The challenges faced by people with a stoma and dementia

A holistic approach to person-centred care

Rebecca Fossett, Colorectal Nurse Specialist (2018)
Aims and objectives

• To identify the role and responsibilities of the Colorectal Nurse Specialist.

• The impact of dementia on – cancer diagnosis and stoma formation.

• How we can improve the patient experience.
Patients referred to the Colorectal specialist nurse include:-

- Colorectal cancer.
- Stoma formation.
- Functional bowel disorders.
- Enterocutaneous fistula management.
- Emergency presentation with bowel obstruction or ischemic bowel following surgery.
- 2 week Nurse-led fast-track telephone triage clinic.
Colorectal cancer

• The Colorectal CNS offers specialist knowledge and experience in caring for patients with colon, rectal and anal cancers.

• The CNS aims to be present at diagnosis and offer continued specialist support pre, peri and post treatment into survivorship.

• To support the patients family and carers.

• To complete a MacMillan Health Needs Assessment.

• To signpost the patient to access appropriate resources and support.
Colorectal Cancer

- To explain the treatment options.
- To discuss the treatment plan once agreed.
- To provide a link between the patient and hospital to maximize communication and minimize worry and anxiety.
- To provide advice on symptom management, eg pain management, bowel function, low fibre diet.
- To inform the GP of cancer diagnosis and treatment plan.
Stoma formation

- Pre-operative stoma information and pre-operative stoma siting.
- Following stoma formation to provide both physical and psychological support.
- To arrange and complete stoma reviews following discharge from hospital.
- To provide contact details for ongoing support.
- To arrange regular stoma review clinics and annual user review clinics.
Reasons for stoma formation:

- To protect the anastomosis following surgery, e.g. pouch surgery.
- When the rectum or anus is removed.
- To de-function the colon.
- On removal of the colon and/or rectum.
- To relieve a bowel obstruction.
- Surgical morbidity (Ischemia, oedema, inflammation, perforation or low protein levels).
Types of stomas

‘Stoma’ is a greek word which means opening or mouth. It is a surgically created opening of the bowel on the surface of the body.

- Colostomy (formed from the colon).
- Ileostomy (formed from the ileum).
- Mucus Fistula
- Urostomy
Consent to treatment is the principle that a person must give permission before they receive any type of medical treatment, test or examination.

- Verbal
- Written

www.nhs.uk
Assessing capacity to consent

‘Capacity means the ability to use and understand information to make a decision and communicate any decision made.

A person lacks capacity if their mind is impaired or disturbed in some way and this means the person is unable to make a decision at that time.

www.nhs.uk
Determining a person’s best interests

If an adult lacks the capacity to give consent, a decision made by the health professionals must be agreed to go ahead with the treatment in ‘the patient’s best interest’.

Several elements need to be considered when determining the person’s best interests.

• Can the person communicate their decision?
• Can the person understand their decision?
• Can the person retain what has been discussed?
• Can the person weigh up the information?
Consider if…

• Is it safe to wait or defer treatment until the person can give consent (if it is likely they could regain capacity, eg delirium).

• Involving the person in the decision as much as possible.

• Try to identify any issues the person may encounter if they were making the decision themselves. This must include religious, cultural or moral beliefs.
• If the person is believed to lack capacity, and there is no-one suitable to help make decisions about medical treatment, such as family, friends, care-staff, an independent mental capacity advocate (IMCA) must be consulted.

• If there is serious doubt or dispute about what is in a incapacitated person’s best interests, healthcare professionals can refer the case to the Court of Protection for a ruling.

Mental Capacity Act (2005)
Advanced decisions and power of attorney

If a person is aware their capacity to consent may be compromised in the future, they can draw up a legally binding ‘advance decision’ or ‘living will’.

You can also opt to formally arrange for someone, most often a close family relative, to have a lasting power of attorney (LPA) if you wish to anticipate your loss of capacity to make important decisions, both medically and financially.
Safeguarding

*Safeguarding* is protecting vulnerable adults or children from abuse or neglect. It means making sure people are supported to enable access to health care and stay well.

It is deemed wrong if vulnerable people are not treated by professionals with the same respect as others.

www.England.nhs.uk
Deprivation of Liberty (DoLs)

‘The Deprivation of Liberty Safeguards (DoLs) are part of the Mental Capacity Act 2005.

The safeguard aims to ensure that people in care homes and hospitals are looks after in a way that does not inappropriately restrict their freedom.’
Dementia is a condition that affects the brain

Signs and Symptoms are:-

• Memory loss
• Difficulty performing familiar tasks
• Problems with language
• Poor or decreased judgement
• Difficulty organizing or prioritizing events
• The ability to maintain attention and not be easily distracted
• The ability to have insight and recognize safety
Managing stoma needs for those people who have dementia fall into two categories

1. Established ostomists who develop dementia.
2. People with dementia who undergo stoma formation.

It is paramount the established ostomist maintains their level of independence with their stoma management. Equally, it is also important to educate the person with dementia who has a stoma formed and to promote and maintain a level of independence that is achievable.
‘About Me’ assessment tool.

This is a document that has been implemented within The Royal Wolverhampton Trust.

It aims to create a connection between hospital life and home life for people with dementia.

It identifies the daily routines of a person to allow the same routines to be followed in hospital wherever possible.

This includes information about communication, eating and drinking, pain, sleep and rest, mobility, sight, hearing, washing and dressing, elimination (including stoma care).
Challenges faced with stoma management

• Impaired memory causes the person to forget to empty or change their stoma pouch appropriately.
• Difficulty in learning a new skill, changing a stoma pouch.
• Communication problems and reasoning can create complications explaining stoma management.
• Dexterity, to be able to change the stoma bag or empty a drainable bag.
• Teaching a person with dementia how to care for their stoma is not always possible, but attempts should be made to encourage them to participate.
What can we do to improve and/or maintain independence with stoma management?

• Continuity in teaching, repetician.
• Changing the bag in a quiet and familiar environment, eg bathroom.
• Prompt cards
• Pre-cut bags and plenty of equipment.
• Register with a delivery company and request a rolling order.
Case study No. 1

- 78 year old female with dementia, presenting with low rectal cancer.
- Lives in a care home within an established dementia unit.
- Treatment options included no active treatment and surgery.
- Lacks capacity to consent.
- No power of attorney.
- IMCA.
- Surgery with permanent stoma.
Case study No. 2

- 74 year old female presenting with colo-vaginal fistula.
- No consenting issues identified.
- Temporary stoma formed.
- Post-op confusion, memory impairment, low mood, dis-engaged.
- Referred to dementia outreach nurse.
- Husband managed stoma until reversal surgery.
Further support and reading….

- Colostomy UK
- Ileostomy Association
- Powell C (2013) Using reflection to treat stoma patients with dementia, Gastrointestinal Nursing; 11(7):52-60
- www.gov.uk