

Order placed by an 86-year-old lady, not known previously to the team but according to system has a colostomy formed many years previously for a possibly Perforated diverticulum.

Order volumes high and product noted to be an older type of pouch with plastic clip. Previous order history on the GP system shows volumes are higher than she was previously ordering, so suspect there is a problem.

Consultation

Call made and patient tells me she's having leaks which is why she's changing so often, she says "I never had any trouble before but now every day I leak at least once." Housebound but tells me she could ask her daughter to bring her to clinic, note address very rural so home visit offered as we are already seeing some patients in that area on a specific day.

Patient is in a drainable bag with a formed stool. She has a colostomy and is experiencing some pancaking, seepage is evident and stoma at skin level on a pronounced outward, firm, uniform abdomen; probable parastomal hernia.

Drainable pouch has plastic clip which is now very challenging with her decrease in dexterity. Skin is excoriated (DET6)and skin excoriation is causing serous seepage which is compromising adherence of the pouch.

Template adjusted and more modern closed pouches demonstrated, which would eliminate clip, but she favours drainable as likes to empty and let out the flatus.

Therefore, shown drainable pouches with different closure systems but no plastic clip, time given to practice with each closure to see which she is most able to manage. Dressing applied to peristomal skin to absorb serous exudate and heal excoriation, pouch that she has selected applied, and stock given (from our free issue stock).

Whilst there we called her daughter to arrange for her to bring her mum to the next clinic in four days' time to reassess.

Attended clinic with her daughter the skin has healed DET 0, although she had not yet changed the bag. Revisited the closed bag scenario, but she still declined so we changed the bag together to ensure that she was able to use this new pouch. She seemed confident more stock given, asked her to change this pouch every other day (or daily if she preferred) and then we would be in contact within a week to make sure that this is the appropriate product for her.

On leaving the clinic her daughter disclosed that she had become worried about her mum as she had stopped going out, we agreed this was probably due to fear of leakage.

Follow up

Call arranged for one week and our contact details given, patient reports that the new pouches are working well, so order placed for correct volumes of new product and adhesive remover, pre-cut to the template by the delivery company for her so that she does not need to worry about doing this with her decreased ability and her poor dexterity. Unnecessary and inappropriate order averted.

Current Status

This lady will not be seen or contacted by us at least annually and is fully aware that she or her daughter can call whenever they need.