Anorexia Nervosa within the Inpatient Paediatric setting: Protocol for Medical / Nursing management (including dietetic guidelines)

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CARE PLAN ON ADMISSION TO THE PAEDIATRIC WARD

When a young person with an eating disorder is admitted to the ward they, and their family, will be very anxious about what is going to happen. Emotions are often running high (the family will have been struggling with the eating disorder for weeks or months) and the young person may be in a dangerously malnourished state. Patients with anorexia rarely accept treatment willingly (due to their terror of weight gain) and may present as obstructive and non-compliant to the treatment plan being offered. An approach that has been shown to be effective in reducing non-compliance is clearly setting out the care plan on admission to the ward. The following plan should be clearly explained on admission:

1) Young people should, if possible, be admitted to a 5-bedded bay, not a single cubicle.

2) There will be two allowed dislikes during the admission (specific food, not food groups). Staff will not enter into any discussion or negotiation around this.

3) All food choices will be decided by the staff team based on the agreed dietetic plan.

4) On admission the young person will be offered 1/3 portions of their current meal plan (Appendix 4 or what they were eating pre-admission, **whichever is larger**), along with multi vitamins as per local hospital policy, pending the initial assessment by the ward dietician. The subsequent meal plan will be agreed by the dietician and will not be changed unless agreed by the dietician.

5) Meals will be plated up by the catering department, in line with the dietician advice. This will reduce the risk of nursing staff being drawn into discussions and negotiations about portion size. It is important that once plated up by the catering department, no changes are made to the meal at ward level.

6) The ideal rate of weight gain for recovery is 0.5kg – 1.0kg/week. The MDT will set an expectation for this admission and this is not open to discussion or negotiation.

7) The young person will be weighed twice per week - Monday and Thursday, prior to breakfast and in their nightwear (not in a dressing gown), an hour post morning wee. Ensure the same scale is used - sitting if possible. The first weight should be the morning after admission. The default, unless otherwise stated- to be discussed and agreed at MDT review, the young person should be informed of their weight (to avoid the distorted perception that their weight is rising at an uncontrolled rate).

8) Multi-vitamins should be given on admission and regularly as per local hospital policy.

9) The eating regime should be presented as the 'prescribed medicine' that the young person requires because their low weight is having such a severe impact on their physical state.

10) The following time-limits should be adhered to:

➢ Breakfast & lunch	30 minutes
➢ Evening meal (including dessert)	30 minutes
➢ Snack	20 minutes

At the end of these times, leftover food should be removed. Follow dietetic guidelines for non-completion of meals. If the meal has not been eaten at all, the young person should be given Oral Nutritional Supplement (ONS) (see ONS details in Appendix 5). This should always happen, even if the ONS is refused. The aim is to give a clear and consistent message that if they do not eat, the ONS needs to be drunk to ensure their medical condition does not deteriorate to the point where NG tube feeding will be required. The ONS should be presented once at the end of each meal that has not been completed. If the ONS is refused / thrown away that is the end of the nursing intervention for that meal / snack.

11) The young person should go to the toilet before their meal or snack. This ensures they have no reason to visit the toilet after eating and reduces the risk of them purging after food has been consumed. The young person should not visit the toilet (or bath/shower) for 1 hour after each meal.

12) Fluids: Patients should have their fluid intake carefully monitored. Fluids (e.g. bottled water) should be dispensed by the nursing staff. Patients should not have access to fluids in bedside cupboards etc. due to the risk of water loading (either to manipulate weight or to fill stomach making eating more difficult). Patients should be restricted to maintenance fluids over 24hrs.

13) In order to minimise disruption to the refeeding programme, parents and carers should be advised to visit during the evening, or between the main mealtimes of the day. If they visit during meal or snack time, they should be advised at admission that they will need to leave the ward until the meal or snack is completed. Unless agreed at twice weekly MDT reviews for parents/ carers to support with meal times (as documented on care plan). (*By the time of admission, it is not uncommon for parents to have become entrenched in colluding with the anorexia and feel disempowered by the resistance they meet at mealtimes. It is therefore not unusual for parents to appear to support the young person in their attempts to avoid eating)*

14) On admission, the young person should be informed they will be on bed rest (resting on bed or sitting in chair). They will take a wheelchair to the toilet / bathroom. This arrangement can only be changed at formal care plan review meetings and is non-negotiable.

15) On admission, a date for an initial Care Plan Review meeting should be arranged. This meeting must include the named paediatric staff nurse, senior paediatrician, a senior member of the CAMHS TEDS team, the ward dietician, the young person and their family. This meeting should be held on the next working day following admission with subsequent meetings on a twice weekly basis throughout the admission. Changes to the care plan must only be made via this care plan review process. In the event of an

urgent need to review the care plan, this should be done between the consultant paediatrician and senior member of the TEDS team.

It is essential for the successful implementation of the refeeding programme that staff on the unit are all consistent with this approach. The nature of anorexia means that the young person will use every opportunity to disempower staff through splitting and drawing them into negotiation. This behaviour is part of the illness and is a direct consequence of starvation.

GUIDELINES FOR BEHAVIOURAL MANAGEMENT OF MEALTIMES

Managing mealtimes is often a very difficult and emotionally exhausting experience for ward staff. The young person with anorexia may show high levels of distress and animosity towards staff. Their anorexic thinking will drive them to attempt to engage staff in negotiations about the food and to try to distract staff so they can dispose of food (some young people are very skilled at this). Staff will therefore need to be highly vigilant during meals. Staff should adopt a calm, but firm approach in their refusal to engage in negotiations around food.

Staff can use mealtimes to build rapport with the young person by engaging them in conversation. Staff must be careful that conversation is not used to avoid eating. The young person should be consistently reminded that conversation can continue as long as they are eating their food.

Staff should communicate a high expectation to the young person that they need to complete all meals and snacks plus drinks. This may be met with resistance and fierce protestations; continuing to give this message is very helpful in breaking down anorexic resistance.

HOW TO ENGAGE A YOUNG PERSON WITH ANOREXIA

A young person with anorexia can evoke very powerful responses within staff ranging from extreme anger to a sense of wanting to befriend them and make them better. Anorexia can be powerful in 'sucking' staff in to unhelpful alliances with the young person. Although at the time this feels like it is helping the young person, it is quite destructive to their management as it becomes harder to set firm boundaries and enforce the food prescription. The following behaviours may indicate this is happening:

THE YOUNG PERSON BEGINS TO REQUEST SPECIFIC STAFF TO LOOK AFTER THEM

- Do not make staff changes in response to this
- Make the young person aware that they cannot request this and that all staff are able to look after them

DRAWING STAFF INTO DISCUSSIONS ABOUT OTHER STAFF AND THEIR LIKEABILITY (SPLITTING BEHAVIOUR)

- Make the young person aware this is not an appropriate discussion and you cannot discuss other staff with them
- Encourage them to discuss their concerns with the staff member directly or with their keyworker

BRINGING GIFTS IN FOR CERTAIN STAFF

- Adhere to trust policy re: the receiving of gifts

INDICATING ONLY CERTAIN STAFF UNDERSTAND THEM

- Reinforce to the young person that all staff are there to support and understand them

DEALING WITH SPECIFIC BEHAVIOURS

ATTEMPTS TO DRAW STAFF INTO NEGOTIATIONS / ARGUMENTS REGARDING FOOD CHOICES AND DISLIKES

- Calmly and consistently remind the young person of the rules set out at admission: this is not open to discussion
- Attempt to direct the conversation away from the argument

USING CONVERSATIONS / TV / MUSIC / GAMES / PHONE TO AVOID EATING AT MEALTIMES

- Explain that you are concerned the conversation /TV etc are being used to avoid eating and that they will not be available during mealtimes

PARENTS ENGAGE IN NEGOTIATIONS WITH STAFF RE: FOOD CHOICES AND ARE ON THE WARD PRIOR TO MEALTIMES

- Staff to remind parents of the agreement at admission and support parents to disengage from the young person before and during mealtimes. Parents to be advised they can return to the ward once mealtimes are finished.

RELUCTANCE TO BEGIN THE MEAL

- The young person is to be firmly told that they need to pick up their cutlery and start eating. This may need to be firmly and calmly repeated. *(The resistance is driven by extreme anxiety and the longer the young person sits in front of the meal without eating, the more likely the anxiety will be reinforced).*

WEARING OF BAGGY CLOTHES AND LONG SLEEVES, CONSTANTLY WIPING HANDS ON BEDCOVERS AND CLOTHES DURING MEALS, DROPPING FOOD ON THE FLOOR, CRUMBLING UP FOOD, LETTING FOOD DROP OFF THE SIDE OF THE PLATE.

- Staff to supervise all meals and sit with the young person for the duration of the meal / snack.
- The young person is to be firmly told that if they dispose of food it will be replaced by staff
- Young person's sleeves to be rolled up if food is being hidden in them
- All crumbs on plate to be gathered together and eaten at the end of the meal

(The young person may not be aware they are doing these behaviours but may be very skilled at disposing of food. Staff need to be extra vigilant during mealtimes).

SCREAMING / SHOUTING / THROWING FOOD OR OBJECTS

- Be firm and persistent, calmly telling the young person that you understand their distress, but they need to eat their food
- Any thrown food is to be replaced either by food, or by an ONS as per dietetic feeding plan
- Seek support of colleagues if the level of distress is overwhelming and difficult to manage

(A young person's level of distress at mealtimes can be very high and the above behaviour is often driven by the sheer terror of having to eat. Staff can be left feeling powerless and distressed themselves).

HELPFUL THINGS TO SAY AT MEALTIMES

- "You need to pick up your knife / fork / spoon and begin to eat"
- "you need to eat as it is part of your prescribed treatment here"
- "I know you don't want to eat it but you have no choice as I am saying you have to eat it"
- "I am not prepared to get into any discussion with you about the food – I am telling you to eat it"
- "I cannot get into a discussion with you about how much of the meal you are to eat – you are expected to eat all the food"
- "I am reminding you that you have …..minutes left to eat your food. You need to put the food in your mouth and eat it"

Do not enter into discussions about number of calories taken of the total calories of the meal plan.

If behaviours persist discuss with the CAMHS MDT. Consideration may be given for use of anxiolytic medication e.g. olanzapine. This would be recommended by a CAMHS psychiatrist but would need to be prescribed by ward staff.

NON-COMPLETION OF MEALS

If any of the main meal or dessert is left (e.g. if one mouthful is left) then an ONS (See Appendix 5) must be given. If a young person would rather have a second attempt to finish their meal rather than an ONS, they should be allowed to do so. 10 minutes should be allowed for this. If the meal is not completed in this time, an ONS should be offered as before.

It is reasonable for a young person to finish the ONS in 10 minutes. If the main meal is not completed in full, provide the ONS, then offer dessert. If dessert not eaten in full, then offer another ONS.

GUIDELINES FOR MANAGING PHYSICAL ACTIVITY

It is important to remember that any energy that the young person takes in through eating is reserved for restoring tissue in order to stabilise their medical health. Therefore, a young person being treated for anorexia on a paediatric ward should engage in minimal physical activity.

Young people with anorexia will be driven to exercise at every opportunity in order to reduce their weight. This can be done via quite subtle behaviours:

(1) Constantly standing up
Remind the young person that they are currently on bed rest due to the level of concern about their physical state

(2) Constant arm and leg movement / walking up and down the ward / offering to help staff give out meals / delivering post / checking on other patients / finding odd jobs to do
Remind the young person of the severity of their illness and firmly insist that they return to sitting down on their bed or a chair

(3) Going to canteen / coffee shop with visitors / walking outside in the cold / wanting to sit outside in the cold / wanting to sit in the heat with large jumpers on (these are ways of expending energy)
If the young person wishes to have fresh air, they must be taken out in a wheelchair with a clear instruction to whoever takes them out that they are not to walk anywhere. Trips out should be agreed at the MDT care plan review meetings, should be time-limited and only granted if the young person is co-operating with their treatment.

(4) An eagerness to be very helpful around the ward
Acknowledge the young person's wish to be helpful but remind them that because of their physical health they are not able to help in a physical way. They could be offered opportunities to engage in alternative activities such as making a card, playing a game (sitting down), reading, listening to music, watching TV.

NASOGASTRIC FEEDING

(Please see NG feeding flowchart: Appendix 2)

The first line in dietary management should always be with normal food in line with the dietetic 'mealtime prescription'. If this proves difficult the diet can be supplemented with ONS (See appendix 5).

Nasogastric feeding should always be seen as a very last resort in the dietary management of a young person with anorexia nervosa. It may be medically necessary in some cases, but it does not allow the patient to become engaged with the recovery process and is of very limited use when looking at longer term recovery outcomes.

If nasogastric feeding does need to be used due to the young person's medical needs, then **the aim is to use it for the shortest time possible and to continue to strongly encourage the young person to eat if they are physically able to tolerate it. <u>The hospital guidelines must be adhered to when initiating enteral feeding.</u>**

IMPLEMENTATION OF NASOGASTRIC FEEDING

Initiating nasogastric feeding should be based on a review of the young person's progress, considering their level of compliance with the prescribed meal plan and/or deterioration of their medical condition below the parameters set at admission. **Unless in an emergency situation (very rare), the decision to commence nasogastric feeding should be taken at the MDT care plan review meeting with TEDS and ward staff.** Hospital guidelines should always be followed. Progress should then be reviewed by the paediatric team and at the weekly review meetings. The paediatric dietician should oversee the NG feeding regime.

The decision to initiate NG feeding should be made following consultation with the young person and their family. If the young person refuses, the consent of those with parental responsibility can be sought. However, in these circumstances it is helpful to seek legal advice through the trust to ensure the rights of the young person are being met. Use of the Mental Health Act may need to be considered.

GUIDELINES FOR NASOGASTRIC FEEDING

- Pass the NG tube and leave in situ.
- Use bolus feeds unless otherwise indicated.
- Staff should continue to offer food as per the meal plan and communicate a high expectation that the food will be eaten. If food is refused or no attempt is made to eat or complete the meal in the time limit, then a bolus feed is given via the NG tube (guidance for managing partial meal completion will be set by the ward dietician).
- If the young person does eat, they need to comply fully with the daily meal plan until the next review day when a decision will be made as to whether the tube can be removed. The young person should be given a positive message that the tube will be removed if they fully comply with the prescribed meal plan.

WEIGHT

The ideal rate of weight gain, for recovery, is a weekly gain of **800g,** which is considered optimum as a psychiatric inpatient (NICE). The team will set an expectation for this at admission as weight gain may not initially happen in some patients and so the expectation will instead be agreed for the weight to be maintained and for a regular eating pattern to be established. There may be variations in the early stages of refeeding. Often once a young person starts building up their intake you may notice an initial weight gain followed by stabilisation or even slight weight loss. This can be due to unmatched nutritional requirement. Fluid retention and oedema can occur in the initial stages of refeeding; this should resolve in 7-10 days.

OTHER ISSUES THAT MAY ARISE DURING ADMISSION

1. **Running away from the ward**
   Staff to adhere to the Trust Missing Person Policy
2. **Self-harming behaviour**
   Staff to seek advice from the TEDS / CAMHS liaison service
3. **Young person refuses to consent to treatment interventions, including refeeding**
   Staff to discuss with TEDS consultant and consider legal framework for provision of treatment
4. **Young person exhibits obstructive or aggressive behaviour towards staff**
   The young person is to be given a clear message that this will not be tolerated. Staff to adhere to Trust policy on management of aggressive behaviour towards staff.