Supporting highly restricted intakes and ARFID in Autism

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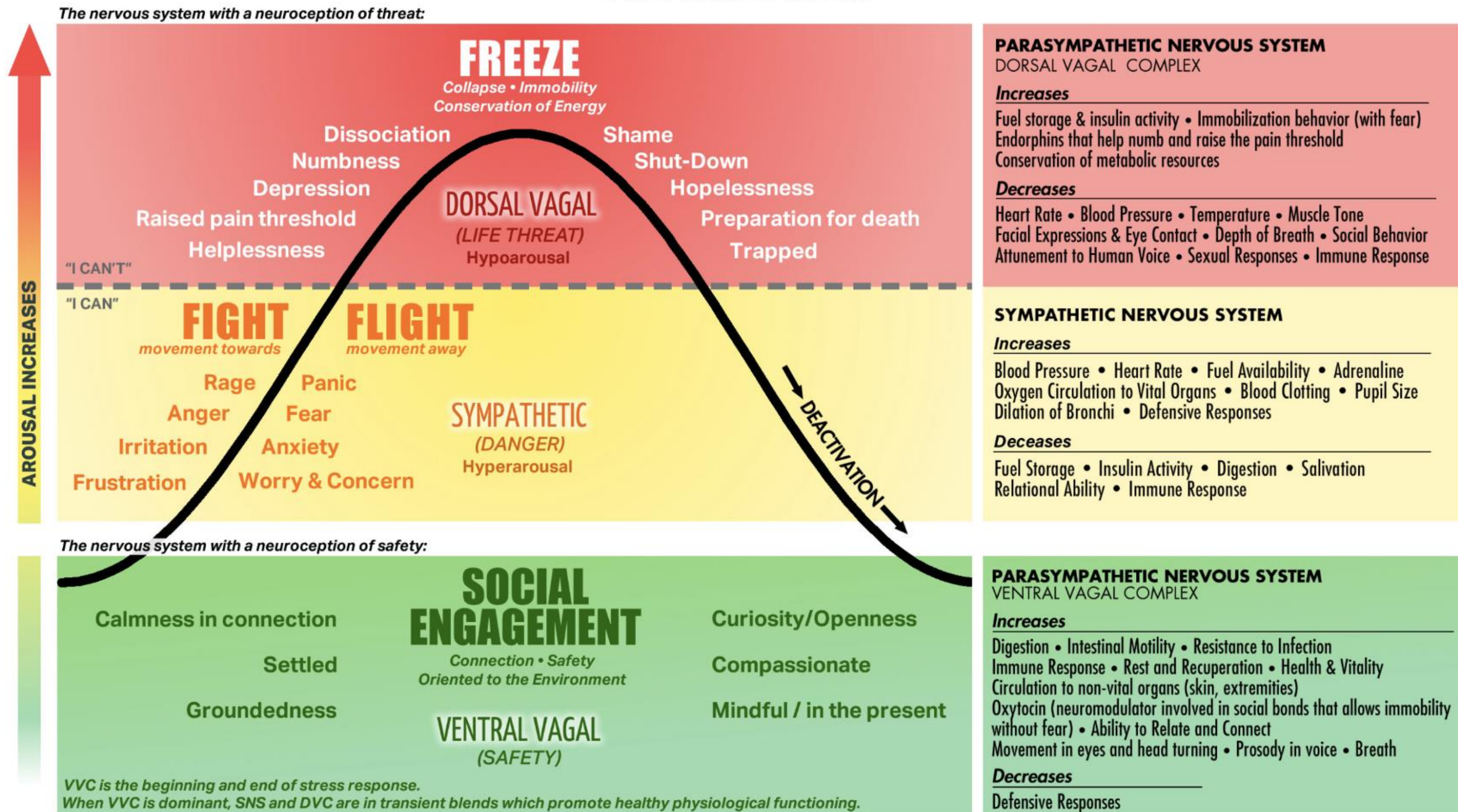
PART OF THE ARFID BDA COMMITTEE

If you are to take anything from today…

- Validate family experience and reduce anxiety and guilt
- And trust that if you are Autistic inclusive and informed you are already doing an amazing job

The nervous system



The Co-regulation

WHAT IS CO-REGULATION?

A Guide to Nervous System Harmony

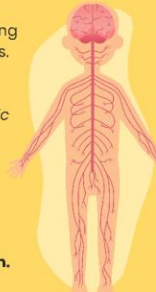
The Role of Co-regulation

Co-regulation is a supportive process where one person helps another manage their emotions, behavior, and physical responses through warm, connected interactions.

This shared experience helps individuals gradually develop self-regulation skills, **making it easier to handle life's challenges on their own.**

The Science of Co-regulation

The autonomic nervous system is key in regulating our emotional responses.



Co-regulation helps balance our *sympathetic* ("fight or flight") and *parasympathetic* ("rest and digest") systems.

This helps us achieve a state of safety and calm.

Why It Matters

Co-regulation fosters a sense of **safety**, especially for people with attachment challenges or trauma backgrounds.

It provides tools to help us understand and regulate our emotions, which supports overall **emotional resilience**.

A regulated client is **better able to engage** in therapeutic activities and learning, and participate in daily life tasks.

Barriers to Co-regulation

and How to Avoid Them

Provider Dysregulation
Use grounding techniques to stay calm when a client is highly dysregulated.

Sensory Overload
Simplify the environment or use soothing sensory tools to ease co-regulation.

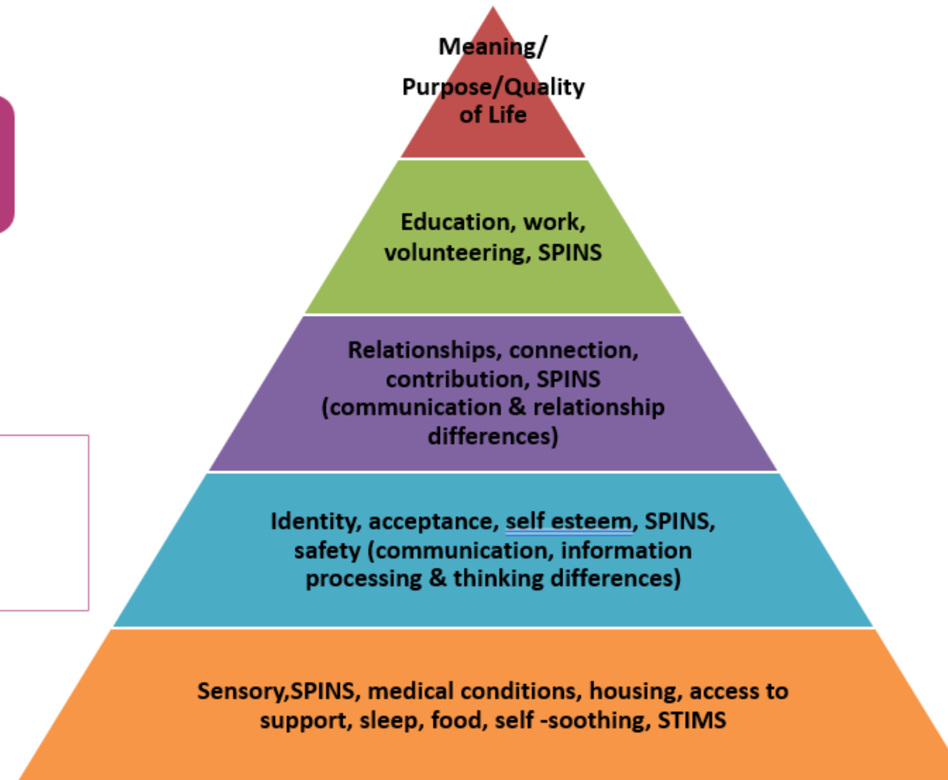
Emotional Escalation
Respond to aggressive behavior with empathy and clear boundaries to encourage calm.

Special thanks to Daphne Boucher BA, MScOT, OT Reg.
Visit unyte.com for more educational resources and to learn more about therapeutic tools for nervous system regulation.

Hierarchy of needs

AUTISTIC PERSON'S HIERARCHY OF NEEDS

EMBED THE AUTISTIC PERSON'S HIERARCHY OF NEEDS



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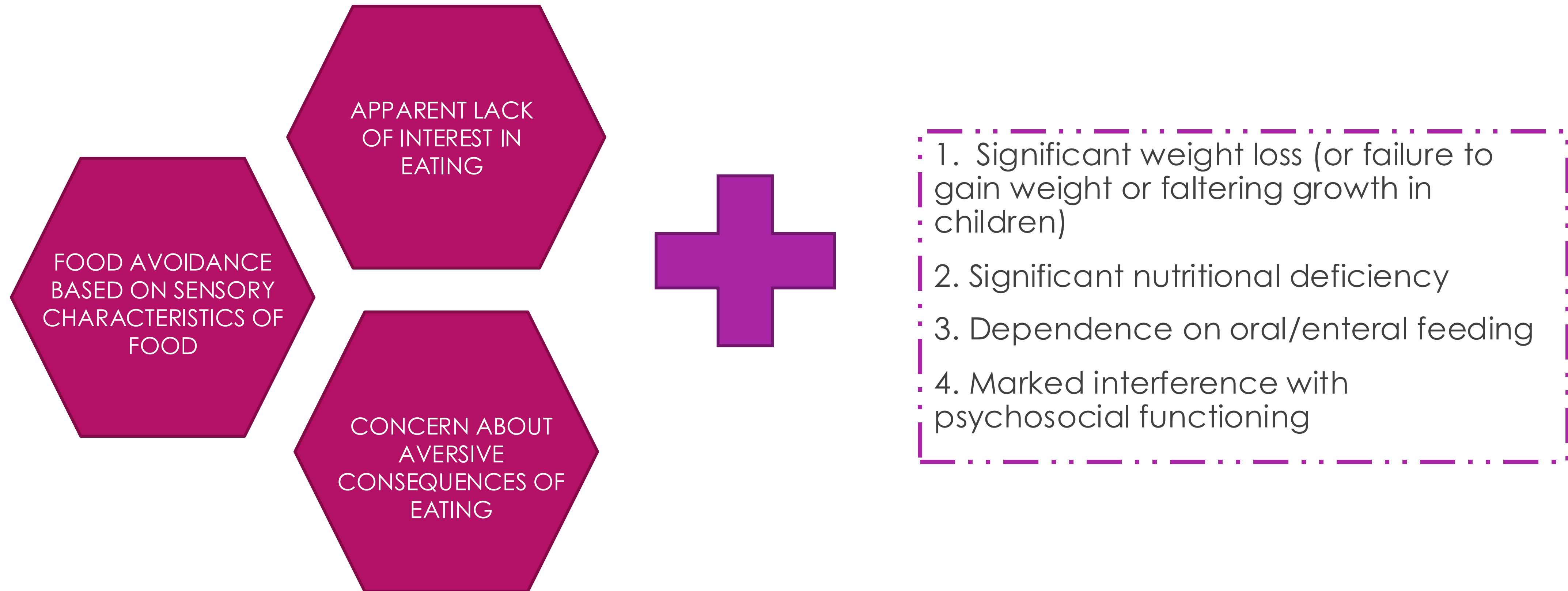
ARFID main drivers



DSM 5, 2013

Boundary with Autism

- ***Boundary with Autism Spectrum Disorder:*** In some individuals with Avoidant-Restrictive Food Intake Disorder, the pattern of food avoidance stems from sensory sensitivities related to the smell, taste, temperature, texture or appearance of foods. For example, an individual may eat only foods of a particular colour or will refuse solids or will accept only a very narrow range of foods based on packaging or a particular brand. Some individuals with Autism Spectrum Disorder may also restrict intake of certain foods because of their sensory characteristics (e.g., hypersensitivity to food texture) or because of inflexible adherence to particular routines (e.g., eating the same foods at the same time in the same order or only eating specific brands of food with specific packaging). However, Autism Spectrum Disorder is also characterized by persistent deficits in initiating and sustaining social communication and reciprocal social interactions and persistent restricted, repetitive, and inflexible patterns of behaviour, interests, or activities that are unrelated to food. If a pattern of restricted eating in an individual with Autism Spectrum Disorder has caused significant weight loss or other health consequences or is specifically associated with significant functional impairment, an additional diagnosis of Avoidant-Restrictive Food Intake Disorder may be assigned.

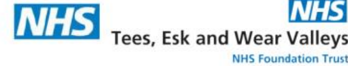
https://icd.who.int/browse/2024-01/mms/en#1242188600

Differential diagnosis

	Food neophobic child	Picky/Fussy eater	Child with ARFID
Rejects new foods	✓	✓	✓
Rejects known foods	✗	✓	✓
Weight loss	✗	✗/✓	✓
Nutrient deficiency	✓	✓	✓
Dependency on supplements	✗	✗	✓
Sensory sensitivity	✗	✓	✓
Engages in food avoidance	✓	✓	✓
Anxiety	✗	✗	✓
Responds to simple exposure	✓	✗	✗

Dovey, T. (2018). Avoidant/restrictive food intake disorder: An eating disorder on a spectrum with food neophobia. In Food neophobia (pp. 329–349). Woodhead Publishing. ISBN 9780081019313. https://doi.org/10.1016/B978-0-08-101931-3.00016-1.

Matrix Tool



Children and Young People
ARFID Severity Index and Severity Matrix Tool

Severity Index Triage Tool			
Mild	**Mild-Moderate**	**Moderate-Severe**	**Severe (meets all or any)**
1 area of impairment (Score 1) which is low-risk / well managed / shows low deterioration Remains in school and psycho-social impact is low / managed with mild adjustments May benefit from non-intensive interventions* (such as third sector, brief group intervention, self-help resources)	1-2 areas of impairment (Scores 1 and 2) requiring occasional use of sip-feeds and/or micronutrient support to manage nutritional risk Remains in school / able to carry out most aspects of routine daily life but these require more support and adjustments Would benefit from short-term targeted therapeutic support - potentially with access to dietetic and medical support depending on the individual need.	2 or more areas of impairment (Scores 2 and 3) requiring consistent use of sip-feeds and/or micronutrient supplementation to support nutrition where the physical impact of this impairment has/will have a notable impact on normal growth and development and meeting physical milestones School attendance and education is impacted and/or requires substantial professional input to sustain with significant support adjustments Meets AMBER risk categories according to the MEED guidelines for physical risk or would meet these if supportive treatment was withdrawn Requires regular therapeutic support including access to a specialist dietitian (with ARFID training) and medical support as needed (speciality determined by need)	Multiple areas of significant impairment (Score 4) resulting in a potentially life-threatening risk (not necessarily an acute risk to life, e.g., substantial nutritional deficiency) and severe impact to quality of life, and long-term health and prognosis Requires/is likely to require inpatient admission Requires extensive/exclusive use of sip-feeds or nasogastric tube feeding to meet nutritional needs Is out of school and is unable to function as normal in most/all psycho-social aspects of daily life Meets multiple RED/AMBER risk categories according to the MEED guidelines for physical risk or would meet these if supportive treatment was withdrawn Requires full and comprehensive support of a specialist dietitian (with ARFID training) and multi-disciplinary team including medical (speciality determined by need) and psychological support

The matrix below is not a specific, sensitive nor validated tool. It is intended to help inform local care planning by giving severity indicators for impairment across domains. A higher score is indicative of a higher level of impairment and/or risk. The tool should not be used in isolation to offer or withhold care. Each case should be considered holistically, informed by individual needs, and in view of local support options.

Authors: Clare Ellison, Ursula Philpot, Sarah Fuller, Kirsty Thompson, Paola Falcoski
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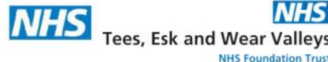
Matrix tool



RISK SCORE	Weight, growth, and physical development	Nutritional adequacy of diet (check food diary with dietitian if unsure about nutritional safety)	Impact on young person's social and emotional development	Impact on family functioning
0 = no risk identified	No concerns regarding weight, height, growth, and physical development	Sufficient intake across food groups (protein, carbohydrates, dairy, fruits, and vegetables) for example >20 foods from 4+ food groups **and/or** adequate intake of vitamin and minerals / **or** is able to take micronutrient supplementation.	Able so participate in a range of usual social events / school settings with some small adjustments	Family are able to make reasonable adjustments to support their young person
1 = some risk but not of immediate concern	Weight is less than 2 centiles below height centile **and/or** growth and height has plateaued for <3 months	>10 foods from 4 food groups **and/or** suboptimal intake of vitamin and minerals but is not deficient / **or** is able to take micronutrient supplementation **and/or** oral nutritional supplementation is being considered	Unable to eat with friends in school though is able to take in their own familiar foods and eat these within school / other social settings	Young person is only able to eat in restaurants or other unfamiliar settings if their safe food is brought from home
2 = moderate risk. Requires consideration when prioritising the intervention	Weight is 2 centiles below height centile **and/or** growth and height has plateaued for >3 months	<10 foods from 2-3 food groups **and/or** deficient in essential vitamins and minerals (Vitamin D/C, Calcium, Iron etc) **and** cannot take micronutrient supplementation **and/or** routine consumption of oral nutritional supplements	Education (academic and/or social-emotional experience) is impacted (e.g. time taken to eat, inability to eat during school). The impact is not better explained by other reasons **and/or** unable to eat in restaurants or other unfamiliar settings / misses social opportunities with peers due to food avoidance and restriction **and/or** mild-comorbid mental health difficulties / neurodiversity impact	Young person is missing out on opportunities to join the family on social occasions outside the home despite considerable accommodations **and/or** family are unable to eat in restaurants or other unfamiliar settings
3 = high risk requiring planned action	Weight is more than 2 centiles below height **and/or** growth and height has plateaued for >3 months **and/or** loss of height centiles **and/or** 2 or more Amber MEED physical risks identified **and/or** symptoms of pubertal delay	<5 foods from 1 – 2 food groups **and/or** multiple nutritional deficiencies known/suspected **and/or** unable to take appropriate supplementation **and/or** routine consumption of oral nutritional supplementation is recommended but the young person is unable to tolerate/consume these **and/or** enteral feeding is being considered	Education (academic / social-emotional experience / attendance) is impacted for reasons related to ARFID **and/or** unable socialise outside the home for reasons related to ARFID (e.g., social events related to food) **and/or** moderate mental health difficulties / neurodiversity impact (e.g. low mood/anxiety, significant comorbid MH difficulties, significant fear of adverse consequences, food distress etc)	Family are unable to consume food outside the home and socialise for reasons related to ARFID **and/or** family are severely limited in their food routine (e.g., only one person can cook / shop / prepare food; family are limited to buying specific products from specific shops on specific days) **and/or** family ill-health or mental-health decline as a direct result of ARFID-related restrictions **and/or** sibling school attendance, mental health negatively impacted as a direct result of ARFID related consequences
4 = very high risk requiring immediate action	Weight is more than 3 centiles below height **and/or** growth and height has plateaued for >3 months **and/or** no height growth for >6 months **and/or** 1 or more **Red** MEED physical health risks identified **and/or** symptoms of pubertal delay **and/or** risk of re-feeding syndrome is identified	Severe malnutrition identified **and/or** enteral feeding is indicated **and/or** multiple nutritional deficiencies known/suspected **and** unable to take the appropriate supplements which is having a significant detrimental impact on physical health (e.g., vision impairment, bone density)	Education attendance is not possible due to reasons related to ARFID **and/or** severe mental health difficulties / neurodiversity impact (e.g., low mood/anxiety, significant comorbid MH difficulties, significant fear of adverse consequences, food distress etc) **and/or** increase in shut-down/arousal behaviours negatively associated to an increased risk to self or others	Family are limited from being able to leave the home for ARFID related reasons **and/or** food routine specificities are causing significant financial stress/burden. **and/or** increase in family high-expressed emotion / violence / aggression **and/or** placement breakdown for LAC families **and/or** sibling(s) unable to attend school as a result of ARFID related consequences

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Overlap with Autism

- Sensory sensitivities
- Anxiety
- Interoception differences – recognising hunger and fullness,

Assessment

- Sensory needs – sensory profile
- Eating patterns – food diary
- Environmental factors – able to eat in different places?
- Emotional factors – what happens when emotions are intense and big?
- Physical health risk – not only weight

Practical strategies

- Prioritise nutritional adequacy using preferred foods: work with the current diet, not against it
- Introduce new foods via food chaining or graded exposure
- Use visual meal planners to reduce anxiety and increase predictability
- Offer choices within structure, avoid pressure or bribery
- Work with families: validate their experience, offer realistic goals, and reduce Guilt
- Adapt the mealtime environment: reduce noise, smells, visual clutter, consider eating in another room
- Offer sensory accommodations: preferred cutlery, plate colour, seating, temperature of food
- Use routines and visual cues: e.g. “first-then” boards, countdown timers, social stories
- Respect food rituals: same brand, shape, packaging- these are often safety signals, not fussiness
- Use visual tools
- MDT work
- Use recovery-informed language: avoid “good/bad foods”, “healthy eating”, or weight-focused goals

What are the expectations?

- Explore this with the family and referrer:
  - Just ‘want a diagnosis’ for school purpose/ extended family/ validation
  - Treatment – what is the the goal and what they expect to change

- We need to explain what are the real expectations and also provide psychoeducation:
  - What hunger looks like and the impact of that in behaviours
  - i.e. if overwhelmed, hunger is not there, sensory sensitivities are heightened
  - Focusing on eating when not addressing basic needs - it will probably not work

What success look like?

- Eating out
- Going to school
- Not being admitted again
- Tolerating food in the room?
- Eating a new brand

- Progress is not linear and the eating cannot 'be fixed'
- Discuss the idea that 'if the eating improves everything will be fine' – they will likely to remain VERY sensitive

Further resources

- Sensory admission document
- Autism position statement
- PEACE pathway

insighteating
insighthealth
Specialist help for eating disorders and health

NHS
North East and North Cumbria
Mental Health, Learning Disability and Autism Partnership

Practical Advice and Tools

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

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

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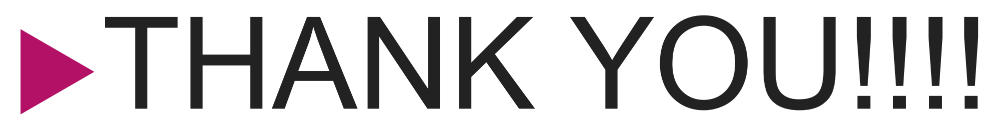
Emergency re-feeding plans for patients with a sensory restrictive eating disorder admitted to acute hospital wards.

Acute hospitals can be the right location to meet the temporary medical needs of young people and adults requiring urgent medical support for an eating disorder, if the correct reasonable adjustments are made to support the admission. Although any acute re-feeding plan needs to be delivered in the context of a highly individualised and formulation-driven treatment plan, physical health and mental health must be taken care of concurrently.

Who is the guidance for?

A sensory restrictive eating disorder is one in which a person restricts their eating due to the sensory characteristics of the food and/or environment. They would typically require adaptations for their sensory differences to support an effective admission. This guidance is intended to support re-feeding admissions on acute wards by providing practical advice and tools for patients with the following diagnoses, or suspected diagnoses: ARFID (avoidant/restrictive food intake disorder), Autism and/or Sensory Processing Disorder.



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