

## Practical Advice and Tools

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### - *For patients with a sensory restrictive eating disorder admitted to acute hospital wards*

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#### Introduction

Acute hospitals can be the right location to support patients with an eating disorder, including when they have short-term, urgent medical needs. However, the right adjustments are needed to support a helpful admission.

We have made this document to support re-feeding admissions on acute wards. This includes giving practical advice and tools you can use. A guideline for professionals is available to help direct medical staff. This is called: **'Emergency re-feeding plans: for patients with a sensory restrictive eating disorder admitted to acute hospital wards.'** The guideline for staff includes advice on risk assessment, re-feeding and medical management. A copy of the ward staff guideline is available via the dietitian or local mental health team. Alternatively, ward staff can contact: [clare.ellison@cntw.nhs.uk](mailto:clare.ellison@cntw.nhs.uk) (lead author) for a copy.

#### Who is it for?

This document supports the staff guideline. It is for patients (or their families) admitted to a hospital ward for treatment for their sensory restrictive eating disorder. This is when a person restricts their eating because of the sensory properties of the food and/or environment. These individuals would usually need adaptations for their sensory differences. These adaptations would support an effective admission.

This document is not intended to support those with anorexia nervosa. This is because different eating disorders differ in how they are best treated. However, you can use this document to support and inform sensory adaptations for those with anorexia nervosa who may also have autism or a sensory processing disorder. These patients should have reasonable adjustments made to their treatment and care (Cobbaert and Rose, 2023) to support a sensory-sensitive treatment approach.

#### What is the aim?

This guidance aims to equip patients and families with some practical tools. You can give these to the ward staff yourself. This can help you to feel more in control of your admission.

#### What is a 'reasonable adjustment'?

*Reasonable adjustments* are mentioned a lot throughout this document. We also use this term in the guidance for staff. An *adjustment* is when your care team make changes to your treatment to accommodate your specific needs. *Adjustments* help to ensure that any treatment you receive is effective. They also minimise any potential harm or disadvantage. *Reasonable* means that the adjustment is appropriate to the care setting. This means that it could be achieved on an acute ward. *Reasonable* ensures that any adjustments are still able to comply with hospital policy: meaning the ward is still able to deliver safe, life-saving treatment according to the clinical need.

This guidance document was written and co-produced by dietitians from: Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust, Tees, Esk and Wear Valleys NHS Foundation Trust, InsightEating, and Bedfordshire and Luton CAMHS Eating Disorders Team

## What does malnutrition, re-feeding and re-feeding syndrome mean?

*Malnutrition* describes a person who has not been getting the nutrition and energy that their body needs. *Re-feeding* describes a person with malnutrition who starts to feed again. *Re-feeding syndrome* is the name of a dangerous medical syndrome. This is something that can happen to some malnourished people who start to consume nutrition again. The risk of developing *re-feeding syndrome* is complex. Your risk is calculated by qualified healthcare professionals (like dietitians and doctors). Your risk depends on things like how long you were malnourished for, how little you were eating, and your current weight or weight loss. *Re-feeding syndrome* is a series of chemical reactions in the body. It is dangerous because it changes the chemical levels in your blood which can affect your heart rhythm.

### Sensory specific re-feeding considerations:

To manage the risk of developing re-feeding syndrome we use scientific evidence and guidelines. Current evidence suggests using a mineral called thiamine. Thiamine should be prescribed daily and for the first 10 days of re-feeding, alongside an age-appropriate multivitamin and mineral. These medications help to keep the heart beating normally. This can help to prevent you from developing re-feeding syndrome. A medication called Forceval is the preferred option of multi-vitamin and mineral. Forceval is available as a tablet or soluble-tablet (called an effervescent). It is also available for both adults and children. Forceval is preferred because it is usually available on the wards and it is 'nutritionally complete'. This means that it provides all the vitamins and minerals that the body needs.

For people with sensory restriction, taking a multivitamin is not usually straightforward. This means that it is not as easy as taking the recommended version and it can present challenges.

If you or your loved one is not able to take Forceval you should discuss alternative options with the ward staff. Some examples of alternative options to consider together might be:

- a. Liquid multi-vitamin (such as Abidec multivitamin drops for babies and children or ketovite liquid in adults)
- b. Other dissolvable preparations (such as paediatric Seravit)
- c. Chewy multi-vitamin/mineral (such as age-appropriate Centrum fruity chewables)
- d. Vitamin spray (such as BetterYou MultiVit oral spray for those aged >13 years)
- e. Vitamin sprinkles (such as Nutrigen Vitamixin for children and young people)
- f. Spatone liquid iron (if applicable)
- g. Chewable calcium (such as calcichew (if applicable))

Please do not bring any medication onto a ward without agreement from the ward staff. This includes multivitamin and mineral supplements. This is because it can be very dangerous. Sometimes, it is not possible to prescribe alternative options, in which case staff may give special permission to bring agreed alternatives onto the ward with you.

### Ward location

Side-room admissions are generally preferable. Side room admissions reduce the total sensory input compared with a ward or bay. This means that the sights, sounds, and smells are fewer. Where possible, using rooms with blinds and neutral colours are preferable. Where possible, separate sensory-friendly spaces are also welcome. Unfortunately, these are not always available.

Hospital staff should be mindful of monitors, trolley sounds and making noise when walking past. They should try to minimise this wherever possible. However, there are often many limitations within the ward setting which make this difficult.

If a side room is unavailable, it may be possible to adjust your location within a bay to make it more helpful. This could include being closer to a window or further away from a bathroom or

nursing station. Ideally any location moves would be planned and wouldn't take place unless necessary.

## Recovery-limiting behaviours

Sensory eating difficulty admissions are not driven by weight/shape concern and weight loss. This means that individuals have not been restricting their eating to lose weight. Therefore, staff need to support those with sensory restrictive eating difficulties differently from those with anorexia.

If you use vomiting to regulate your emotions (rather than to lose weight), this should be discussed with your care team. You should think together about how this risk could be managed or minimised. Think together about what would need to be put in place to safely support, or reduce, this behaviour.

The use of a wheelchair and bed rest should only be used if it is medically necessary for your safety. This is because confined movement for a sensory-sensitive person can be extremely difficult. Movement for these individuals is not driven by trying to lose weight. However, it can often have this *unintended consequence*. An *unintended consequence* means that weight loss could happen as a result of movement, but this wasn't the intention. Because movement can have this unintended consequence it can increase your health risks. We recommend sharing with the ward about how your sensory needs are best managed. This includes any use of movement to regulate your arousal (emotions). You and your medical team can then consider and agree safe options for supporting this.

Example supportive management examples might include:

- Permitting 1 minute of pacing in the room before or after meals
- Supporting an environment that enables you to eat standing up
- Using physiotherapy balls to support movement whilst limiting energy expenditure

Full meal supervision or observation is also not routinely recommended. Instead, the following questions should be considered by you and your care team. These can help to support you in creating an ideal eating environment, which can help to reduce your anxiety:

- 1) *Is there any unwanted sensory stimulus that may cause distress or discomfort before, during or after mealtimes?*
- 1) *Do you prefer to eat with other people? If so, who might this be and can the ward accommodate this person visiting during meal times?*
- 2) *Do you like people to talk to you and encourage your intake? Or do you prefer to eat in silence?*
- 3) *Do you prefer to watch your favourite TV show, use a tablet device or listen to music whilst eating?*
- 4) *Does it help you to wear noise cancelling headphones?*
- 5) *Does it help you to eat alongside reading, puzzles or other distractions such as tablets and radio?*
- 6) *Does your chair have to face the door? Or a specific direction?*
- 7) *Do you prefer to have the curtains closed (if in a bay)?*
- 8) *Can other people touch/prepare your food? Such as others removing lids from food pots.*
- 9) *Does it help you to eat standing, on a beanbag, on or against a hard surface, or sitting on a physiotherapy ball for meals?*
- 10) *If you are sat in a chair, is it of an appropriate size and support? (e.g. can this be modified by adding blankets and cushions to enable you to feel tight and secure in your chair? or raisers placed under your feet as a footrest to make a more stable position for eating?)*
- 11) *Do you prefer to eat in your room or an alternative location?*
- 12) *Do you prefer to be served first or last? Or at a specific time (if possible)?*
- 13) *Do you prefer to eat with your hands?*
- 14) *Do you prefer to eat outside usual mealtimes?*

Additional questions for children and young people:

15) Does it help when the person with you models eating (eats the same food with you)? Or do you prefer to eat alone?

16) Do you prefer it when someone sits next to you? In front of you?

Thinking these through, sharing them with staff, and writing them down can all help the ward to support you in your preferences.

*“I found it very difficult eating in a bay with other people also eating due to the smells and noise, plus ward mealtimes are typically chaotic. It helps pulling curtains around but for cold meals I chose to eat these outside of the typical mealtimes when it was quieter and less smelly!”  
(patient with lived experience)*

Try to consider broader options about how your food is managed in hospital. This means thinking about how your food can be presented so it looks the same. Or how it could be made more acceptable to you (e.g., using specific brands or being kept separate on the plate). It also includes thinking about the type of crockery and cutlery used.

**This checklist (below)** can be used to support your re-feeding menu. It should be completed by you (or your family, as appropriate). It is intended to support your experience and provide guidance to the ward staff. It should be printed and kept in the appropriate place in your care file. Ward staff can then refer to this throughout your admission:

Reasonable adjustment (all if applicable)	Tick if 'Yes'
I would like to bring in and use my own plate / bowl / cutlery/ straw from home	
I would like my milk served separately from my cereal portion	
I would like my beans served separately from my toast	
I would like my butter served separately from my bread/toast so I can add this myself	
I would like my sandwich filling to be served separately	
I would like my fruit cut up rather than served whole	
I would like any 'hot food' to be served cold	
I would like drinks to be served cold from the fridge	
I would like my jacket potato and filling to be served separately	
I would like my baked beans to be ( ) brand	
I would like my biscuits to be ( ) brand	
I would like my cereal to be ( ) brand	
I would like my bread to be ( ) brand	
Where a meal has 2 items I would like these to be served separately rather than put in front of me at the same time. This may mean I have lots of 'eating episodes' but this helps me to avoid feeling too full and reduces my anxiety	
Where possible, I would like my parent to be in charge of bringing me my specified meals and snacks so that they can give me these at more consistent/precise times each day	
Where possible, within health and safety restrictions, I would like to request that my own preferred foods are brought onto the wards	
(If bringing own food onto the ward) I would like to keep this in my room if possible, or to know where this will be stored and how to access it if not	
I would like to request that all my foods remain separate and don't touch one another	
I would like to request a milk alternative e.g. soya/almond/oat/rice/pea/coconut/other (please specify: )	
I would like my food to be served in its original packaging	
I would/would not like to be asked to fill in ward menus	
I would like to know in advance with as much notice as possible of any changes to my planned meals	

This document is unlikely to cover everything that you consider to be helpful. Please use the extra lines to add anything else important or useful to you. You can also add more lines or use a separate sheet of paper. You may find that showing a picture of how you usually like your food to be presented is also helpful.

Further information on supporting sensory eating difficulties can be found from: [PEACE Pathway – Supporting Eating Difficulties](#)

## Self-regulation strategies

*Self-regulation* means ways in which you manage your difficult feelings and emotions. Self-regulation strategies are very different for different people. They depend on your own unique sensory profile. Your sensory profile is often best completed by a specialist sensory Occupational Therapist (OT). However, a useful and simple starting point comes from sharing information. You (and your family) should make a note of any strategies that you use which help you/your child to self-regulate. You can then share these with your care team. Although this list won't apply to everyone, **the checklist** (below) can be used to support you in communicating your self-regulation needs. It should be completed by you (or your family, as appropriate). It should be printed and kept in the appropriate place in your care file. Ward staff can refer to this throughout your admission:

Reasonable sensory adjustment	Tick if 'Yes'
I use stimming* to help me manage difficult feelings. Please give me space to do this and don't draw attention to this or ask for it to stop.  Stimming I find helpful is:.....	
*Example of stimming might include: rocking, tapping, finger-flicking, arm/leg flapping, humming and word repetition.	
I like to use fidget / spinning toys or blu-tack / moulding clay	
I like to use weighted blankets / weighted lap pads	
I like to use temperature extreme objects (such as hot water bottles or ice-packs)	
I like to use a fan (due to the noise it creates and/or how it makes my skin feel)	
I like to use chewing toys / jewellery	
I like to use deep breathing strategies	
I like to use the grounding '5,4,3,2,1 technique'. This means naming 5 things you can see, 4 that you can touch, 3 that you can hear, 2 that you can smell and 1 that you can taste	
I like to use sunglasses in all environments	
I like to have blinds/curtains open or closed at times that you might think are unusual	
I like to use noise cancelling headphones or noise filtering ear-buds	
I like to use white noise machines or background sound	
I like to use engaging activities such as puzzles, art and modelling	
I like to use radio or background music	
I like to use TV or interactive devices	
I like to use	
I like to use	
I like to use	

This document is unlikely to cover everything that you consider to be helpful. Please use the extra lines to add anything else important to you. You can also add more lines or use additional sheets.

In some cases, occupational therapy (OT) departments may be able to support some equipment needs. However, in most cases they will need to be brought onto the ward from home. Anything

you bring from home will need to be agreed with the ward. They must ensure that it complies with their health and safety policy for the safety of all patients. It can be frustrating if something you find helpful isn't allowed. Therefore, try to discuss what is helpful and why, and what you'd like to bring in with you in advance. Your ward should try to support these items, but it may not always be possible.

## Accessible Communication

Patients admitted with sensory restrictive feeding difficulties often feel anxious and concerned. This is a very unpleasant feeling and experience. Many patients have also had previous experience of feeling unheard, judged or blamed. All staff should treat you with kindness and respect. They should try to be empathetic to the challenges you are facing. The ward staff should also make reasonable adjustments in their communication with you, especially if this helps to better support you. Ensuring that their communication with you is accessible and helpful is very important.

Although this list won't apply to everyone, **the checklist** (below) can be used to help you tell staff about your communication needs. The staff can then use this information to better support you. The checklist should be completed by you (or your family, as appropriate). It should be printed and kept in the appropriate place in your care file. Ward staff can then use this throughout your admission:

Reasonable communication adjustment	Tick if 'Yes'
Please use simple and direct language	
Please ask clear, non-ambiguous questions (tailored to my age so I understand you)	
Please only ask only one question at once	
Please slow down your rate of speech	
Please accept that there may be a communication delay. Please give a purposeful pause between your question and expecting a response	
Please give me time to make a decision about something you have asked and come back later	
I prefer to communicate with you without speaking. I like to use ( ) to do this	
Wherever possible, please use visual aids to help me understand your explanations	
Please follow your verbal communication with clear, written information and plans	
Please don't ask me to look at you – I don't like eye contact	
It helps me to have background TV/Music/Other on when you are talking. I am listening to you and I'm not being rude.	
Please check my understanding	
Please speak to me when my parent/carer/nominated-person is with me	
Where possible, please give me a time-frame of when someone will be seeing me, and who they are	

This document is unlikely to cover everything that you consider to be helpful. Please use the extra lines to add anything else that is important or helpful to you. You can also add more lines or use additional pages.

## What is a social story?

A *social story* is a simple, clear description of a certain situation, event, or activity. They include the steps involved in the process and what the person might feel or experience. Social stories can be helpful because they support the safe and meaningful exchange of information. They

can help people understand and feel more comfortable in facing new or challenging experiences.

## Naso-gastric tube feeding considerations

*Naso-gastric tube feeding* is the process of inserting a feeding tube into the nose that goes down into the stomach.

This procedure is sometimes necessary for medical purposes and managing significant risks.

Inserting a naso-gastric tube can be a difficult and distressing procedure for anyone. This is especially true for a person who is neurodivergent or sensory-sensitive. To support as positive an experience as possible, your care team should allow you to be in a sensory-safe environment. This means an environment with dimmed lighting, and one which is quiet. There should also be as few people present as possible during the procedure. Ideally, those present should be individuals you are already familiar with. Inserting a naso-gastric tube can be very overwhelming from a sensory perspective. Being in a safe, low-sensory environment may help to lessen a potentially traumatic experience.

Your care team should discuss the possibility that a naso-gastric tube may be necessary as early as possible. Discussing this at the beginning of your admission may be of benefit and help you better prepare. Some medications can also be used to help you feel more relaxed or to reduce your memory of the process. All medication options must be discussed with you in full. This includes details about their risks and benefits. This information should be communicated with you in a way that you understand.

Unless there is a legal reason, the use of medication and naso-gastric tube feeding will be your choice. Legal reasons include being treated under the mental health act or mental capacity act. If this is the case, you will be made fully aware and informed of this process from the start.

[Appendix 1](#) has an example of a social story to support your understanding about the process of having a naso-gastric tube fitted.

Naso-gastric tube feeding is most usually used when other oral methods of re-feeding have not been possible. This could be for a variety of reasons. An example of a social story about the steps involved in nutrition progression can be found in [Appendix 2](#).

Supporting the explanation of the nasogastric tube process with visual aids can also be helpful. Visual aids are things like pictures or videos or being shown the equipment. These are not always possible but if you think it would help, please ask your care team if it is available. If you have prior experience of naso-gastric tube feeding please share your experiences with your care team. This helps give them information about any preferences-by-experience that you may have.

## Handing over information

Hospital wards always include changes in staff and a process called *staff handovers*. This is where staff share your information and any recent updates with their next colleague. It's important that all your information is handed-over between those working shifts. This helps to reduce how many times you have to tell your story to different people. This helps you to feel heard and helps to develop trusting relationships. Unfortunately, staff handovers can be time pressured. When this happens, despite best intentions, handovers are not as detailed as we'd like. Because of this, we have created **an example template** below that you can complete and print. This can be kept confidentially inside your hospital notes or files. Or, with your consent (agreement), it can be printed and put onto your hospital door. Printing and displaying this 'patient needs' template can work as a practical reminder to all staff before they enter your room.

*To use this template:* staff complete the timings for protected mealtimes in the box below. You (and your family) select your preferences from the list of sensory sentences below. You should delete/cross-out any which do not apply or make sense to you. You can also add any others of your own into the box.

<b>I require protected mealtimes, therefore staff <u>must not</u>:</b>
<ul style="list-style-type: none"> <li>• Enter my room for any non-emergency reason at meal/snack times, for a total duration of 30 minutes</li> </ul>
<b>My meal/snack times are:</b>
1) . 2) . 3) . 4) . 5) . 6) .
<b>I have sensory needs therefore please remember:</b>
<ul style="list-style-type: none"> <li>• I prefer to keep my blinds/curtains drawn at all times</li> <li>• I prefer to keep my lights dimmed at all times</li> <li>• I often choose to wear sunglasses even though you may not think I need them</li> <li>• I like to have something in my hands</li> <li>• I like to keep things in a set order in my room. When you clean, please be very mindful of this. Please ask me how cleaning can be done in a way which best reduces my anxiety or distress</li> <li>• I choose to stand up for my meals</li> <li>• I choose to eat in my chair/bed</li> <li>• I do not like to engage in small-talk</li> <li>• I do not like to talk about food</li> <li>• I use distractions at mealtimes to help manage my anxiety</li> <li>• I often move my arms and legs to help me feel relaxed</li> <li>• I like to be asked questions slowly and clearly</li> <li>• I like to be given time to answer any questions</li> <li>• I prefer to communicate non-verbally (without speaking to you)</li> <li>• I don't like eye-contact</li> <li>• It's important to me that I know who enters my room, please introduce yourself</li> <li>• I struggle to remember faces so please introduce yourself in full every time</li> <li>• I do not like lots of people to visit me at once. Please keep the number of staff to a minimum</li> <li>• Where possible, I prefer to be seen by staff I'm familiar with</li> <li>• It's important to me that I know what is happening – please use language I can understand</li> <li>• I like to know what will happen next</li> <li>• I like to understand the details of what is going on around me</li> <li>• I often ask lots of questions to help my understanding and anxiety. I appreciate you taking the time to provide these details</li> <li>• I like to follow fixed routines</li> <li>• I like to follow fixed time schedules</li> <li>• I do not like surprises or things which are unexpected. Wherever possible, please give me notice and an explanation of anything that is about to happen. This includes anything that may be asked of me</li> <li>• .</li> <li>• .</li> <li>• .</li> </ul>

## Re-feeding meal plans

When a person has a sensory restrictive eating disorder, their food preferences are usually very unique to them. This makes it very difficult to create an example or emergency plan. Although we know this, hospital wards need guidance to help start the re-feeding process. This is essential because it is necessary to keep you safe. This is especially important if you are admitted when there are no specialists available. This is because specialists can help create your individualised plan. There are less likely to be specialists available during a weekend or a bank holiday. Having a 'standardised' re-feeding meal plan available at these times helps to stop people from becoming more unwell. Example re-feeding plans are therefore available in the staff version of this document. This is called: *'Emergency re-feeding plans: for patients with a sensory restrictive eating disorder admitted to acute hospital wards.'*

**Within this staff guidance, we have tailored these example plans for people with sensory selective eating disorders. The ways in which we have done this are as follows:**

### Using naso-gastric tube (NGT) feeding

It is recommended to initially feed a small amount over a longer period. This helps manage blood sugar levels. It also reduces the feeling of nausea and fullness, especially in those with sensitive interoception.

### Using nutritional supplements

*Nutritional supplements* are drinks containing lots of nutrition in a ready-made pre-bottled drink. They can be a very helpful tool. They can help ensure that a patient consumes enough energy, protein, vitamins and minerals. This can be especially helpful for those who require liquid nutrition. This could be due to fears of choking, for example. It can also help those who can only manage small volumes of nutrition due to sensitive interoception. Nutritional supplements can be helpful because they are highly consistent. This is useful if you struggle with taste and texture variation. They can also be helpful for a person who may be avoiding foods due to fears of contamination. This is because they are pre-packaged and ready-sealed. Supplement drinks can be used as the only source of 'food'. Alternatively, they can be used alongside a food or naso-gastric tube feeding plan.

For those with sensory eating difficulties we recommend using a high calorie per millilitre version. This keeps the volume low and helps manage any feeling of sickness. Neutral flavours (e.g., neutral or vanilla) may be better tolerated. It would also be recommended that they are served cold as this can reduce the smell and taste.

Oral nutritional supplements can be given in their original bottle, with a straw. Alternatively, they can be decanted into your own preference of drinking cup. Ice can be added (if helpful and available).

Some people may struggle to tolerate large doses of supplement (e.g., 6 times per day). If this is the case, we have suggested that these are split into smaller, more frequent doses. This can better suit those feeling extreme fullness or sickness. Timings for giving supplements should be clear. This is especially important if you are using a frequency which differs from the ward's usual medication routine.

We recommend that the full range of available supplement options is discussed with you. This can increase the probability that you will find a version best suited to your sensory preferences.

Ward staff should make sure that your preferences are documented and included in their handover. This should include details about your preferred flavour and temperature. It should also include details about how you like supplements to be served.

## Using food

The oral food plan was created using guidance from the award-winning PEACE Pathway menu ([PEACE Pathway - The PEACE Menu](#)). It is intended to give a broadly sensory-accepted menu preference, at specific mealtimes. However, we know that it will not meet the unique sensory preferences of everyone. In many cases, specific foods will need to be brought in from home (such as branded items). This is often due to catering limitations. These alterations should be discussed with the ward staff. Where possible, they should help to support reasonable adjustments for these.

Alternative milk options (e.g. non-dairy) are another example of a reasonable adjustment.

Within the staff document version, there is also an alternative plant-based re-feeding plan available.

## Working with common co-occurring behaviours

Within sensory-restrictive and neuro-diverse patients we often notice obsessive and/or compulsive behaviours (Rhind *et al.*, 2014; Dell'osso *et al.*, 2024). These can include contamination fears and/or practicing specific food routines. These behaviours help to increase the sense of safety around food for an individual. Staff can help you to manage these anxieties by ensuring that you know where your food is stored. Knowing how you can access it, and how it is kept safe and uncontaminated can also help.

Where obsessive and/or compulsive behaviours are observed, it is important to include the mental health team. The mental health team can help support and develop an understanding of these behaviours. This understanding can then be included into your holistic plan of care. A holistic plan of care is an approach that focuses on the whole person and all their wider needs.

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## Review Date

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If you wish to share any comments or feedback about this document, or suggest any ways that the project could be expanded upon, please contact the project lead: [clare.ellison@cntw.nhs.uk](mailto:clare.ellison@cntw.nhs.uk)

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## Glossary of Terms

ARFID	Avoidant Restrictive Food Intake Disorder
OT	Occupational Therapy
TV	Television

## Appendix 1

### **Social Story about Naso-Gastric (NG) Tube placement**

*This social story is an example. Where possible, the language and content of any social story should be tailored to the individual, including considering the circumstance of the admission (e.g. treating under the Mental Health Act) and the specifics of the procedure in your hospital. It may also be beneficial to use photographs of the equipment used/people involved.*

I am getting an NG tube.

An NG tube is a tube that goes into my nose and down to my stomach.

My NG tube will help me to get enough food to stay healthy.

A nurse will put my NG tube in.

I will be awake while I get my NG tube fitted.

I can usually stay in my hospital bed.

Someone can stay with me if I want.

I can ask for medication to help me relax if I feel worried.

I can ask as many questions as I like about my care and what is happening.

The nurse will set up the supplies on a table next to me.

I can choose which nostril I want the tube in.

Sometimes, the nurse will put a piece of tape on my cheek.

This will protect my skin.

It might feel strange, but this is okay.

The nurse will hold the NG tube to my nose.

The nurse will wrap the tube around my ear and measure to my belly.

This helps the nurse know how long the tube needs to be.

The nurse will put some clear gel on the end of the tube.

This will help it slide in my nose easily.

I am now ready for my NG tube.

I need to keep still while I get my NG tube put in.

Someone can help hold my head or hands to remind me.

Sometimes the nurse may ask other nurses to come to help hold my body still to keep me safe.

They might lightly hold my arms, head, or legs.

The nurse will slide the tube into my nose.

I will feel the tube in the back of my throat.

This might feel funny or make me cough, but that is okay.

Usually, the nurse will ask me to take sips of a drink.

This will help the tube find its way to my stomach.

It might feel different when I drink, but it is safe.

When the tube is in the right place, the nurse will tape the tube to my cheek.

This helps the tube stay in the right place and not move.

The nurse will attach a small syringe to the end of the tube.

This helps the nurse check that the end of the tube is in my stomach.

The syringe will not touch me.

Sometimes, the nurse will take me to the X-ray room.

An X-ray is a picture of the inside of my body.

The picture will help the nurse know if the tube is in the right place in my body.

I am all done.

I have an NG tube.

## Appendix 2

### **Social Story about Nutrition Progression**

*Written by a patient with lived experience.*

I am in hospital because I am unwell.

I have been struggling to eat enough of the foods that my body needs.

Me and my family are not to blame.

Food is fuel to my body.

Sometimes it will be difficult to eat solid food because of my sensory difficulties and differences.

I will be offered my safe/preferred foods first.

If I don't manage to eat them,  
Adjustments will be made to support my intake of these.

If I don't manage to eat them,  
I will be offered a liquid replacement called a nutritional supplement.

If I don't manage to drink these,  
I will be offered alternatives that I might find acceptable.

If I don't manage to take these,  
I will be offered nasogastric tube feeding.

If I don't manage to accept this and my life is at risk,  
I will need to be assessed to be given nutrition without my consent as my body needs energy.

The hospital staff will help to explain each of these steps in a way that makes sense to me.

If I am struggling to understand any part of my care,  
I can ask as many questions as I like.

I am not being difficult.

I am trying to get better.