

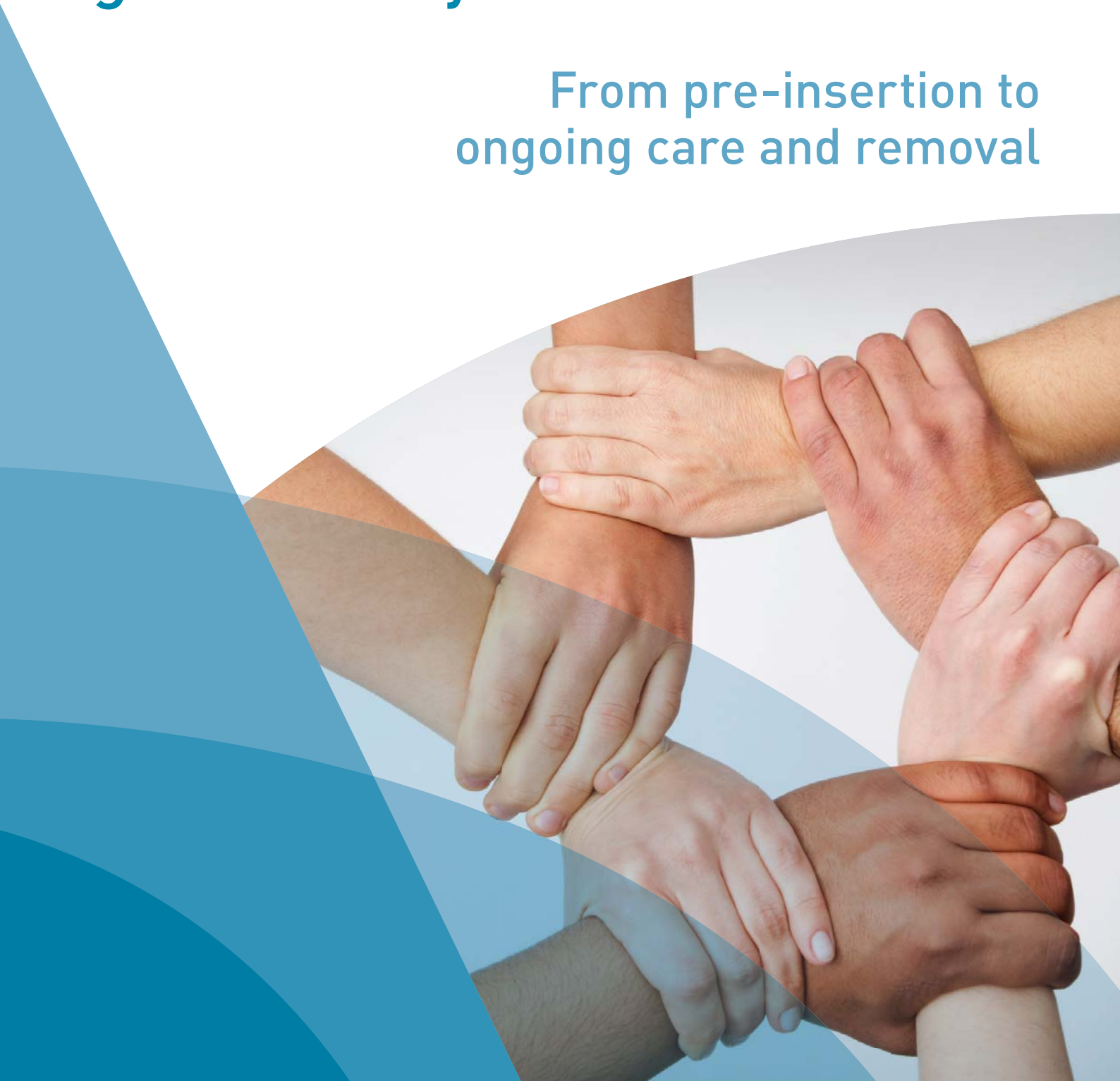


ACI NSW Agency
for Clinical
Innovation



A Clinician's Guide: Caring for people with gastrostomy tubes and devices

From pre-insertion to
ongoing care and removal



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The ACI will undertake a review of the document within 2-5 years of its release and will liaise with relevant stakeholders during the revision process.

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FOREWORD

There are many situations where a person may not be able to eat or drink enough to maintain adequate nutrition and hydration. The need for a gastrostomy tube or device to provide nutrition support can be overwhelming for patients, their family and carers. Patients and families may also be managing chronic medical conditions or disabilities that require specialised treatment.

The support and services available to people with a gastrostomy tube or device differ greatly across Australia, particularly in rural and remote areas. Many patients, carers and families have reported positive experiences with the care they have received. However, a number are not satisfied with the level of access they have to services and health professionals with experience in gastrostomy care, nor with the amount of support and follow up they receive after going home.

It is therefore important that health professionals have the knowledge and skills to provide safe and appropriate care in the most efficient and accessible way possible, and that services are structured to meet the needs of patients and families.

A Clinician's Guide: Caring for people with gastrostomy tubes and devices; from pre-insertion to ongoing care and removal is the result of collaboration between the Agency for Clinical Innovation (ACI) and the Gastroenterological Nurses College of Australia (GENCA). It provides national evidence based guidelines for caring for people with a gastrostomy tube or device. Using the guidelines, clinicians can access practical information about the different stages of the patient journey from deciding to initiate gastrostomy tube feeding to permanent tube removal transition or transfer of care.

The ACI works with clinicians, consumers and managers to design and promote better healthcare in NSW. ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to design improved models of patient care. A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers and consumers to develop mechanisms to improve clinical practice and patient care.

GENCA facilitates the provision of education, standards and credentialing of gastroenterological nurses in Australia, and encourages members to share their knowledge and expertise with their colleagues. The College is dedicated to the safe and effective practice of gastroenterology and endoscopy nursing through its mission To Promote Excellence in Gastroenterology Nursing Practice.

On behalf of the ACI and GENCA we would like to thank the Guideline Development Group for lending their expertise, time and commitment to develop these important guiding principles. We also acknowledge and thank those who contributed to the project through the comprehensive consultation process.



Dr Nigel Lyons
Chief Executive
NSW Agency for Clinical Innovation



Ms Debbie-Ann McQueen
President
Gastroenterological Nurses College of Australia

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INTRODUCTION

Gastrostomy tubes and devices are an established means of providing long term enteral nutrition. A gastrostomy tube or device is inserted into the stomach through the abdominal wall, so that liquid nutrition, fluids and medication can be given.

Within these guidelines **enteral nutrition** is defined as the delivery of nutrition support into the gastrointestinal tract (GIT) and can include *oral nutrition support and enteral tube feeding*.¹ Enteral nutrition is used to support a person in meeting their nutritional requirements when their medical condition prevents them from maintaining adequate hydration and nutrition through oral diet alone.

The primary goals of long term enteral nutrition are to:²

- maintain body weight or facilitate weight gain where clinically appropriate
- correct nutritional deficiencies and maintain adequate hydration
- promote growth in children with growth faltering
- prevent deterioration and/or improve quality of life.

Enteral tube feeding is the provision of liquid nutrition via a feeding tube or device into the GIT.³ It may be the sole source of nutrition or may supplement oral intake.

People of all ages may need enteral tube feeding and many can be safely supported in the community if appropriate services are provided. Establishing adequate home enteral tube feeding services can be cost effective, and can reduce presentations to hospitals and readmissions for avoidable complications.⁴⁻⁶

1. Purpose of this document

The aim of these guidelines is to provide all health care professionals with recommendations and practical advice related to the care of adults and children with gastrostomy tubes and devices. It covers the different stages of the patient journey from deciding to initiate gastrostomy feeding to ongoing care, permanent tube or device removal and transition or transfer of care.

The guidelines are a reference document intended to inform and support clinicians in the care of people with gastrostomy tubes and devices. They are applicable across health care settings and are designed to provide a framework for the development of local policies and procedures.

The recommendations contained within these guidelines are derived from a combination of clinical evidence, clinical experience and expertise. A significant amount of evidence in this area is of a low grade or in some cases there is none available. Randomised control trials are limited due to ethical constraints and research challenges. Further research is required in most aspects of gastrostomy tube/device care, especially in the area of ongoing care.

These guidelines do not cover:

- other types of feeding tubes such as oro-gastric, nasogastric, or jejunal feeding tubes
- the procedure for insertion of a gastrostomy tube or device
- parenteral nutrition
- specific disease states and the current evidence base for the role of gastrostomy tube feeding in their clinical management
- enteral tube feeding instructions (e.g. determination of requirements, selection of enteral tube feeding formulas, recommended feeding rates/protocols).

The guidelines do not cover every aspect of gastrostomy care and are not designed to replace a health care professional's clinical training and judgement, knowledge and skills.

Healthcare professionals should refer to local policies and procedures in conjunction with these guidelines.

2. The Patient/Carer experience

The need for enteral tube feeding can be confronting, challenging and overwhelming for patients, their family and carers. They are often also dealing with chronic medical conditions or disabilities and require specialised treatment or therapy.⁷ It is important that health professionals have the knowledge and skills to provide safe and appropriate care.

Support and services available to patients with a gastrostomy tube or device differ greatly between and within the different Australian states and territories, especially in rural and remote areas. A recent survey of more than 100 parents and carers of children receiving enteral tube feeding in NSW showed that 42% were dissatisfied with access to services and health professionals and 36% were dissatisfied with the support and follow up they received post discharge.⁸

Patients needing enteral tube feeding and their families and carers tell us they want:^{8,9}

- access to timely and coordinated care and support by skilled health professionals
- adequate communication, collaboration, information and resources
- to be involved in their own care.

These opinions are often echoed by the health professionals involved.

"In hospital they showed me, but when I got home I used to cry"

Parent

"I was sent home from the hospital with no training and no ideas about what to expect"

Patient

"Arrangements were ad hoc and remained informal for a long time despite recurring hospital stays"

Carer

"By practising as individual clinicians we provide disjointed and inconsistent care, which ends up far from holistic"

Clinical Nurse Consultant

"Often we don't even see the patients before they go, there is no warning, no consultation, and patients are just discharged"

Dietitian

3. Key definitions

Throughout this document, the following terms are used

Term	Meaning or definition
Carer	An individual providing care to the person with a gastrostomy tube or device e.g. parent, patient advocate, guardian.
Enteral nutrition	All forms of nutritional support delivered to the gastrointestinal tract - oral nutrition supplements or enteral tube feeding. ¹
Enteral tube feeding	Nutrition support given directly into the gastrointestinal tract via a tube or device. ³
Gastrostomy	Establishment of a new opening into the stomach. ¹⁰
Gastrostomy feeding tube or device	A medical tube or device inserted directly through the abdominal wall into the stomach to allow administration of nutrition, fluids and medications. ¹¹
“Mature” gastrostomy tract	A gastrostomy tract where the procedure was performed more than 30 days prior (the Guideline Development Group recommends at least 6 weeks). <i>See Section 4</i>
Medical specialist	This could include the proceduralist or physician i.e. gastroenterologist/endoscopist/paediatrician/surgeon, depending on the age of the patient, the service location and gastrostomy tube or device insertion method.
Must	Indicates a mandatory action.
Nutrition support	The provision of nutrition to patients orally and/or by administration through a tube/device into the stomach or intestine and/or by intravenous infusion (parenteral) for the purpose of improving or maintaining a patient’s nutritional status. ³
Nutrition support team	An interdisciplinary group that includes physicians, registered nurses, dietitians, pharmacists, speech pathologists and/or other healthcare professionals with expertise in nutrition who manage the provision of nutrition support therapy. ¹²
Should	Indicates an action to be followed unless there are sound reasons for taking a different course of action.

A glossary and an abbreviation list are included at the end of the document (see pages 65-66).

4. The Guideline development process

Background to the project

In 2012, the NSW Agency for Clinical Innovation (ACI) was notified by the NSW Ombudsman about the death of a patient after the reinsertion of a gastrostomy tube. The ACI was asked to comment on the existence of policies or guidelines within NSW Health related to the insertion and management of gastrostomy tubes.

A previous NSW Ombudsman’s Report of Reviewable Deaths (2006) had also highlighted that poor enteral nutrition management and lack of coordination of care resulted in increased hospital admissions with feeding tube related complications and poor health outcomes, including two deaths.

On further investigation, the ACI’s Gastroenterology and Nutrition Networks identified that there were no state wide NSW guidelines in place and agreed to lead a project on this. Members of the Gastroenterological Nurses College of Australia (GENCA) who were also members of the ACI’s networks reported that GENCA had recently discussed the need to develop guidelines in this area. Consequently, in 2012 the two organisations agreed to work on a joint project to develop national evidence based guidelines relating to the care of people with gastrostomy tubes and devices.

The Guideline Development Group

A multidisciplinary Guideline Development Group (GDG) was established with members from both organisations to prepare initial content and oversee the project. Members of the GDG include experienced nurses, allied health professionals and medical specialists from New South Wales, Queensland and South Australia. *Please see Appendix 1 for a full list of the GDG members.*

The GDG conducted an initial literature review, developed the content outline and then incorporated recommendations from an evidence check review into the first draft.

Evidence Check Review

The Alfred Hospital's Nutrition and Gastroenterology Departments were commissioned by the Sax Institute, on behalf of ACI's Gastroenterology and Nutrition Networks, to conduct an Evidence Check review.² The purpose of the evidence check was to critically appraise and summarise existing evidence relating to specific areas of gastrostomy tube and device care.

Three senior clinicians reviewed government and key agency guidelines and conducted a literature review on relevant papers from 2003-2013. Evidence quality was graded against the National Health and Medical Research Council (NHMRC) evidence hierarchy available in the 'NHMRC additional levels of evidence and grades for recommendation for developers of guidelines'.¹³

Recommendations were then formed by the clinicians and graded according to the NHMRC grades of recommendations. The definitions used by the NHMRC are as follows:

- Grade A: Body of evidence can be trusted to guide practice
- Grade B: Body of evidence can be trusted to guide practice in most situations
- Grade C: Body of evidence provides some support for recommendation(s) but care to be taken in its application
- Grade D: Body of evidence is weak and recommendation must be applied with caution.

The clinicians made the recommendations with

the Australian context in mind. A copy of the evidence check review can be found at www.saxinstitute.nsw.gov.au.

Consultation process

Stage 1: Initial review by external stakeholders

A small number of external reviewers from key organisations were invited to review the first draft of the full document in February 2014. These organisations included:

- Gastroenterology Society of Australia (GESA)
- Australasian Society for Parenteral and Enteral Nutrition (AuSPEN)
- Dietitians Association of Australia (DAA)
- Speech Pathology Australia (SPA)
- Australian College of Nursing
- NSW Surgical Services Taskforce (NSW SST)
- ACI General Practice Clinical Advisory Group
- NSW Ambulance – Extended Care Paramedics
- Gastrostomy Information and Support Services (GISS)

One hundred and forty comments were received, with many supporting the need for and content of the Guidelines. All comments and suggestions were carefully considered by the GDG in March 2014 before agreement on the next draft.

Stage 2: Formal review by external stakeholders

The second draft was circulated to the following organisations for comment in May 2014:

- ACI Networks, Institutes and Taskforces
- Aged and Community Services of NSW and ACT
- Ageing Disability and Home Care (ADHC) NSW
- Australian and New Zealand Society of Geriatric Medicine
- Australian Association of Gerontology
- Australian College of Nursing (ACN)
- Australian Society for Parenteral and Enteral Nutrition (AuSPEN)
- Cerebral Palsy Alliance
- Dietitians Association of Australia (DAA)
- Disability Council of NSW
- EnableNSW
- Gastroenterological Society of Australia (GESA) - includes Digestive Health Foundation (DHF) and Australian Gastrointestinal Endoscopy Association (AGEA) and Australian Society for Paediatric Gastroenterology, Hepatology and Nutrition (AUSPGHAN)
- Gastrostomy Information and Support Service (GISS)
- GENCA
- General Practitioners NSW (GPNSW)
- Motor Neurone Disease Australia
- NSW Clinical Excellence Commission (CEC)
- NSW Health Education and Training Institute (HETI)
- NSW Kids and Families
- NSW Ministry of Health, Local Health Districts and Specialty Networks
- Pharmaceutical Society of Australia (PSA)
- Royal Australian College of General Practitioners (RACGP)
- Royal Australian College of Physicians (RACP)
- Royal Australasian College of Surgeons (RACS)
- Speech Pathology Australia (SPA)

Three hundred comments were received from individuals and organisations. All comments and suggestions were carefully considered by the GDG in July 2014 before agreement on the final version.

Endorsement and revision

The final version was endorsed by the ACI and GENCA Executives in September 2014.

The ACI will undertake a review of the document within two to five years of its release and will liaise with relevant stakeholders during the revision process.

5. Use of this document

The Guidelines are designed to support all health care professionals who are involved in the care of people with gastrostomy tubes and devices. The guidelines are also applicable for health care organisations and governments who are responsible for health service planning.

Algorithms and flowcharts have been included in the document to guide decision making on gastrostomy tube and device insertion. However, they should be used with caution in order to allow for individual assessment and variation between patients.

The recommendations made in this document may not be appropriate for use in all circumstances. Decisions to adopt any particular recommendations should be made by practitioners in light of:

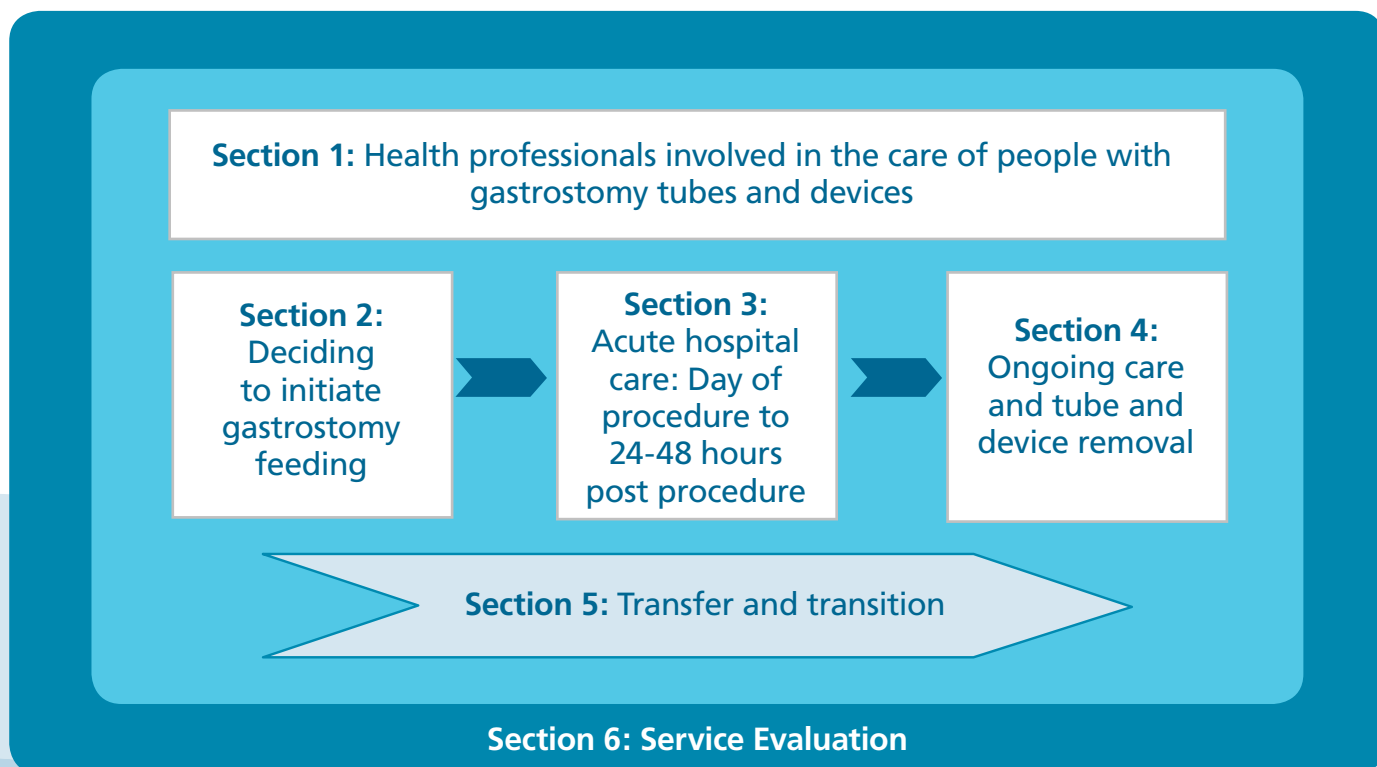
- the patient's circumstances and wishes
- the clinical experience and judgement of the practitioner

- available resources
- local services, policies and protocols
- knowledge of more recent research findings.

Refer to the companion document "Key principles and practice points" for a summary of the key principles and recommendations.

6. Structure of the document

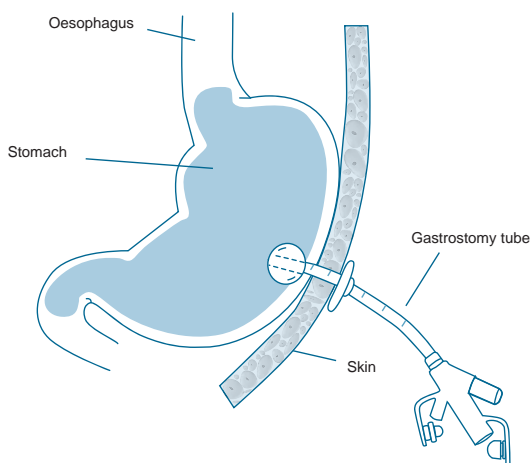
This document is organised in the following sections that align with the patient care journey:



QUICK GUIDE TO GASTROSTOMY FEEDING TUBES AND DEVICES

A gastrostomy feeding tube or device is one which has been inserted directly through the abdominal wall into the stomach. It is secured by an internal retention device (either a balloon or a soft disc known as a “bumper”) on the inside and a firm external retention device (known as a “flange”) on the outside.¹¹

Placement of a ballooned gastrostomy tube



Cross-section: non-ballooned tube

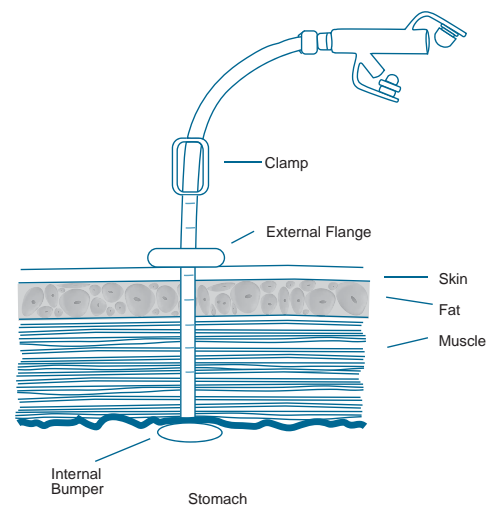


Photo: A Kennedy

Patient with a ballooned gastrostomy tube insitu



Photo: M Sutherland

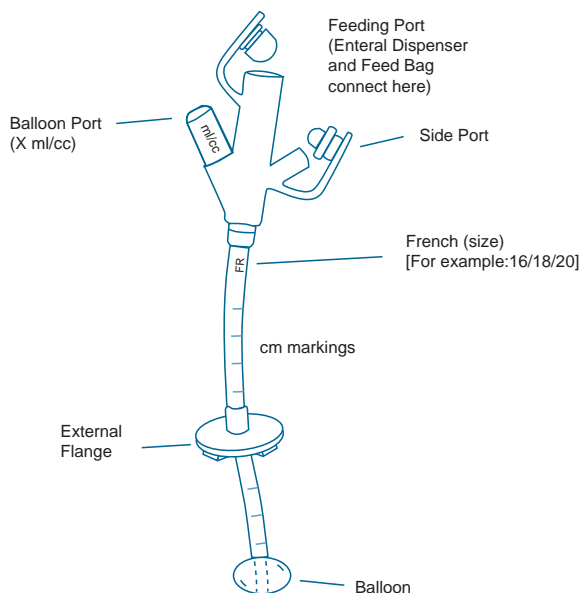
Patient lying down with a non-ballooned gastrostomy tube in situ

See page 8 and 9 for a summary of the different types of tubes and devices you might see.

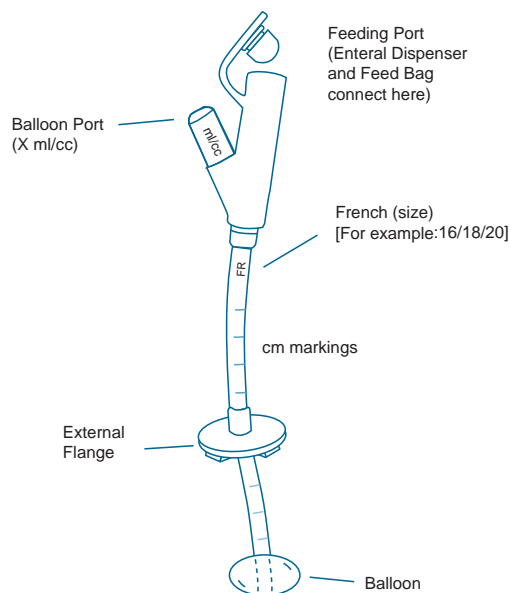
Common features of gastrostomy feeding tubes and devices include, but are not limited to:

Refer to manufacturer's guidelines for advice on brand specific tube and device features

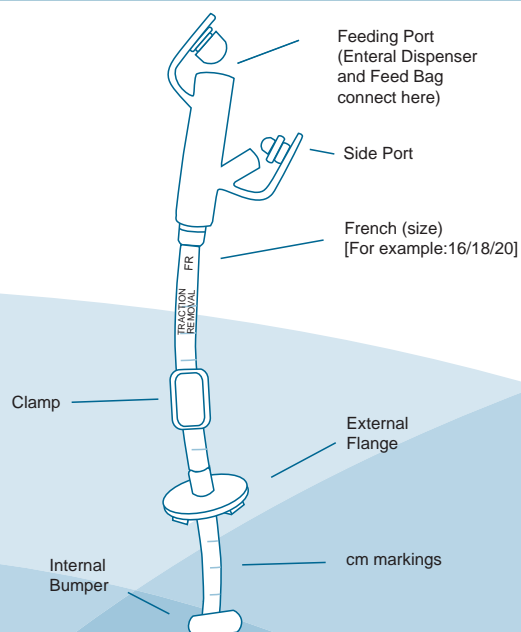
Ballooned Gastrostomy Tube With side port



Ballooned Gastrostomy Tube Without side port

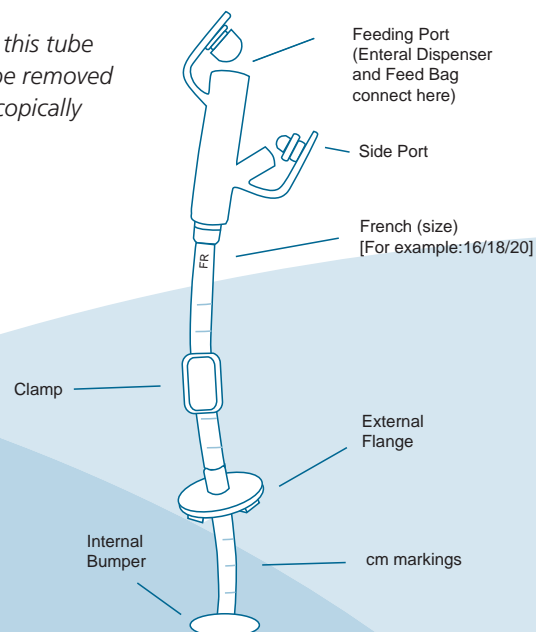


Non-ballooned Gastrostomy Tube with collapsible internal bumper



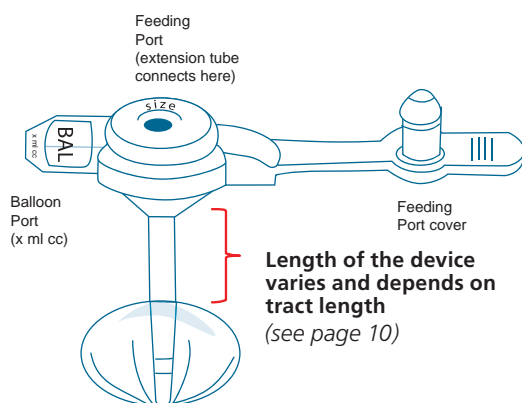
Non-ballooned Gastrostomy Tube With rigid internal bumper

NOTE: this tube must be removed endoscopically



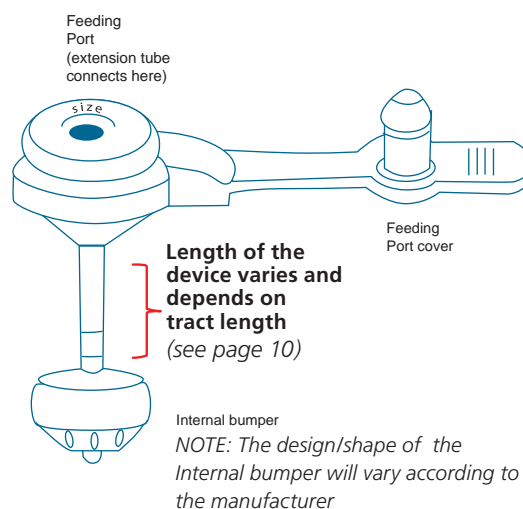
Low Profile (skin level) Gastrostomy Device With a balloon

Used with compatible extension tubes - see below.



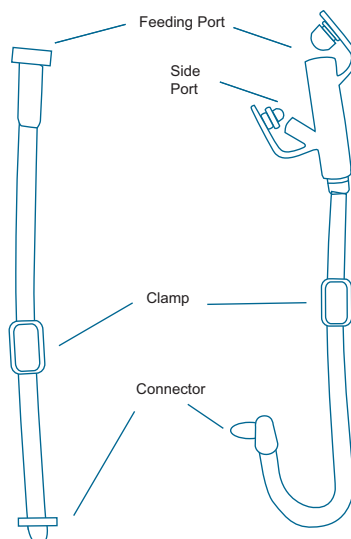
Low Profile (skin level) Gastrostomy Device Non-ballooned (obturator or traction removal)

Used with compatible extension tubes - see below.



Examples of extension tubes (used with compatible low profile device)

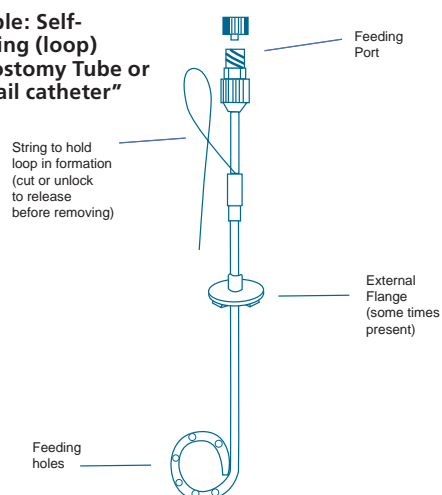
Bolus extension tube



Extension tube with right-angled connector (different lengths are available)

Specialised tubes and devices

Example: Self-retaining (loop) Gastrostomy Tube or "pig-tail catheter"



NOTE: New international design standards for medical device tubing connectors are anticipated to be released in 2014/2015 as part of a phased patient safety improvement initiative called "Stay Connected". The new design standard impacts connectors within the entire enteral feeding system, for example - the way a feeding tube or an extension set connects with the giving set.

For the most current information, visit:
www.StayConnected2014.org

The initial gastrostomy tube or device may be placed endoscopically, surgically or radiologically.

The insertion of a gastrostomy tube or device is considered a relatively safe procedure for adults and children, depending on the underlying medical condition of the patient. The rates of complication with the formation of gastrostomy are estimated in the range of 8-30% depending how a complication is defined. ⁽⁶⁻¹⁰⁾ The rate of acute and severe complications such as perforation, serious abdominal haemorrhage or peritonitis requiring significant surgical intervention is less than 0.5%. ¹⁴⁻¹⁸ Consideration should also be given to the risks associated with sedation and anaesthesia.

Health care organisations providing care to patients with a gastrostomy tube or device should have local policies and guidelines in place to ensure best practice across the continuum of care including:¹⁹

- patient selection
- selection process for optimal access route where options available i.e. percutaneous endoscopic gastrostomy (PEG), laparoscopic or open gastrostomy or radiologically inserted gastrostomy (RIG)
- immediate pre and post gastrostomy tube/device placement guidelines (i.e. prophylactic antibiotics, oral care and wound care)
- education pre and post insertion
- systems for routine monitoring and review
- transition from paediatric to adult services
- termination of tube feeding.

Measuring the length of a stoma tract

- The length of the gastrostomy tract can be measured using the existing gastrostomy tube or a special “stoma measuring device” that is inserted into the stomach via the stoma.
- The length of the gastrostomy tract is the distance from the internal retention device to skin level (as measured by the centimetre markings) when the tube or measuring device is pulled gently to ensure the internal retention device is against the stomach wall.

See photos below



Measuring the length of the stoma tract



Post measurement – low profile gastrostomy device in situ

PHOTOS: A Kennedy

SECTION 1: Health professionals involved in the care of people with gastrostomy tubes and devices

There is consensus supporting the role of a multidisciplinary nutrition support team for best management and care of people with gastrostomy tubes and devices.^{3, 16, 19-24} The team provides a system for health professionals with unique perspectives and skill sets to deliver timely, safe, appropriate, and cost-effective nutrition support therapy.²⁵

Nutrition support teams with clearly defined roles and a lead co-ordinator can improve patient outcomes and decrease complications.³ It is essential that patients and/or their carers are involved in all stages.¹⁶

A nutrition support team* should include the following health professionals:^{3, 16, 22, 26, 27}

- Registered Nurse#
- Medical Specialist
- Dietitian
- General Practitioner
- Speech Pathologist
- Other health professionals as required
- Pharmacist

*Dedicated nutrition support teams do not always exist, particularly in the community setting and non-metropolitan areas. In the absence of a dedicated nutrition support team, an interdisciplinary or multidisciplinary collaborative approach should be provided to ensure the best care for people with gastrostomy tubes and devices and their families.^{3, 27, 28} The establishment of "virtual teams" using telehealth could be considered.

"We come down for the week and see everyone we need to – worth the trip"

Carer

The table below is a guide to the key health professionals who ideally should be involved in the different stages of caring for people with gastrostomy tubes and devices. This is dependent on service location, local policy, skill mix and scope of practice.

Table 1: Roles of key health professionals involved in gastrostomy care and management.

	Registered Nurse#	Dietitian	Speech Pathologist	Pharmacist	Medical Specialist	GP
Deciding to initiate gastrostomy feeding						
Determining indication for a feeding device	☒	☒	☒		☒	☒
Formal swallow assessment			☒			
Decision regarding the role of oral intake	☒	☒	☒		☒	
Formal nutrition assessment		☒				
Planning method of insertion and device selection	☒	☒			☒	
Patient education prior to procedure	☒	☒	☒		☒	
Initial insertion/acute hospital care						
Patient preparation for insertion (weight, NBM, bloods etc.)	☒				☒	
Actual placement/confirmation of tube or device placement	☒				☒	
Monitoring the patient post procedure	☒				☒	

	Registered Nurse#	Dietitian	Speech Pathologist	Pharmacist	Medical Specialist	GP
Managing early complications	<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>	
Assessment of nutrition requirements and nutrition regimen		<input checked="" type="checkbox"/>				
Instruction on device care	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	
Assessment and/or education for medication administration	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Instruction on enteral tube feeding	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	
Information on supply and delivery of equipment/formula/thickened fluids	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			
Instruction on relevant contact persons for troubleshooting	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	
Organising transfer of care	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	
Ongoing care						
Device/stoma care	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Monitoring of nutritional status	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Oral hygiene	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Swallow management			<input checked="" type="checkbox"/>			
Management of troubleshooting/ complications (tube feeding, device, stoma)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Determining if there is an ongoing need for enteral tube feeding	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Replacing a gastrostomy tube or device*	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Permanently removing a gastrostomy tube or device*	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Transfer and Transition		<input checked="" type="checkbox"/>				
Transfer of care	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Transition from paediatric to adult services	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

#There are various specialist nurse roles and titles which describe the Registered Nurse (RN) function. Some examples are RN, Clinical Nurse Specialists, Clinical Nurse Consultants, Nurse Practitioner and Clinical Nurse Educator. These vary greatly across organisations, districts and states. RNs involved in gastrostomy care may work within a variety of clinical areas such as Gastroenterology, Endoscopy and Stomal therapy/wound care. In addition, there is not always a specialist RN available in every facility.

For the purpose of this document and scope of practice, RNs, irrespective of specific title, will be referred to as RNs.

- Other nursing staff (such as Enrolled Nurses) may form part of the team and participate in the care of people with a gastrostomy tube or device under supervision.

*A formal extended scope of practice training program should be in place for clinicians where gastrostomy tube or device changes are not considered an entry level competency (e.g. allied health). This should include:²

- gastrostomy tube/device identification including recommended removal methods
- identification and management of complications post initial insertion and as part of ongoing care
- risks and complications associated with removing and replacing gastrostomy tubes/devices and their management
- the ability to identify when escalation of care is required.

Health care professionals caring for patients with a gastrostomy tube or device should have adequate training and experience in order to undertake the tasks required of their role.² The removal of different device types requires different levels of expertise, especially non-ballooned devices.

"The Clinical Nurse Consultant was easy to approach and very knowledgeable"

Patient

"We love our dietitian; she is caring and can help straight away"

Parent

"The people who have looked after us have been wonderful"

Carer

SECTION 2: Deciding to initiate gastrostomy feeding

1. When a gastrostomy tube or device should be considered

Selecting the most appropriate enteral tube feeding route.

Once the decision to initiate enteral tube feeding of any kind is made, there are a number of factors that need to be considered when selecting the most appropriate feeding route (refer to diagram below).

Insertion of a gastrostomy tube or device should be considered early when:

- the underlying condition of a patient with a functional gastrointestinal tract indicates that they require long term enteral tube feeding (i.e. for more than 4-6 weeks),^{15, 16, 23, 24} and

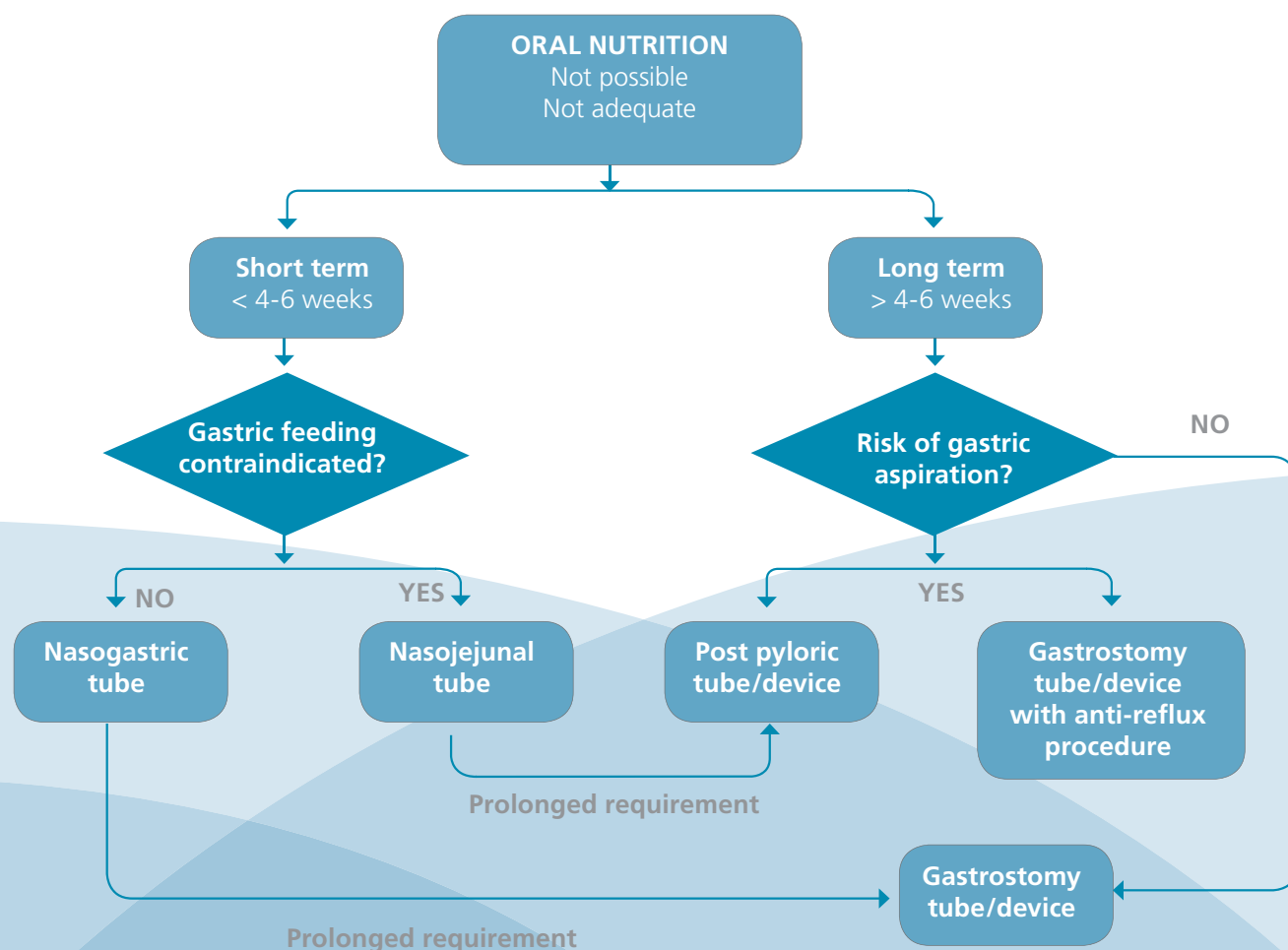
- other causes of malnutrition/growth faltering (apart from inadequate intake) have been excluded by appropriate investigations.



NOTE: Gastrostomy tubes and devices may also be indicated for gastric access where gastrointestinal decompression, hydration or medication administration is required.

For further information see:

- Appendix 2 – Is enteral tube feeding indicated?
- Ethical considerations (page 16).



(This Figure was adapted from ESPEN Guidelines on Artificial Enteral Nutrition, page 849)¹⁵

The decision to recommend the insertion of a gastrostomy tube or device should be based on a multidisciplinary team assessment (*refer to Table 1, page 11*), evidence based practice, clear communication regarding the goals of treatment and should ensure that adequate resources are available for ongoing optimal support and management.^{3, 22, 28}

The decision to initiate the use of a gastrostomy tube or device should always maintain the patients best interest as the focus of care and support independence as much as possible.

It is a general principle of law and medical practice that people have a right to consent to or refuse medical treatment.^{29,30} A competent patient, or an agent/guardian acting on behalf of an incompetent patient, can therefore make informed decisions about the insertion, replacement and/or use of a gastrostomy tube or device.^{3, 5, 16, 31, 32}

Where clinically appropriate, it should be made clear from the outset whether the device is to be placed permanently or temporarily. If the tube/device is to be temporary, goals should be set to work towards adequate oral intake and subsequent permanent removal of the tube/device. This is particularly important for paediatric patients.

"Before the tube life was generally unbearable. Since he had the tube inserted he has put on weight. Sleeping also improved with time. It has been life changing"

Parent

Indications

A summary of clinical indications for gastrostomy feeding is outlined below:

Table 2: Conditions whereby a gastrostomy tube or device may be considered include, but are not limited to: ^{15, 21, 24}

- Neurologically impaired patients with associated dysphagia e.g. stroke, post-traumatic brain injury, motor neurone disease, multiple sclerosis, cerebral palsy
- Head and neck cancer
- Chronic upper oesophageal obstruction e.g. stricture, cancer
- Increased metabolic requirements in patients with acute or chronic diseases (e.g. heart disease, renal disease, cystic fibrosis, Inflammatory Bowel Disease, liver disease, cancer) who are unable to meet caloric requirements with oral diet alone
- Organic or non-organic growth faltering in paediatric patients and severe malnutrition where supplemental long term enteral tube feeding is required to meet nutritional requirements. Treatable causes for growth faltering need to be excluded first.
- Chronic requirements for mechanical ventilation (e.g. tracheostomy)
- Medical conditions where patients require medications on a regular basis and are unable to tolerate oral administration
- Congenital abnormalities of the GIT e.g. oesophageal atresia
- Paediatric and adult patients requiring specialised formulas for a prolonged period that the patient is unable to tolerate orally e.g. rare metabolic conditions, patients with multiple food allergies who need elemental formula.
- Disorders of gastrointestinal (GI) motility/digestion/absorption e.g. short bowel syndrome/chronic intestinal pseudo-obstruction, long segment Hirschsprungs
- Other clinical conditions such as reconstructive facial surgery or wasting in AIDS.

Continued overleaf

Ethical considerations

- The decision to insert a feeding tube or device should be determined on the basis of whether it will provide benefit to the patient, will not cause harm and whether the benefits outweigh the risk of the procedure itself.⁵
28, 31, 33
- Enteral tube feeding should never replace good nursing care to make oral feeding easier.^{1, 15}
- Challenging ethical decisions often surround patients with various conditions including but not limited to terminal/progressive conditions, stroke, progressive dementia, intellectual disability, impaired neurological function impacting on decision-making ability and persistent vegetative states.^{3, 7, 28, 32, 33-35}
 - Health professionals should be familiar with current evidence related to the clinical condition and where to seek formal advice about ethical issues.^{31, 32}
- Informed consent for a gastrostomy tube or device insertion should include information about ongoing care requirements and should not be limited to the insertion procedure alone.²
- Patients should be encouraged to have living wills and/or advanced care directives and to discuss with their next of kin their wishes in the event of a serious accident or diagnosis of a terminal disease.^{28, 31}

- patient mobility and need for tube or device concealment
- access to services for tube/device replacement
- insertion site (anatomical).

2. Tube/device characteristics

- size/diameter of tube/device
- low profile device or longer tube
- balloon retention for ease of change or non-ballooned/internal bumper device
- availability of tube/device and feeding adaptors
- familiarity with tube/device types.

2. Planning for tube/device insertion

If a gastrostomy tube or device is being considered as an appropriate feeding route, further assessment is required to determine if both the planned device and the insertion method/procedure are suitable for the patient. Selecting the most appropriate gastrostomy tube or device to insert will involve consideration of the following individual patient characteristics and what is anatomically possible.

1. Patient factors

- patient/carer preference
- patient/carer abilities and support available post insertion (short and long term, and during periods of illness)
- age of the patient
- anaesthetic risk
- risk of patient pulling tube or device out

Gastrostomy tubes and devices - types and characteristics

Gastrostomy tube and devices can be categorised as either externally removable or not externally removable and can be made from different materials such as silicone or polyurethane.

Table 3: Gastrostomy tubes and device types

Not externally removable from stomach through stoma	<ul style="list-style-type: none"> Non-collapsible internal bumper 	<ul style="list-style-type: none"> Rigid internal retention device Removed endoscopically Advantage that they are not easy to displace accidentally (patient should not be able to pull out)
	<ul style="list-style-type: none"> Collapsible internal bumper 	<ul style="list-style-type: none"> Deforms for removal with firm continuous traction
Externally removable from stomach through stoma	<ul style="list-style-type: none"> Balloon retention device 	<ul style="list-style-type: none"> Examples - balloon replacement device, low profile balloon device
	<ul style="list-style-type: none"> Self-retaining loop or "Pigtail" 	<ul style="list-style-type: none"> Pigtail loop shape held in place with a suture When suture is cut the tube can be removed and straightens on removal
	<ul style="list-style-type: none"> Obturator removal 	<ul style="list-style-type: none"> Manufacturer's specific instructions and purpose built removal kit/equipment required during insertion/removal

Methods of insertion

Gastrostomy tubes and devices can be inserted by endoscopic, radiological and surgical techniques: ^{15, 32, 36}

Table 4: Methods of insertion

Endoscopic	
Percutaneous endoscopic gastrostomy (PEG)	<ul style="list-style-type: none"> Endoscopic procedure using an endoscope Requires sedation (always general anaesthesia in children) Two operators, the endoscopist and an assistant, who may be another medical officer or appropriately trained nurse (typically performed in conjunction with a surgeon in children) "Push" or "pull" techniques to establish gastrostomy
Radiological	
Percutaneous radiologic gastrostomy (PRG) or radiologically inserted gastrostomy (RIG)* <i>*Rarely performed on children. Paediatrician, surgeon and gastroenterologist should be consulted regarding feasibility of performing this procedure in children.</i>	<ul style="list-style-type: none"> Radiologically/fluoroscopically/ultrasound/CT guided placement Gastropexy may be performed Requires sedation Nasogastric tube may be inserted to distend stomach with air Patient may be required to ingest bicarbonate granules to distend stomach Cannulation of the stomach may also be achieved using CT/US guidance Gastrostomy device inserted after sequential dilation (using fascial dilators or angioplasty balloon), or passage of guide wire up the oesophagus and PEG device drawn back down Device may be pigtail tube over the guide wire or balloon device using a peel away sheath system Low profile device also may be inserted over a dilator/guide wire (balloon or mushroom retained button device) Self-retained/"pigtail" device or balloon device or button/low profile device

Table 4: Methods of insertion continued

Surgical	
Surgical gastrostomy/laparotomy	<ul style="list-style-type: none"> • Insertion of a gastrostomy tube/device via laparotomy • Gastropexy may be performed • Device may be sutured in
Laparoscopic gastrostomy (LAPG)	<ul style="list-style-type: none"> • Laparoscopic guidance • Gastropexy performed • Insertion of gastrostomy tube or device under vision of laparoscope • Confirmation of position of gastrostomy in stomach by laparoscope
Laparoscopic assisted percutaneous endoscopic gastrostomy (LA PEG)	<ul style="list-style-type: none"> • Laparoscopic guidance • Endoscopic procedure using a gastroscope • Always under general anaesthetic (GA) in children • Two operators, a gastroenterologist and a surgeon performing the gastric puncture under direct vision of laparoscope • “Push” or “pull” techniques to establish gastrostomy.

**NOTE:**

- In many cases the procedure can be performed as a “day only” procedure. However, due consideration should be given for the time taken to learn how to manage the tube/device, use the tube/device, determine the tube feeding regimen and tolerance, and arrange access to appropriate equipment and supplies.
- Patients need to be assessed to determine if they require admission and follow-up post-procedure according to their co-morbidities and clinical status.

Contraindications

An initial gastrostomy tube or device should not be considered if it is unlikely to improve long term outcome or enhance life. It is rarely indicated in patients with short life expectancy or advanced dementia.^{15, 16, 22, 32} Evidence suggests that patients with advanced dementia may not benefit from long term enteral tube feeding as it does not improve longevity or quality of life.

There are a number of potential contraindications to the insertion of a gastrostomy tube or device (*refer to Table 5 on page 19*). Individuals with these conditions are at significant risk and therefore appropriate selection of patients is paramount to good outcomes.³⁷ Consideration should also be given to the risks associated with sedation and anaesthesia.

Table 5: Potential contraindications to the placement of gastrostomy tubes and devices

Contraindication	Rationale	Alternative insertion technique / other feeding route
Endoscopic insertion		
Total oesophageal obstruction	Risk of oesophageal perforation during PEG or inability to pass the endoscope	Consider open or laparoscopic gastrostomy Radiologically inserted gastrostomy (RIG) or jejunostomy
Obstructive head and neck tumours	Inability to pass endoscope	Consider open or laparoscopic gastrostomy or RIG
Surgical insertion		
Peritonitis	Risk of sepsis	
Bowel obstruction (except for decompression purposes)	Risk of worsening obstruction	
Extensive tumour infiltration of the stomach	Risk of bleeding/seeding of tumour	
All insertion methods		
Anorexia Nervosa	Need to address underlying psychiatric issue	Not applicable
Inability of patient and/or carer to comply with required care including appropriate home environment	Risk to health of patient	Not applicable
Portal hypertension (potential presence of varices)	Risk of haemorrhage during procedure	Further assessment and consider open/ laparoscopic gastrostomy or jejunostomy
Known varices		
Severe coagulopathy		Further assessment
Gastric outlet obstruction	Contraindication to gastric feeding	Consider jejunal feeding
Upper gastrointestinal malignancy where surgical intervention is being considered	Stomach may need to be preserved for future surgical procedures. Surgical opinion should be sought prior to gastrostomy	Consider jejunal feeding
Ascites (PEG and laparoscopic gastrostomy contraindicated)	Risk of poor tract formation (difficult to approximate stomach to abdominal wall)	Consider open gastrostomy
Sepsis	Risk of worsening sepsis	
Advanced dementia	As outlined on page 18	
Significant hepatomegaly (liver extends across abdomen)	Risk of liver laceration – requires surgical advice	
Intra-abdominal mass	Risk of perforation Contraindication for endoscopic/ laparoscopic gastrostomy	In exceptional circumstances the procedure could be executed without anatomical interference. Expert surgical/medical advice should be sought.
Morbid obesity (PEG and laparoscopic gastrostomy contraindicated)	Risk of poor tract formation (difficult to approximate stomach to abdominal wall)	Consider open gastrostomy

Continued overleaf

Table 5: Potential contraindications to the placement of gastrostomy tubes and devices continued

Contraindication	Rationale	Alternative insertion technique / other feeding route
All insertion methods continued		
Paralytic or mechanical ileus	Risk of worsening ileus	
Interposed organs	Risk of injury to organs	Consider open gastrostomy
Marked peritoneal carcinomatosis	Seeding of carcinomatosis	Consider open gastrostomy
A person that presents with challenging behaviours	Risk to health of patient (e.g. self-removal of tube or device)	The underlying reasons for the challenging behaviours should be investigated
Head and neck cancer (contraindication for PEG if an overtube is not used)	Risk of seeding ³⁸	Use of over tube
Incurable disease in terminal phase (prognosis <3 months)		Consider palliative care using nasogastric tube feeding

The referral process/pathway

Once the decision is made to insert a gastrostomy tube or device, the referral should follow a defined pathway as detailed by local arrangements of the organisation. The referral should only be made after all attempts to support the patient to meet their nutrition/fluid/medication needs orally have been unsuccessful (or if it is anticipated that attempts will be unsuccessful due to the projected course of their disease).

Details of the referral process may vary but should include:^{15, 22}

- A written or electronic referral detailing indication/s for gastrostomy tube or device placement
- A method of communicating when tube or device insertion is to take place i.e. written appointment, recorded in patient medical record
- Re-assessment of co-morbidities, current medications (especially anti-coagulants) and prior surgery that may be relevant to the procedure
- The pre-procedure protocol to prepare the patient, i.e. a checklist for ward staff to detail pre-procedure workup/preparation
 - Anaesthetic consult
- Screening for Multi-resistant Organisms (MRO) with swab from the nose, throat, perineum and skin areas as per local policy

- Obtaining informed consent
 - Consider if the patient is competent to give consent or if there are consent issues that require management
(Refer to *Ethical considerations page 16*).
- Nutrition assessment
- Notifying appropriate staff to prepare for education and care of the patient with a new gastrostomy
- Engaging carers prior to insertion to ensure education and equipment are in place ready for care.

3. Patient and carer education and preparation – Pre-insertion

Patient and carer education ^{7, 11, 19, 21}

The patient and/or carer should be aware of and/or meet with all members of the nutrition support team involved in the process of gastrostomy insertion and ongoing care. See *Table 1: Health Professionals Involved* (page 11).

Professional health care interpreters should be used for all patients who are not fluent in English, as per local policy.

Prior to tube/device insertion, patients and/or carers should receive verbal and written education* as early as possible by the relevant health professionals regarding:

- What is a feeding tube/device?
- Why a feeding tube or device is recommended, the type of tube or device recommended, and how long the tube or device is likely to be required
- Risks and benefits - this will be different for each patient, therefore teams should consult available evidence to ensure they are providing accurate information to patients and/or carers
- Whether oral intake is recommended in conjunction with tube feeding, and if so whether food and/or fluid modifications are recommended (as per speech pathologist)
- An oral desensitisation/oral stimulation programme for paediatric patients to avoid oral food aversion - where oral intake is not recommended for the short term (as per speech pathologist)
- Pre-procedure review requirements (e.g. bowel management, weight)
- The procedure (e.g. how the tube or device is inserted, how long the procedure will take, who will perform it; what to expect in the immediate post-procedure period)
- Medication management in preparation for the procedure in consultation with the relevant medical specialist/GP (e.g. ceasing anti-coagulants prior where appropriate and as per medical team)
- Basic tube/device care, feeding regimens, equipment and costs etc.
- Plans for future feeding provision (i.e. supply of feeds and feeding equipment).



*NOTE: Information and education should always be age and developmentally appropriate for patients/carers, taking into account any augmentative or alternative communication systems in place. Written information should be presented in the person's native language and/or a simple easy English format for people who require additional literacy support.

See page 35 for education post-insertion of a gastrostomy tube or device.

Documentation^{11, 19, 32}

All information regarding the pre-insertion stage should be clearly documented in the patient's medical record. This information should include, but not be limited to:

- reason for insertion, insertion method and tube/device type and brand selected
- consent for insertion from patient and/or carer
- education of patient and/or carer
- all pre-procedure assessments by the treating team, which may include gastroenterologist, physician, surgeon, radiologist, dietitian, speech pathologist and nurse.

"It was all so rushed – too much to take in"

Patient

SECTION 3: Acute hospital care – Day of procedure to 24-48 hours post procedure

1. The day of procedure

Patients should be re-assessed on the day of the procedure to ensure that there have been no changes in their condition or social situation or worsening of any pre-existing conditions which may either preclude proceeding with gastrostomy insertion or alter the insertion method or device.

If the decision is made to proceed, the health professionals involved in patient care should be re-engaged. *Refer to Section 1 page 11.*

Patient preparation

Patients undergoing insertion of an initial gastrostomy tube or device should undergo a standard pre-procedure checklist according to local guidelines. The following pre-insertion checks and interventions may be included (and may have been performed prior in an outpatient or pre-admission clinic):

- Informed consent
- Height and weight
- Full blood count
- Coagulation profile
- Urea and electrolytes
- Confirm current medication regimen
- Ascertain current MRO status
- Check oral hygiene has been carried out/performed
- Anaesthetic consult if required
- Nil by mouth - fasting times vary depending on patient's age, type of device and method of placement.
- Prophylactic antibiotic (a single dose of prophylactic antibiotics is effective for decreasing peristomal infection post gastrostomy device insertion).³⁹⁻⁴¹ (GRADE C)

The following question should be asked of all patients to establish whether they are Aboriginal and/or Torres Strait Islander:⁴²

- *"Are you (is the person) of Aboriginal or Torres Strait Islander origin?"*

If the patient identifies as being Aboriginal or Torres Strait Islander he/she should be referred to the Aboriginal Hospital Liaison Officer/Aboriginal Health Education Officer.

The procedure and documentation

The formation of a gastrostomy and the initial insertion of a gastrostomy tube or device should be performed by, or under the supervision of, a suitably credentialed and qualified medical specialist following local guidelines.

A procedural report must be completed and included in the medical record. The type, brand and gauge of the gastrostomy device should be clearly documented.

A clear set of instructions must be included in the clinical handover once the procedure has been completed. The following information should be included:

- Type, brand and gauge of gastrostomy tube or device inserted
- External tube measurements
- Fasting time required post-procedure
- Time flushing of the tube or device can commence
- Time feeding can commence if patient is to commence feeds
- Instructions for removal of dressing where applicable
- Instructions for after-care, including warning signs that indicate the need for medical review (such as new abdominal swelling or distension, bleeding or haematoma, increased pain on administration of fluids via the tube, leakage, fever, redness or discharge).

2. Immediate post insertion management

Monitoring and identification of early complications

It is important that the patient is monitored adequately to assess for early signs of potential complications to ensure timely medical attention and good clinical outcomes.

The most common early complications after the insertion of a gastrostomy tube or device include abdominal pain, peristomal infection and leakage.⁴³⁻⁵⁰

See Table 6, page 24.

Post procedure instructions

There should be routine post-operative care and protocols in place. However, patient-specific instructions may also be provided and these should be followed in cases of exceptions or non-standard insertions.

Vital Signs

- Local policies for post-operative recovery should be followed. This may include observations for the following:
 - Pulse
 - Blood pressure
 - Respirations
 - Temperature
 - Oxygen saturations
 - Pain score.
- These observations should be performed and plotted for comparison and identification of trends (e.g. deteriorating trend).
 - Utilise patient deterioration alert criteria e.g. 'Between the Flags' in NSW⁵¹
 - Any deterioration of vital signs should be promptly reported for a medical review.
- Aspiration is a potential complication associated with upper gastrointestinal endoscopy. Supine procedure position, sedation, neurological impairment and ageing are contributors to aspiration risk. The patient's respiratory state, including oxygen saturation and vital signs should be monitored in the post procedure period.

Day procedure patients: Vital signs as above for immediate recovery period. Ensure early follow up contact with patient/carer post procedure to assess for potential complications after discharge from hospital.

Abdominal Assessment

Inadvertent puncture/perforation of the bowel or other organs is a potential complication of the formation of a gastrostomy. As a result there may be spillage of bowel contents into the peritoneal cavity which can then lead to peritonitis - demanding immediate medical attention. If untreated, peritonitis can lead to severe and potentially life-threatening complications.

- Abdominal assessment should be performed hourly, with vital signs for four consecutive hours and then should continue post procedure at least fourth hourly for the next 24 hours whilst an inpatient. If the patient has been transferred home they and/or their carer should be educated to monitor their condition.
- Abdominal assessment should monitor for signs of peritonism, including:
 - Abdominal pain, tenderness or guarding
 - Abdominal distension, rigidity or bloating
 - Increased pain post administration of fluids via the tube
 - Diarrhoea, nausea or vomiting
 - Low urine output
 - Absence of flatus or bowel sounds, or inability to open bowels.
- Patients no longer within a hospital setting should be advised to present to the emergency department if any of the above occur post procedure.

The following table gives a guide to possible symptoms and potential complications.⁵²⁻⁵⁶

Any concerns should be referred for a medical review.

Table 6: Possible symptoms and potential complications ⁵²⁻⁵⁶

Symptom	Assessment and Monitoring	Potential complication
Fever	<p>Assess for high grade temperatures with or without rigors or altered temperatures, swaying from the baseline.</p> <p>Assess white cell count and other potential markers of infection.</p> <p>Assess abdomen for purulent wound discharge or signs of abscess/collection.</p>	<ul style="list-style-type: none"> • Sepsis/Peritonitis • Wound infection
Deranged vital signs, haemodynamics and other possible signs of septic shock	<p>Minimum monitoring of vital signs hourly for 4 hours and then should continue post procedure at least 4 hourly for the next 24 hours (unless day only).</p> <p>Additional monitoring and medical review as indicated by local patient deterioration protocol.</p>	<ul style="list-style-type: none"> • Peritonism • Bleeding • Perforation • Aspiration
Nausea and/or vomiting	<p>In the event of intractable nausea or vomiting, aspirate the gastrostomy tube or device to assess residual gastric volumes and decrease the risk of aspiration pneumonitis.</p> <p>Gastrostomy tube or device can remain on free drainage as required.</p>	<p>Large residual volumes might be suggestive of:</p> <ul style="list-style-type: none"> • Gastric stasis • Outlet obstruction • Impaired gastric motility • Ileus • Peritonism
Abdominal pain	<p>Adequate routine post procedure pain relief is necessary. Patients may experience some localised pain from the new incision for up to 7-10 days.</p> <p>Some patients experience shoulder tip pain from insufflation and retention of air during endoscopic or radiological insertion procedures. Gentle mobilisation may assist in the dispersion and emission of this air.</p> <p>Any pain beyond the expected, local insertion site or beyond the acute phase needs medical review.</p>	<p>Potential signs of peritonism include:</p> <ul style="list-style-type: none"> • Diffuse, rebound tenderness • Guarding • Distension, bloating, rigidity
Low urine output	<p>Ensure an accurate and complete fluid balance chart is maintained and recorded. This includes water flushes, feeds, medication volumes, and any input/output.</p>	<ul style="list-style-type: none"> • Dehydration • Sepsis • Bleeding
Absence of bowel sounds, flatus or inability to open bowels	<p>Auscultate abdomen to monitor bowel sounds.</p> <p>Monitor type and frequency of bowel function and consider the patients baseline norm.</p> <p>Exclude bowel obstruction with abdominal x-ray</p>	<ul style="list-style-type: none"> • Ileus • Peritonitis • Obstruction
Diarrhoea	<p>In the event of the onset of diarrhoea consider potential procedure complications. Perform abdominal assessment and consider referral for surgical review.</p>	<ul style="list-style-type: none"> • Gastro colic fistula • Bowel perforation • Contamination

Pain management ^{22, 57, 58}

- Adequate post-operative pain relief is essential to optimise patient outcomes.
- Regular assessment of pain, including changes in intensity or pattern is necessary in the acute phase. The use of pain score charts may be beneficial in some settings.
- Pain relief medication should be charted by the medical team. Paracetamol is most commonly prescribed, given regularly (if not contraindicated) for pain relief. Other medications may also be prescribed.



NOTE: if the patient usually requires analgesia, additional pain relief may be needed in the acute phase post device insertion. Patients requiring narcotic analgesia must be reviewed by the medical team.

- Gastrostomy insertion sites can be quite painful for up to 7-10 days. After this initial period, the site should not be painful. Any episode of pain beyond the acute phase needs investigation and referral for medical review.

Oral Hygiene ⁵⁹⁻⁶¹

Even when a patient is “nil by mouth” and receiving all of their nutrition and hydration via a feeding tube it is important that oral hygiene continues. Evidence has consistently shown a link between poor oral hygiene and serious illnesses, such as hypertension, stroke and pneumonia.

Oral hygiene should include gentle brushing of the teeth, gums, tongue and palate, preferably with a soft toothbrush and mild toothpaste. Mouthwash may also be used as recommended by a medical specialist however caution should be used to avoid aspiration. Swabs may be used in place of rinsing where appropriate. Suction devices and suction toothbrushes may also be useful for patients with oropharyngeal dysphagia. Regular review by a dentist/hygienist is recommended for these patients.

Prevention and management of gastrostomy associated gastric ulcer ^{62, 63}

There are cases where gastric ulcers have occurred after gastrostomy tube/device insertion. Patients require ongoing monitoring to determine if further treatment is required.

Technical aspects of tube or device care

The following table gives a guide to assessing the insertion site and technical aspects of device care in the first 48 hours. Any concerns should be referred for a medical review.



NOTE:

- Effective hand hygiene is the single most important strategy in preventing health care associated infections. Hospital acquired infections (HAIs) can be life-threatening, especially for people with serious pre-existing conditions.
- All contact with the patient and the device/ equipment should follow hand hygiene principles. Refer to local policies or Hand Hygiene Australia’s “**5 moments for hand hygiene**”.⁶⁴

Table 7: Assessment of the insertion site/technical aspects of gastrostomy tube or device care in first 48 hours

Assessment and Management	Rationale	Action
Gastrostomy Insertion site The new insertion site should be assessed for signs of: <ul style="list-style-type: none"> • Bleeding - moderate to large amount of fresh bleeding (a small amount of bleeding is expected) • Haematoma. 	Haemorrhage from puncture site, or from the gastric wall.	Site assessment should be performed with vital signs monitoring, i.e. hourly for 4 hours and then should continue post procedure at least 4 hourly for the next 24 hours (unless day only) then once per shift minimum and as required. Seek medical review if any deviation from expected.
<ul style="list-style-type: none"> • Redness • Increasing pain • Excessive swelling • Unusual discharge or smell 	May indicate site infection.	
<ul style="list-style-type: none"> • Leakage (of gastric content) 	May indicate malposition.	
Surgical wound site (if applicable) The surgical wound site should be assessed for signs of: <ul style="list-style-type: none"> • Bleeding • Haematoma 	Haemorrhage from puncture site, or from the gastric wall.	As above. Dressings to site should be left in situ unless wet or heavily soiled. Refer to post-operative instructions for removal guidance.
<ul style="list-style-type: none"> • Redness • Increasing pain • Excessive swelling • Unusual discharge or smell. 	May indicate site infection.	
Wound sutures/ clips/T fasteners (if present) Observe for: <ul style="list-style-type: none"> • Redness • Increasing pain • Excessive swelling • Unusual discharge or smell. 	May indicate site infection.	Seek medical review if any symptoms present. Refer to post-operative orders for removal timeframe.
Insertion site care/hygiene Clean site according to local wound management policy using aseptic technique. Adhere to safe hand washing policy prior to touching device or site.	Reduces the risk of site infection.	Promote good hygiene practices. Patient can shower if local policy permits.
The use of dressings is not recommended.	Dressings can obscure visualisation of site. Bulky dressings under the external retention device can increase the tension and lead to displacement or migration of the device or pressure injuries.	

Table 7: Assessment of the insertion site/technical aspects of gastrostomy tube or device care in first 48 hours continued

Assessment and Management	Rationale	Action
Securing the device (see photos below) The external flange should be positioned to ensure that the tube or device is neither fitted too tightly nor able to move freely in the tract. A distance of 2-5mm is recommended from the external flange to skin level. ^{15, 16, 24, 65-67} (GRADE C)	If the external flange is too loose it will result in excessive device movement/migration and may result in gastric content leakage or pyloric obstruction. Potential failure of tract formation. Too tight can lead to pressure related injury, potential gastric mucosal erosion and buried bumper. ^{15, 16, 22, 24, 26, 65-72} (GRADE B)	Correct positioning of the external flange should be determined by observing the patient when in reclining and sitting position to ensure correct fitting. <i>NOTE: Suturing the external flange to the skin to secure it is generally not recommended as there are minor complications associated with this practice including skin excoriation/ulceration and local site infection.</i>
Rotation of the tube or device and the external flange Unless sutured, anchored or specifically contraindicated, standard gastrostomy devices (ballooned or non-ballooned) should be rotated 360° daily.	Rotation of the tube or device promotes patency of the fistulous tract and relieves pressure from internal bolster on gastric mucosa.	Rotation of the gastrostomy tube or device is encouraged to commence 24 hours post insertion. ^{15, 24} (GRADE D) Rotate tube/device daily when the patient is comfortable and pain free post insertion.
Tube or device position The centimetre mark of the tube or device at skin level (excluding low profile devices) should be recorded clearly in patient records and observed prior to each use. ⁷³ (GRADE C)	Provides a baseline for future comparison and monitoring of tube/device migration. Deviation from initial observed measurement may indicate device movement either internally or into the tract.	Discrepancies in tube or device length between observations should be investigated by appropriately trained clinician.
Clamp on endoscopically placed tubes (not usually seen on balloon style tubes/devices) Leave in closed position when device not in use. Change position along device length regularly.	Used to prevent retrograde flow of gastric content in tubing. Moving the clamp will prevent compression of tubing through repeated use.	Ensure clamp is open prior to use. Flush tube or device with water and then close clamp to ensure no gastric content is left in tubing.
Balloon style tubes/devices and low profile/skin level devices Has inflation or "balloon" port/valve which is used to instil water into internal balloon once tube/device is positioned in stomach.	Over inflation/ filling can result in: <ul style="list-style-type: none"> - balloon failure - decreased gastric capacity (especially in a paediatric setting). Inappropriate use can lead to tube/device failure and loss of medications if delivered via inflation port.	Never flush or administer formula or medication via the inflation/balloon port. The inflation/balloon port is only accessed to check inflation volume or re-inflate balloon (follow manufacturers/health professionals' guidelines).



Photo: A Kennedy

Too tight



Photo: A Kennedy

Too loose

3. Nutrition assessment

A comprehensive formal nutrition assessment should be performed by a dietitian prior to the commencement of feeding through a long term feeding tube or device. Nutrition assessment may not necessarily occur at the time of tube/device placement and may occur in an alternative setting.

The timing and setting of the nutrition assessment is in part determined by:

- local organisational policy
- whether the individual has an established feeding plan (oral and/or tube feeding), or
- whether the patient is commencing feeding via a long term feeding tube or device for the first time.

Other considerations include:

- whether the tube or device is required immediately post insertion for nutrition support, or
- if it is a prophylactic placement in anticipation of upcoming treatment side effects (e.g. individuals embarking on treatment for head and neck cancer), or
- progressive clinical conditions (e.g. neurological conditions with progressive dysphagia).



NOTE: It should be confirmed at the time of decision of tube or device placement whether the individual has been linked with the appropriate health professional (dietitian)/ nutrition support service. If not, appropriate referral should be made.

A comprehensive nutrition assessment is required to formulate an individualised nutrition care plan for the patient. This will guide the appropriate selection of enteral formula (type and volume), mode and pattern of nutrition delivery and starting regimen. A validated nutrition assessment tool (appropriate to the patient group) should be used where available (e.g. Patient Generated Subjective Global Assessment, Subjective Global Assessment, Mini Nutrition Assessment Tool)⁷³ for diagnosing protein energy malnutrition.

The nutrition assessment should include, but not be limited to the following parameters:

- **Anthropometry** – an evaluation of weight history, current body weight and Body Mass Index (BMI), growth or weight recovery needs. For infants and

children, serial linear length/height and weight measurements should be plotted for (corrected) age and interpreted using an appropriate tool for growth comparison (may need disease specific growth charts).

- Examples can be found at this link:

<http://deptswashington.edu/nutrpeds/fug/growth/specialty.htm>

- **Biochemistry** – evaluation of hydration status, identification of electrolyte abnormalities (e.g. in relation to risk of refeeding syndrome or indicative of renal or liver impairment). Consider baseline nutritional parameters required to assist in the monitoring of enteral feeding long term (e.g. measurement of minerals, trace elements, vitamins and albumin), being mindful that some biochemistry may be influenced by an acute phase response.
- **Clinical** – medical history; diagnosis and clinical trajectory; individual nutrient requirements and factors impacting; gastrointestinal symptoms; physical capacities of the patient and medications. Details of medications are required in case they interact with feeds or affect the volume and/or timing of feeds that can be given.
- **Dietary** – quantitative and qualitative evaluation of recent changes in intake and current capacity/level of intake (both oral and enteral tube feeding).
- **Psychosocial and socioeconomic** – social support systems, current level of services, home environment, personal or cultural beliefs and financial status.

Consideration should also be given to identifying those patients at risk of refeeding syndrome. The clinical and biochemical sequelae associated with refeeding syndrome are potentially life threatening.^{3, 74} Therefore identification of at risk individuals and the subsequent management of that risk are essential components of a comprehensive nutrition assessment.

A patient is defined as being a high refeeding risk if he/she

has one or more of the following:³

- BMI less than 16kg/m²
- Unintentional weight loss greater than 15% within the last 3-6 months
- Little or no nutritional intake for more than 10 days
- Low levels of potassium, phosphate or magnesium prior to feeding.

Or if the patient has two or more of the following:³

- BMI less than 18.5 kg/m²
- Unintentional weight loss greater than 10% within the last 3-6 months
- Little or no nutritional intake for more than 5 days
- A history of alcohol abuse or drugs including insulin, chemotherapy, antacids or diuretics.

Paediatric patients are at risk of developing refeeding syndrome more quickly than adults. The criteria for assessing risk therefore differ.⁷⁴⁻⁷⁷

- BMI less than 5th percentile for age
- <80% ideal body weight for length/height
- 5-10% weight loss in previous 1-2 months
- Little or no nutritional intake for 7-10 days
- Low levels of potassium, phosphate or magnesium prior to feeding
- Prolonged and severe vomiting
- Pre-existing cardiac or respiratory conditions or prolonged "QTc" interval on electrocardiogram.

Potentially high risk paediatric groups include:^{75, 76}

- Patients with anorexia nervosa
- Oncology patients receiving chemotherapy or undergoing bone marrow transplantation
- Post-operative patients
- Chronic malabsorption syndromes or chronic malnutrition due to gastrointestinal disorders
- Chronic malnutrition secondary to neurological disorders.

For both adult and paediatric patients, the level of refeeding risk will dictate the rate at which nutrition is introduced and how quickly it is progressed to goal rate. If the delivery of nutrition is too rapid it may precipitate a refeeding response in at-risk individuals.³

4. Using the tube or device for feeding

It is recommended that prior to the administration of anything via the gastrostomy tube or device that the external length of the tubing (markings at skin level) is checked to ensure it has not changed since initial insertion (for non-skin level devices). If there is a significant change the position of the device must be confirmed prior to use by consulting with a medical officer.²³ (GRADE C)

Commencement of feeding - water trials and enteral formula

There is no evidence to support the practice of water trials prior to commencing enteral nutrition via the gastrostomy tube or device.²

ADULTS

- Current evidence suggests that for adults with uncomplicated gastrostomy tube/device placement, enteral tube feeding can commence within two to four hours of the procedure.^{3, 15, 22-24, 65, 69-72, 78-83} (GRADE B)
- The time frame will vary according to patient age, condition and preference of the medical specialist.

CHILDREN

- In paediatric patients a minimum of four to six hours is recommended post gastrostomy tube/device insertion before commencing the administration of enteral tube feeds.^{3, 15, 22-24, 65, 69-72, 78-83} (GRADE B)

A dietitian should be consulted prior to the commencement of feeding to advise accordingly.³ The medical specialist who placed the gastrostomy tube or device is responsible for providing post-operative orders regarding when to commence feeding through the tube or device and when the patient can recommence oral intake if they are continuing to take some form of nutrition or hydration orally.

- Refer to local policies and guidelines about starting enteral feeds out of hours or prior to a dietetic review.

General recommendations to consider when planning an enteral tube feeding regimen include:^{16, 23, 24, 65, 66, 84-88}

- Commercially prepared formulas are recommended for enteral tube feeding. (GRADE B)
- Commercially prepared liquid enteral nutrition formulas should be used in preference to reconstituted powdered formulas whenever possible as it reduces the risk of contamination. (GRADE C)
- Diluting or mixing anything into an enteral formula is not recommended as it increases the risk of bacterial contamination. (GRADE B)
- Dilution of enteral formula is not required and may affect osmolality and delay achieving nutritional targets. (GRADE C)
- Home-made formula (including blenderised, pureed and vitamised foods) is not recommended in adults or paediatrics due to increased risk of bacterial contamination and nutritional inadequacy. Home-made formula has been shown to have a higher viscosity, higher osmolality and inconsistent and uncertain nutrient composition when compared with commercially prepared formula. (GRADE B)
 - Patients / carers wishing to prepare their own formula should receive education and information from a dietitian.
 - The dietitian should work in partnership with the patient/carer to ensure they receive the individualised information they need to make safe and informed choices.⁸⁹
- Flushing a gastrostomy tube or device with substances other than those prescribed is not recommended. (GRADE D)

The mode by which enteral formulas are delivered via the tube or device (bolus or continuous infusion) and the rate at which they are introduced and progressed will be dependent upon a number of factors. Patients who are clinically stable and have been receiving adequate intake via a tube prior to the placement of the long term feeding device may be commenced at their previous goal rate.²³ Slower rates of introduction and progression will be required for:

- Clinically unstable/critically ill patients
- Patients being fed via an enteral feeding tube for the first time or who have not been fed for an extended time
- Infants and children
- Patients at risk of refeeding syndrome.

The use of enteral formula/feeds at room temperature is recommended. Bypassing the oral route prevents the patient's ability to regulate or adjust the temperature of ingested food and fluids. Fluids that are too hot can scald the gastric lining, too cold can cause abdominal cramping (with/without diarrhoea).

Enteral dispensers or non luer lock-type syringes should be used for the administration of liquid (be it water, feed or medication) through a gastrostomy tube or device.⁹⁰

Positioning of the patient for feeding

To reduce the risk of gastro-oesophageal reflux and potential aspiration during feeding, wherever possible patients should be positioned at greater than 30-45 degrees from horizontal during enteral tube feeding and for 30-60 minutes after feeding has ceased.^{16, 22, 65, 66, 73, 91-95} (GRADE B)

In instances where the medical or postoperative condition precludes positioning upright*, strategies to reduce the risk of gastro-oesophageal reflux may need to be considered prior to commencing enteral tube feeding. Such strategies may include the use of an enteral feeding pump to deliver feeds, use of lower infusion rates or smaller volume intermittent feeding, or the use of prokinetic agents for patients with delayed gastric emptying. Consideration should also be given to allowing the recommended time to remain seated upright after the feeding has ceased (30-60 minutes) before moving the patient for personal cares, lifting the patient with hoists etc.

Refer to Table 15, page 51.

Such strategies may also be considered in instances where the individual presents with aspiration in spite of having been positioned upright for feeding. However it should also be noted that aspiration of the individuals own saliva is a risk in many clinical conditions and this may need to be managed independently. The feeding strategies employed should still take into consideration the delivery of adequate volumes of enteral formula to meet nutritional needs.



*NOTE: A referral to an Occupational Therapist or Physiotherapist to assess and recommend seating and positioning options may be beneficial.

Water flushes

Regular water flushes are utilised in gastrostomy feeding to:

- test and maintain patency of the tube or device (i.e. to manually clear the device of medications, formula and gastric contents to help prevent blockages) and

are given before and after medications and enteral tube feeds; and

- b. assist the patient to meet fluid needs.

Even if a gastrostomy tube or device is not currently being used by a patient for feeding (e.g. in the case of prophylactic tube placements prior to the onset of anticipated side effects from a given medical treatment) it requires daily flushing with water to maintain the patency of the tube/device.

The volume and frequency of water flushes will vary according to the:

- age of the patient (smaller flushes required in paediatrics compared with adults)
- length and type of the tube/device
- feeding regimen
- medication regimen
- total fluid needs or fluid restrictions relative to the fluid contribution from the enteral formula and any oral intake
- individual patient tolerance.

Sterile water is advised for water flushes in immune compromised patients, patients in critical care and children under 12 months of age in hospital. For children under 12 months of age at home cooled boiled water can be used for water flushes⁹⁶ (i.e. boiled on stove top for three minutes then cooled). Tap water is acceptable for use in all other patient groups.² (GRADE C)

Monitoring of feed tolerance

Whether an individual is discharged immediately post tube/device insertion or whether they remain an inpatient for a period afterwards, patient/carers and health professionals need to be aware of how to monitor the tolerance of nutrition support.

During the early stages of enteral tube feeding the indications of feed intolerance generally fall within two realms:

Metabolic – in the short term, electrolyte and fluid balance derangements may reflect a response to refeeding in at-risk individuals.^{3, 74, 77} If the patient has been identified as being at high risk of refeeding syndrome, treating teams need to consider whether it is more appropriate for the person to remain an inpatient whilst the response to refeeding is ascertained, monitored and managed.

If the individual remains in the inpatient setting for the commencement of enteral tube feeding, basic observations

should continue as per local protocol (e.g. temperature, pulse, monitoring of fluid balance).³ For patients being discharged home immediately post device insertion, they or their carers need to be alerted to simple ways to monitor the patient's general condition as is clinically appropriate (e.g. individuals at high risk of aspiration or those who are immune compromised may be educated to monitor temperature if appearing unwell, patients with a cardiac history or renal impairment may monitor for signs of peripheral oedema). Glycaemic response to feeding should be monitored as clinically appropriate for those patients with known impaired glucose tolerance or diabetes.

Gastrointestinal – nausea (with or without vomiting), reflux, diarrhoea, constipation and abdominal distension are possible signs of feed intolerance. If feeding is to commence post discharge from an acute setting, patients and their carers need to be aware that the onset of any such symptoms necessitates review by a health professional.

Within inpatient settings, some facilities utilise measurement of residual gastric volumes to assess feed tolerance as it is being progressed toward goal volume in the first 48 hours.^{3, 23} The evidence for checking gastric residual volumes (GRV) in patients with a gastrostomy tube or device is limited. Gastric aspirates may be obtained four hourly however they are not a definitive measure of feed tolerance alone and are subject to significant variability.³ Most research on GRV is conducted in mechanically ventilated patients with nasogastric feeding tubes (as opposed to gastrostomy tubes or devices) in the critical care setting. There is no evidence to recommend checking GRV in patients with a gastrostomy tube or device outside of the critical care setting.^{3, 16, 22, 82, 97-101} (GRADE D)

If signs of intolerance such as significant abdominal distension, nausea and vomiting are present, all feeding should be stopped and medical review sought.²⁶ The possibility of gastrointestinal obstruction needs to be medically evaluated. If this is eliminated as a cause of the delayed gastric emptying, the patient's current medications should be reviewed to determine if there are any pharmacological agents contributing to the problem and if not, a prokinetic motility agent should be trialled.³

Common gastrointestinal complications and recommended options for management are presented in Section 4.4 Gastrointestinal Complications (page 51).

5. Medication administration

Pre-assessment/prescription

Depending on the reason for tube or device insertion, some patients may still be consuming food and/or fluids orally and/or may be able to continue oral medications. A speech pathologist should be consulted for patients with oral or pharyngeal dysphagia to provide appropriate advice and instruction regarding the continuation of oral diet, fluids and medications.

If the patient is unable to tolerate medications orally, a review should be conducted at the time of insertion of the tube or device with a pharmacist. The following may be some points to discuss and implement with the medical specialist/GP.¹⁰² Refer to the flow chart on page 34 for guidance.

- Consider the size of the tube or device as this may determine the ease with which medications can be administered.¹⁰³
- The consistency of liquid medicines should be carefully considered as medicines can readily block devices. Patient/carer education on appropriate mixing with water to dilute before administering is important.¹⁰⁴
- The appropriate use of medication presentation is also important - i.e. a suspension may be more suitable than crushed tablets but can have a financial implication.
- Dose calculations should be reviewed as the bioavailability may vary between solid and liquid medications. Occasionally the salt of the medication is different in the liquid when compared to the solid form and again this can cause differences in the amount of actual drug prescribed e.g. phenytoin.^{104, 105}
- Caution is advised when prescribing large quantities of some liquid medication containing the sweetener and sugar substitute sorbitol due to its laxative effect when given in high doses.¹⁰³
- Crushing of tablets or opening of capsules should only be considered as a last resort and when a pharmacist has confirmed the medicine is safe to be crushed or opened.¹⁰⁶ Medicines that should not be crushed or opened include:
 - Modified or slow release preparations
 - Enteric coated preparations
 - Buccal or sublingual tablets
 - Cytotoxics and hormonal products

- The Society for Hospital Pharmacists of Australia has

developed a relevant resource: The **"Australian Don't Rush to Crush Handbook. Therapeutic Options for People Unable to Swallow Solid Oral Medicines"** (2011)¹⁰⁶

- This information is also available via MIMS online.

- Pharmaceutical compounding of medications to suspension formulation may be considered as an option.

Administration

IMPORTANT

- To reduce the risks associated with route of administration, any medications administered via enteral feeding tubes and devices must be given using an enteral dispenser (non-luer compatible syringe) with non luer-connections.⁹⁰
- It is essential that the medication is administered into the correct port of the tube or device.



NOTE: Do not administer medications into the balloon inflation port.

"The liquid pain medication my daughter was ordered in hospital was given into the balloon port instead of the feeding port. This caused her discomfort and over-inflated the balloon. The device became too tight"

Parent

Table 8: Medication administration methods¹⁰²

- If a tablet is crushed or capsule opened in order to

Alternative preparations	Alternative routes
Dispersible tablets Suspensions or syrups Patches Suppositories or enemas Cream, ointments	Sublingual Topical Subcutaneous Intradermal Intramuscular Rectal Intranasal Buccal

administer it via a feeding tube/device, this practice will render the formulation unlicensed. Medical officers must document that they wish the tablet to be crushed or capsule opened.^{105, 106}

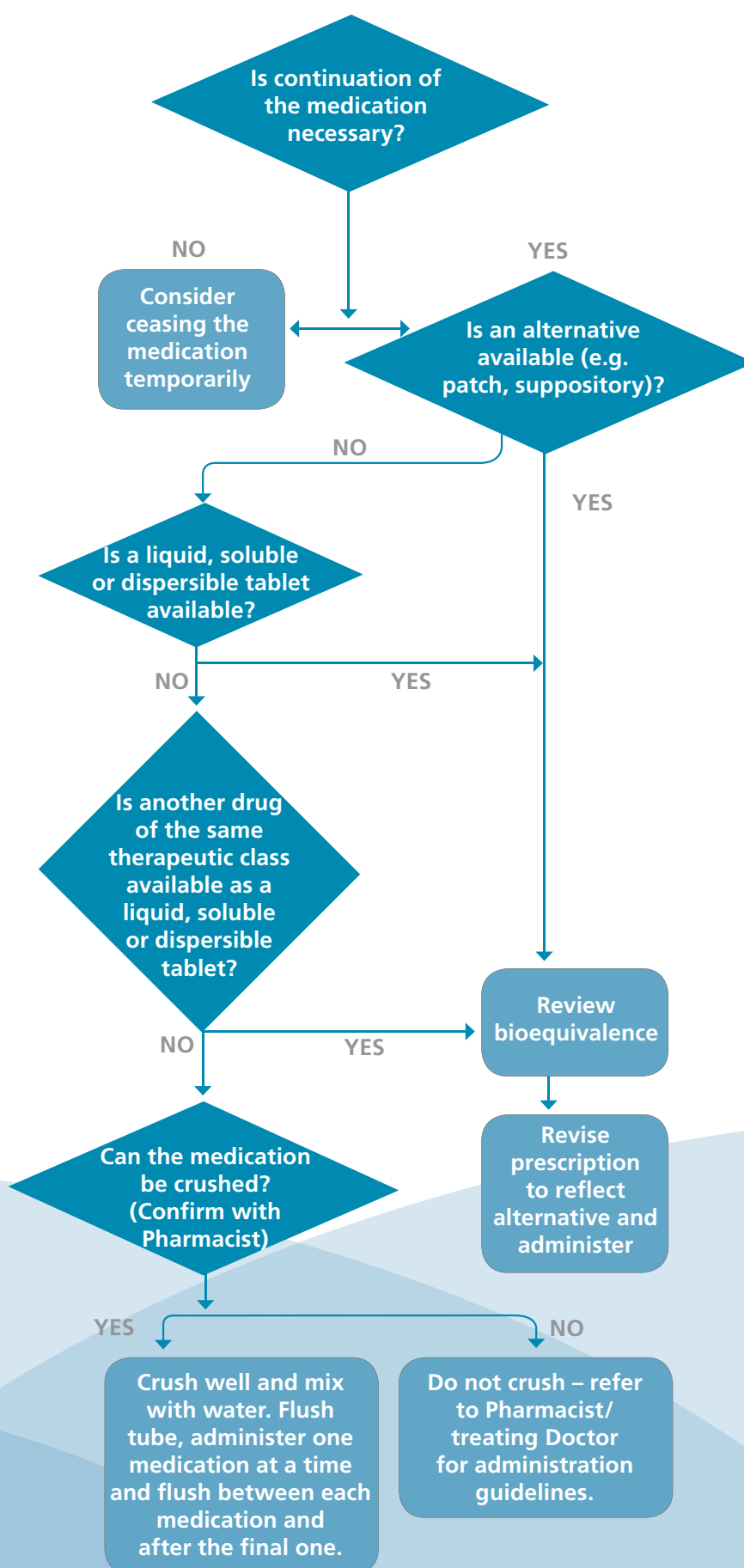
- An appropriate tablet crushing or capsule opening

technique is essential to ensure the patient receives the full dose safely and without compromising the feeding tube or device in any way. A pharmacist can provide guidelines on administering medications via a feeding device, and best practice in crushing tablets and opening capsules. These guidelines should be followed and all practitioners involved in the prescribing and administration of medications via enteral feeding tubes should be fully aware of all the associated issues.^{104, 106}

- When more than one medication is required to be given at the same time, each individual medication should be crushed separately (if applicable) and administered separately with a water flush before, after and in between each medication.
- If the medication needs to be taken on an empty stomach the patient should be advised to take it at least half an hour before and two hours after food and/or enteral tube feeds.¹⁰⁶
- When prescribing for administration via enteral feeding tube or devices there is the potential for interactions between the feed and the medication and between different types of medications themselves. If in doubt, a pharmacist should be consulted.^{105, 106} Feeding regimens may need to be adjusted according to medication requirements.
 - For example, the functionality of medications for Parkinson's disease can be affected by food. Enteral tube feeding regimens should be altered around the times the medication is given. Consultation between the dietitian, pharmacist and prescriber is important.¹⁰⁵
 - Once daily dosing regimens are preferable for enteral administration where the medications interact with the enteral feed as this reduces the number of feed manipulations needed.¹⁰⁶
- It is essential that patients/carers are reminded to flush the tube or device with water before and after administering medicines and between different medicines to reduce the chances of blockage.¹⁰³ The volume of the flush depends on the age of the patient, the number of medications, fluid requirements/restrictions and the clinical condition of the patient.

Algorithm to assist in determining a suitable medication regimen via gastrostomy tube/device.

This algorithm should be used as a guide only – consultation with a Pharmacist is recommended.



6. Transfer of care/discharge planning

Planning

In order to optimise care of the person with a gastrostomy tube or device, planning for transfer of care should start as soon as possible.^{7, 11} The treating team should develop a plan with the patient/carer for the transfer of care to a destination and accepting care team that best suits the ongoing care needs of the patient.

Individuals within the community setting who are dependent upon tube feeding require access to a multidisciplinary nutrition support team to provide ongoing care (see Section 1). Referrals should be made accordingly.³

Factors that should be considered when preparing for transfer of care:

- What is the expected duration of gastrostomy feeding?
- Where is the patient going to be residing?
 - What impact (if any) does this have on the preferred mode of delivery for gastrostomy feeding and the feeding formula and regimen?
 - Is supported accommodation required on a temporary basis to promote independence?
- Will the patient be independent, or require support from a carer or community service?
 - Does the patient/carer/service require education prior to discharge?
 - Is the patient able to continue the care required during episodes of illness or will support be required during these times?
- Who is available to provide support to the patient?
 - Who can provide functional, practical or personal support on a daily basis/as needed?
 - What referrals if any are required to ensure necessary services/supports are in place prior to discharge?
 - What ongoing health professional support is required?
- What are the equipment and tube feed provision/supply needs of the patient/carer?
 - Does the home setting dictate a need to change the feeding prescription?
 - Does the patient need a supply of equipment and/or tube feed on transfer of care?

- What referrals are needed to ensure the patient has access to tube feeding formula and equipment on an ongoing basis? Have these referrals been actioned prior to transfer?
- Does the patient qualify for any support schemes to assist with the cost of equipment and/or tube feed (e.g. DVA, Community care packages, HEN program, EnableNSW, Chronic Disease Management programs)?



NOTE: If any concerns are raised in relation to patient safety, transfer of care should not occur until these are resolved.

"I was sent home from the hospital with no training and no ideas about what to expect"

Patient

Education: Post-insertion

See page 21 for pre-insertion education

If the patient is to be transferred home, the patient/carer should receive education and training about the care of their gastrostomy feeding tube/device from the nutrition support team according to their individual capacity for learning, physical ability and social circumstances.^{7, 107, 108}

- Time must be taken to explain what is needed and why, and to establish clear routines. This supports independence and can help prevent adverse events.

There should be written instructions for the education of the patient/carer which are regularly updated in order to reflect developments in insertion methods, tubes/devices, formula and delivery systems.¹⁰⁹

- In NSW, the My Health Record and Home Enteral Nutrition (HEN) cards should be used as appropriate.¹¹⁰

The patient/carer should be instructed and provided with written information on safe and effective gastrostomy tube or device care and feeding, including:^{3, 11, 21, 23, 25, 107, 111}

1. The function of the gastrointestinal tract and the reason for the gastrostomy tube or device.

2. Care of the gastrostomy tube or device and insertion site, including:
 - a. Tube or device type including brand, size, how it is held in place, balloon volume where applicable, how often it needs to be changed, how it will be changed and by whom
 - b. Skin care
 - c. Checking the position of the tube or device
 - d. Rotating the tube or device (where appropriate)
 - e. Flushing the tube or device
 - f. Tube/device-specific management (e.g. external clamps, balloons, anti-reflux valves, anchoring clips, extension sets)
 - g. Hand hygiene
 - h. Showering and bathing
 - Showering from day one, but the site should not be submerged in water until it heals.
 - i. Swimming with the device
 - Patients can swim once the gastrostomy site/skin wound has healed. Ports and/or clamps (if present) should be closed; the tube/device should fit snugly and be secured well (e.g. within the bathing suit or rash vest). Waterproof tape can be used as an additional precaution. The site should be cleaned and dried afterwards.
 - Patients and/or carers should be advised to consider the quality of the water before swimming.
3. Care and administration of formula, including:
 - a. Nutrition care plan outlining type, volume, frequency and timing of formula administration
 - b. Storage and preparation of formula and equipment
 - c. Method of administration and use of equipment
 - d. Hang times and regular change of consumables as per manufacturers guidelines
 - e. Disposal of expired formula and used equipment
 - f. Ordering process for additional formula and equipment.
4. Recommendations for oral intake (if required):
 - Recommendations regarding oral intake (including safety, consistencies and amount) should be made by a speech pathologist, in conjunction with the nutrition support team, where appropriate.
 - Where safe, continuation of oral feeding is critical in all infants receiving enteral tube feeding. Allowing the opportunity to feed orally (provided it is not a negative experience) may reduce the amount of oral aversion so commonly seen in tube fed infants. It is also critical that older children receiving tube feeding are allowed to eat and drink once safety has been established.
 - It may also be appropriate for adults, following the insertion of a gastrostomy tube, to recommence oral intake, even if small amounts, to maintain swallow integrity and in severe dysphagia, recommencement for quality of life should be considered.
 - A detailed feeding or meal management plan may be given by the Dietitian and Speech Pathologist
5. Oral Hygiene (*Refer to previous section on Oral Hygiene page 25*).
6. Medication management including dosage, route, frequency, and the potential for adverse effects and drug interactions.
7. Techniques for self-monitoring of therapy and identification of potential complications.
8. Troubleshooting, or action to be taken in the event of complications such as:
 - a. Tube or device blockage, deterioration, displacement, leakage or dislodgement
 - b. Gastrostomy site infection or hypergranulation
 - c. Gastrointestinal symptoms such as nausea, vomiting, diarrhoea or constipation
 - d. Late or missed administration of formula or medication.
9. The responsibility of each health care professional involved and their contact details
 - a. Emergency contact details
 - b. When to seek medical attention (*see Appendix 8: Useful links and resources*)
10. Follow-up arrangements:
 - a. Medical assessment



NOTE: detection and treatment of complications need to be carefully thought through where the patient may have diminished capacity to recognise them (e.g. fever or swelling) and/or act on things as they arise.

- b. Tube or device and site care
- c. Nutrition assessment and monitoring
- d. Swallow assessment (if required).

11. Details of relevant support groups or organisations.^{3, 11, 111}



NOTE: Age, developmentally and culturally appropriate information and resources should be provided for patients and families. Aboriginal and Multicultural Health Workers can also provide support.

See Appendix 3 for an example of an education checklist and Appendix 8 for a list of useful links and resources.

Following education, the patient/carer should be willing and able to demonstrate the following:

1. Clean and dry the stoma site
2. Check the stoma site for redness, swelling or discharge

3. Check the tube or device position
4. Rotate the tube or device (where appropriate)
5. Flush the tube or device
6. Prepare and administer formula through the tube or device
7. Prepare and administer medication through the tube or device
8. Irrigate a blocked tube or device.

The patient/carer should be provided with, or have access to, an adequate supply of products and/or equipment at all times (i.e. enteral formula, enteral tube feeding equipment).¹¹²

The following table provides a summary of HEN programs across Australia. This information should be used as a guide only as services may vary within states and health services.

Table 9: Home Enteral Nutrition (HEN) services and programs across Australia

Australia wide	<p>Some government funded community care packages may include the provision of enteral feeding formula and equipment. Refer to http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/home-care-packages-program-guidelines</p> <p>It is also important that clinicians remain up to date with changes brought about by national disability reforms. Refer to http://www.ndis.gov.au/</p> <p>Aboriginal people with one of the 5 targeted chronic illnesses (Diabetes; Renal disease; Respiratory disease; Cancer; Cardio Vascular disease) that need HEN may be eligible to access enteral feeding formula and equipment through the Indigenous Chronic Disease Package - Care Coordination and Supplementary Services Program. This is currently coordinated nationally through Medicare and may change with the introduction of Primary Health Networks across Australia in July 2015. Refer to www.health.gov.au/tackling-chronic-disease</p> <p>Department of Veteran Affairs (DVA) members may be entitled to enteral feeding equipment and replacement feeding tubes as well as subsidised enteral formula. For prescriber guidelines and forms, refer to www.dva.gov.au</p> <p>Private patients can access dietetic support through private dietitians (see Dietitians Association of Australia website www.daa.asn.au) and may be eligible for subsidised care through the Medicare Primary Care program for Chronic Disease Management. Patients should check with private health funds as cover varies for nutrition support.</p>
ACT	Public patients may be eligible to access some enteral feeds and equipment through the Home Enteral Nutrition Program. Contact the local hospital for more details.
NSW	Patients can purchase formula and feeding equipment at a NSW Government contract price if they are under the care of a clinician working for NSW Health, a Government agency or a registered public body. Contact the ACI Nutrition Network for more details www.aci.health.nsw.gov.au or (02) 9464 4666. They may also be eligible to receive enteral tube feeding equipment and replacement feeding tubes through EnableNSW. For prescriber details and forms, refer to www.enable.health.nsw.gov.au
NT	Public patients who are eligible for the HEN program can access fully subsidised enteral formula and enteral tube feeding equipment (replacement devices are managed separately to this program). For more information, please contact HENCoordinatorRDH.THS@nt.gov.au (Darwin/Top End) or dietitians@ths.nt.gov.au (Alice Springs/Central).
QLD	Eligible public patients may access the partially subsidised Home Enteral Nutrition Scheme (HENS) for the provision of enteral feeding supplies and feeding equipment. A Queensland Health dietitian prescription and payment of a patient contribution is required. Please note that due to Queensland tendering processes not all products will be available and therefore equivalent product substitution may be required. Details of HENS can be found at http://www.health.qld.gov.au/directives/docs/gdl/qh-hsdgdl-030-2.pdf and the overarching directive regarding the provision of consumables (including those required for home enteral nutrition provision) at http://www.health.qld.gov.au/directives/docs/hsd/qh-hsd-030.pdf

Table 9: Home Enteral Nutrition (HEN) services and programs across Australia continued

SA	<p>Patients may be provided with free or subsidised enteral formula, equipment and dietetic support through the hospital where the gastrostomy device was placed, through their local country hospital if their ongoing medical care has been transferred to their GP, or their Disability Service.</p> <p>Patients under the care of a private dietitian can obtain feeds and equipment through one of the commercial Home Enteral Nutrition programs at a discounted cost.</p>
TAS	<p>The Tasmanian Home Nutrition Program supports people who are assessed by a dietitian as needing nutrition support at home. Clients make a contribution towards the cost of feeds, some equipment and supplements. People living in Tasmania and visiting Tasmania are eligible to receive supplies. Visitors may be offered a suitable alternative product if their usual one is not on the Tasmanian contract. Contact the dietitians at one of these hospitals for an assessment (or, if visiting, bring a letter from your usual dietitian):</p> <p>Launceston General Hospital (03) 6348 7111 - North-West Regional Hospital (03) 6430 6666 Royal Hobart Hospital (03) 6222 8308</p>
VIC	<p>Public patients are eligible for enteral formula, equipment and dietetic support through the hospital providing the Dietetic service. To be eligible for HEN in Victoria, patients must live in the community, be managed by a public health care provider and receive ongoing HEN care by a public health care facility. Exclusions – DVA card holders (see above) and people living in high level care.</p>
WA	<p>Public patients can purchase formula and feeding equipment at a tendered price. Patients with financial concerns living in some regional/remote areas may be eligible for a government funded supplement scheme which provides formula and/or equipment at no cost to the patient. Patients should contact their local hospital or health service for information about local HEN programs.</p>

Communication and documentation

A detailed written transfer of care summary should be provided to the patient's accepting or ongoing care team, ideally **prior** to transfer. A copy should be made available to the General Practitioner. *Refer to Appendix 4 – Transfer between services form.*

The written summary of care should include, but is not limited to the following:

- Patient/carer contact details
- Details of patient's hospital admission and medical history
- Reason for insertion of gastrostomy feeding tube or device
- Tube or device details including manufacturer, generic and trade name, size and date of insertion
- Centimetre skin markings (where applicable)
- Psychosocial and socioeconomic history, language/interpreter requirements or other special needs
- Nutrition assessment and care plan including weight history, growth history (for infants and children), oral diet if applicable, estimated requirements, nutrition goals and enteral tube feeding regimen

"Despite my daughter receiving all her nutrition through a tube, I never even heard about the HEN program until I heard about them through mothers at a respite facility when my daughter was 18 months old. They were appalled I didn't have any of the contacts"

Parent

- Enteral formula and enteral feeding equipment required, including supplies provided for home, and details of registrations, orders and/or applications for assistance (e.g. HEN registration, applications made to the Department of Veterans Affairs, community care packages or other relevant state or national organisations)
- Education and written information provided to the patient/carer.

The treating team should contact the accepting or ongoing care team by phone and in writing. All details regarding the transfer of care plan and education provided to the patient/carer should be documented in the patient's medical record.

For further information on transfer of care, including transition from paediatric to adult services, *refer to Section 5 – Transfer and Transition.*

SECTION 4: Ongoing care and tube or device removal

1. Standard care and follow-up ¹¹³⁻¹²⁰

A person with a gastrostomy tube or device should receive coordinated care and be monitored regularly by a nutrition support team. The initial period at home can be overwhelming for patients and carers and a high level of care within the first few months may be needed.¹²¹ There is support for a review of enteral tube feeding in the home setting within the first 1-2 weeks.^{8, 122}

Once stable, monitoring should occur every three to six months or more frequently if there is a change in clinical condition or if transitioning to oral intake.^{3, 11, 21}

Infants and children may need to be monitored more frequently than adults. Frequency of monitoring depends on gestational age, corrected age, the nature and severity of the underlying disease and degree of malnutrition.^{23, 24}

A holistic approach to the care of people with gastrostomy tubes or devices is recommended, as gastrostomy tube/device care and nutrition support are not independent of each other.²

"A multidisciplinary clinic would make coming in for reviews more worthwhile"

Parent

The feeding tube/device and the stoma

A system for routine and regular gastrostomy tube or device review should be in place in all settings where a service is provided to people with gastrostomy tubes or devices.²

Each time the patient is seen, the following should be reviewed and discussed - tube/device patency, external flange, stoma site and surrounding skin, medication, flushing routines.

General tube/device and site care¹²³

Health professional to review the following:

1. Hand hygiene – hands must be washed before and after touching the tube/device.
2. Ensure the tube/device is supported and secured appropriately.
3. Ensure a distance of 2-5mm from the external flange to skin level and readjust if needed.
4. For gastrostomy tubes and devices with an internal balloon, consider checking and replacing the fluid in the balloon as per manufacturer's instructions.
5. Assess for signs of tube/device migration - check the external length of the tubing (review the markings at skin level – non-skin level devices only) to ensure it has not changed significantly since the last review. If changed, investigate causes and assess for complications. Consider medical review if required.

Health professional to consider discussing the following with the patient/carer:

1. Hand hygiene – hands must be washed before and after touching the tube/device.
2. Ensure the tube/device is supported and secured appropriately.
3. Prevent tube/device blockage – keep the interior of the device clean by flushing regularly:
 - Flush before and after medications and enteral tube feeds and as prescribed. Use an appropriate volume of water. Use a stop/start flush action to create a turbulent flow.
4. Rotate the tube or device 360° each day (unless sutured, anchored or otherwise contraindicated).
5. Keep the stoma clean and dry.
6. Ensure a distance of 2-5mm from the external flange to skin level and readjust if needed.
7. For gastrostomy tubes and devices with an internal balloon, check and replace the fluid in the balloon as per manufacturer's/health care professional's instructions.

8. Each time the gastrostomy tube or device is used, the external length of the tubing (review the markings at skin level – non-skin level devices only) should be checked to ensure it has not changed significantly. If the position has changed significantly, the patient/carer should contact the relevant health professional.³

Gastric venting/decompression via a gastrostomy⁷⁰.

124-126

The process of releasing excess air or gas from the stomach via the gastrostomy is called venting or decompression (and may be known as “burping” or “de-gassing”).

Excessive air or gas in the stomach may cause abdominal discomfort, distension, bloating and/or enteral feed volume intolerance. If any of these symptoms occur, the stomach can be vented or “decompressed” after a feed to help provide relief. Venting may also be recommended prior to or during enteral tube feeding depending on the symptoms. The frequency of venting is also determined by the symptoms and the individual’s response.

The most commonly used method is to attach the empty barrel of an enteral dispenser to the feeding port of the gastrostomy tube (or the extension tube of the low profile device) and raise it above the level of the patient’s stomach, making sure any clamps are open. This allows excess air to escape upwards without loss of stomach contents. It may be helpful to gently massage the abdomen to help release the air. Any liquids captured in the dispenser barrel should be allowed to flow back into the stomach once venting has occurred.

A venting gastrostomy may also be inserted to remove gastric contents and help relieve nausea and vomiting where total bowel obstruction or stasis is present. This is usually in a more terminal stage of malignant disease. Gastrostomies formed for the purpose of venting (as opposed to enteral feeding) are usually placed lower in the gastric anatomy.

Nutrition

The role of nutritional monitoring is to ensure safety, to detect and treat clinical complications in a timely fashion and to determine if the objectives of nutrition support have been met or need to be revised.²³ The monitoring parameters selected should relate to the goals/objectives of nutrition support for that individual. Therefore the frequency and type of monitoring will depend upon several factors including: ^{23, 24, 65}

- clinical indication for the initiation of gastrostomy feeding

- disease state, severity of illness and anticipated trajectory of the clinical condition
- baseline nutritional status of the patient
- initial tolerance when nutrition support was introduced
- age of the patient
- nutrition support goals/targets
- expected duration of nutrition support.

Where safe, continually set goals to increase oral intake and reduce enteral tube feed intake, whilst ensuring nutritional adequacy.

Long term patients receiving ongoing tube feeding who have been stabilised on nutrition support should be reviewed by a nutrition support health professional at least every 3-6 months.³ Infants and children may need to be monitored more frequently than adults.

The nutrition parameters that should be monitored for patients requiring long term gastrostomy feeding include, but are not limited to, those in Table 10 (page 41):^{20, 65, 127}

Table 10: Nutrition parameters

Suggested frequency for longer term patients			
Parameter		Paediatrics	Adults
Nutritional	Nutrient intake from all sources - oral, tube and parenteral	Infants: Monthly.	Monthly to every 3-6 months.
	<ul style="list-style-type: none"> • energy • protein • total fluid • micronutrients Enteral tube feeding delivery method. Re-evaluation of requirements according to anthropometry or changes in clinical status.	Children: monthly to every 3-6 months.	
Anthropometry	Weight	Infants: Weekly-monthly. Children: monthly to 3-6 monthly.	Daily if monitoring fluid balance, weekly then reducing to monthly if stable.
	Height	Monthly – 3 monthly.	Not applicable.
	BMI (age >24months)	Monthly – 3 monthly.	Monthly.
	Length and head circumference (age < 36 months)	Monthly – 3 monthly.	Not applicable.
	Mid-arm circumference. Triceps skinfold thickness.	Monthly to 3 monthly, where clinically indicated e.g.: when weight is difficult to measure or interpret.	Monthly if weight unattainable.
Biochemistry	Blood glucose levels	Varies with diagnosis and diabetes mellitus management plan.	Daily if known IGT or diabetes mellitus, or as deemed clinically appropriate.
	Iron studies	As indicated by clinical condition and ideally at least annually to ensure enteral regimen meets requirements.	Every 3-6 months.
	25-OH Vit D		Every 6 months.
	Micronutrient studies		As indicated by clinical condition.
	UEC, CMP, LFTs		As indicated by clinical condition or monthly if possible.
	Lipid studies	As indicated by clinical condition.	As indicated by clinical condition.
GI Function	Nausea, vomiting, reflux. Bowel function – diarrhoea, constipation. Urine output.	As reported or at every review	
Physical	Clinical signs of nutrient deficiency/excess. Change in conditions that affect oral intake (e.g. oral feeding skills, dysphagia) or impact on self-feeding ability (orally and/or via the tube/device). Functional status and mobility.		
Psychosocial	Social support systems, current level of services, home environment. Patient and carer competence and confidence administering enteral tube feeding regimen. Quality of life.		

Swallow

People with oral and/or pharyngeal dysphagia whose swallow is likely to improve (e.g. post-stroke, premature or unwell infants or children with poor oral-motor skills) or deteriorate (e.g. degenerative conditions) should be reviewed by a speech pathologist at intervals deemed appropriate by the speech pathologist in conjunction with the attending medical team and according to the individual condition.

The speech pathologist should liaise with other health professionals involved with the patient so that enteral tube feeding can be adjusted or ceased as necessary in a timely manner. In the paediatric population an oral-feeding program is strongly recommended for any infant who is expected to return to oral feeding in order to minimise negative or aversive oral stimulation and maintain or build oral motor skills.¹²⁸

People who are unlikely to experience changes in their swallowing do not need ongoing speech pathology reviews. However, people who are continuing oral intake should be re-referred to speech pathology should they experience new dysphagia symptoms (e.g. following a stroke).

2. Trouble shooting/device complications¹²⁹⁻¹³⁵

Outlined below are possible complications that may be experienced by people with a gastrostomy tube or device and recommended options for management.

Pain/discomfort

Some discomfort is to be expected. The site should be checked for tightness (especially after the initial insertion and if weight gain has occurred), redness, swelling or signs of infection (e.g. malodour, skin that is red and warm, or pus). Simple analgesics can be used to relieve the pain.

Unrelieved pain or pain associated with the gastrostomy and extending greater than one week post initial insertion should have a medical review to exclude potential complications.¹³⁶

Regular assessment of pain using pain score charts may be beneficial in some settings.

Hypergranulation

Hypergranulation (also known as over granulation or proud flesh) is a common non-life threatening phenomena. Hypergranulation is characterised by the appearance of light red or dark pink flesh that can be smooth, bumpy or granular and forms beyond the surface of the stoma opening.¹³⁷ It is often moist, soft to touch and may bleed easily. It is normal to expect a small amount of granulation around the site.



Mild hypergranulation



Excessive granulation tissue

Photos: A Kennedy

The exact aetiology of hypergranulation tissue is unknown although it is thought to occur when there is an extended inflammatory response. It has been associated with wound healing before the stoma has reached maturity; therefore it often occurs during the six weeks post procedure healing phase. Not all hypergranulation tissue growth requires treatment as it will often resolve spontaneously.¹³³

Hypergranulation tissue can also develop at mature stoma sites and may be due to excess moisture and friction caused by device movement.¹³⁸

Care/Treatment ^{133, 136, 139, 140}

Treat any localised sepsis or colonisation. Swabbing of the affected area should be considered. If no localised infection is present, the interventions and treatment options outlined in Table 11 (page 44) may be considered for use:

"I had no help with granulation tissue and ended up getting more help on the internet than my local hospital"

Patient

Table 11: Care and Treatment of hypergranulation

Possible Causes	Routine Stoma Care	Further Options for Management
<ul style="list-style-type: none"> Moisture Infection Excessive device movement Ill-fitting devices 	<ul style="list-style-type: none"> Cleanse and dry the skin surrounding the stoma using soap and water or consider using hypertonic saline. Keep site free of moisture – avoid use of moisture retentive dressings. Prevent excessive movement by securing the external retention device with a 2-5mm gap (when gentle traction is applied) between the device and the skin. Avoid continuous traction on the device. 	<ul style="list-style-type: none"> Application of a foam dressing (without causing excessive traction). Apply hypertonic saline/hypertonic dressing to granulated tissue every 2 hours. Short term use of topical corticosteroid as directed by the prescriber and not in cases of suspected infection. Consider biofilm prevention with the use of antiseptics and other open wound cleaning agents. Consider the application of a caustic agent such as silver nitrate or copper sulphate (with appropriate protection for surrounding skin). This should only be used by persons familiar with its application and possible complications. If unresponsive to the above refer for a medical review. <p><i>Note - Mechanical removal (surgical excision and diathermy) is not recommended.¹⁴¹</i></p>

Once the hypergranulated tissue has been removed treat the wound on its merits and employ routine stoma care.



Chemical burn after inappropriate use of silver nitrate

PHOTO: A Kennedy

Gastric Fluid Leak

Some gastrostomy tubes and devices can leak intermittently. This isn't always gastric fluid and may not cause problems. However, this should be evaluated by a health care professional.

Common problems related to gastric fluid leak with possible causes and recommended options for management are included in *Table 12 below*.



Gastric fluid leak
PHOTO: A Kennedy

Table 12: Gastric fluid leak

Problem	Possible causes	Options for Management
Balloon is not inflated enough	<ul style="list-style-type: none"> Valve failure Pin-hole in the balloon Volume loss by osmosis Balloon inflation volume not as per manufacturers guidelines 	<ul style="list-style-type: none"> Regular checking of the balloon fill and valve competency Refer to manufacturers guidelines Consider high volume balloon
Balloon rupture	<ul style="list-style-type: none"> Accidental balloon over fill Inappropriate access to balloon port Age of device Yeast colonisation Product fault 	<ul style="list-style-type: none"> Replace the device
Gastrostomy position	<ul style="list-style-type: none"> Site too close to the pylorus Conditions where the relative positions of the stomach and the stoma tract change (e.g. worsening scoliosis) 	<ul style="list-style-type: none"> Review enteral tube feeding regimen - consider reducing volume and increasing bolus frequency or transition from bolus to continuous Review device type and consider change of brand or to a tube/device with different features of the internal bumper for less interference with the gastric outlet If not resolved, medical review; consider re-siting
Inadequate stoma seal	<ul style="list-style-type: none"> Weight loss or patient growth Poor device fit and/or correct device fit not maintained Movement of device by external forces (e.g. wheelchair straps, belts, clothing etc.) 	<ul style="list-style-type: none"> Dietetic review and consider change in tube feeding regimen Assess stoma seal - review the fit and condition of the existing device. Consider over filling of the balloon within manufacturer's device specifications. Adjust or replace the device as appropriate Note the external flange should move away from the skin by a few millimetres when traction is applied to the device Patient/carer education
	<ul style="list-style-type: none"> Increased intra-abdominal pressure (coughing, straining to open bowels, retching) Infection 	<ul style="list-style-type: none"> Medical review Manage constipation if present Consider venting of the gastrostomy (See page 40)
Poor gastric emptying	<ul style="list-style-type: none"> Gastroparesis associated with conditions including but not limited to Parkinson's disease, multiple sclerosis, diabetes mellitus, idiopathic.¹⁴² 	<ul style="list-style-type: none"> Consider regular prokinetics If not resolved, medical review; consider post-pyloric feeding.¹⁴²

Skin/Site complications

Some common skin/stoma site complications with identified causes and recommended options for management are included in the table below:

Table 13: Skin/stoma site complications

Problem	Possible causes	Options for Management
Excoriation/skin breakdown³²	<ul style="list-style-type: none"> Leakage of gastric secretions Moist dressings left in contact with skin 	<ul style="list-style-type: none"> Correct cause of leakage – see previous table Application of barrier cream Keep the site clean and dry Ensure that dressings are frequently changed and not left moist Consider pharmacological options such as proton pump inhibitors and/or prokinetics
Pressure related injury	<ul style="list-style-type: none"> Improper fit of device (too tight) Inadequate rotation or adjustment of device Excessive traction Dressings causing pressure between external flange and skin 	<ul style="list-style-type: none"> Relieve pressure and ensure correct size and fit of device Perform daily rotation and position adjustment No routine application of dressings without clinical indication Seek wound management advice for skin breakdown
Embedded sutures	<ul style="list-style-type: none"> Sutures dwell time 	<ul style="list-style-type: none"> Discuss the option of removing sutures with the surgeon/admitting team Seek wound management advice for skin breakdown
Infection³² <ul style="list-style-type: none"> Signs - redness, swelling, bleeding, and discharge, warmth at site or foul smell Assess for abscess or cellulitis Folliculitis 	<ul style="list-style-type: none"> Encouraged by excessive moisture around stoma site Invading micro-organism – may be fungal or bacterial Infection may be introduced at time of device insertion Inflamed hair follicle 	<ul style="list-style-type: none"> Avoid excessive moisture around stoma site Perform swabbing/culture and sensitivities Consider treating with anti-fungal preparations or antibiotics where appropriate Seek wound management advice for skin breakdown



Mild erythema at stoma site
PHOTO: A Kennedy



Embedded external flange
PHOTO: I Martincich



Red irritated peri-stomal skin
(unwashed, dry scaly skin, exudate build-up
under flange)

PHOTO: A Kennedy



Severe Excoriation (partial thickness skin damage
and permanent scarring)

PHOTO: A Kennedy

3. Tube or device dysfunction


Some common device-related complications with identified causes and recommended options for prevention and management are included in the table below:

Table 14: Tube or device dysfunction

Problem	Possible causes	Options for prevention and management
Tube or device blockage (See photo on page 49)	<ul style="list-style-type: none"> Use of poorly crushed medications or medications unsuitable for crushing and placing down gastrostomy device. 	<ul style="list-style-type: none"> Seek pharmaceutical advice prior to using crushed medications. Consider the use of liquid/compounded medications or medications which dissolve where possible. Give medications individually followed by a flush in between and after each medication.
	<ul style="list-style-type: none"> Inadequate water flushing post feeding and/or administration of medications. 	<ul style="list-style-type: none"> Routine flushing should be included in the enteral feeding regimen. Advice should be sought when prescribing a flushing regimen to paediatric patients or patients on fluid restrictions. Including a stand-alone flush prior to longer periods between access (e.g. before going to bed) may also assist in the prevention of device blockage.
	<ul style="list-style-type: none"> Siphoned gastric fluid has flowed back into the device by fluid displacement and solidified. 	<ul style="list-style-type: none"> Use of clamp on device when possible.
	<ul style="list-style-type: none"> Material fatigue associated with device aging or mishandling. 	<ul style="list-style-type: none"> Replace device.

Continued overleaf

Table 14: Tube or device dysfunction continued

Problem	Possible causes	Options for prevention and management
Tube or device displacement	Migration Out: <ul style="list-style-type: none"> • Material failure e.g. balloon or internal bumper • Balloon deflation • Traction – inadvertent or intentional <i>See flowchart on page 56 for Inadvertent removal of device</i>	<ul style="list-style-type: none"> • Replace device • Routinely check balloon volume • Consider changing to a low profile device if the patient is consistently pulling at the gastrostomy tube or device. Appropriate garments may help keep patients from pulling at the device.
	Tight fitting device	<ul style="list-style-type: none"> • Reposition external flange to allow a minimum 2-5mm clearance from skin when gentle traction is applied to the device.
	Migration In: <ul style="list-style-type: none"> • Inward device migration (into duodenum) from peristalsis - usually associated with incorrect placement of the external flange or slippage of the external flange (note - patient typically presents with vomiting) 	<ul style="list-style-type: none"> • Deflate balloon and retract device into stomach, then reinflate balloon before pulling internal bolster up to the gastric wall – refit external flange (as above). Confirm device placement (as per planned replacement) • Replace device if external flange continues to slip.
Tube or device deterioration	<p>The following is specific to silicone tubes and devices (the most common type of gastrostomy device):</p> <ul style="list-style-type: none"> • Gastrostomy tube or device deterioration is characterised by structural changes in the device that render it fragile and no longer freely patent. This increases the risk of breakage. A fragile perished device becomes useless and problematic due to the risk of unrepairable hole formation, increased risk of balloon failure (if present) and increased difficulty to remain intact on removal. The following are characteristics that a device may display as it reaches its end stage of function: <ul style="list-style-type: none"> - the device becomes very soft, pliable and easily kinks, - the device's contour becomes distorted, - the wall thickens thus narrowing the internal lumen. - white and/or black dots may appear on the internal wall of the device and these dots maybe microorganism colonies. There appears to be a correlation between fungal colonisation, changes in the devices' structure and the devices' functional lifespan.¹⁴³ - discolouration of the device can occur early in the devices' life and can be caused by a number factors i.e. medication. • The decision of when to replace a gastrostomy device should be based on the following criteria: manufacturer's recommendation, patient requirements and the first sign of the device's change in contour. 	
	 <p>Discolouration and warped tubing</p> <p>PHOTO: A Kennedy</p>	



Extensive tube blockage
PHOTO: I Martincich

General guidelines for unblocking a gastrostomy tube or device^{22, 144}

- Visually inspect for mechanical occlusions e.g. clamps, ports, connectors
- If the majority of the gastrostomy tube or device is external, massaging the tubing may allow for obstructions to be freed
- Use a small enteral dispenser with 10-20ml of warm water and an aspiration (or “push and pull”) flush technique. This process may need to be repeated a few times. Excessive force should not be used
- Evidence in support of specific solutions to unblock devices is scarce. The GDG does not recommend cola beverages or acidic juices
- Acid, alkaline or enzyme solutions may be deemed appropriate by the health care team to unblock a device if flushing with warm water using an aspiration flush technique is unsuccessful.

Buried Bumper Syndrome

Migration of the gastrostomy device's internal bumper out of the stomach and into the gastrostomy tract or peritoneum with partial or complete loss of tract patency between the device's distal tip and stomach is termed the Buried Bumper Syndrome. This is usually due to excessive external traction on the device from a tight external flange that causes the bumper to migrate up into the tract or erode through the gastric wall.^{22, 145, 146}

Presentation may include:

- Induration surrounding the stoma
- Localised pain
- Partial or complete loss of gastrostomy patency (difficulty, or inability, to instil any fluids through the tube)
- Delivery of fluid via the tube or device may result in leakage around the stoma (where the distal end of the tube/device is in the tract instead of the stomach)
- The internal bumper may be visible in the tract
- Inability to advance or rotate the tube/device.

Identification

1. Marks at skin level have changed
2. Tube or device is difficult to advance or rotate
3. Leakage of feed, fluid, pus or other bodily fluids
4. Pain with tube or device use
5. Continual pain at site.

Prevention - maintain snug fitting gastrostomy tube or device and readjust as needed i.e:

- The external flange should be able to be lifted 2-5mm from the skin when gentle traction is applied to the tube or device
- Avoid unnecessary pulling or traction
- Gently push the tube in slightly and pull back out once per week.^{3, 22}
- Ensure the tube or device is adequately secured under the clothes
- Ensure that the tube or device selected is an appropriate one for the patient.

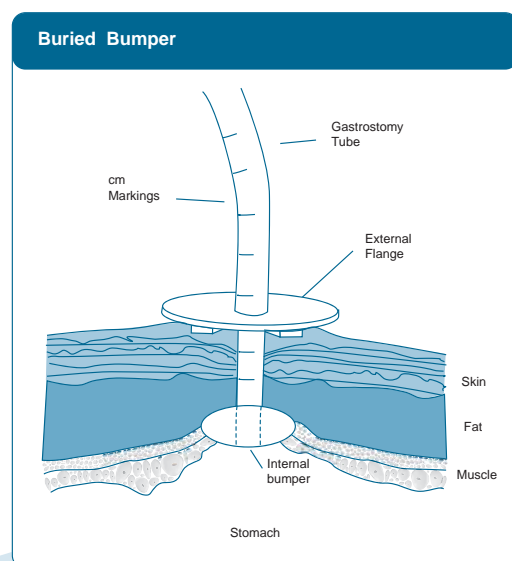
See Section 4.1 "Standard care and follow-up" for more information (Page 39).

Investigations if Buried Bumper Syndrome suspected:

1. CT scan
2. Plain X-ray with contrast (a plain X-ray is insufficient)
3. Fluoroscopic screening and then reestablishment of correct tract
4. Endoscopy.



Buried bumper
PHOTO: A Kennedy



4. Gastrointestinal complications^{5, 16, 113, 115, 116, 118, 120, 147-149}

Common gastrointestinal complications and recommended options for management are included in the table below.

If the condition does not improve with simple measures the patient should be referred back to the medical specialist.

Table 15: Gastrointestinal complications

Problem	Possible causes	Options for management
Diarrhoea <ul style="list-style-type: none"> Key questions to determine the extent of the problem and potential causes: <ul style="list-style-type: none"> What is the patient's normal bowel pattern, when did it change? When does the diarrhoea occur? Is it associated with feeding times (oral or tube)? How often does it occur? What is the consistency/appearance/colour? Compare to Bristol stool chart (See APPENDIX 5) Exclude other causes of diarrhoea before changing the feeding regimen: <ul style="list-style-type: none"> Have there been any recent changes to the feeding regimen (feed type and/or rate/mode of administration)? Does the patient eat/drink orally? Have there been any recent changes? Have there been any recent changes to medical management (e.g. medications and aperients)? Are there any other clinical symptoms – fever, nausea, pain, urgency? Exclude intercurrent infection/gastroenteritis. Has anyone in the family/social contact been unwell? Check feed storage and preparation practices Is the patient/carer following safe preparation and handling practices? (cleaning, hang times, feeding rate) 	Infection	<ul style="list-style-type: none"> Referral for medical review Stool sample Ensure patient remains hydrated until medical review
	Overflow diarrhoea (from faecal impaction due to constipation)	<ul style="list-style-type: none"> Referral for medical review Ensure patient remains hydrated until medical review
	Commonly implicated medications: <ul style="list-style-type: none"> Antacids (magnesium salts) Antibiotics Histamine H1 receptor blockers Laxatives Cytotoxics Proton Pump Inhibitors Hyperosmolar medications (e.g. ferrous sulphate, multivitamins, potassium chloride) Magnesium sulphate Sorbitol elixirs. 	<ul style="list-style-type: none"> Referral for review of medications/aperients

continued overleaf

Table 15: Gastrointestinal complications continued

Problem	Possible causes	Options for management
Diarrhoea continued	Enteral tube feed delivery issues (temperature, rate, volume, concentration, osmolality)	<p>Ensure the tube feed is at room temperature prior to feeding. If the feed is kept in fridge, measure required volume and allow to stand for 30 minutes before use.</p> <p>Consider adjusting the feeding regimen:</p> <ul style="list-style-type: none"> • Reduce rate of feeding • Reduce concentration of feed • Change from bolus to continuous feeding or administer bolus of a longer time period • Change to iso-osmolar feed • Consider specialised feed if impaired gut function (e.g. amino acid/ peptide based). <p>Consider adjusting fibre content of feed:</p> <ul style="list-style-type: none"> • Consider fibre-enriched feed or fibre supplementation if current feed does not contain fibre • Try a fibre-free feed if diarrhoea is occurring with fibre-enriched feed. <p>Adjust intake of fibre in oral diet (if relevant)</p>
Constipation <ul style="list-style-type: none"> • Key questions to determine the extent of the problem and potential causes: <ul style="list-style-type: none"> - What is the patients normal bowel pattern, when did it change? - When did the patient have their bowels open last? - Is there any straining/tearing/pain? How often? - What is the consistency/appearance/ colour of the stool? (See Appendix 5: Bristol Stool Chart) - Does the patient eat/drink orally? Have there been any recent changes? - Have there been any recent changes to medical management (e.g. medications and aperients)? - Are there any other clinical symptoms e.g. fever, night sweats? 	Inadequate hydration	<ul style="list-style-type: none"> • Assess fluid requirements • Monitor fluid input
	Disruption of normal routine: <ul style="list-style-type: none"> • Inactivity/ immobilisation • Lack of toileting privacy. 	<ul style="list-style-type: none"> • Discuss activity with physiotherapist/ managing team or GP • Consider change of feeding regimen.
	Other causes: <ul style="list-style-type: none"> • Neuromuscular disorders or brain injury • Hypothyroidism • Hypokalaemia • GI motility disorder 	<ul style="list-style-type: none"> • Refer for review of medications • Consider adding: <ul style="list-style-type: none"> - Stool softeners - Appropriate laxatives - Prokinetic agents. • Consider establishing a bowel management regimen
	Commonly implicated medications: <ul style="list-style-type: none"> • Anticholinergics • Non-steroidal anti-inflammatory drugs (NSAIDs) • Bile acid sequestrants • Frusemide • Antidepressants. Previous misuse of laxatives	
	GI obstruction	<ul style="list-style-type: none"> • Refer to managing team or GP • Cease feeding

Continued overleaf

Table 15: Gastrointestinal complications continued

Problem	Possible causes	Options for management
Nausea <ul style="list-style-type: none"> Key questions to determine the extent of the problem and potential causes: <ul style="list-style-type: none"> When did the nausea start? Is it persistent or intermittent? Is it feed timing related? Is it disease related? Is it anxiety related? Consider other issues that could be contributing to nausea (such as chemotherapy, radiotherapy, medications, antibiotic use) 	Intolerance of current enteral tube feeding regimen: <ul style="list-style-type: none"> Volume of feed too great Rate of infusion too fast 	Adjust regimen, consider: <ul style="list-style-type: none"> Reducing bolus volume and/or delivery over longer period Replacing bolus feeds with continuous feeding More concentrated feed Slower rate of feeding/extend period of feeding. Consider referral for trial of prokinetic
	Feed too cold when administered	Ensure feed at room temperature prior to feeding. If feed kept in fridge, measure required volume and allow to stand for 30 minutes before use.
	Increased intra-abdominal pressure due to constipation	See section on constipation (page 52)
	Side effect of medication	<ul style="list-style-type: none"> Request review of medications Consider prescribing anti-emetic/pro-kinetic medication
	Incorrect positioning of patient during feeding or movement/ repositioning too soon after completion of feeding	<ul style="list-style-type: none"> Ensure patient is upright (>30 degrees) during feeding and for 30 minutes after feeding Consider lying patient on right side Liaise with other health professionals to ensure appropriate timing of interventions and care
	Stress and anxiety related to feeding	<ul style="list-style-type: none"> Pleasant feeding environment Relaxation techniques Consider referral to other health professionals for anxiety management Support from family/carers
Vomiting <ul style="list-style-type: none"> Key questions to determine the extent of the problem and potential causes: <ul style="list-style-type: none"> When did the vomiting start, was it sudden onset? What is the volume? What is the appearance? (colour, consistency) Important to determine if it is bilious or blood stained When does it occur? Is it associated with oral intake or feeding? Is it preceded by nausea? Has anyone in the family/social contacts been unwell? <p><i>NOTE: Some conditions may result in pooling and regurgitation of saliva, therefore the management strategies discussed here do not apply. Refer for medical review.</i></p>	Intolerance of current feeding regimen: <ul style="list-style-type: none"> Volume of feed too great Rate of infusion too fast 	Consider adjusting the feeding regimen: <ul style="list-style-type: none"> Reduce bolus volume and/or delivery over longer period Replace bolus feeds with continuous feeding Consider more concentrated feed Slow rate of feeding/extend period of feeding Consider referral for trial of a prokinetic
	Incorrect positioning of patient during feeding	<ul style="list-style-type: none"> Ensure patient is upright (>30 degrees) during feeding and for 30 minutes after feeding Consider lying patient on right side Liaise with other health professionals to ensure appropriate timing of interventions and care
	Gastro-oesophageal reflux disease (GORD)	<ul style="list-style-type: none"> Optimisation of anti-reflux therapy with PPI Consideration for use of prokinetics/post pyloric feeding Referral back to surgeon for consideration of anti-reflux surgery
	Stress and anxiety related to feeding	<ul style="list-style-type: none"> Pleasant feeding environment Relaxation techniques Consider referral to other health professionals for anxiety management Support from family/carers

5. Inadvertent removal of a gastrostomy tube or device

Important considerations

Immature stoma tract (i.e. less than six weeks since insertion)

- If the tract is immature time is of the essence. Patients should be encouraged to present to the emergency department as soon as possible.
- If the gastrostomy tube or device is accidentally pulled and/or partial displacement of the internal bumper is suspected in an immature stoma tract the patient should present to the emergency department. A radiological contrast study or endoscopy should be performed. If displacement is confirmed the device will need to be removed (as per recommendations in Planned replacement of gastrostomy tubes and devices – page 57) and replaced with the appropriate gastrostomy tube or device.^{16, 20, 22, 26, 69, 150-155} (GRADE D)
- If it is known that the stomach was securely sutured to the anterior abdominal wall during laparoscopic surgery the risk of gastric wall separation and tract disruption is reduced when the initial device is removed and on replacing balloon gastrostomy devices.¹⁵⁶⁻¹⁵⁸ After consultation with the responsible surgeon it may be agreed that a suitably trained clinician can replace the device without the need for endoscopy.



NOTE: if the time between insertion and inadvertent removal is greater than 6 weeks but less than 12 weeks, consider radiological intervention.

Mature stoma tract

- If the gastrostomy tube or device has been accidentally removed the priority is to preserve the tract by replacing the tube or device as soon as possible (ideally within two hours) and securing with tape.²
- Determine the size and type of the previous tube or device and obtain a new tube or device.
- A dedicated gastrostomy tube or device is the device of choice for gastrostomy access because:
 - It will have dedicated feeding, flushing and medication ports
 - It will have proximal end hinged caps

- It will have an external flange to prevent device migration
- Tube length (distal tip to base of the y-port) is usually less than 20cm
- The distal end is open and reduces the probable risk of device obstruction
- Most have a recessed distal tip, to reduce probable ulceration of the posterior gastric mucosa
- If a dedicated gastrostomy device is not available a Foley catheter can be used for this purpose as a **temporary** measure to protect the tract.^{16, 20, 22, 26, 69, 150-155} (GRADE D)
 - A Foley catheter of equivalent size that is adequately secured can be used in the interim for medication or feeding but should be **replaced with a dedicated gastrostomy tube or device as soon as possible.**
- Foley catheters are not recommended as a long term replacement feeding tube or device because:
 - They do not have an external flange increasing the risk of migration and obstruction and are not designed as a long term gastrostomy device ^{16, 20, 22, 26, 69, 150-155} (GRADE D)
 - A "spigot" or stopper is required to cap off the proximal end when not in use and it may be at risk of being lost or being unavailable
 - Standard tube length is 40cm – outlet obstruction becomes a risk if the tube is allowed to migrate in (see the point above)
 - Their closed distal end causes the tube to be at risk of obstruction
 - There is increased risk of posterior gastric mucosa ulceration due to exposed distal tube past the balloon
 - The manufacturer's guidelines are for urinary bladder insertion.

"We had no replacement tube – we had a terrible 3 days where we had to use a catheter tube and watch stomach contents leak and burn her skin"

Carer

- A balloon gastrostomy tube or device that has been pulled out or fallen out can be replaced before the stoma closes.
 - If possible, the tube or device selected should be the same diameter as the one previously inserted.
 - If resistance is felt when trying to insert the tube or device then consideration should be given to preserving the tract by using a tube or device with a smaller diameter as the first priority and secondly reinserting a functional gastrostomy tube or device. This avoids the need for further surgical intervention, including endoscopy. ^{16, 20, 22, 26, 69, 150-155} (GRADE D)
- Low profile replacement gastrostomy devices should be considered in patients who are at high risk of inadvertent device dislodgement or who have an active lifestyle. ^{16, 20, 22, 26, 69, 150-155} (GRADE D)

There is no evidence to support recommendations for the bedside confirmation of partially dislodged tubes or devices that require replacement (in mature tracts). The following checks should be undertaken by a trained health professional to confirm if the tube or device is dislodged:

- Ballooned tubes or devices - check if the balloon is intact by aspirating the balloon contents
- Non-skin level devices - confirm the current external markings with the usual position
- Rotate the tube or device and perform "in-out play" to ensure no resistance.

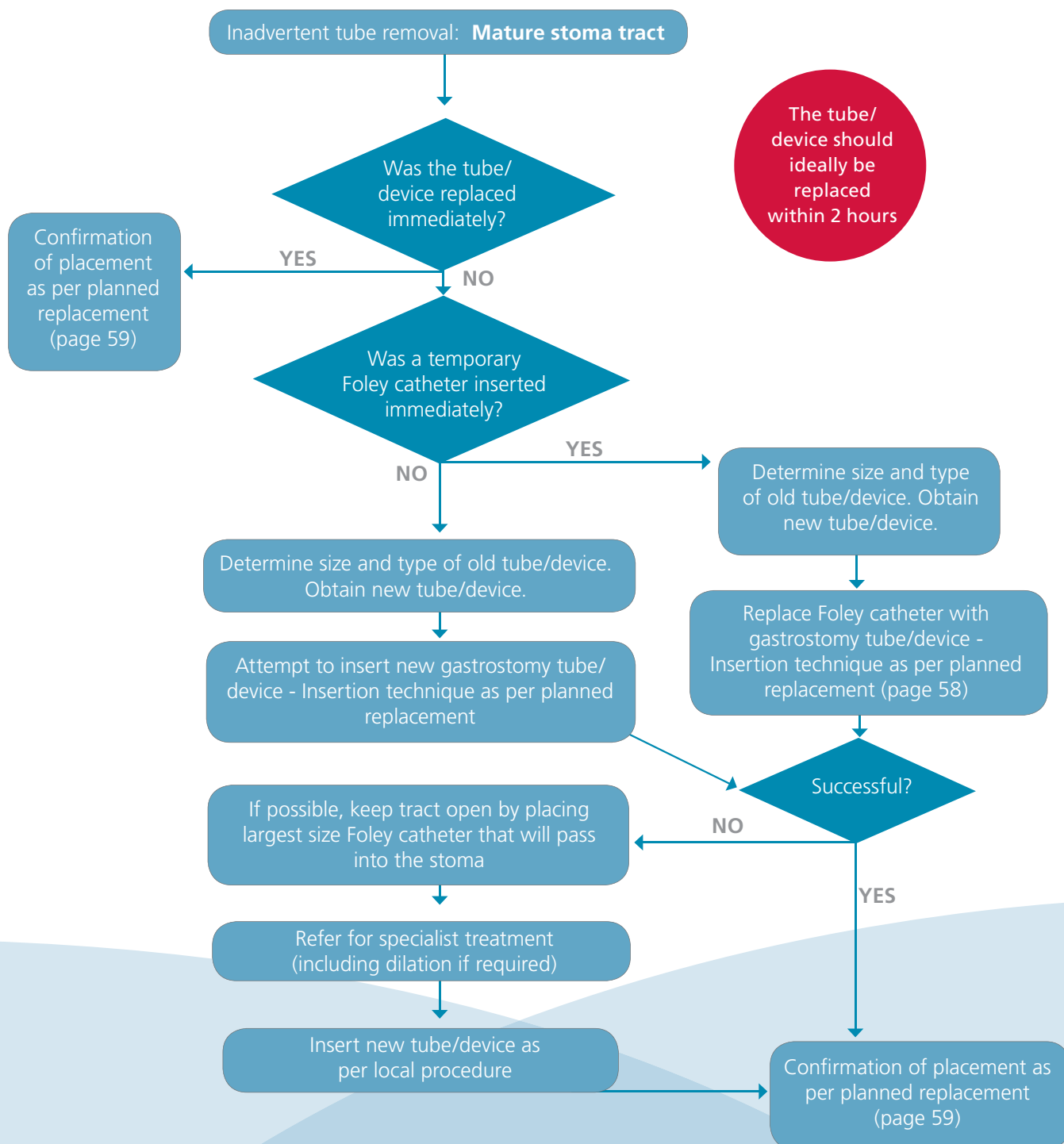
If the position of the tube or device is still unclear a radiological contrast study or endoscopy should be arranged.²



NOTE:

- Changing a gastrostomy tube or device at the bedside or in a clinic/home setting should only be performed by individuals who have adequate skills and training.
- If inadvertant removal of a gastrostomy tube or device occurs frequently, the patient should be assessed to determine if the device is the most suitable type and/or if ongoing gastrostomy feeding is appropriate.

The algorithm below describes the actions that should be taken if a device is inadvertently removed from a mature tract. The type of the tube/device should be carefully checked.



6. Planned replacement of a gastrostomy tube or device^{147, 159-166}

Gastrostomy tubes and devices (initial and replacement) should be monitored and changed at a time deemed necessary (not at a fixed period of time).^{22, 66, 69, 70, 82, 92, 150, 151, 167-170} (GRADE C)

Reasons for replacing a gastrostomy tube or device can include:

- The device is not functioning adequately (leaking, blocking regularly or blocked and patency is unable to be restored)
- The device has deteriorated
- The device is causing stoma site complications
- The device is being changed to a low profile gastrostomy device
- The device has accidentally fallen out.

"How do I know when the tube should be changed to a bigger size?"

Parent

Reasons for not replacing a gastrostomy tube or device may include:

- An immature stoma/tract (less than 30 days from original procedure)
 - Whilst there is Grade C evidence to suggest a tract matures after 30 days,^{22, 66, 69, 70, 82, 92, 150, 151, 167-170} the GDG recommends at least 6 weeks.
- Where the patient has an advanced care plan that states that tube/device replacement is not to occur
- If the patient is competent and fully informed and refuses replacement.
- If the gastrostomy tube or device is no longer required.

Patient assessment

The assessment should determine the following:

- If this is the first replacement device – the time from initial insertion.
 - Initial gastrostomy tubes and devices should not be replaced before 6 weeks post insertion.
- How long the gastrostomy tube or device is expected to

be needed for

- The need for changing the tube or device
- The need for procedural sedation
- How it will be replaced and who will be involved in the procedure
- The underlying reason for the gastrostomy tube or device and
- The preferences of the patient/carer.

Consent should be obtained prior to removal of or change of the gastrostomy tube or device.

For paediatrics, the first change of a gastrostomy device is usually done in the hospital environment. Play therapy/distractive techniques may help prevent future fears.

Selecting and accessing the most appropriate replacement tube or device

The Nutrition Support team will discuss the most appropriate replacement options with the patient and/or carer i.e. balloon gastrostomy device, low profile gastrostomy device (with or without balloon) etc. Low profile gastrostomy devices are the preferred choice for children and adolescents due to body image and activity.

- Education on tube/device characteristics should be provided to the patient/carer if they differ from the original.

There should be a system in place to ensure people needing a replacement gastrostomy tube or device can access one when required. The patient/carer should be provided with information about how and where to access replacement tubes or devices.

Who should change the tube or device?

Changing a gastrostomy tube or device at the bedside or in a clinic/home setting should only be performed by individuals who have adequate skills and training.

There should be a process in place to ensure health care professionals replacing gastrostomy tubes and devices are appropriately qualified.

- Each service should develop their own training, supervision and assessment programs regarding insertion, reinsertion and ongoing care of gastrostomy tubes and devices. Training should include:²
 - gastrostomy tube/device identification including recommended removal methods
 - identification and management of complications post initial insertion and as part of ongoing care
 - risks and complications associated with removing

and replacing gastrostomy devices and their management

- when escalation of care is required.

- Patients/carers should have access to trained clinicians such as nurses, dietitians and medical specialists in the appropriate setting.

An experienced health care professional may train a patient/carer to change their own gastrostomy tube or device. This can empower patient/carers, however appropriate and ongoing support should be provided.

Persons involved with changing gastrostomy tubes and devices should know who to seek assistance from when necessary, as per local policy.

Replacing the gastrostomy tube or device

a) Removing the existing tube or device

The method of removing a gastrostomy tube or device depends on its type. Always confirm the method of removal with the device manufacturer - access product information or contact the company directly.^{20, 22, 26, 69, 150, 171-173} (GRADE D)

There are several well recognised and documented complications related to the removal of a gastrostomy tube or device. These have primarily been due to components

of the gastrostomy tube or device being retained in the bowel. This has consisted of remnants of broken devices or, more commonly, of detachable internal bumpers like cross-bars/domes.¹³¹

There are risks if the tube or device is not removed completely intact.

- If the gastrostomy tube or device breaks, every attempt should be made to retrieve it, or monitor for excretion.
- Remnants left within the stomach can fail to pass through the intestinal tract in adults and children. These remnants can lodge at different sites causing poor outcomes such as persistent vomiting, bowel obstruction and bowel perforation.¹³² However, the most severe complications have occurred following proximal migration of the remnants into the oesophagus and include oesophageal stricture and death.^{174, 175}

Table 16: Gastrostomy tube/device types and removal processes

Tube/device type	Removal process
Non-ballooned gastrostomy tubes and devices	Collapsible internal flange - external traction/vigorous pulling at the bedside. These devices may also be removed by endoscope to reduce trauma. ^{22, 23, 66, 69, 70, 82, 92, 150, 151, 167-170} (GRADE D)
	Rigid internal flange - endoscopy. The "cut and pass" method should not be used - there is a risk of small bowel obstruction. ^{20, 22, 26, 69, 150, 171, 172} (GRADE C)
	Obtured devices – Should be removed using manufacturer's specific instructions and purpose built removal kit/equipment. This process should only be undertaken by experienced clinicians.
Balloon gastrostomy tubes or devices	Deflation of balloon and gentle external traction <i>NOTE: if the balloon does not deflate, seek specialist advice.</i>
Self-retaining tubes (e.g. pig-tail catheter)	Release of the loop or "pig tail" (as per manufacturers guidelines) and traction

Gastrostomy feeding tube introducers should not be re-inserted into the feeding tube while the tube is in the patient (due to risk of tube perforation and serious injury) unless absolutely necessary and should only be performed by expert clinicians.²

Appropriate pain relief should be given to minimise patient discomfort during the removal process.

b) Inserting the replacement tube or device

- Local guidelines should be followed when replacing a gastrostomy tube or device.
- Where the tract is mature the procedure can be performed in an appropriate setting (including bedside, clinic or home) by an adequately trained health care professional.^{22, 66, 69, 70, 82, 92, 150, 151, 167-170} (GRADE C)
 - An experienced health care professional may teach a patient/carer to change their own gastrostomy tube or device.

Fasting times for the procedure will vary depending on the type of tube or device and the method of placement. This should be discussed with the proceduralist.

Before restarting feeds, tube or device placement should be confirmed and advice obtained from the proceduralist.

Confirmation of placement

The gold standard method to confirm the position of a replacement gastrostomy tube or device is radiological contrast study or endoscopy.^{20, 22, 66, 69, 71, 82, 150, 152, 153, 167, 168, 176-181} (GRADE A)

However, these methods may not always be practical due to the resources available. In this situation, confirmation of the position of the replacement gastrostomy tube or device in a mature stoma should ideally be done using all of the following methods:

- Aspiration of gastric content^{20, 22, 66, 69, 71, 82, 150, 152, 153, 167, 168, 176-181} (GRADE D)
 - This may be limited as the inability to obtain an aspirate does not always indicate the tube or device is in the incorrect position.
- pH testing of aspirate (where available) with universal indicator paper to ensure pH <5.^{20, 22, 66, 69, 71, 82, 150, 152, 153, 167, 168, 176-181} (GRADE D)
 - This method is unreliable if the patient is on gastric acid suppression medication or continuous enteral feeding.

- Confirmation of the external length of the gastrostomy tube^{20, 22, 66, 69, 71, 82, 150, 152, 153, 167, 168, 176-181} (GRADE D)
 - Not applicable to low profile devices.
- Flush with a volume of sterile water appropriate for the patient (for example 30-50mls for adults) and ensure no resistance, pain or leakage.^{20, 22, 66, 69, 71, 82, 150, 152, 153, 167, 168, 176-181} (GRADE D).
- Rotate the tube or device and perform “in-out play” to ensure free movement of the tube or device in the tract.



NOTE: If there is any concern or doubt about the position of the replacement tube or device a radiological contrast study must be performed. This includes if firm resistance is encountered or several attempts are required to reinsert the tube or device.^{20, 22, 66, 69, 71, 82, 150, 152, 153, 167, 168, 176-181} (GRADE C)

Air insufflation to confirm tube or device position is unreliable and should not be used.^{20, 22, 66, 69, 71, 82, 150, 152, 153, 167, 168, 176-181} (GRADE B)

If the patient complains of pain, check that the tube or device moves in and out freely and rotates easily. If the patient continues to complain of discomfort a radiological check is required.

Once the correct placement has been documented and there are no other contraindications, use of the tube or device may resume as per local procedure.

Documentation

Documentation of the replacement procedure in the medical record should include:

- The type, brand and size of the gastrostomy tube or device
- The method of insertion and the procedure used to confirm the correct placement of the tube or device
- Appearance of the gastrostomy site - any ooze, firmness, or signs of infection
- Markings at skin level for relevant devices (i.e. where the external flange is sitting at skin level)
- Ballooned tubes/devices - how much sterile water was inserted into the balloon
- Patient tolerance of the procedure
- Planned follow-up arrangements
- Any other relevant tube/device-related information.

Please see Appendix 6 for an example of a gastrostomy tube or device replacement record.

Documentation provided to the patient/carer/local service should include:

- Tube or device details including manufacturer, generic and trade name, size and date of insertion:
 - Markings at skin level for relevant tubes.
 - Schedule for balloon inflation checks.
- Follow-up time frames and details, including replacement plans and local contacts
- How to care for the tube or device if the replacement device is different to the original
- Any changes to the nutrition care plan, the formula or equipment required including supplies provided for home, and details of registrations, orders and/or applications for assistance (e.g. HEN registration, applications made to the Department of Veterans Affairs).

In NSW the “My Health Record Book”, HEN Cards and HEN factsheets could be used.

7. Planned permanent removal of a gastrostomy tube or device

Permanent removal of a gastrostomy feeding tube or device should be considered when the patient is clinically stable and able to consume adequate oral intake in order to maintain their goal weight and other nutrition parameters.²

The time frame for removing the gastrostomy tube or device is variable and needs to be decided on an individual basis by the Nutrition Support Team in collaboration with the patient and/or carer. The patient’s underlying condition, their nutritional status, possible future needs for nutrition support and personal wishes should be considered.²

When considering permanent removal of gastrostomy tube or device the following questions should also be considered:²

- Does the patient have a mature stoma?
 - If not, the tube or device should not be removed.^{20, 22, 69, 150-155, 159, 165} (GRADE C)
- What are the wishes of the patient/carer?
 - Are there any ethical and/or palliative care considerations?
- Can the patient eat and drink safely?
 - Can the patient take medications orally?
- Is the patient consuming adequate oral intake in order to maintain:
 - Goal weight?
 - Appropriate growth trajectory in infants and children?
 - Hydration?
 - Micronutrients (with or without supplementation)?
- Is the patient clinically stable?
- What are the patient’s likely future health care needs?
 - Could they impact on their ability to meet nutritional requirements?
- Does the patient and/or their carer understand the implications of removing the tube or device and the process, including risks if reinsertion if required?

Methods of Removal

The method of permanently removing a gastrostomy tube or device depends on its type. The method of removal should always be confirmed with the device manufacturer - access the product information or contact the company directly.^{20, 22, 26, 69, 150, 171-173} (GRADE D)

See “Removing the existing tube or device” for different removal methods (page 58).

- Once the tube or device is removed, the gastrostomy is likely to close within 2-4 days. If the tract does not heal within one week or if there is an output from the tract or stoma, the patient should be referred for medical review.
 - Review potential causes of delayed wound healing i.e. malnutrition, co-morbidities.¹⁷¹⁻¹⁷³
 - Initial management is conservative and focused on the patient’s comfort, maintenance of the skin and acid reduction with proton pump inhibitor medication.
 - See also “Failure of the stoma to close” on page 61.
- If a gastrostomy tube or device is required again in the future, the initial insertion procedure and reestablishment of a gastrostomy should be followed.
- If the procedure was a non-surgical removal, the patient should fast for approximately 2 hours post procedure and consume small frequent meals until the stoma has closed (or as otherwise advised by the proceduralist).
- For surgical closures, refer to proceduralist’s post-operative instructions.

Failure of the stoma to close

Persistent gastro cutaneous fistula (GCF) has been defined as the absence of closure of the gastrostomy one month after removal of the tube or device.^{182, 183} There is little or no incidence data in adults regarding persistent GCF¹⁸⁴ however, development of a GCF after non-surgical gastrostomy device removal is a well-recognised sequela in the paediatric population with reported incidence rates of up to 44%.¹⁸⁵

A GCF is associated with significant morbidity including skin and soft tissue damage, pain and discomfort and loss of nutrients through leakage of gastric content.¹⁸⁶

Several studies have tried to determine the predictive or relevant factors which may contribute to the development of a GCF post gastrostomy removal in children.^{171, 187-189} The only statistically significant finding related to the length of time the gastrostomy tube or device was insitu - the longer the duration the more likely that the fistula won't close spontaneously. Most studies found that paediatric gastrostomies insitu greater than eleven months had the highest risk of not closing within an acceptable timeframe. Formal surgical closure is often performed at the same time as device removal to avoid these complications in children whose gastrostomy has been in situ for more than one year.

It is recommended that prior to permanently removing a gastrostomy tube or device, opinion is sought from the treating surgeon in regards to removal management. Parents/carers should be advised of the incidence rates and risks of non-spontaneous closure.

Documentation

After the gastrostomy tube or device is removed, the following should be documented in the medical record:

- Date and time of procedure
- Method of removal
- Complete or incomplete device removal
- Condition of stoma site and surrounding skin
- Type of dressing applied if applicable
- Spare dressings given to patient/family
- Any follow-up required
- The provider of the tube or device should be notified to cease supply where relevant (e.g. EnableNSW).

SECTION 5: Transfer and Transition

This section provides information about patients transferring between services, states/territories, countries and those transitioning from paediatric to adult services.

Continuity of care is very important to enable timely, efficient and appropriate care of patients, their gastrostomy tubes and devices, other feeding needs and required assessments. Planning for transfer of care should commence as soon as possible. Every attempt should be made to ensure a relevant and thorough clinical handover to treating and local health care teams, as well as ensuring consumer involvement in transitioning care.

1. Transfer of care between services, states/territories and countries

As services and resources differ between suburban and rural facilities, interstate and internationally, it is vital that patients are set up and linked in with all necessary resources, key health providers and programmes in their new environment **prior** to transfer. This is the responsibility of the treating team and should be included in the clinical handover to the new treating team.

Handover should include:

- Current details - patient and carer name, date of birth, address, contact number as well as new contact details if relevant
- Language and/or cultural requirements
- Support requirements – educational, physical etc.
- If the patient identifies as Aboriginal or Torres Strait Islander or both
- Relevant details of medical history, including medications, allergies etc.
- Indication for enteral tube feeding and expected duration
- Current nutrition care plan including details of gastrostomy feeding regimen, oral ability/feeding skills and oral intake (where safe), requirements for food/fluid modification, aspiration risk
- Feeding history where relevant e.g. previous feeds tried and tolerance record

“We need a checklist to ensure transfers/discharges are thorough”

Nurse

- Tube/device details (date of initial stoma formation/insertion as well as subsequent replacement date, type, size, brand, device position/mark at skin, securement etc.)
- Facility where the most recent gastrostomy tube or device insertion was undertaken
- All current and new healthcare professionals involved
- Community services providing care and support
- Pump and consumables order details
- Current and new suppliers of formula and equipment.

See Appendix 4 for an example Transfer between services form.

2. Transition from paediatric to adult services¹⁹⁰⁻¹⁹³

Transition is a process that occurs in childhood and adolescence in preparation for living as an adult with a chronic condition. Children’s services can differ to adult services - resources, staff to patient ratios and access to financial support and assistance programmes can vary. Clinical practice may also differ. For example – sedation methods used in paediatric care may not be available in the adult health setting.

Preparation for transition may occur in a number of ways with input from multidisciplinary team involvement. There is frequently an overlap period in transition from paediatric to adult services where a paediatric health care team begins to share care with adult health care providers and eventually hands care over. Young adults may continue being cared for within a paediatric setting until they finish school.

In the transition of health services from paediatric to adult populations the following key principles apply:

- The young person should be empowered, to the best of their ability, to participate in clinical decision making regarding their gastrostomy tube or device and their medical care according to their level of maturity and capacity.
- Support a self-management focus which is developmentally and age appropriate. The aim is for the young person to gradually become more involved in self-care by answering questions about their gastrostomy tube or device, feeding requirements etc. without the guidance of their carer. They will start to see clinicians on their own as occurs in an adult setting. This can be very difficult for the carer initially and appropriate support should be provided.
- Where the young person will not be able to independently manage their health care, empower the carer to enable them to understand and negotiate adult health services.
- The transition process should commence at the earliest opportunity (usually around the age of 14) and patients should be given organised times to meet members of the adult multidisciplinary team who will be involved in their care, attending specialist condition related clinics for adolescents.
- Patients should be referred to other support services (such as Trapeze and ACI Transition Care Co-ordinators in NSW).
- Transfer of care from the paediatric to adult service can occur when a mutual agreement between the consultant/specialist/treating team and the patient/parent has been reached.
 - It should occur at a time of medical stability and not coincide with important life events (e.g. final year of school exams).
- Prepare the young person and their family for the potential changes in practice between adult and paediatric services for e.g. replacing tubes/devices.
- Ensure a holistic approach to the needs of the patient.
- Review medications and ensure these are available through the Pharmaceutical Benefits Scheme.
- All relevant information should be documented in the Medical record.

See Appendix 7 for an example of a transition checklist.

SECTION 6: Service evaluation

Facilities and services providing care to people with gastrostomy tubes and devices should undertake ongoing evaluation activities to improve quality of care including patient safety.

Data collected as part of audits or surveys could include but not be limited to:¹⁹

- Mortality
- Hospital readmission
- Complications
- Patient satisfaction
- Staff satisfaction
- Incident reporting and resolution.

GLOSSARY

Bolus: the administration of a single dose of enteral nutrition over a short period via gravity or pump.

Decompression (via a gastrostomy): The removal of gas or fluid from the stomach (also called venting).

Endoscope: An instrument used for the examination or surgical manipulation (e.g. biopsy, resection, reconstruction) of the interior of a canal or hollow viscus. A flexible endoscope is an optical instrument that transmits light and carries images back to the observer through flexible (about 10 micrometers) transparent fibres, and used to inspect and treat interior portions of the body. These instruments are generally equipped with mechanisms for steering and may have additional ports for allowing sampling and/or operative instruments along their axis to the internal site.¹⁰

Endoscopy: Examination of the interior of a canal or hollow viscus by means of an endoscope.¹⁰

Enteral dispenser: a non-luer compatible syringe specifically designed for the administration of fluids, medications or flushes via enteral feeding equipment.

External “flange” or retention device (also may be referred to as an external skin retention disc, bumper or bolster): may be a rod or square, triangular or circular in shape, dependant on the manufacturer preference. Together with the internal bumper or retention device, the device is kept in place and inward movement of the device and probable pyloric obstruction is minimised.^{194, 195}

French Gauge (Fr): Also called French Scale. It is used for denoting the size of catheters, feeding tubes and other tubular instruments (1Fr = 0.33mm approximately).¹⁹⁶

Friable skin: skin that is fragile and prone to tears and bruising.

Gastropexy: The technique used to pull the stomach closely against the anterior abdominal wall to reduce the risk of peritoneal leakage and to prevent the stomach wall being ‘pushed away’ during device placement.

Percutaneous gastropexy is performed during radiological device insertion using a device known as a T fastener, which consists of a small metal bar with an attached protruding suture. The metal portion is inserted into the stomach lumen and the suture exits on the surface of the

skin. The suture(s) are anchored onto the skin. After a recommended period of time the sutures are cut and the T fasteners are left behind to be passed through the GI tract.¹⁹⁷

In paediatrics, with the laparoscopic assisted insertion of a low profile feeding device, the stomach is usually sewn securely onto the anterior abdominal wall

Gastroscopy: Inspection of the interior of the stomach through an endoscope.¹⁰

Gastrostomy: Establishment of a new opening into the stomach.¹⁰

Gastrostomy tube (may be called a G-tube): Is a dedicated feeding gastrostomy tube that is inserted into the stomach via a gastrostomy tract.^{10, 198}

Granulation: Is the formation of lumpy, pink tissue containing new connective tissue, fibroblasts, white cells, collagen and capillaries that forms around the edges of a wound or site of infection during the earliest stage in the normal healing process.¹⁹⁹⁻²⁰¹

Granuloma: A mass of granulation tissue which forms at the site of bacterial infections.¹⁹⁹

Hypergranulation, overgranulation or exuberant tissue or proud flesh: Is soft tissue that will not progress toward healing. Made up of granulation tissue and is in excess of that is required to replace the tissue deficit which often results in a raised mass (peduncle or ‘proud’ flesh) and inhibits migration of epithelial cells.^{201, 202}

Hypertonic saline: Highly concentrated salt solution, often 3-6%. It is used to clean the gastrostomy site and reduce the risk of infection.

Internal retention device (internal “bumper”): (also may be referred to as an internal bolster or flange). Holds the gastrostomy tube or device up against the anterior wall of the stomach and helps prevent accidental removal and probable gastric fluid leak.^{194, 195}

Jejunal tube (or J-tube): Is a tube/device that is inserted into the jejunum via a jejunostomy.^{10, 198}

Jejunostomy: Operative establishment of a fistula from the jejunum to the abdominal wall, usually with creation of a stoma.¹⁰

Laparoscope: An endoscope used for examining the peritoneal cavity.¹⁹⁸

Laparoscopy: Examination of the contents of the abdomino-pelvic cavity with a laparoscope passed through the abdominal wall. *Closed laparoscopy* is a laparoscopy attained by insufflation of the abdominal cavity, using a percutaneous placed needle. *Open laparoscopy* is a laparoscopic procedure that involves insufflation of the abdomen, using a trocar placed under direct vision after making a small celiotomy incision.¹⁹⁸

Laparotomy: A surgical procedure involving an incision through the abdominal wall to gain access into the abdominal cavity.^{10, 198}

Naso-gastric Tube (NGT): A tube inserted through the nose, down the oesophagus and ends in the stomach. It can be used to administer feeds and medications; or to aspirate stomach contents or for stomach gas decompression.

Percutaneous Endoscopic Gastrostomy (PEG): Is a procedure where a gastrostomy is performed by percutaneous puncture without the need for a laparotomy. It is performed under endoscopic guidance with gastric insufflation. A special tube is passed through the gastrostomy via the mouth/oesophagus for the purposes of feeding.^{10, 198, 203}

Percutaneous Endoscopic Gastro-jejunostomy (PEGJ) or Percutaneous Endoscopic Jejunostomy (PEJ): May involve gastroscopy or fluoroscopy and insufflation of the stomach. A dedicated device is passed via a previously inserted gastrostomy device or gastrostomy, through the pylorus and into the small intestine. Such a device offers gastric decompression and/or drainage and post-pyloric feeding.^{10, 198}

Percutaneous Radiological Gastrostomy (PRG): A gastrostomy performed without opening the abdominal cavity; involves insufflation of the stomach, and puncture of stomach and abdominal wall under fluoroscopic guidance, followed by placement of a special device.^{10, 204}

Peritonsim: A condition of having the clinical signs of shock and peritonitis. Its symptoms are similar to peritonitis but without actual inflammatory process, due instead to functional disease.²⁰⁵

Refeeding syndrome: a syndrome encompassing severe fluid and electrolyte shifts, acute micronutrient deficiencies and disturbances of organ function and metabolic regulation that may occur in malnourished patients (or those that have been subject to prolonged fasting) in response to oral, enteral or parenteral refeeding.^{3, 206}

Stoma:

1. A minute opening or pore.
2. An artificial opening between two cavities or canals, or between such and the surface of the body.¹⁰

Y-port (adaptor or connector): A Y-port is a dual access point feature that allows irrigation and medication administration without disconnecting the feeding set. The Y-port may be fitted with closing caps that help avoid accidental gastric fluid loss and minimise the risk of contamination. The Y-port may or may not be removable.²⁰⁷

Abbreviations

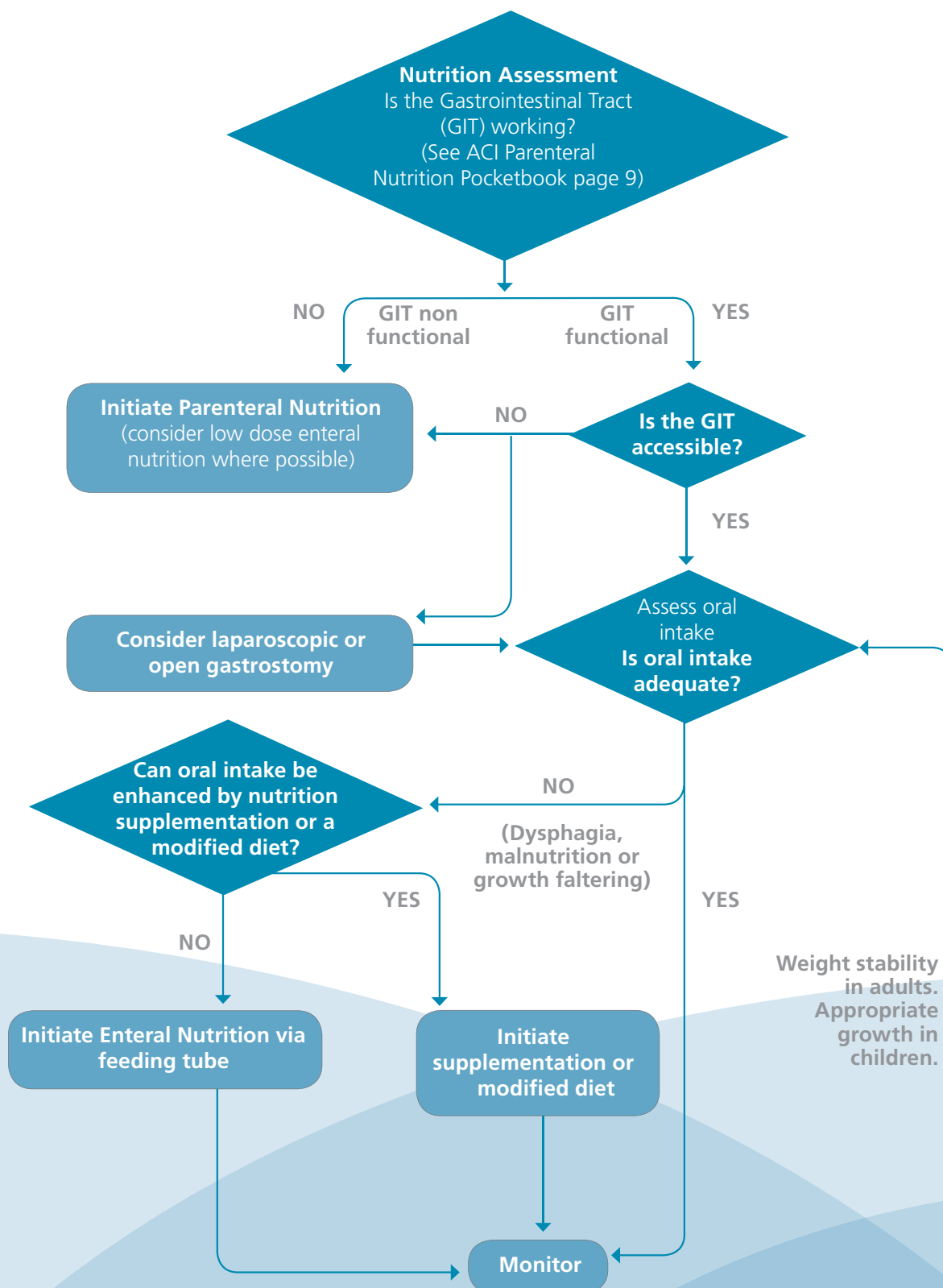
BMI	Body Mass Index
GDG	Guideline Development Group
GENCA	Gastroenterological Nurses College of Australia
GP	General Practitioner
GRV	Gastric residual volume
HEN	Home enteral nutrition
IV	Intravenous
LAPG	Laparoscopic gastrostomy
LAPJ	Laparoscopic jejunostomy
LAPEG	Laparoscopic gastrostomy with endoscopic guidance
LAPEJ	Laparoscopic jejunostomy with endoscopic guidance
MRO	Multi-resistant organism
ND	Nasoduodenal
NG	Nasogastric
NJ	Nasojejunal
PEG	Percutaneous endoscopic gastrostomy
PEJ	Percutaneous endoscopic jejunostomy
PN	Parenteral nutrition, sometimes called Total Parenteral nutrition (TPN)
RIG	Radiologically inserted gastrostomy

APPENDIX 1: Guideline Development Group

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First name	Last name	Position	Location
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APPENDIX 2: Is enteral tube feeding indicated?



APPENDIX 3: Example of an education checklist

Education	Verbal	Written	Patient/carer understands & can implement	Name	Profession	Signature	Date
Tube/device and site care							
Type of tube/device							
Cleaning equipment							
Stoma care							
Tube/device care							
Unblocking the tube or device							
Flushing the tube/device							
What to do if the tube/device is dislodged/removed							
Broken adapter							
Balloon volume monitoring							
Management of stoma infections							
Nutrition and Hydration							
Feeding plan/regimen							
Preparing formula							
Administering formula – syringe/gravity/pump							
Positioning							
Hydration monitoring							





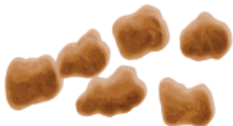
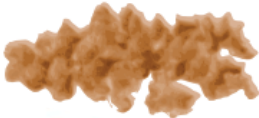

APPENDIX 4: Example Transfer between services form

Contact details	
Patient Name:	
Address:	
Telephone Number:	Mobile:
Language Spoken:	Interpreter required: Yes <input type="checkbox"/> / No <input type="checkbox"/>
Aboriginal: Yes <input type="checkbox"/> / No <input type="checkbox"/>	Torress Strait Islander: Yes <input type="checkbox"/> / No <input type="checkbox"/>
Carer Name:	
Relationship:	
Address:	
Telephone Number:	Mobile:
Language Spoken:	Interpreter required: Yes <input type="checkbox"/> / No <input type="checkbox"/>
Report by:	
Date of Report:	
Profession:	
Contact Details:	
Telephone Number:	Email:
Address:	
Patient's Professional Contacts:	
Specialist	T:
GP	T:
Dietitian	T:
Community Nurse	T:
Palliative Care Nurse	T:
Speech Pathologist	T:
Aboriginal Health Workers / organisations	T:
Other.....	T:
	T:

Patient History		
Diagnosis / reason for enteral tube feeding:		
Other history		
Medications		
Allergy status		
Nutrition		
Nutrition goals		
Oral intake / ability		
Feeding regimen		
Equipment and Supplies		
Formula and Supplier:		
Equipment and Supplier:		
Pump and Supplier:		
Tube/Device and site details		
Date of initial tube/device insertion:		
Hospital where initial tube/device was inserted:		
Initial tube/device inserted by (service):		
Department where initial tube/device was inserted:	<input type="checkbox"/> Endoscopy Unit	<input type="checkbox"/> Operating Theatre
	<input type="checkbox"/> Medical Imaging	<input type="checkbox"/> Other _____
Type of tube/device:		
Tube/Device size (Fr and cm):	Brand:	
Cm marking at skin level (if applicable):		
Adapter type (if applicable):		
Condition of stoma site:		
Date of review appointment:		

APPENDIX 5: Bristol Stool Chart

Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely Liquid

Types 1–2 indicate constipation, with 3 and 4 being the ideal stools (especially the latter), as they are easy to defecate while not containing any excess liquid, and 5, 6 and 7 tending towards diarrhoea.²⁰⁸

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APPENDIX 7: Checklist for transition from paediatric to adult services

This checklist is designed to stimulate thought and discussion about transition issues at various developmental stages for young people with a gastrostomy device. It is intended to serve as a guide only.

It is impossible for any one health professional to have the time, or all the skills required, to address all the issues that might be relevant for a young person and their family. It is, therefore important that a young person and his/her family are given information on resources and that other professionals are involved to address specific issues relevant to the adolescent.

Health professionals, such as occupational therapists, social workers, youth health teams and psychologists can support young people in the areas of educational and vocational planning, social connectedness and sexual health. The checklist can be used by professionals, parents and young people either on their own, or in conjunction with other more detailed tools such as the Assessment for Readiness Checklist available on the ACI Transition Care website <http://www.aci.health.nsw.gov.au/networks/transition-care>. A list of relevant adolescent websites can also be found on this website.

HEALTHCARE PROVIDER TRANSITION CHECKLIST – Gastrostomy tube and devices Checklist is adapted from the “ACI Transition Care Checklist – Gastrointestinal”

Age	Young person	Health care team
Early adolescence 12-14 years New knowledge and responsibilities <ul style="list-style-type: none"> The young person and family are introduced to the transition process. The young person begins to participate in his/her own care. Skills are supported and practised at home with the family. 	<ul style="list-style-type: none"> Can describe their underlying health condition and how it affects daily living Can describe what a gastrostomy tube or device is, why it is needed Can name medications, amount and times taken Can describe common side effects of medications Can name enteral tube feed, amount and times given Can describe how feed is administered Can manage usual medications at school Knows relevant health professionals names, contact numbers and roles Has a GP Management plan 	<ul style="list-style-type: none"> Educate the young person to be able to describe their health condition and the need for a gastrostomy tube or device including: medications taken, enteral tube feeds used, feeding regimen, how to get help and the signs of deterioration. Encourage the young person to ask questions during each appointment, direct questions to them and begin to set specific self-management goals such as knowing how to make or change an appointment. Discuss purpose of Medical Alert ID bracelet and emergency treatments if relevant, and advise how to seek help from others. Discuss transition and why it is undertaken. Direct them to relevant resources such as the ACI Transition Care Network website http://www.aci.health.nsw.gov.au/networks/transition-care Talk about the importance of having a GP that they trust. Encourage them to appropriately use their GP. Discuss puberty changes, differences from peers and the impact of puberty on their condition and discuss where the young person and parents can obtain information about sexuality and puberty. Talk to the young person about social activities, school, peer involvement and supportive relationships. <p>Parents:</p> <ul style="list-style-type: none"> Discuss with parents how they might facilitate their adolescent's independence and encourage them to prepare and support their adolescent to start asking their health care team questions Raise the idea of in the future allowing the young person to spend time with the doctor and relevant health professionals without parents being present

Age	Young person	Health care team
Mid adolescence 15-16 years Building knowledge and practicing independence <ul style="list-style-type: none"> The adolescent and family gain understanding of the transition process and the expectations of the adult system. The young person practises skills, gathers information and sets goals for participating in his/her care 	<ul style="list-style-type: none"> Spends time with their doctor/other health professionals without parents, knows medical history and is able to answer questions about their condition Knows names and purpose of tests that are done regularly Understands the impact of drugs and alcohol on their condition Knows about transition to adult services Has a GP they trust and use appropriately Has a GP Management plan 	<ul style="list-style-type: none"> Continue to discuss the importance of preparing the young person for independence and address any anxieties. Focus on the patient rather than parent/carer, provide the opportunity to meet with the young person alone and allow the young person to determine when the parent or carer is present. Inform the young person of what aspects of care the parent/carer must legally be informed about and inform them that their GP will be updated. Continue to set specific self management goals such as filling a prescription, ordering feeds/equipment, making appointments, keeping a list of medications and medical contact information in wallet. Discuss in more depth the impact of smoking, drugs, alcohol, and non adherence and the impact of their condition on sexuality and fertility. Start to discuss genetic risks and mental health issues. Discuss timing of transfer to adult health service. Regularly update the young person's GP about their progress and transition plan. <p>Parents:</p> <ul style="list-style-type: none"> Discuss with parents their changing role as support person rather than main care giver to young person. Encourage time for the parents to express their own issues or concerns about transition. Explore ways that parents can help educate and support their adolescent to further increase independence.
Late adolescence Taking charge <ul style="list-style-type: none"> The young person and family prepare to leave the paediatric system with confidence. The young person uses independent behaviours (as able) to move into the adult system. 	<ul style="list-style-type: none"> Can manage all aspects of their condition both at home and at school/work Sees doctor/health professionals alone or chooses who is present Carries emergency information in wallet and knows how to get emergency help Knows how to get further information about medical condition Understands the adult health system, who pays for appointments and how to make appointments Understands the process for referral to the adult health services, chooses and meets their new team Has a GP Management plan In NSW - Knows the name and contact number for the ACI Transition Coordinator or the Transition Service in their area. 	<ul style="list-style-type: none"> Discuss choices for adult care. Assist in choosing adult providers (specialists/hospitals/community, GP). Discuss the process of how the young person will be introduced to the adult health team. Check that the young person knows who to contact for future health needs - names and telephone numbers of health team and Transition Coordinator. NSW - refer to the Trapeze or ACI Transition Coordinator using referral form. Ensure the young person has met with the adult specialists/GP before care is transferred to the adult service. Send a summary of paediatric care to the adult specialist/s, GP and other health professionals involved in gastrostomy care. Provide a copy to the young person. Check that the young person has a plan of who to contact in the event that new care arrangements at the adult facility do not meet expectations. Encourage them to feedback about their encounter with their new health care providers. Discuss genetic risks, sexuality, fertility and mental health issues. Have the young person identify person(s) he/she can contact for help or advice. Discuss in more depth the use of smoking, alcohol and drugs, the interaction with medication and impact on illness/condition and any other risk-taking behaviour. Discuss employment or vocational options. Identify any needs for personal assistance in care or issues of living away from family. <p>Parents:</p> <ul style="list-style-type: none"> Discuss with parents their changing role as support person rather than main care giver to young person. Encourage parent to feedback issues around the transition process. In NSW - ensure they know name and contact of the ACI Transition Coordinator or the Transition Service for their area.

APPENDIX 8: Useful links and resources

Australia

- **Gastroenterological Nurses College of Australia** (GENCA)
- **Gastroenterological Society of Australia** (GESA)
 - **Gastrointestinal procedure factsheets**
- **Australian Society for Parenteral and Enteral Nutrition** (AuSPEN)
- **Dietitians Association of Australia** (DAA)
- **Speech Pathology Australia** (SPA)
- **Department of Veterans Affairs** (DVA)
- **Living Longer Living Better** (Government website) <http://www.livinglongerlivingbetter.gov.au/>
 - Home care packages <http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/home-care-packages-program-guidelines>
- **Gastrostomy information and support service** (GISS)
- **Vision Australia**
- **National Disability Insurance Scheme**

NSW

- **Agency for Clinical Innovation** (ACI)
 - **Consumer factsheets** (HEN)
 - **Clinician factsheets and guidelines** (HEN)
- **Kids Health Factsheets:**
 - **Home Enteral Nutrition**
- **EnableNSW**
- **Ageing, Disability and Homecare** (ADHC)

QLD

- **Nutrition Education Materials Online** (NEMO)
- **QLD Health guidelines**
 - HEN <http://www.health.qld.gov.au/directives/docs/gdl/qh-hsdgdl-030-2.pdf>
 - Provision of consumables (including those required for home enteral nutrition provision) <http://www.health.qld.gov.au/directives/docs/hsd/qh-hsd-030.pdf>

International

- **American Society for Parenteral and Enteral Nutrition** (ASPEN)
- **British Association of Parenteral and Enteral Nutrition** (BAPEN)
- **The European Society for Paediatric Gastroenterology Hepatology and Nutrition** (ESPGHAN)
- **European Society for Clinical Nutrition and Metabolism** (ESPEN)

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