



# Clinical nurse specialists Stoma care

## Acknowledgements

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## Foreword



Stoma nurse specialists are pathfinders who help guide patients on their journey to a new life that should be free from disease and of a better quality. However, adapting to life with a stoma involves a number of physical and psychological challenges, and the partnership formed between a patient and a stoma nurse specialist is central to making this transition a successful one.

Stoma care patients face a number of issues, many of which are still considered taboo and which can lead to embarrassment and distress. They rely on stoma nurse specialists to resolve these issues effectively, provide support and guidance on a broad range of practical issues such as stoma management and personal nutrition, and contribute to improved social and personal confidence levels.

Many stoma patients are independent people who have experienced serious illness and long complex treatments. Making the transition back to ‘normality’ – a world where they must maintain and create relationships, care for others and support themselves financially – can seem a daunting prospect and requires great fortitude.

Any failure on the journey to achieving an effective return to normal life may make the treatment and its long term consequences, particularly the stoma, seem worse than the original illness. The stoma nurse specialist therefore plays a key role in the

rehabilitation process, by providing information, education, as well as encouragement and counselling for patients and their carers, all of whom have a diverse range of fears, needs and aspirations.

Patients have stomas created as part of treatment for a wide spectrum of diseases including cancer, chronic inflammatory disease and incontinence. Stoma nurse specialists also support patients with incurable disease, where only palliation is possible. Consequently, stoma nurse specialists need a broad knowledge base, and must be capable of working within the diverse clinical teams that give support to these vulnerable patients.

Stoma nurse specialists were the first clinical group to establish widespread, independent, sub-specialist skills in gastroenterology and urology; a model which is now widely followed by doctors and other nurses. As a clinical group they were also one of the first to recognise the importance of a patient’s ‘quality of life’, both in terms of treatment planning and the measurement of treatment outcomes. They are founder members of the multidisciplinary teams which today provide increasingly complex care to patients.

The comprehensive holistic care provided by stoma care nurse specialists has become central to enabling stoma patients achieve a successful recovery and rehabilitation after a major illness.

### **R H Diament**

Lead Clinician, West of Scotland Managed Clinical Network for Colorectal Cancer

## Introduction

Serious conditions of the bowel and bladder can affect people of any age, from babies through to the elderly. The surgical treatment of these conditions – which include bowel and bladder cancer, inflammatory bowel disease and diverticulosis, functional problems or trauma – often requires the formation of a stoma.

A stoma is an artificial opening on the abdomen to divert the flow of faeces or urine into an external pouch located outside of the body. This procedure may be temporary or permanent. It is estimated that there are 100,000 people in the UK with a stoma (Williams and Ebanks, 2003).

### There are three basic types of stoma:

- colostomy – an opening into the large bowel (colon), usually sited on the lower left side of the abdomen; a transverse colostomy, which is sited above the waist, can be on the left or right side
- ileostomy – an opening into the ileum (small intestine), usually sited on the right lower side of the abdomen
- urostomy – an opening into the urinary tract and usually sited on the right lower side of the abdomen.

Stoma formation will have an impact on the wellbeing and lifestyle of the person and their family whatever their age (Waller, 2008). Quality of life can deteriorate following a stoma procedure and specialist support during the first few weeks post-stoma is vital. Fear of rejection by friends and family as well as being ostracized by society is constant for this group of patients (Williams, 2008). The stoma nurse specialist has a key role in offering patients reassurance,

support and guidance on how best to manage all these issues and how to manage their stoma around their activities of daily living in order for them to achieve a successful rehabilitation.

Having a stoma is a major event, and can lead to patients becoming very anxious and depressed. What's more, stoma surgery often has a huge impact on body image and personal relationships can suffer. Patients need reassurance, support and guidance on how best to manage all these issues and how to manage their stoma around their day-to-day activities, in order to review or achieve acceptable quality of life.









## Clinical nurse specialists

There have been clinical nurse specialists (CNS) in stoma care since the early 1970s, when it became evident that patients undergoing a stoma procedure needed extra support to help them through the very challenging journey back to living a normal life.

The impact of this surgery can be overwhelming, causing distress, fear and feelings of hopelessness. It can take up to two years for some individuals to come to terms with the way they look and function

and to acquire a positive self image; others may never achieve this stage (Dryden, 2003). The role of the CNS in stoma care is to support patients, using specialist knowledge and skills to enhance their quality of life. In this respect, the stoma care service is a recognised invaluable resource:

*“Access to a stoma nurse specialist increases patient satisfaction and optimal independent functioning.”*

Clinical Standards Board for Scotland, 2001

## A day in the life of a CNS

### A day in the life of Jackie Macleod, Clinical Nurse Specialist

I am based in Raigmore Hospital, Inverness where there is a team of three full time CNS in stoma care and colorectal surgery. Today I will start in the wards before heading to Fort William – a round trip of 128 miles – for my nurse-led clinic and teaching session with district nurses.

In the hospital I review a patient who had emergency surgery yesterday resulting in the formation of a stoma, and a lady who has been extremely anxious after bowel cancer surgery. After support and encouragement this lady is now managing her care and is due for discharge soon. I review another patient who has had an ileostomy as a result of an ischaemic bowel. Her weight loss has contributed to the delay of her wound healing, and difficulties in applying the bag. The visit requires time with the staff to ensure they are aware of the complexities of stoma care and the psychological support needs for this patient. Finally, I give advice regarding diet, exercise, and lifestyle issues to a patient who is scheduled for discharge.

I head to Fort William where I discuss troubleshooting problem stomas with the district nurses, looking at different types of bags and accessories, which can often give solutions.

My colleague phones to refer a patient who has sore skin around her stoma. I arrange to visit on my way back to Inverness, as she lives not far from Fort William. Patients and families in these remote places are extremely grateful to have these visits, as it gives them time to discuss issues they may have forgotten or were too embarrassed to ask about whilst in hospital.

Four patients in the clinic have come along for general support and advice and the opportunity to see new products. Typical issues or concerns brought up by patients include sore skin, fear of bag leakage, and worries about planning a holiday, or their relationship with their partner.

Clinic over, I head for Inverness with a quick visit en route. The patient’s stoma has changed size, causing sore skin. I order different bags for her to resolve this. I will telephone the district nurse with an update and call the patient next week for a progress report.

## The CNS stoma care role

A CNS in stoma care is a registered nursing professional working within the NHS who has acquired additional knowledge, skills and experience together with an academically accredited post registration qualification. These specialists practice at an advanced level, and work autonomously to deliver a high standard of care. The role of the CNS in stoma care is complex and challenging, as well as rewarding.

The key aspects of the role are clinical, education, research and audit, consultancy, and management (Rust, 2009, Humphris, 1994).

### Clinical

The CNS in stoma care provides a specialist service for patients of all age groups, as well as their relatives and carers. Information and support is delivered prior to surgery, during the patient's hospital stay, and following discharge into the community.

This will encompass:

- pre-operative assessment for patients undergoing elective surgery
- pre-operative assessment for patients in hospital for emergency surgery
- specialist nursing care during the hospital stay, and continuing support to patients and family
- education and liaison with all health care professionals involved in the care of the stoma patient
- development of a comprehensive and flexible discharge plan with hospital and community health professionals

- ongoing support to patient and family and specialist back-up for community health care professionals
- availability to all stoma patients (new and established) and their families to provide support and advice when necessary.

Throughout the life-changing experience of having a stoma, the care provided by the CNS will encompass not only the physical but the psychological, spiritual, cultural, sexual and social needs of the individual.

In its publication *Guidelines for the management of colorectal cancer* (2007) the Association of Coloproctology of Great Britain and Ireland emphasises the vital role played by the CNS in stoma care:

*“The patient should be seen by a stoma nurse prior to surgery and the referral should be made at the earliest opportunity to allow adequate time for preparation.”*

In its colorectal cancer guidelines (2003), the Scottish Intercollegiate Guideline Network also states:

*“Patients with colorectal cancer who require stoma formation generally experience more problems than those who do not and the support and advice of a stoma nurse specialist is widely acknowledged to be of considerable value.”*



## A day in the life of a CNS

### Fiona Winslow, a Glasgow-based CNS, gives an insight into a typical day

I lead the stoma care service at the Western Infirmary and Gartnavel General Hospital and also at The Beatson, the West of Scotland's regional cancer centre. The day begins answering messages and checking for any new patients. All in patients within the various wards are visited. I am informed of a patient at the Western who is to have emergency surgery today. I travel to the Western Infirmary and have a brief chat with the lady going to theatre. She does not feel up to receiving much in the way of information but is keen to see what a bag looks like and know how the stoma will work. I mark the site for the stoma, which is difficult due to her swollen abdomen. I'm informed of a patient who had an emergency colostomy during the night due to trauma. I chat with him, check his stoma and supply bags for him as well as literature to read. I attend the multi-disciplinary team meeting in the Beatson, where all patients having undergone or about to undergo surgery for colorectal cancer are discussed.

A 28 year old is struggling to cope with his stoma and his mother has contacted me to request a review as she is concerned about him; I call and arrange to meet with him. A patient who had a urostomy a couple of years ago telephones. Practically she is managing her stoma well but psychologically she is having issues with her new body image. I arrange to see her the following day to chat about lifestyle issues, clothing and suggest a suitable person for her to chat with. This can benefit patients as it gives them insight into how others adapt to life following stoma surgery. The voluntary organisations can assist with this as they offer a patient visitor service. The Beatson refer a



lady who is about to be transferred to the hospice. I ensure she has supplies, reassuring her that the nurses at the hospice are able to assist with care, that they will contact me if there are any issues, and I will see her when I next visit the hospice.

Finally, I visit a man at home who had surgery a few weeks ago and is recovering well. He is keen to go on holiday and I offer advice including taking adequate supplies, and supply a travel certificate which states in various languages that the person is wearing an external bag. I arrange to see him again in a couple of months at the nurse-led clinic at Gartnavel.



## Patient story

### **Kenny, a colostomist, shares his story**

I was first diagnosed with bowel cancer in the summer of 2001, and was operated on to remove the tumour in the December of that year. Unfortunately about a week after my operation I developed a leak where my bowel had been joined. This necessitated an emergency operation in the early hours of Christmas morning. When I came round from the operation I was shocked to find that I now had a colostomy and was very apprehensive about how I would cope with it.

I need not have worried because once the team of stoma nurse specialists became involved I became a lot less concerned. They really put me at ease, taking me through care of my stoma, changing of my bag and so on, so that by the time I was discharged from hospital, I felt a lot more confident about things. However, any niggling doubts that I still had proved to be groundless as the support I received from the stoma nurses was excellent, with regular home visits for the first few weeks, advice over the telephone if I called and seeing me at an outpatient clinic, if necessary.

A couple of years ago I had difficulty obtaining the bags and flanges I used and which I had great confidence in. The assistance I got from the stoma nurses in obtaining and using suitable alternatives was invaluable.

I have had further cause to be grateful to the skill and care of the stoma nurses recently. A few months ago the skin around my stoma started to blister, then peel off, leaving raw flesh. The stoma nurses did an excellent job of making things bearable for me, and through their persistence they discovered that my condition was in fact caused by an unusual skin condition for which I am at present being treated. So I will always have cause to be grateful to the stoma nurses and the work they do.



## Education

The delivery of education is central to the role of the nurse specialist in stoma care. Dissemination of specialist knowledge is of paramount importance to enhancing the patient experience and the education of others including:

- patients and carers
- ward nurses
- community nurses
- general practitioners
- nursing and medical students
- nursing homes
- allied health care professionals.

Education is undertaken in a variety of settings, including the local community, hospitals, as well as at colleges and universities, and incorporates:

- one-to-one sessions
- the use of visual aid such as booklets, videos and DVDs
- informal teaching sessions
- workshops
- formal lectures
- study days
- conferences (local, national and international)
- protected learning sessions with community staff.



## Patient comments

### A selection of comments from patients taken from the Quality Improvement Scotland Audit 2008

*“The care given to me by the stoma care nurse was second to none. She gave me great support during a very difficult period in my life.”*

*“Stoma nurses are very valuable, offering practical advice and guidance.”*

*“My stoma care nurse has been excellent. She has been a constant source of encouragement and support and has always been available for advice and help.”*

*“Having had a problem after discharge with leakage and appliances, my stoma care nurse has been excellent with help and advice and I am able to call her between visits.”*

*“Felt I coped much better with a stoma having visits by stoma nurse in comfort of my own home following surgery. She even helped over anxiety over sexual aspects.”*

*“The confidence and positive attitude I have gained living with my stoma stems from the care, advice and guidance I received from the stoma nurse specialists.”*

## Research and audit

The implementation of current research, initiating research, and publishing best practice is integral to the role of the CNS and is central to ensuring that patients receive evidence-based best practice care.

Through the critical analysis of current research and by embracing change, stoma care continues to be recognised as a highly professional specialty. Since the mainstay research published by Barbara Wade, *A stoma is for life* (1989) to present day authors such as Julia Williams, Patricia Black, Sharon Fillingham and Theresa Porrett, stoma care has become associated with pioneers of the specialty.

To maintain the delivery of quality services, stoma care departments are audited on a regular basis. A variety of methods are employed, including patient questionnaires.

A recent national audit supported by Quality Improvement Scotland (QIS) invited all stoma care departments in Scotland to participate and generated a patient response rate of over 70%. The questionnaire was designed to capture information relating to the patient experience – their stay in hospital before and after their operation, caring for their stoma, and the information provided by the CNS – and 96% of patients that responded rated their experience of care given by the CNS as good or very good (NHS National Services Scotland, 2008).





## Consultancy

Colleagues look to nurse specialists for opinions, information, support and solutions with regard to stoma care issues. This consultancy role ensures a consistent and equitable approach to the management of stoma patients. The service is consulted by nurses, GPs, and staff from nursing homes, community hospitals, as well as NHS24, social services, and any other health care professional seeking advice.

*"I value the expertise of the stoma care service and the support they offer."*

Dr Smith, GP

## Consultancy in action

### **An example of consultancy in action, provided by Nancy, an Ayrshire-based CNS**

I receive a phone call from a district nurse who was quite concerned about one of her patients, who was bleeding from his stoma. I ask her a few questions to help me assess how urgent this problem was, and to establish if the district nurse could resolve this. It becomes apparent I needed to make the journey to meet the district nurse at the patient's home. On arrival I assess the situation; his stoma bag is half filled with fresh blood. I remove his bag to see if I can identify the cause of bleeding; there is an area of over-granulated tissue at the side of his colostomy which had been bleeding and is quite tender to touch. We commence the treatment of silver nitrate, which will be carried out on a weekly basis until the problem is resolved and arrange for the patient to attend my nurse-led clinic where he'll receive ongoing assessment to ensure he is using the most appropriate products.



## Management

Due to the ever-changing needs of the patient, daily schedules frequently have to be re-arranged to accommodate emergencies. A patient may have had a leakage overnight, is distressed and feels unable to come to hospital for fear of further leakage, necessitating a home visit, or a patient may be about to be going into theatre within the hour for emergency surgery and needs to be given information regarding his surgery and the site marked for the stoma.

To satisfy increased service demands, nurse-led clinics have been established to allow the CNS to respond quickly to patients presenting with problems and find solutions which prevent the need for GP or consultant intervention. At these clinics, patients can talk about their feelings and gain reassurance about returning to work or going on holiday. Patient reviews are also undertaken to ensure that appropriate products are being prescribed in order to prevent problems from occurring.

## Consultancy in action

### **An example of consultancy in action, provided by Isobell, a Lanarkshire-based CNS**

I received a referral from a GP practice asking for a young gentleman, who'd had surgery and an ileostomy six months previously, to be reviewed at the nurse-led stoma care clinic. Although coping very well with his stoma management, in the last weeks he'd been having pain and bleeding from his stoma and was unable to get a bag to stick.

An urgent appointment was arranged for the nurse-led stoma care clinic and the gentleman was reviewed within 48 hours. On review, his stoma and peristomal skin were examined; while his stoma was healthy, his peristomal skin was excoriated and numerous ulcerated areas noted. During the consultation the gentleman explained that the surrounding area had become very painful to touch over the last few weeks. In order to initiate a treatment plan I had to define the cause of the problem. Was the excoriated skin due to appliance leakage or management, allergy to the product, or another issue?

Due to the fact that his stoma was performed for ulcerative colitis, there was ulcerated areas noted and that he was experiencing severe pain, I decided to refer for a dermatology opinion, he was seen within five days; biopsies were taken and a skin disorder confirmed and treatment was commenced.



## Summary

There are a reported 100,000 people in the UK with a stoma (Williams and Ebanks, 2003), and it is thought that about 20% of them will have experienced clinically significant psychological problems following their stoma-forming surgery (White, 1997). Most people who have a stoma operation have some worries or concerns after surgery. The practical and psychological support given by a CNS in stoma care – both in hospital and at home – contributes significantly to an individual making a successful adjustment to life with a stoma. The continuity of care delivered by a CNS enhances the patient’s ability to cope, which in turn promotes reduced readmission to hospital and earlier discharge.

*“Clinical nurse specialists are a necessity, not a luxury, for the patient faced with stoma surgery.”*

Anne Demick, National Secretary of the Ileostomy Association

The CNS in stoma care also contributes in other ways. Significant savings for the NHS are achieved through the undertaking of patient product reviews, involvement in national procurement and budgeting at a local level, and in the reduction of surgical and GP consultations.

*“The health service cannot afford to lose specialist nursing posts. These posts have been created to improve outcomes and they are still needed...”*

Sue Thomas, RCN Nurse Adviser (2007)

## Patient story

### Cheryl shares her story

I think of my stoma as my new body part that saved my life. In June 2006 I returned home from holiday in Mexico with my boyfriend. A couple of weeks went past and I was suffering bad stomach cramps and had to run to the loo quite often. In August I was admitted to Crosshouse Hospital and diagnosed with ulcerative colitis, an inflammatory condition causing bloody diarrhoea. For the next few months after this I was given a variety of medication but with little improvement. I was losing a lot of weight and felt very weak; I went from being a healthy 9 stone to 7.5 stone. My consultant at Ayr hospital knew that I wasn’t responding to medication and on 18 November I had emergency surgery and was given an ileostomy, which has totally changed my life. At 19 I thought that having a stoma would be the end of my life but I now actually have a better quality of life.

Throughout this time I had regular visits from my stoma nurse specialist who is fantastic and I also had great support from her colleague. They both kept me up to date with new products and really helped me by answering lots of questions – including advice when I planned to go on holiday.

In April I opened my own hair salon and I am now back working full time. I have so much more confidence and such positive thinking but that’s thanks to my stoma nurse specialists who reassured me things would only get better and my family have also given me great support. After all that I had two weeks holiday in Bulgaria in July. I just wonder what my next challenge will be.

Having a stoma has made me respect my own individuality and I have learned to live with it in my own way.

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