Patients who have a permanent tracheostomy have complex needs that require specialised care after they have been discharged from hospital.

TRACHEOSTOMY: PART 3 OF 4

Care of patients with permanent tracheostomy

In this article...
- Why a permanent tracheostomy is inserted
- Physical/psychological effects of a permanent tracheostomy
- Key points for safe-discharge planning

5 key points
1. A permanent tracheostomy is non-weanable and cannot be removed.
2. Patients have to cope with an altered body image and communication difficulties.
3. Pre- and postoperative psychological assessment/counselling can help reduce depression and reclusive behaviour on discharge.
4. Patients need support to learn new ways to communicate.
5. Discharge needs to be planned carefully, as patients have complex needs.

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Abstract

The third article in our series on tracheostomy care discusses the care of patients with a permanent tracheostomy. While these patients make up a small proportion of all patients who have a tracheostomy inserted, they have complex needs. This means they require practitioners in both acute and community settings, who have time, support and competent tracheostomy-care skills, to achieve a successful discharge and ongoing management of their tracheostomy.

Approximately 20% of patients who have a tracheostomy will be discharged with the tracheostomy in situ (Eibling and Roberson, 2012). However, discharging them can be a complex process; the National Confidential Enquiry into Patient Outcome and Death (2014) found that, out of the 91 patients reviewed who were suitable for discharge from hospital, 14 were still awaiting discharge after 30 days due to difficulties in securing appropriate community care, while 16 had difficulty finding a specialist rehabilitation-unit bed.

A permanent tracheostomy is non-weanable and cannot be removed. It is inserted for a number of underlying long-term, progressive or permanent conditions, including cancer of the larynx or nasopharynx, motor neurone disease, locked-in syndrome, severe head injury, spinal-cord injury and paralysis of vocal cords.

Nursing care
Daily tracheostomy care is the same for temporary and permanent tracheostomy tubes, and is outlined in part 1 of this series (Everitt, 2016a). However, patients with a permanent tracheostomy need to be cared for by nurses who have the skills to teach them and their carers/relatives to be independent with tracheostomy care; many patients find this a daunting prospect.

Patients with a permanent tracheostomy may be in hospital for months with complex health issues and often become dependant for physical and emotional support on nurses in the acute care setting. They may be anxious about the transition to their home environment and it is important to start teaching them to care for their tracheostomy as soon as possible. This will help to reduce their length of stay in hospital and ensure they are, where possible, fully independent with their tube care before discharge.

Many hospitals have, or are developing, tracheostomy multidisciplinary teams, some of which include critical-care outreach and/or tracheostomy-specialist nurses who can assist nurses with patient teaching and discharge planning (NCEPOD, 2014; National Tracheostomy Safety Project, 2013).

Although some may also have an outreach in the community, these services are not common, despite the ongoing risks associated with tracheostomy (Paul, 2010); no matter how long patients have a
Body image/psychological support

The need to adapt to breathing through a tracheostomy tube, the limitations it imposes on communication and the appearance of the tube can have a negative psychological effect; patients may require psychological support and antidepressants.

Where possible, patients having an elective tracheostomy should receive pre-operative counselling; Hashmi et al (2010) recommends a perioperative psychological assessment. At this point, they should also be offered the opportunity to meet other patients with a permanent tracheostomy, who can give them a personal account of what living with it is like, and help them to see the benefits of having the tube.

Pre- and postoperative psychological assessment tools also provide evidence of patients’ emotional state; their use can be continued by community practitioners to ensure patients receive psychological care when needed. Failure to address their altered body image can result in reclusive behaviour once patients are discharged home. If possible, they should be referred to counselling services to help with this transition.

Adapting to the tube

The first step for patients in accepting their altered body image is to be able to look at the tube; however, looking at their reflection can be difficult and this process should not be rushed. When preparing for this, they should be given the undivided attention of a nurse, and time to look at the tube and how it has changed their body. Patients need to be able to express their feelings about the changes, such as sadness and sometimes guilt; the emotional effects of this process should be acknowledged by all staff caring for them.

The hospital environment offers some degree of shelter from the general public, and patients need to learn how to cope with others react to their tube when they go home. Taking them off the ward to walk outside or go to the hospital shop, or arranging day leave, are all ways of preparing them for everyday socialisation.

The presence of a permanent tracheostomy tube can negatively affect relationships and sexual intimacy with spouses/partners who had a previously close and loving relationship. For example, the presence of respiratory secretions in the tracheostomy tube or around the stoma site, or breathing or coughing onto a partner’s neck while kissing, can cause embarrassment and lead to the couple becoming emotionally distant. The relationship may also change from loving partners to patient and carer.

Ideally, a tracheostomy nurse specialist will provide support in the community on discharge, so that patients have a knowledgeable person who can continue to provide emotional support, as well as ensure continuity in tracheostomy care.

Communication

A key factor in coping with a permanent tracheostomy is the ability to communicate. Everyday things that most people take for granted, such as telephone banking, phoning for a taxi, asking for assistance in a shop or simply telling a partner “I love you” are difficult and often frustrating. Such frustrations can be a catalyst for depression and negatively affect relationship dynamics. Not being understood by partners, family and friends can also lead to patients becoming isolated and reclusive.

Patients with cuffed tubes are unable to speak, as air cannot pass into their upper airway and through the vocal cords, so they have to rely on other forms of communication, such as pen and paper, tablet computer or keyboard-based communication aids. However, some may have literacy problems, which will affect their ability to communicate and use these methods; picture boards may be required.

Patients who do not require a cuffed tube can use a simple method known as “finger occlusion” to produce voice; this involves inhaling, then placing a finger over the end of the tracheostomy tube to occlude the opening and force air up and through the vocal cords. Patients often use finger occlusion in the early stages after tube insertion, but will go on to use a speaking valve (Fig 1). See Everitt (2016b) for more information on speaking valves.

Speaking valves can be extremely tiring, so periods of use should be increased gradually to build up tolerance. During such incremental use, patients should use the valves when relatives or friends visit, or during ward rounds, so that they are able to communicate their needs or concerns more effectively. Periods of use should be documented to ensure continuity of care. Box 1 lists further points on valve care.

Fenestrated tracheostomy tubes can also be used to produce speech. However, they are not widely used in practice due to contraindications, as well as the marginal benefits they offer in voice production and strength (Everitt, 2016a).

Eating and drinking

NCEPOD (2014) suggests that dysphagia in patients with a tracheostomy warrants ongoing study, as swallowing difficulties can occur throughout the care pathway.
Nursing Practice

The type of tube used and the reason for its insertion will influence if, and when, a patient can have a trial of eating and drinking. It is recommended that cuffed tubes are deflated during trials, as this can impede swallowing by restricting laryngeal elevation.

Patients must be referred to a speech and language therapist for a specialist swallowing assessment as soon as a tracheostomy is inserted. Before the assessment, the cuff on a cuffed tube needs to be deflated using a synchronised cuff-deflation technique (Everitt, 2016b).

Once patients are able to swallow safely, they may start eating and drinking following the speech and language therapist’s instructions. Some patients will require long-term enteral feeding, for example, following head injury, stroke, and patients receiving palliative care for head and neck cancers.

This patient group has complex conditions and are prone to malnutrition pre- and postoperatively. They should have regular nutrition assessment using the MUST score, and referral to a dietician if there are concerns about dietary intake.

**Discharge planning**

The discharge process is complex and needs to be started as soon as possible, as community resources for tracheostomy care are limited. The tracheostomy multidisciplinary team will formulate a discharge plan, working with the patient, relatives, ward staff and discharge liaison teams to meet care needs. Care providers, including staff in care homes and community nurses, must be competent in tracheostomy care and must be given training if necessary. This may be difficult to provide in areas that do not have specialist tracheostomy nurses; in these circumstances, community staff will need to visit the ward for training and must be deemed competent before a patient can be discharged into their care. It is therefore important to involve community and nursing home teams as early as possible in the discharge planning process. When available, hospital trACHEostomy care teams should continue to support patients and community staff on discharge. Box 2 lists key points for discharge planning.

Patients should be discharged with a competent understanding of what to do in an emergency. A tracheostomy safety box should be sent with the patient, as well as a portable suction and nebuliser machines. The patient and their carers should complete a competency training programme prior to discharge, covering basic and emergency care needs, and what to do if they have other concerns, such as pressure ulcers under a tube flange or managing a chest infection.

Discharge documentation from the hospital to community should be detailed and structured, and follow the recommendations laid out by NCEPOD (2014). However, the NCEP0D (2014) enquiry showed that this occurred in only 54% of hospital transfers/discharges.

Patient passports can also help with multidisciplinary communication as they provide information about patients’ routine tracheostomy care and essential information for emergency practitioners, such as the patency of the patient’s upper airway.

Unfortunately, support groups, and networks and counselling services specific to the needs of tracheostomy patient, are limited and there is lack of a supportive community for this patient group.

**Conclusion**

Discharge planning and ongoing support is essential in supporting patients who live in the community with a tracheostomy. Community practitioners, general practitioners, district nurses and paramedics need clear guidance to ensure continuity of care on discharge and to maintain patients’ safety. Locally agreed numbers of tracheostomy beds in nursing homes would help in reducing the length of stay in the acute care settings for many permanent tracheostomy patients, as well as enabling discharge teams and clinical commissioning groups to provide a more robust and cost-effective discharge pathway. NT

**References**


**ARTICLES IN THE SERIES**

- Part 1: caring for patients with a tracheostomy, 11 May
- Part 2: managing the weaning of a temporary tracheostomy, 18 May
- Part 4: care of people following a laryngectomy, 1 June (online only)