



Tube feeding: *from hospital to home*



with

Keryn Coster and Lina Breik

Supported by **AVANOS**



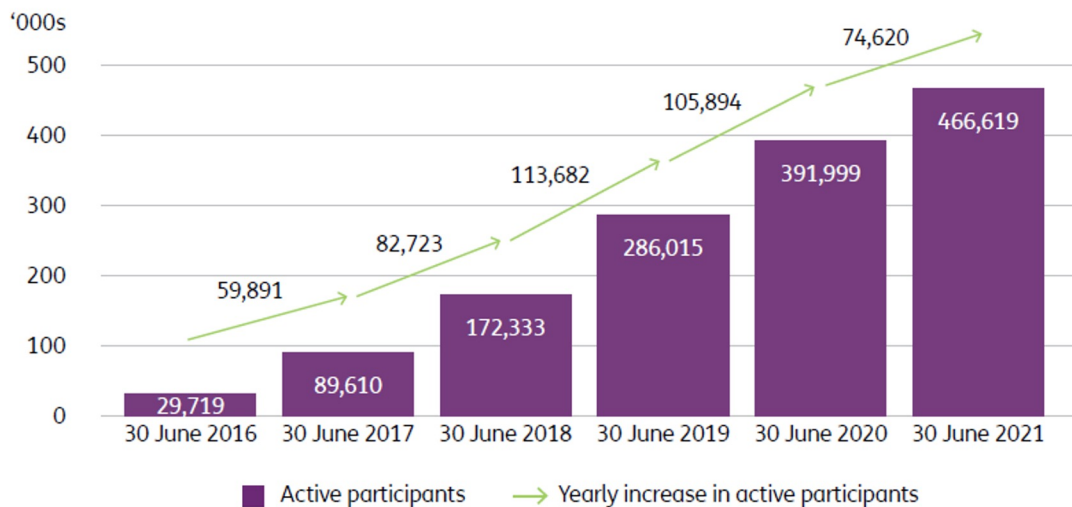
National Disability Insurance Scheme (NDIS)

Australia's first national scheme for people with a disability, commenced 1 July 2013

4.4 million (17.7%) Australians who have a disability

466,619 total participants (June 2021)

Figure 2.1A: The number of active participants has increased from around 30,000 after 3 years of trial, to 466,619 5 years later





Disability related health supports

Information for providers

[ndis.gov.au](https://www.ndis.gov.au)

September 2019

ndis

From 1st October 2019:

Continence supports

Diabetic management supports

Dysphagia supports

Epilepsy supports

Nutrition supports


Podiatry supports

Respiratory supports

Wound and pressure care supports

<https://www.ndis.gov.au/understanding/supports-funded-ndis/disability-related-health-supports>





Disability-related nutrition supports may include:

- a dietitian to work with you to create a disability-related meal plan
- support to help you follow a meal plan
- HEN and PEG equipment
- products to help you eat safely and get the nutrition you need like food thickeners
- support to manage your HEN or PEG.

We won't fund nutrition supports for health issues that are not related to your disability. This includes:

- weight loss
- eating disorders
- food allergies
- diabetes
- cardiovascular disease
- renal disease
- polycystic ovarian syndrome
- irritable bowel syndrome.

You can get support for these health issues through health and other systems.



Check your
state.....

Enteral Feeding Funding

Differs in every state and territory

“Fully” funded vs patient co-payment

Rarely individualised / patient centred

Inequity in delivery of care and variation in cost burden



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Original article

A benchmarking study of home enteral nutrition services

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SUMMARY

Background & aims: Patients receiving home enteral nutrition (HEN) via an enteral feeding tube often have complex healthcare requirements. There is limited information regarding how HEN care is provided within Australia and New Zealand. This study aimed to investigate the characteristics of HEN services and the provision of nutrition care to individuals receiving HEN within Australia and New Zealand.

Methods: A cross-sectional study, surveying lead HEN dietitians for HEN services was conducted from the period 09 July 2019 to 20 September 2019 inclusive. An online survey was used to obtain data relating to the demographics, funding and clinical resources of respondents' HEN services. Services were benchmarked against a HEN service implementation checklist adapted from the Agency for Clinical Innovation (ACI).

Results: Responses were received from 107 HEN services, with an estimated combined population of 7122 HEN patients. Services were predominantly government-funded ($n = 102$, 95.3%) and operated from acute hospitals ($n = 57$, 53.3%). The reported combined cost of all HEN equipment to the patient ranged from \$0-\$77 per week or \$0-\$341 per month. Fifty-two services were reported to have a dedicated HEN dietitian/coordinator, which was positively associated with the undertaking of quality improvement activities ($p = 0.019$). Mean compliance to the ACI HEN implementation checklist was 70.4% ($\pm 15.7\%$) with a range of 13.0–98.2%. Mean compliance was significantly higher in services with a HEN dietitian/coordinator than services without one (75.5% ($\pm 12.0\%$) vs 64.3% ($\pm 16.6\%$); $p < 0.001$).

Conclusions: This study provides detailed information regarding the characteristics of HEN services and nutrition care provided to enterally-fed patients across Australia and New Zealand. The majority of HEN services are not adhering to the ACI HEN service guidelines and there is considerable variation in cost burden for consumers indicating inequitable delivery of care to patients.

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Victoria



Home-delivered enteral nutrition and total parenteral nutrition: Funding arrangements for Victorian public health services

June 2020

What is home enteral nutrition and total parenteral nutrition?

Enteral Nutrition is the administration of nutritionally complete liquid formulae directly into the gastrointestinal tract via a narrow, specifically designed, tube. Enteral nutrition can be used as full or partial oral nutrition support (ONS).

The Home Enteral Nutrition (HEN) program supports patients who require exclusive ONS, or ONS providing greater than 70 percent of their daily nutritional requirements and who, without a health care provider present, self-administer enteral nutrition in their home. Nutritional supplements and partial ONS can be self-funded or partially funded through another hospital-based service.

Parenteral Nutrition is the administration of nutrition by means of an infusion of an intravenous nutrition formula. Total parenteral nutrition (TPN) is generally only used to provide a person's complete nutritional requirements, that is when it is not possible to meet a patient's nutrition requirements through an oral or enteral route.

The home TPN program supports patients who require TPN to provide their complete nutritional requirements and who, without a health care provider present, self-administer parenteral nutrition in their home.

The department's funding arrangements for both HEN and home TPN is consistent with the Independent Hospital Pricing Authority's (IHPA) funding model. Funding definitions of the HEN and home TPN programs are set out in the IHPA's Tier 2 Non-Admitted Services Definitions Manual. HEN and home TPN services are classified to Tier 2 classes 10.18 and 10.17, respectively.¹

This document refers to Victoria's home enteral nutrition and home total parenteral nutrition program.

National Disability Insurance Scheme (NDIS)

Additional disability-related health supports are now available to purchase using NDIS funding. The need for these supports must directly relate to [an](#) NDIS participant's functional impairment, where the support need is ongoing and is and most appropriately funded or provided by the NDIS.

In many situations, participants may be able to select their existing provider to deliver these supports.

The NDIS funds disability-related health supports including nutrition supports (refer to <https://www.ndis.gov.au/understanding/supports-funded-ndis/disability-related-health-supports> for updates):

- dietetic consultations and the development and periodic review of a nutritional meal plan by [an](#) NDIS-funded suitably qualified and competent clinician.
- implementation of a nutritional meal plan by [an](#) NDIS-funded suitably qualified and competent worker.
- training of [an](#) NDIS-funded suitably qualified and competent worker to implement the nutritional meal plan.
- percutaneous Endoscopic Gastrostomy (PEG) Stoma Changes (to assist feeding).
- provision of PEG maintenance and care by a suitably qualified and competent worker.
- training of [an](#) NDIS-funded suitably qualified and competent worker to provide PEG maintenance and care.
- home enteral nutrition, PEG, [equipment](#) and consumables excluding food.
- HEN formula/nutritional supplements (to meet participant's nutritional needs).

Health services are expected to:

- support changes to a patient's NDIS plan to better cover their enteral nutrition needs
- support NDIS participants in their enteral nutrition needs, if participants choose the health service as their care provider
- to identify NDIS participants, or those eligible to become participants, accessing their HEN and home TPN services and ensure NDIS-eligible activity feeds, consumables and equipment is billed to the NDIS
- establish systems to process payments through the NDIS.



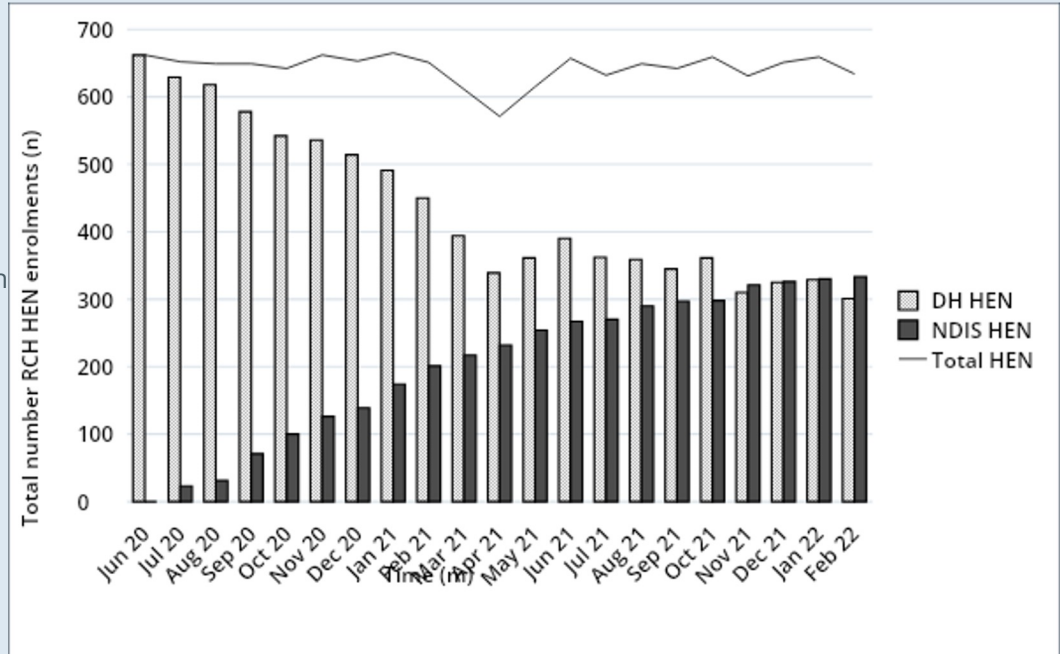


RCH NDIS
Nutrition Service



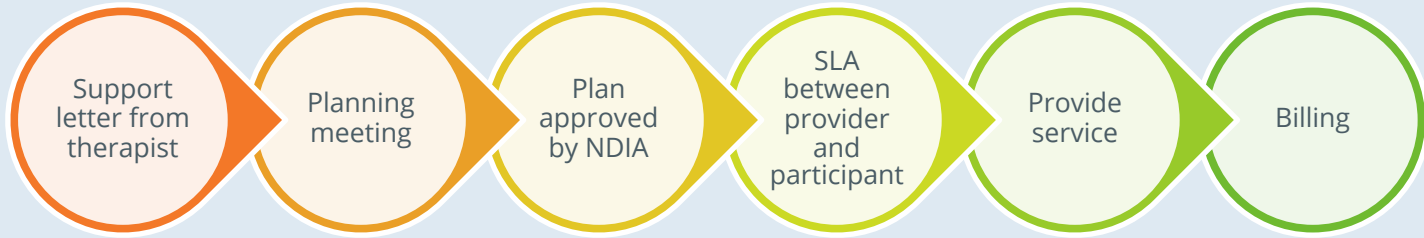
RCH NDIS Nutrition Service

- Service established April 2020
- NDIS registered providers (department)
- Comprehensive service with provision of both dietitian consultations and nutrition-related consumables (all HEN products)
- Total 634 patients enrolled on HEN. Of these, 333 are now NDIS funded (52%)
- Additional 72 accessing ONS program or general outpatient service

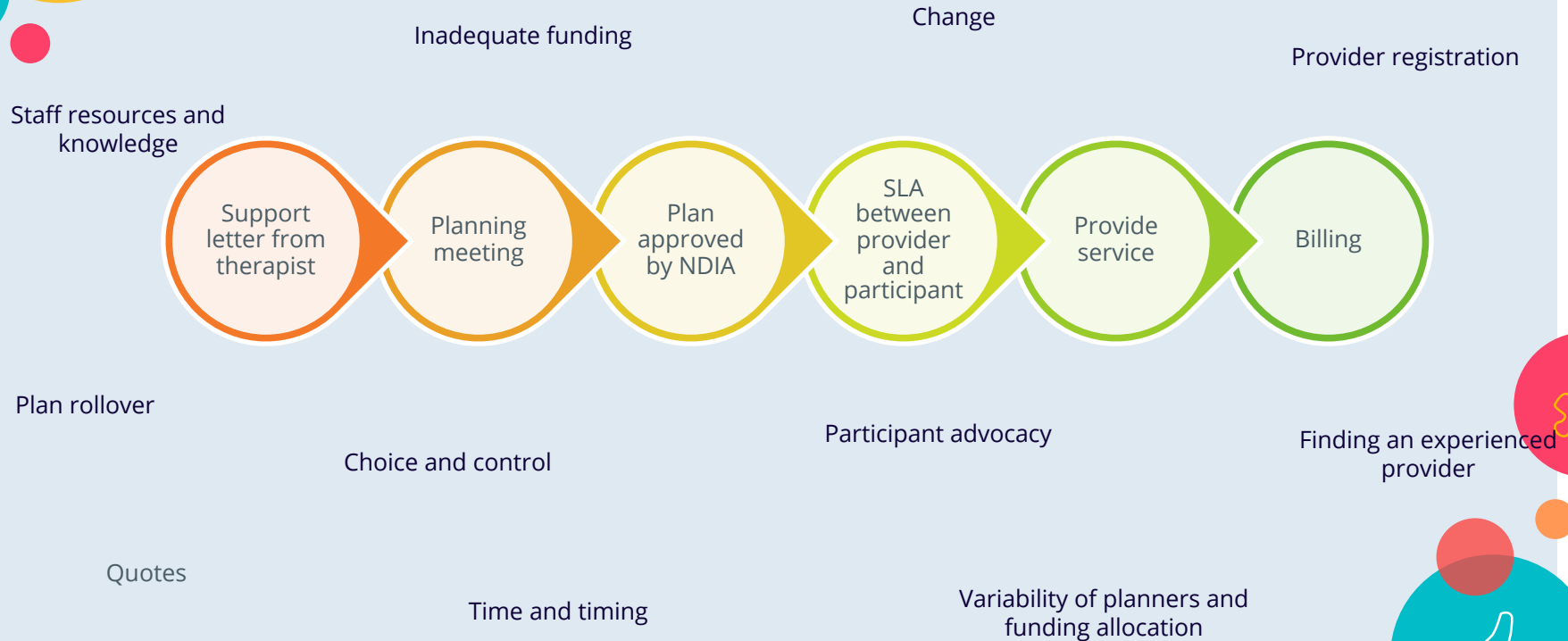


Data from the RCH NDIS HEN Service QI Project (Ethics QA/85395/RCHM-2022)





How this affects your patients (....patience?)

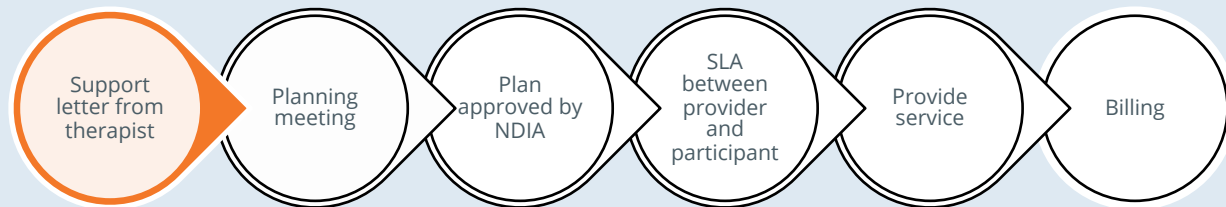




Case Study: Baby Elsie

- 4 month old baby girl (ex 32/40, 2 months old CA) with evolving CP secondary to HIE.
- Has required full EN support via NGT since birth. Currently receiving EBM/IF Q3H bolus feeds via pump over 1 hour to TFI 150 ml/kg/d.
- Parents and wider MDT preparing for initial NDIS plan review next month.
- Request for supporting documentation from medical and AH therapists to fund appropriate disability-related supports going forward.



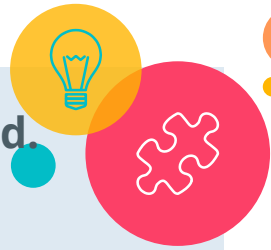


Structure:

- Participant details including relevant diagnosis (NDIS Act S24)
- Functional impact of disability, rather than symptom
- Progress
- Nutrition-related goals and outcomes, ensure related to participant's overall NDIS goals
- Recommended supports required for participant to meet goals, ensuring reasonable and necessary:
 - Estimated time for therapy (including time spent both with and for them)
 - Consumables required (for example, HEN consumables or oral nutrition supplements)
- Summarise the effect of the disability without support
- Quote*



Nutrition goals must be **functional, measureable** and **participant-led**.



NDIS Act Section 24:

The impairment/s result in substantially reduced functional capacity to undertake, or psychosocial functional in undertaking, one or more of the following activities: **communication, social interaction, learning, mobility, self-care and self-management**.

Writing nutrition goals:

1. Consider participant's desired outcome of therapy, then
1. Establish goals that relate to outcome

Clinical outcome:

Weight gain

Clinical goal:

Meet 100% nutrition requirements



Functional outcome:

Stand independently

Functional goal:

Maintain weight/growth to ensure adequate energy/strength for other therapies and daily activities



Language Counts





Reasonable and necessary

Functional impairment

As a result of their disability

Most appropriately funded by the NDIS

Lifelong and permanent

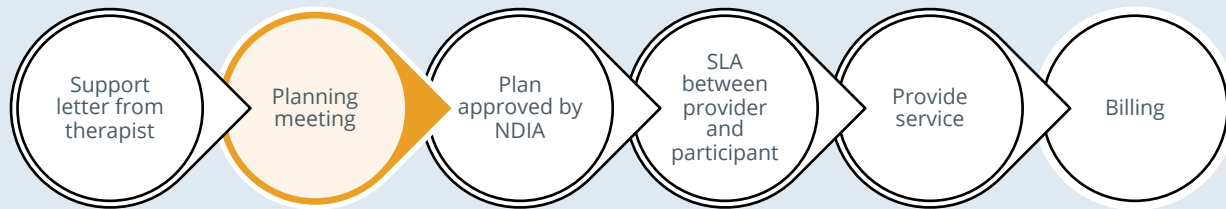
Long-term feeding device

Above the everyday living cost of food

In order for the participant to meet these goals, they require...

This participant's condition directly impacts...





REASONABLE and NECESSARY

- Assists participant to meet goals
- Likely to be effective and beneficial, having regard to good practice and evidence
- Related to a participant's disability
- Most appropriately funded by the NDIS
- Represent value for money
- Excludes day-to-date living costs not related to a participant's disability support needs
- Takes into account support given to a participant by other government services, family, carers, networks and the community



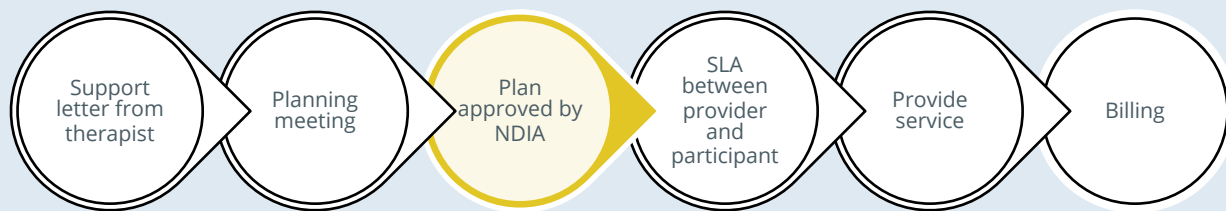
Elsie: Quote



Considerations:

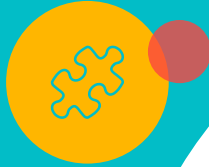
- Current feeding plan and predicted changes
- Type of feeding tube. Routine and non-routine changes
- Method of feeding (gravity, pump etc) and relevant consumable items
- Planned transition from NGT to PEG device
- Requirement for fortification to support growth, if directly related to disability
- Transition from EBM/IF to paediatric enteral formula once >12 months of age
- Feeding items utilised for typical child of this age, regardless of disability background (e.g. bottles)
- Additional support required to implement feeding plan
- Manufacturer's recommendations of product use, parental request(s) and clinician input around fair/reasonable

Support Item Number	Support Item Name	Annual Quantity	Unit
12_025_0128_3_3 (Improved health and wellbeing)	Dietetic consultation* (as per NDIS price guide)	12	Per hour
03_710930080_0103_1_1	Delivery fee (EDC items)	6	Per year
03_150930078_0103_1_1	Pump	1	Each
	Gastrostomy(PEG) device	1	Each
	Extension set	0	Each
	PEG cleaning brush	0	Each
	Nasogastric tube	14	Each
	pH strips	26	Packet of 100
	Giving Sets	12	Carton of 30
	Syringes - Enfit	240	Each
	Flocare Container 1000ml	0	Each
	Bolus adapter	6	Each
		48	500ml Pack (Carton of 8)



- Elsie's parents notify team regarding new NDIS plan, with a 12 month duration. Full funding for nutrition-related supports (as outlined in support letter/quote) have been approved and confirmed by Support Coordinator.
- As this is their first experience with the NDIS, they have decided to 'Plan Manage' allocated funds in Core Supports (HEN consumables) and Capacity Building (Dietitian Consultations) with support from a Plan Manager.
- Discharge planning is underway.
- Elsie resides in a regional town approximately 3.5 hours from Melbourne.

CHOICE AND CONTROL



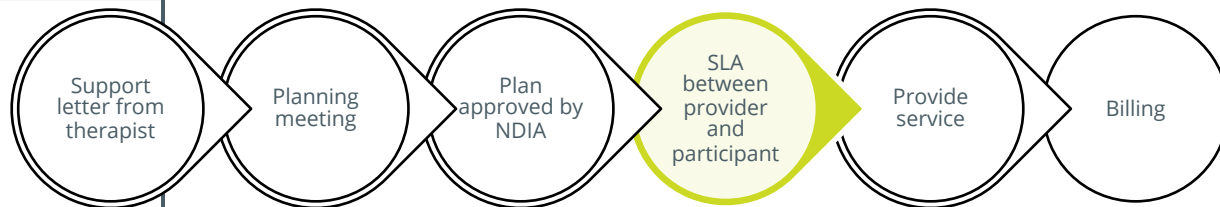


NDIS Service Agreement Allied Health

Name:	
Date of Birth:	
RCH MRN:	
NDIS Number:	

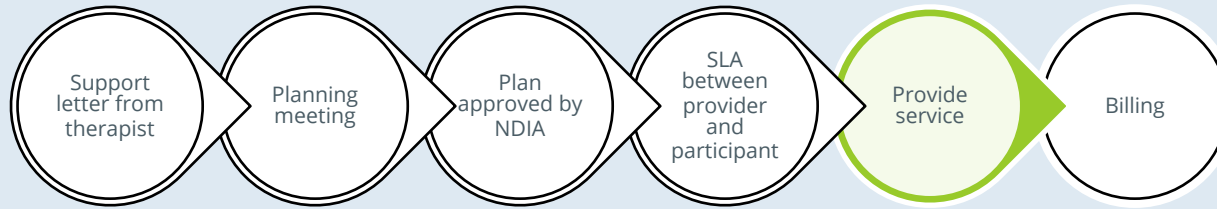
NDIS Registered Service Provider

50 Flemington Road
Parkville, Victoria, 3053
Provider Number 4050009811



Service Level Agreements

- Supports and services the agreed upon, including prices
- Duration of supports
- Rights and responsibilities of both participant and provider
- Cancellation policy
- Process for feedback, compliments and complaints
- Description for service (both time with and for the participant)
- When and how the document will be reviewed
- How the participant or provider may change or end the SLA



Discharge considerations:

- NDIS / HEN service eligibility
- Role of NGF
- Checking position of tube
- Feeding methods, specifically using pump
- Pump training and allocation of home device
- Care and storage of feeds
- Cleaning equipment
- Routine and non-routine tube replacements
- Possible issues and troubleshooting
- Home feed recipe and plan
- Discharge formula and equipment
- Purchasing consumables post discharge
- Contact details and appropriate follow-up plan



What makes a successful NDIS HEN discharge ?

*adequate funding to meet goals, regardless of which
dietitian/provider manages care going forward*





The NDIS Code of Conduct applies to:

- **Registered NDIS providers** and their employees
- **Unregistered NDIS providers** and their employees

NDIS Commission e-Learning:
NDIS Worker Orientation Module

<https://www.ndiscommission.gov.au/providers/ndis-code-conduct>



NDIS Quality
and Safeguards
Commission

The NDIS Code of Conduct

The NDIS Code of Conduct applies to all NDIS providers, registered and unregistered, and all persons employed or otherwise engaged by an NDIS provider.

In providing supports or services to people with disability, a person covered by the Code must:

- act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with applicable laws and conventions
- respect the privacy of people with disability
- provide supports and services in a safe and competent manner, with care and skill
- act with integrity, honesty and transparency
- promptly take steps to raise and act on concerns about matters that may impact the quality and safety of supports and services provided to people with disability
- take all reasonable steps to prevent and respond to all forms of violence against, and exploitation, neglect and abuse of, people with disability
- take all reasonable steps to prevent and respond to sexual misconduct.



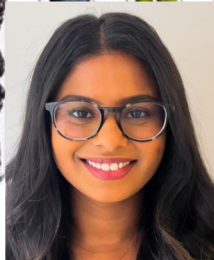
Registering as an NDIS provider

Individuals and organisations in all states and territories can get more information about how to register as an NDIS provider by visiting the **NDIS Quality and Safeguard Commission** website.



Can register a service rather than individuals

Bridging the gap between hospital and home for people with feeding tubes.






Tube Dietitian - NDIS registered provider

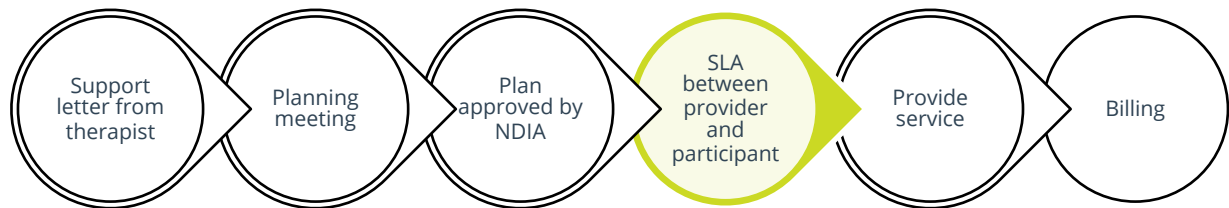
- Why?
 - To be able to see all NDIS patients with plans
 - For street cred ...
- How?
 - Fill out NDIS provider application form (32 pages)
 - Develop incident mx / risk / privacy / complaints mx policies
 - Complete NDIS code of conduct online training
 - ABN number / business name / medicare number / BLS / CV etc.
 - Submit all documents, hire an auditor & pay





Case Study: Mr Happy

- 66 year old male with cerebral palsy
 - Had a PEJ tube for feeding since age 42
 - Relevant clinical information - ileostomy, anemia, pressure sore
 - Lives in supported accommodation with 24/7 carers
 - Wheelchair bound, brilliant sense of humour
 - Feeding regimen - 1.5cal/ml feed, 50ml/hr for 20 hours via pump, 150ml water flushes 4/24
 - Initially being managed by private hospital outpatient dietetic service
- 



- Already have NDIS funding for dietetics for the rest of the year
- **Draft service agreement contract** highlighting - goals, mode of assessment, frequency, cost, etc.

For Mr. Happy -

- Home visits every 6 months
- Video consult every 2 months
- *"To maintain adequate nutrition and hydration for optimal **health and wellbeing**"*



Service Agreement Contract

Thank you for choosing Tube Dietitian to care for your nutritional needs. At Tube Dietitian, our care is focused on you and your health goals. We will support you with safe, evidence-based, individualised nutrition care plans until we achieve your goals for optimal health, strength, and well-being.

As a valued patient of Tube Dietitian, you have direct access to your dietitian in the following ways:

- By email on admin@tubedietitian.com, or
- By filling out an online form on the Tube Dietitian website; www.tubedietitian.com/contactus

Now, let us get started on the details of your nutrition care plan.

Who is making this agreement?

Tube Dietitian Name	Lina Breik (Specialist Dietitian)
Patient Name / Carer	
NDIS Client Number	



Service provision inclusive of ...

- Attendance at care team meetings every 2 months
- Writing NDIS reports / GP letters after assessments
- Liaising with NDIS coordinator re formula / regimen changes
- Linking Mr.Happy to **community nursing supports** to ensure optimal tube / stoma care
- Travel to and from Mr.Happy's home
- Writing NDIS nutrition advocacy letters / reports for ongoing dietetic / tube feeding equipment funding for the new year
- Liaising with his private **surgeon** who initially inserted the tube





Tube Dietitian

Date: XXX

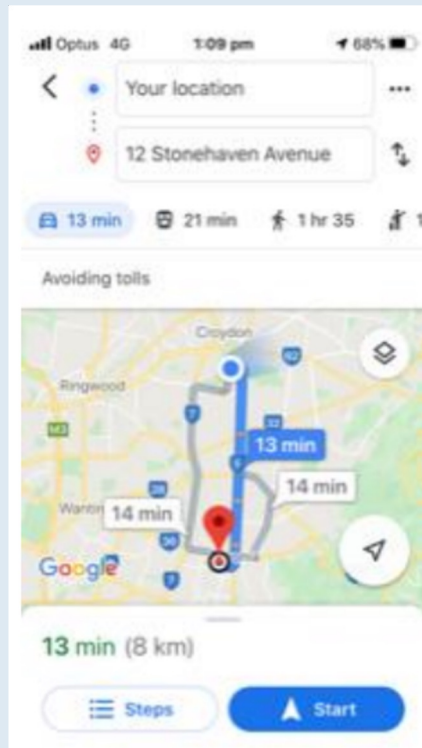
To whom it may concern,

Re: NAME/DOB

XXX requires PEG (percutaneous endoscopic gastrostomy) feeding as she has progressive apraxia of speech and dysphagia. She has been on home tube feeding since December 2017. XXX meets her full nutrition and hydration needs through her feeding tube. Without a PEG feeding tube, XXX would be at a high risk of malnutrition and dehydration. Her feeding tube requires specialized liquid food and equipment to help deliver this food through her PEG.

Furthermore, to avoid emergency department presentations for a dislodged or blocked feeding tube, XXX requires at least three PEG tube changes every 12 months. XXX also requires regular dietitian input to monitor her progress and ensure she is receiving adequate nutrition and hydration.

Tube feeding equipment, liquid food and dietitian support helps to improve XXX quality of life by optimizing her nutrition and hydration. Below is a list of what XXX requires on a per month bases with a breakdown of costs on an annual basis:



The slide features a light blue background with a large, semi-transparent light blue rectangle in the center. To the left of this rectangle is a large teal circle, and to its right is a yellow circle containing a lightbulb icon. In the bottom right corner, there is a teal circle with a thumbs-up icon, a yellow circle with a puzzle piece icon, and several smaller circles in teal, yellow, and red. The text is centered within the light blue rectangle.

**Set yourself up
for success with
the following
HOT TIPS**

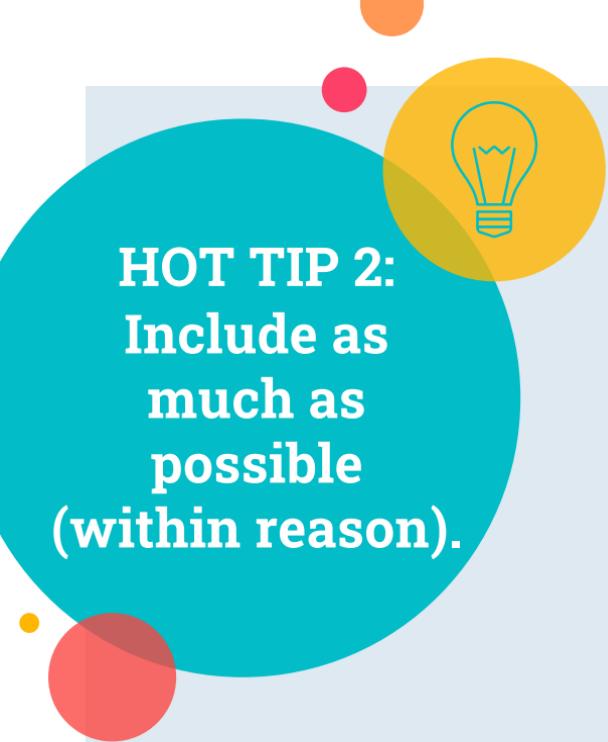


**HOT TIP 1: Get
quotes done for
you.**

- Bright Sky & Independence Australia??
- Engage the formula company to draft NDIS quotes.
- Engage the feeding tube equipment company to draft NDIS quotes.

*You know the patient best while they are in hospital, so you are the best person to advocate for what they need when they leave.

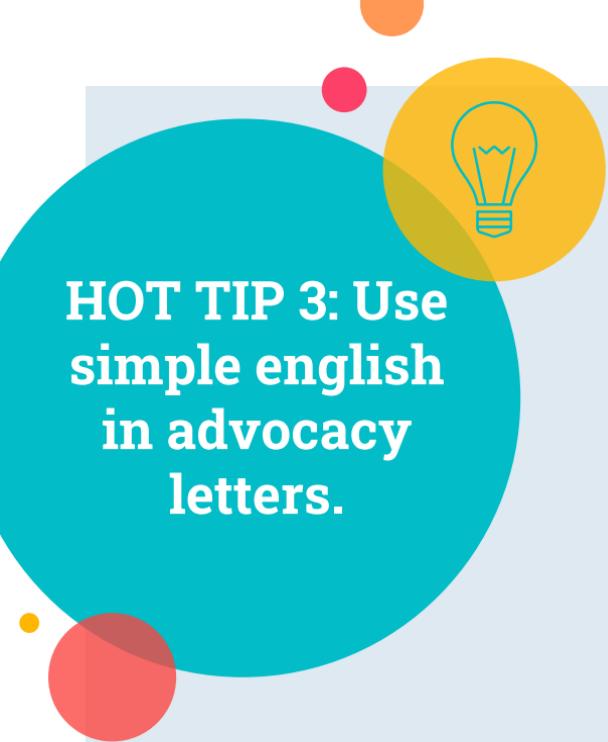




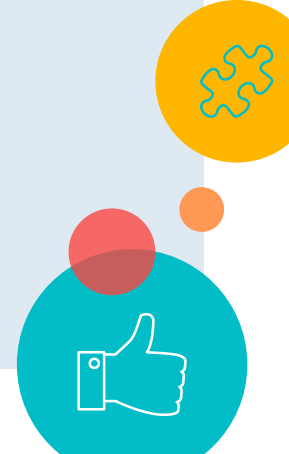
HOT TIP 2:
Include as
much as
possible
(within reason).

- Min. 20 hours of dietetics post-discharge
- Include a minimum of 2 spare feeding tubes in the list of requirements
- Remember:
 - extension sets,
 - giving sets,
 - syringes,
 - pumps,
 - IV poles,
 - pH strips
- **Include nursing hours for tube / stoma care.**
- Liaise with the company representative.





**HOT TIP 3: Use
simple english
in advocacy
letters.**

- “If Mary does not have her regular 5 meals of specialised commercial liquid food through her feeding tube, she will not be able to maintain optimal health, well being and independence.”
 - When writing a report for an NDIS case (or liaising with an NDIS coordinator), write in very simple english. No hospital jargon and **no abbreviations!**
- 

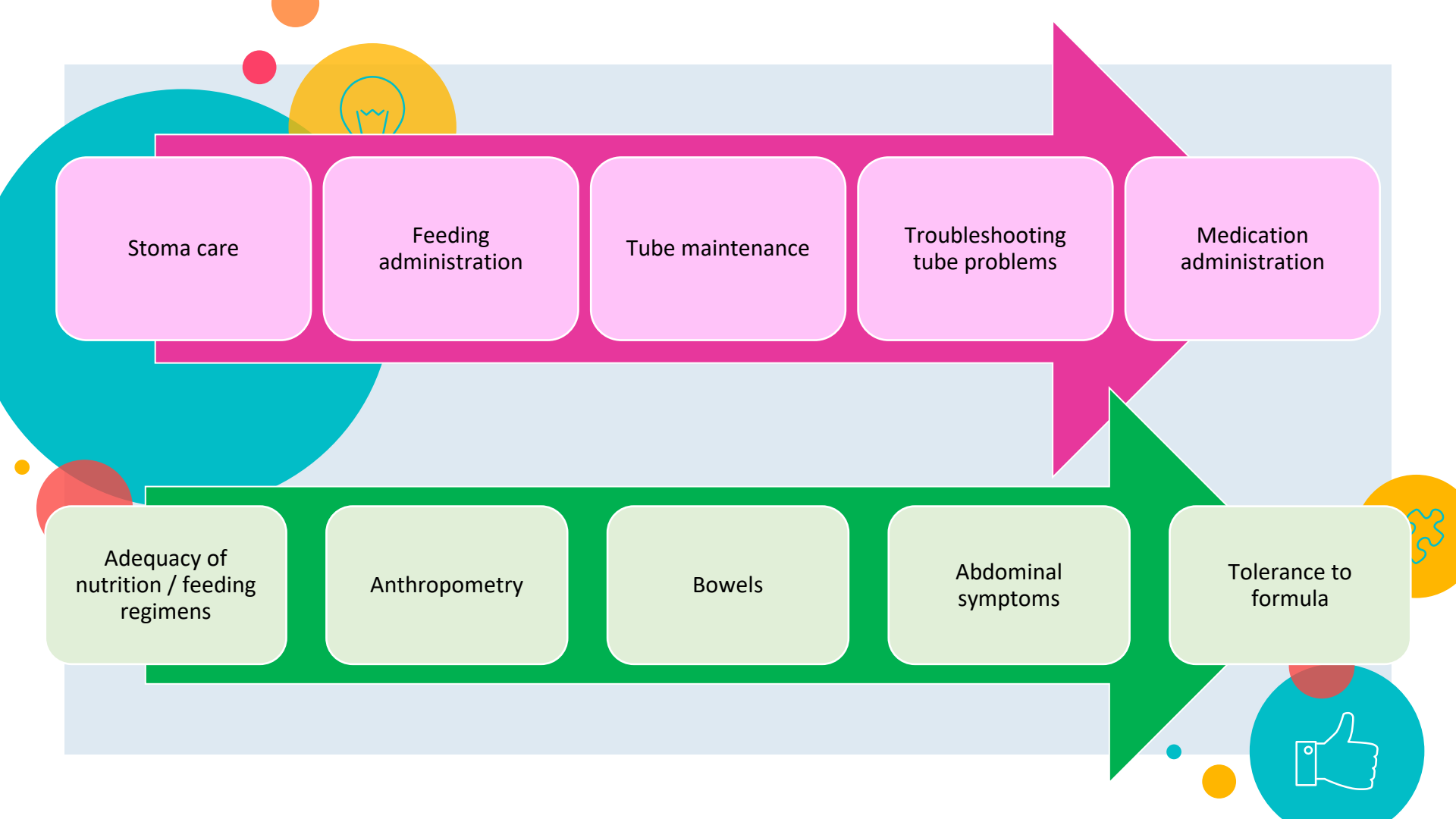
HOT TIP 4: Community nursing is essential.



- Linked to a large hospital nursing service (may not be possible if NDIS funding)
- Managed by a private gastroenterologist funded by NDIS or funded by the patient
- Needs community nursing set up
- What do they do - troubleshooting PEG issues, training, stoma care etc.

Company	Nurse	Contact	Email	Eligibility criteria	How to refer
Abbott	Marissa Mcmanus	0437073955	Marissa.mcmanus@abbott.com	On an Abbott feed	
Nutricia	Jo D'Cruz	0400874575	joanne.dcruez@danone.com	On a Nutricia feed and / or using a Nutricia pump / feeding equipment	Fill out this form and email to Nutricia (homeau@nutricia.com) - https://drive.google.com/drive/u/1/folders/13WVhwQtWJai_FW0I7NlvM3kgcSKrQrkI
Bolton Clark	Rebecca Mathew	0427949420	rmatthew@boltonclarke.com.au	nil	A referral would need to come through by email on hello@boltonclarke.com.au
Nurse Next Door	Sache Biesse	0417031531	sacha.biesse@nursenextdoor.com.au	nil	Call 1300500247 and give them your patients residential postcode then they will link you to the right nurse
Cardinal Health & Nestle	Danielle Knowles	0435828407	Danielle.knowles@regalhealth.com.au	On a Nestle feed and / or using a Cardinal Health pump / feeding equipment	Fill out referral form found here - https://drive.google.com/drive/u/1/folders/1RteMhZmmd3drxQaPVAORWIsaQuiW36c-w And email to - care@regalhealth.com.au





The infographic features two horizontal rows of topics, each contained within a large arrow shape pointing to the right. The top row is pink and the bottom row is green. The background is light blue with various colorful circles and icons, including a lightbulb, a thumbs up, and a puzzle piece.

Stoma care

Feeding
administration

Tube maintenance

Troubleshooting
tube problems

Medication
administration

Adequacy of
nutrition / feeding
regimens

Anthropometry

Bowels

Abdominal
symptoms

Tolerance to
formula



HOT TIP 5: Funding delivered meals.

- Possible but different for adults and kids
 - Funded if delivered meals helps meet the adults goal with “independent living”
 - May not be possible for kids given they have a carer
- Not standardised in NDIS, so need to advocate and bring back to your patients goal.

<https://ourguidelines.ndis.gov.au/would-we-fund-it/improved-health-and-wellbeing/food-and-meal-preparation>






**HOT TIP 6:
NDIS vs.
Hospital HEN
Services - no
double dipping!**

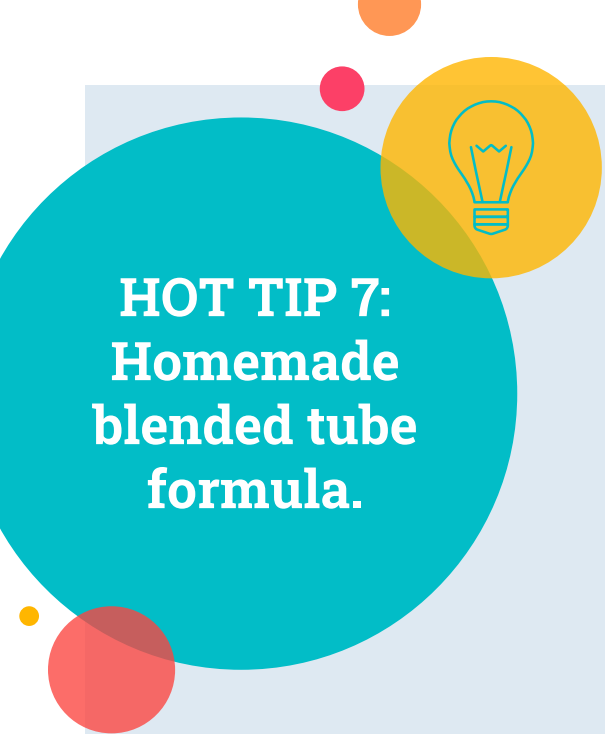
If your patient is under a hospital HEN service and they have an approved NDIS plan ...

Benefits of moving to NDIS?

- Less congestion on our hospital systems / dietitians
- NDIS dietitians are able to attend spontaneous care team meetings
- NDIS dietitians are able to respond to spontaneous NDIS requests for paperwork
- NDIS community dietitians do home visits / individualisation

Avoid - patient under HEN but receiving dietetics through NDIS and visa versa.






HOT TIP 7: Homemade blended tube formula.

Acceptance of BTF is still fairly “new” to Australian clinicians, so imagine what acceptance would be like for NDIS coordinators and planners!

New AuSPEN consensus statement -
<https://www.auspen.org.au/auspen-news/2021/9/22/blended-tube-feeding-in-enteral-feeding-consensus-statement>

If homemade BTF, the bare minimum is for NDIS to provide equipment.

Equipment may include blenders, however these may also be considered normal household kitchenware ...





HOT TIP 8:
**Keep your
friends close.**

- DA mentoring portal
 - Co-managing with hospital dietitian
 - Experienced community dietitians
 - Company representatives
 - NDIS coordinators
 - RPA Gastrostomy Tube Course Online FREE component:
SLHD-GastroStomyTrainingProgram@health.nsw.gov.au
 - Education in Nutrition:
<https://educationinnutrition.com.au/presentations/view/enteral-feeding>
- 