

Role Descriptives of a Stoma Care Nurse Specialist



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Contents

Foreword	5
1. Introduction	6
i. Reasons for surgery	6
ii. Complications of stoma surgery	8
2. The role of the Stoma Care Nurse Specialist	9
i. Defining the role	10
ii. Developing new roles	10
iii. Areas of practice of the stoma care nurse specialist	10
iv. Nursing titles	11
v. Scope of practice of the stoma care nurse specialist	11
3. Attributes and belief systems of the stoma care nurse specialist	12
i. Personal attributes	12
ii. Personal beliefs	12
4. Core descriptors	13
i. Preparation for practice and continuing professional development	13
ii. Specialist knowledge	14
iii. Service development	15
iv. Management and leadership	16
v. Evidence-based practice	17
vi. Education	17
5. Specialist descriptors	18
i. Introduction	18
ii. Appliances and medications	18
iii. Stoma management	19
iv. Management of the patient requiring long term follow-up	20
6. References	21
7. Appendices	22
i. Appendix 1: Courses	22
ii. Appendix 2: Further reading and resources	23



Foreword

Stoma Care Nursing was one of the first clinical specialties to emerge for nursing and was pioneered by Barbara Saunders in the 1970's at St. Bartholomew's Hospital, London. Since then the role has evolved in order to meet the ever changing needs and expectations of both the person with a stoma, and national and local health care services.

Acting as an advanced practitioner the stoma care nurse specialist is a clinician, an educator, a researcher and a consultant. Therefore he/she needs to be resourceful, act as an advocate, be cost-effective and innovative as well as offer effective, evidence based care. Many nurses choose this speciality for the continuity of care offered to the person with a stoma: supporting them through the pre, peri- and post-operative stages of stoma surgery and into the community where the rehabilitation towards a better quality of life progresses.

In achieving a high quality of stoma care the stoma care nurse specialist liaises with other health care professionals, ostomy manufacturing companies and the patient support network, providing the link between all three.

This document should be used to guide the development of best practice and the creation of specialist nurse roles within local organisations. The descriptors are divided into two sections; the first part reflects generic qualities of nurses in the specialty and the second part recognises the specialist skills needed to deliver a stoma care nursing service. It is envisaged that nurses may offer all or part of the services listed and should adapt these descriptors for their local needs and in line with the professional experience of the post holder.

Our guidance is based on the experiences of both clinicians and academics with a specialist interest in stoma care nursing. The experiences are supported by evidence from the literature.

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On behalf of the working party

Introduction

A stoma is an artificially created opening from the gastrointestinal or urological tract. Stoma surgery has been around since the 1700's (Taylor, 1999) but stoma formation was perfected by Sir Bryan Brooke in 1954. The three most common types of stoma are colostomy, ileostomy and urostomy. However, many stoma care nurse specialists are involved in the care of jejunostomy, enterocutaneous fistulas and other restorative procedures for bowel and urinary problems such as ileo-anal pouch and Mitrofanoff procedures.

Stomas can be temporary or permanent and are formed during elective surgery or emergency surgery. It is estimated that there are 102,000 people (Herlufsen et al 2006) with a stoma in the UK, of these 65% will have a permanent stoma (Black 2000). Conditions resulting in stoma surgery include colorectal or bladder cancer, ulcerative colitis, Crohn's disease, severe faecal or urinary incontinence and trauma.

One of the goals of good stoma management is to maintain healthy peristomal skin. Skin around the stoma should be clean, dry and intact; there should be no difference between peristomal skin and the remainder of the healthy abdominal skin. Stoma care is generally best kept as simple as possible, with the use of minimal or no stoma accessories.

All patients undergoing stoma surgery will be seen by the stoma care nurse specialist at some point during the pre, peri and post-operative period.

Reasons for stoma surgery

Bowel Cancer – is the 2nd most common cancer in terms of incidence and mortality in England and Wales (Cancer Research 2005). Of the cancers diagnosed 2 in 3 are in the colon and 1 in 3 in the rectum (Cancer Research 2005). Presenting symptoms include persistent change in bowel habit, anaemia and rectal bleeding, weight loss, nausea, anorexia and abdominal pain. Treatment is multimodal including radiotherapy, chemotherapy, targeted therapies and surgery.

Bladder Cancer – is the 4th most common cancer in men and 9th in women (Cancer Research 2005). 10,000 people are newly diagnosed every year. Symptoms of bladder cancer are painless, intermittent haematuria, dysuria, frequency and pelvic pain. Bladder cancer is treated with radiotherapy, chemotherapy and surgery.

Inflammatory Bowel Disease – Inflammatory bowel disease is an umbrella term used for Crohn’s disease and ulcerative colitis which affects 1 person in 400 within the UK (NACC 2006). Both conditions cause inflammation and ulceration to the mucosal membrane, but ulcerative colitis only affects the rectum and colon and has superficial ulceration whereas Crohn’s disease results in deeper ulceration and inflammation anywhere from the mouth to the anus. Symptoms include urgent bloody diarrhoea, pain, anaemia, tiredness and weight loss. Treatment is usually combination drug therapy including steroids and immunosuppressives as well as biological therapies (Burch 2008). The person’s response to medical management may fail, resulting in the need for surgery, with or without a stoma.

Familial Adenomatous Polyposis – an inherited condition affecting 1 in 7,000 people (Cancer Research UK 2005). Patients are generally asymptomatic as numerous polyps develop that are ultimately pre-cancerous.

Incontinence - uncontrolled loss of faeces and/or urine due to such situations as obstetric trauma. Conservative management is usually first choice; if symptoms persist stoma surgery may result.

Congenital – such as imperforate anus and spina bifida can result in the need for stoma formation. Sometimes reconstructive surgery is possible.

Neurological – stomas may be formed to ease the management of elimination for those with spinal injuries or multiple sclerosis. Again other management modalities will have been tried before progressing to surgery.

Trauma - If the bladder or bowel becomes perforated through trauma such as a stabbing or gunshot, stoma forming surgery may be performed temporarily.

A normal healthy stoma is one that is red, indicating a good blood supply to the bowel, with a lumen that allows evacuation of faeces or urine, is secured to the abdominal wall and protrudes adequately to allow security of an appliance. Complications may occur if any of these issues are compromised. Complications can range from skin damage to bowel ischaemia

Complications of stoma surgery

Early complications

- Necrosis
- Peristomal skin soreness
- Retraction
- High output
- Obstruction
- Mucosal separation

Late onset complications

- Hernia
- Prolapse
- Stenosis
- Peristomal skin soreness –
excoriation/sensitivity
- Granulomas

Psychological adaptation - Many of the concerns which patients with stomas have are often discussed in terms of body image problems and therefore the anxieties and fears amongst many stoma patients include, noise, odour, leakage, visibility of appliance and perceived attractiveness to others. Whilst these anxieties are mainly practicalities of stoma care management the studies suggest that these issues contribute to the psychological adjustment and adaptation of the patient (Wade 1989).



The role of the Stoma Care Nurse Specialist

The role of the Stoma Care Nurse Specialist is often described as multifaceted, acting not only as a clinician but also an educator, researcher, consultant and clinical lead. Prior to the arrival of the stoma care nurse specialist in the late 1960's, the patient with a newly formed stoma was heavily reliant upon the surgeon, appliance manufacturer and/or self help groups for support, information and advice. Whilst these resources are still available the stoma care nurse specialist has brought about remarkable improvements in the quality of life for those patients with new and established stomas. As well as managing clinical issues, they have encouraged surgeons in developing surgical techniques, for example, the size and shape of a colostomy or ileostomy. They took over the pre-operative siting of stomas ensuring the stoma is created in the optimal place on the abdomen for the patient. They also take part in product evaluation, offering feedback to manufacturers so that research and development of stoma appliances can take place.

Preparation for specialist practice continues to vary in the UK and more recently the development of advanced practice has allowed the stoma care nurse specialist to extend the role e.g. nurse-led clinics, nurse prescribing and health assessment as well as developing other roles such as colorectal nurse practitioners.



Defining the role

The stoma care nurse specialist role allows the specialist to offer continuity of care, pre-operative assessment, post-operative care and discharge planning. With follow-up in the community the stoma care nurse specialist offers practical and psychological support to patients thus easing adaptation and adjustment to their new lifestyle. The stoma care specialist nurse also provides ongoing support to the person with an established stoma assisting with longer term stoma management issues.

Developing new roles

When establishing stoma care nurse specialist services the organisation should take into account local need and variation. The following should be considered;

- Duration of the post and funding
- Preparation for the post holder
- Trust wide and/or Primary Care Trust (PCT) agreement and support for the post holder
- Building effective relationships within the team
- Regular review of job description, workload, working hours, cover for sickness and annual leave
- Assuring public safety, performance review, protocols, guidelines, professional regulation, accountability, boundaries and competencies
- Remuneration and resource allocation, i.e., equipment, administration, clerical support, educational plans and career development
- Evaluation of post
- Future planning and role review

Areas of practice

Stoma care nurse specialists working with stoma patients may work in a number of settings;

- Ward areas – medical/surgical, paediatrics, health care for the elderly
- Out-patients
- Primary care clinics/community hospitals
- Home visits

Nursing titles

In order to use the title 'stoma care nurse specialist' it is recommended that the specialist nurse be educated in stoma care nursing to an advanced level, including stoma care, nurse prescribing and physical examination.

Scope of practice of the stoma care nurse specialist

The key components of specialist practice are considered to be the provision of expert clinical care, education, research and consultancy and service management (Porrett and David 1999). These parameters are central to stoma care nursing. More specifically the role is seen as assisting the stoma patient to rehabilitate and regain the quality of life known prior to stoma surgery (Salter 1997). This will include;

- Pre-operative information giving/counselling
- Siting of the stoma
- Stoma appliance and accessory information
- Post-operative management
- Discharge planning
- Alternative stoma management – colostomy irrigation, colostomy plug
- Enterocutaneous fistula/wound management
- Manage stoma complications
- Psychological support
- Internal pouch care
- Paediatric stoma care
- Health education/promotion – diet, exercise, travel, returning to work, family planning, pregnancy
- Nurse-led follow-up clinics
- Nurse prescribing
- Measuring and fitting support garments
- Self help groups – national and local
- Liaising with the multi-disciplinary team involved in the care of the stoma patient

Attributes and beliefs systems of the stoma care nurse specialist

Personal attributes

The challenging nature of stoma care nursing requires nurses to have a wide range of personal attributes. Castledine (1998) suggests that specialist nurses should have

- Motivation and enthusiasm
- Sensitivity to patient needs
- Assertiveness
- Approachability
- Flexibility
- Self-awareness
- Excellent interpersonal skills
- Common sense
- Cultural awareness
- Reflective practice
- Openness to criticism
- A good sense of humour
- Confidence
- Resilience

Personal beliefs

In addition, the nurse should possess the following belief systems as central to the delivery of care to patients with a stoma. The nurse should

- Promote and provide holistic care for patients with a stoma
- Recognize the importance of health promotion
- Possess a high level of interpersonal skills
- Develop and promote positive attitudes towards stoma care and stigmas around bowel care
- Work as an advocate
- Respect culture and diversity
- Work as an innovator and change agent within the specialty of stoma care
- Aim to improve the quality of care for those living with a stoma
- Act as an expert role model for health care professional
- Work in a complementary role to other members of the multi-disciplinary team

Core descriptors

The NHS Knowledge and Skills Framework (NHS KSF) defines and describes the knowledge and skills which NHS staff need to apply in their work in order to deliver quality services. It provides a single, consistent, comprehensive and explicit framework on which to base review and development for all staff. The NHS KSF and its associated development review process lie at the heart of the career and pay progression strand of Agenda for Change (DH, 2004).

Preparation for practice and continuing professional Development

Below we describe the relevant knowledge and skills framework references.

KSF Core 2: personal and people development

The specialist nurse must be able to demonstrate the following:

- preparation for practice – essential qualifications:
 - possess or is working towards a relevant degree
 - evidence of relevant degree level education
e.g. stoma qualification level 3(or 6) or equivalent
- preparation for practice – desirable qualifications:
 - possess a teaching qualification
 - relevant extended role qualifications *e.g.*
 - *advanced stoma care*
 - *counselling skills*
 - *nurse prescribing*
 - *physical examination*
- demonstrate evidence of continuing professional development (CPD) through a portfolio of evidence
- assume responsibility for setting and achieving own CPD needs
- set own professional boundaries within the scope of professional practice (NMC, 2002)
- provide evidence-based care through critical appraisal of current research and literature
- an ability to demonstrate a high level of leadership skills
- participate in giving and receiving clinical supervision.

- develop personal objectives in line with national and local guidelines
- take an active part in education and development programmes of other health care professionals
- network at national and local level with other stoma care nurse specialists through regional groups and conferences
- attendance at one relevant conference per year e.g. World Council of Enterostomal Therapy (WCET), WCET UK, European Council of Enterostomal therapy (ECET), Association of Coloproctology (ACPGBI) – Nurses Chapter, Royal College of Nursing Gastrointestinal and Stoma Care Forum.

Specialist knowledge

KSF Core 2: personal and people development

The Stoma nurse specialist should possess the following:

- in-depth knowledge of the gastrointestinal tract in health and disease
- an understanding of the aetiology and pathogenesis of colorectal disease, bladder disease and genetic conditions affecting the urinary and GI Tract
- understanding of faecal and urinary incontinence
- an understanding of the relevant appliances and pharmacology related to having a stoma.
- in-depth understanding of commercial sponsorship and its effect on stoma nursing services
- in-depth knowledge of the surgical interventions related to forming a stoma, and reversal of stoma surgery, internal bowel and bladder pouch formation
- ability to use knowledge to formulate and negotiate treatment plans leading to the patient's self care
- ability to draw on knowledge in order to support complex issues *e.g. altered body image, sexuality and psychological issues*
- ability to make complex decisions (including timely referral to other members of the multi-disciplinary team) where the patient's situation warrants this.
- ability to recognise and develop opportunities to expand practice while acknowledging own limitations.

Service development

KSF	Core 4:	service improvement
	Core 5:	quality
	G2:	development and innovation
	HWB4:	enablement to address health and wellbeing needs
	HWB5:	provision of care to meet health and wellbeing needs,
HWB7:	interventions and treatments to provide care for patients in an holistic framework,	

- reflecting individuals' needs assess, plan and implement care programmes based on local organisational objectives, national guidelines and contemporary evidence.
- ensure that, where possible, all elective stoma patients are sited for stoma surgery
- provide patients with information and education to empower them to be active in the decision-making process
- adopt extended roles to contribute to enhancing the patient's journey, i.e. abdominal examinations, nurse prescribing
- achieve supported self-management of patients to promote independence.
- undertake onward referral to other health care professionals as required
- be a co-opted member of the colorectal cancer multidisciplinary team (MDT) and co-opted member of the urology Cancer MDT , which may involve acting as the patient's advocate
- liaise with regional Paediatric Stoma Care Nurse specialist for the care of neonates, paediatrics and adolescents with a stoma
- provide a telephone advice line for patients and other health care professionals, especially members of the primary health care team.
- ability to prioritise service provision.
- provide annual appliance use reviews as per Consultation document or Trust guidelines



Management and leadership

KSF Core 4: service improvement
 Core 5: quality
 G5: services and project management

- work as an autonomous practitioner
- manage own workload efficiently
- identify limitations which may affect the service, i.e. capacity and demand
- work in a clinical governance framework, ensuring safe and equitable care for all
- develop services to meet needs within resource restrictions
- have a clear vision of how a stoma nursing service should function in the local health care economy
- demonstrate a clear audit trail to evaluate service effectiveness
- co-ordinate and organise the stoma services
- act as a resource for expert advice within the stoma service across the local health economy
- identify service needs and actively participate in influencing service developments
- assume responsibility for nurse-led clinics and telephone advice line.
- liaise with outside agencies to actively seek the opinions of service users
- be responsible for the production and review of clinical guidelines/protocols/care pathways in conjunction with clinical team
- implement national and local goals and strategies.
- act as a role model as a senior nurse.

Evidence-based practice

KSF **IK2:** information collection and analysis

- review contemporary literature that is relevant to colorectal and urinary disease
- ability to appraise evidence critically
- evaluate practice using a clear audit trail from both clinical and user perspective
- consider the cost-effectiveness of implementing new practices based on the latest evidence
- participate in and undertake own research
- maintain knowledge of all products and accessories available on Part IX of the Drug Tariff
- publish best practice research
- actively conduct and participate in audit, and disseminate results.

Education

KSF **Core 2:** personal and people development

Core 5: quality

HWB1: promotion of health and wellbeing and prevention of adverse effects on health and wellbeing

HWB4: enablement to address health and wellbeing needs

- educate other health care professionals in primary and secondary care, on a one-to-one basis and formally in groups
- disseminate evidence-based practice locally and nationally
- support higher education institutions in the delivery of education programmes
- provide clinical leadership for other nurses
- provide problem-solving strategies and advice to other health care professionals about stoma related issues.
- ensure health promotion strategies are in place and disseminated to other members of the multidisciplinary team.
- promote use of informal education strategies, such as shadowing, including care givers (professional or otherwise) in the planning, implementing and evaluating of stoma management.

Specialist descriptors

Introduction

This section outlines the descriptors for each aspect of a stoma service that the nurse specialist provides.

On an individual basis, nurses should use their own expert knowledge to develop skills in their own areas of practice. This should take into account local need, patient numbers, individual practitioner preferences and organisational structures.

Examples of protocols, guidelines and patient information to support stoma services can be found on...

- RCN Standards of Care: Colorectal and Stoma Care Nursing. 2002 publication code 001728.
- RCN: Caring for People with Colorectal Problems. July 2002, publication code 001757
- NICE guidelines N1264 Faecal incontinence
- ACPGBI website guidelines for care of bowel cancer
- RCN: Documentation in colorectal and stoma care nursing. 2003
- CREST Caring for stoma patients: Best Practice guidelines. 2006

Appliances and Medications

KSF	HWB2:	assessment and care planning to meet health and wellbeing needs
	HWB3:	protection of health and wellbeing
	HWB5:	provision of care to meet health and wellbeing needs
	HWB7:	interventions and treatments

- assessing patient's suitability for stoma surgery taking into consideration patient's vision, manual dexterity, mobility and skin integrity
- ensure patient is empowered to make an informed choice with regards to their stoma appliance
- provide written and verbal explanations of stoma forming surgery to patients to encourage informed consent
- provide pre-operative stoma siting
- annual appliance use reviews as per Consultation document or Trust guidelines

Stoma management

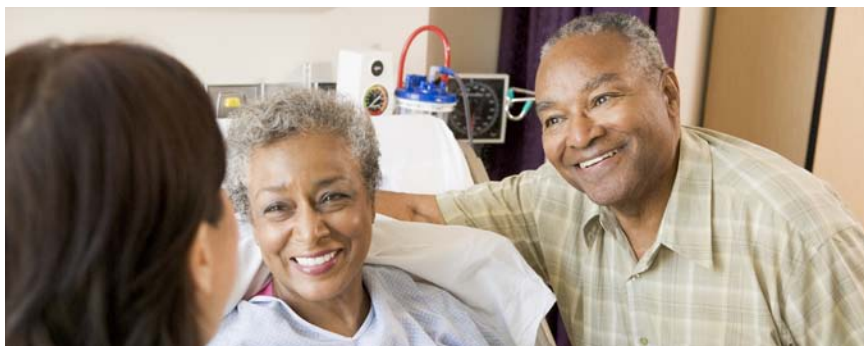
- KSF**
- HWB1: promotion of health and wellbeing and prevention of adverse effects on health and wellbeing
 - HWB2: assessment and care planning to meet health and wellbeing needs
 - HWB3: protection of health and wellbeing
 - HWB4: enablement to address health and wellbeing needs
 - HWB6: assessment and treatment planning

A stoma care nurse specialist working with patients who have newly formed stomas must be able to demonstrate

- the ability to introduce stoma patient to appropriate support network both locally and nationally
- provide information for diseases associated with patient's stoma formation i.e. diverticular disease, inflammatory bowel disease, cancer, incontinence
- Actively participate in health promotion for patients in written and verbal formats regarding issues such as, diet, skin care, resuming exercise and sports
- the ability to counsel and educate patients on individual stoma management plans

Also:

- arrange appropriate follow up for patients in the community setting
- provide a supportive and proactive service and helpline
- foster a culture of support for patients that helps them move towards independence
- educate patients on signs and symptoms of problems with the stoma that may require intervention.



Management of the patient requiring long term follow-up

KSF **HWB1:** promotion of health and wellbeing and prevention of adverse effects on health and wellbeing
HWB2: assessment and care planning to meet health and wellbeing needs
HWB3: protection of health and wellbeing actively participate in the development of services that are efficient, effective and responsive to patients' needs and other service users

- offer education and advice on treatment options to patients in order to improve understanding and to empower them to manage their stoma more confidently and effectively
- offer advice to primary care staff
- develop strong and effective communication links with primary care
- develop relationships with external groups, industry and charitable organisations
- provide ongoing psychological support
- review stoma patients regularly
- monitor clinical activity by regular audits of practice.



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Appendices

Appendix 1: Courses

The following educational institutes offer degree and masters level education for those interested in stoma care nursing or those wishing to specialise.

The Burdett Institute of Gastrointestinal Nursing in partnership with Kings College London and St. Mark's Hospital, Harrow

St. Marks Hospital, Harrow,
Middlesex HA1 3UJ

www.kcl.a.c.uk/nmvc follow link to Study, then search for a course

Level 6 (Degree) – Stoma Care Nursing – Principles and Practice

Level 6 (Degree) – Children's Gastrointestinal Nursing

Level 7 (Masters) – Advanced Practice in Stoma Care Nursing

Several Masterclasses – 'Gut and the mind', 'Sex and sexuality', Skin care in Gastrointestinal Practice, Ileal-anal Pouch care, Enterocutaneous Fistula, Bowel management, Genetics, Palliative care in Gastrointestinal Practice

Bucks New University with Hillingdon Hospital

Uxbridge Campus,
106 Oxford Road,
Uxbridge, Middlesex UB8 1NA
www.bucks.ac.uk

Level 5 (Diploma) – Foundations in Stoma Care Nursing

Level 6 (Degree) – Enhancing Practice in Stoma Care

Birmingham City University

City North Campus,
Birmingham B42 2SU
www.bcu.ac.uk

Level 3 (Degree) – An holistic approach to Stoma Care

Level 3 (Degree) – Paediatric stoma care and continence management

Appendix 2: Further reading and resources

Colostomy Association – www.ca.org.uk

The ileostomy and internal pouch support group – www.the-ia.org.uk

Urostomy Association – www.ua.org.uk

Gay ostomist – www.gayostomates.org

Colon cancer concern – www.coloncancer.org.uk

ACPGBI – www.acpgbi.co.uk

Cancer backup – www.cancerbackup.org.uk

Breakaway – www.breakaway-visit.co.uk

Burdett Institute of GI Nursing – www.kcl.ac.uk/nmvc/burdett

National Association for Colitis and Crohn's – www.nacc.org.uk

Royal College of Nursing – www.rcn.org.uk

WCET (UK) – www.wcetuk.org.uk

Gastrointestinal Nursing Journal – www.gjn.org.uk

British Journal of Nursing – www.britishjournalofnursing.com

Diseases of the Colon and Rectum

Journal of Wound, Ostomy and Continence Nursing – www.medworm.com

World Council of Enterostomal Therapists Journal – www.wcetn.org



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