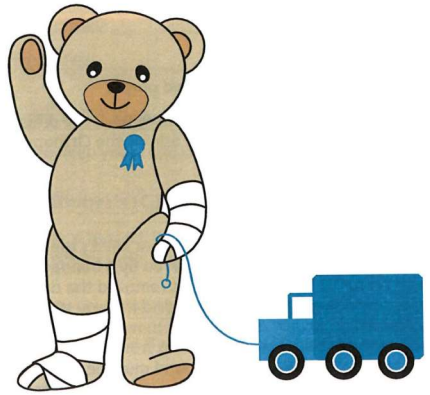
Guidelines for behavioural and physical management of young people with suspected or confirmed Eating Disorder



Information booklet for parents

Admission Process:

Your child has been admitted to the paediatric ward for treatment due to medical concerns relating to Anorexia Nervosa with the aim of stabilising their physical health. An important aspect of their treatment will involve ensuring that they have adequate daily amounts of food and drink.

We know that this can be a very distressing and difficult time both for yourself and your child. We believe that it is most helpful if you are fully informed of your child's treatment plan on admission to help you know what to expect.

Although the following plan may appear strict and rigid, we hope that it will make things clear and you will feel confident about what will happen during your child's admission. We also recognise that every families experience will be different so there may be scenarios in this leaflet that you do not feel apply to you. We are also aware that your child may not have received a formal diagnosis yet but we have assumed that a diagnosis of an Eating Disorder may be given.

Once your child has been admitted and settled onto the ward, we will go over their meal plan.

Meals times:

Breakfast: 8am
Morning snack: 10am
Lunch: 12pm
Afternoon snack: 3 or 3:30pm
Dinner: 5pm
Evening snack: 8pm

The Children's Eating Disorder Team (CEDS) may already be aware of your child's admission. As your child has been admitted to medically stabilise them, they are not often reviewed on the ward by the CEDS during their stay although they may call you if you are known to them. The CEDS hold a weekly professionals meeting to discuss all young people on a ward for re-feeding to help with management. CEDS will

Beat services
• Visit beateatingdisorders.org.uk for information and online support groups.
• Search helpfinder.beateatingdisorders.org.uk for services in your area.
• Call the Youthline on 0808 801 0711 or email fyp@beateatingdisorders.org.uk.

Rethink
Information and support for anyone affected by mental health issues. Visit rethink.org or call 0300 5000 927.

Self-harm UK
A charity supporting young people who are self-harming, which can sometimes occur alongside an eating disorder. Visit selfharm.co.uk.

Books

- Overcoming Problem Eating by Patricia Furness-Smith
- Getting better bit(e) by bit(e), a survival kit for sufferers of bulimia and binge eating disorders by Ulrike Schmidt and Janet Treasure
- Eating Disorders: The Path to Recovery by Dr Kate Middleton
- Anorexia nervosa, A recovery guide for sufferers, families and friends by Janet Treasure and June Alexander

Websites

https://seedeatingdisorders.org.uk/

beateatingdisorders.org.uk

https://www.youtube.com/user/EvaMusby

https://www.sabp.nhs.uk/mindsightsurreycamhs/services/MH-LD/ED-CYP

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be made aware of your child's discharge as needed and community follow up arrangements will be offered where appropriate.

Care Management Plan:

1) Your child will be weighed in A+E and in the morning after their admission. From then on, they will be weighed twice a week, prior to breakfast, in their nightwear (without a dressing gown).

2) Please let us know of any allergies that your child has or any dietary preferences that pre-dated their illness. Dietetic staff will be involved to ensure adequate nutrition. Please do not engage in any negotiations with your child regarding food choices. It is helpful to remind your child that their diet is like a prescribed medicine.

3) All meals and snacks will be supervised by parents and the following time limits will be followed:

- 30 minutes per main meal
- 20 minutes per dessert
- 30 minutes for breakfast
- 20 minutes for snacks

We know that eating can be a very distressing experience for someone with an Eating Disorder. In our experience we have found that the most effective approach to this is to be supportive but firm in the expectation that your child will eat all of the food given to them. At the end of these times any left-over food will be taken away and your child will be given a supplement drink to achieve the calories they need.

4) As there is significant concern about your child's physical health at the moment, they will be on strict bed rest and will be expected to go to the toilet with family or nursing observation. This is to ensure that your child is supported in resisting the urge to exercise or purge following a meal. Minimal physical activity (e.g.; walking short distances around the ward) is planned into their treatment once they are more physically stable.

5) It is likely, that in the weeks leading up to this admission, that you have been extremely worried about your child. We know that a lot of young people will have shown high levels of distress and anger at mealtimes and you may have found yourselves backing down for fear of this behaviour. We would like parents/carers to be able to support their child's meals whilst they are on the ward, so that you feel equipped to continue to support them once you are home.

6) Decisions around your child's care plan will be made by the whole team (paediatrician, psychiatrist, nurses, and dietician) at a weekly review meeting and you will be kept updated of any changes.

7) Your child's physical health will be monitored closely whilst you are here including regular vital signs (heart rate, blood pressure, temperature etc.), daily blood tests and ECG's. When someone starts eating again after a prolonged period of starvation, there is a small chance that someone can develop 're-feeding syndrome.' This is when there is a shift in fluids and electrolytes due to hormonal and metabolic changes which can cause serious complications. The risk of this can be minimised by carefully increasing someone's calorific intake and starting them on a multivitamin, Vitamin B and Thiamine if necessary.

8) Your child's calorie intake will be increased whilst they are here with advice from our dietitians. It is not uncommon for someone to lose a bit of weight as re-feeding commences and before beginning to restore their weight. Your child will be discharged home on a diet that will help them to restore weight and this will be reviewed within the community. This is not a diet they will have to eat forever, and it is important to remind them that this will only be the case whilst they are restoring weight.

We know this care plan may feel daunting at the moment but it is important to remember that the aim is to help your child to be physically well enough to continue their recovery at home, with community support, as soon as possible. We are here to support you with the plan as much as possible. Please feel free to ask any questions to the team caring for you.

distress is overwhelming and difficult to manage.

Guidelines for the management of physical activity

It is important to remember that any energy that the child/young person takes in through eating is reserved for restoring tissue in order to stabilise their medical health. Consequently a child/young person being treated for anorexia on a paediatric unit should engage in minimal physical activity.
Patients with anorexia may be driven to exercise at any opportunity in order to reduce their weight. This can often be done through quite subtle behaviours such as:

Behaviour	Response
Constantly standing up Constant leg and arm movement Walking up and down the ward Offering to help staff give out meals, deliver post. Circulating around the ward under the premise that they are seeing how other children are.	Remind the child/young person that they are currently on bed-rest due to the level of concern about their physical state. Remind the child/young person of the severity of their illness and firmly insist that they return to sitting down on their bed or a chair.
Going to the canteen/coffee shop with visitors. Being desperate for the need for fresh air and a walk outside in the cold. Wanting to sit outside in the cold with very little on or in the heat with large jumpers on (this is a way of expending energy).	If the child/young person wishes to get some fresh air then they must go in a wheelchair with a clear instruction to whoever takes them out that they are not to walk anywhere. Trips out should be time-limited and only allowed if the child/young person is co-operating with their treatment.

We hope that you've found this booklet helpful, but we know that you'll have a lot more questions and may need other resources. Here are some that you might find helpful:

	repeated.	meal without eating then the risk of the anxiety being reinforced increases.
Wearing of baggy clothes and long sleeves. Constantly wiping their hands on bedcovers, clothes during meals. Dropping food on to the floor. Crumbling food up or letting it drop off the side of the plate.	Parents are to supervise all meals and snacks. A staff member/parent should be sat with the patient for the duration of their meal or snack. The child/young person needs to be firmly told that if they attempt to get rid of food during the meal then it will be replaced by staff. Long sleeves need to be rolled up if staff/parents are concerned that food is being hidden inside them. All crumbs on the plate need to be gathered together and eaten at the end of the meal.	A child/young person with anorexia may exhibit all or some of the above behaviours. They are not always aware that they are doing them, although they may also be very skilled at using every opportunity to get rid of food. Consequently staff/parents needs to be extra vigilant during mealtimes for any signs of attempts to get rid of food.
Screaming, shouting, throwing of food and/or objects.	Continue to be firm and persistent, telling the child/young person that you understand their distress, but they need to eat their food. Any thrown food is to be replaced either by other food or a food supplement as per dietetic food plan. Staff and parents to seek support if the level of	A child/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, but can often leave staff feeling powerless and distressed themselves.

Guidelines for the behavioural management of mealtimes

Management of mealtimes can be a very difficult and emotionally exhausting experience. The young person with anorexia may exhibit high levels of distress and animosity towards staff and care givers. Their anorexic thinking may drive them to attempt to engage staff and family in negotiations regarding food and also distract them in order to dispose of food.

This means that parents, carers and staff will need to be extra vigilant during meals, but also calm and firm in their refusal to engage in discussions regarding food.

It is helpful if everyone can communicate a high expectation to the young person that they need to complete all meals and snacks plus drinks. Although this may be met with initial resistance and protestations, continuing to give this message can be very helpful in breaking down anorexic resistance.

From the start of your child's admission it can be helpful for you to have a conversation with your child about working through the admission as a team and that you are on their side, and not on the side of the eating disorder.

It can be difficult to know how to respond to the young person's resistance at mealtimes and people around your child can often feel powerless in being able to get them to eat. The following responses can be helpful. Although the phrases sound very mechanical, repeating them in as neutral a tone as possible gives the young person a clear message that you are in charge and will not become engaged in arguing about the meal.

- "You need to pick up your knife and fork/spoon and begin to eat "

- "You need to eat your food as it is part of your prescribed treatment here."

- "I know you do not want to eat it but you have no choice as I (the doctors/ eating disorders service) are saying that 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 discussion with you about how much you are to eat, you are expected to eat all of 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."

Outlined below are details of some of the behaviour you may experience with and tips on how to respond to this. **Consistency in approach with staff and family is crucial.**

Behaviour	Response	Comment
Attempts to draw staff into negotiations or arguments regarding food choices and dislikes.	Consistently and calmly remind the child/young person of the rules set out at admission and that this is not open to discussion. Attempt to direct the conversation away from the argument.	Dislikes of food are not allowed during treatment unless there is an established medical reason for this. In the majority of cases the dislike can be directly linked to the onset of anorexia and allowing these continues the power of the anorexic thinking. Initially there may be resistance to this but if staff/parents continue to be firm with this approach the young person does accept it.
Evidence of using mediums to avoid food/eating at mealtimes.	Explain to the child/young person that you are concerned that the TV/music/conversation are being used to avoid eating and that they will not be available.	It is not unusual for patients with anorexia to use mediums such as watching TV, listening to music, engaging in conversation to avoid eating. If this is apparent then such mediums should not be available during mealtimes.
Parents engage in negotiations with staff re food choices and are on the ward prior to mealtimes.	Staff to support parents in disengaging from the child/young person.	Often by the time of admission parents have become entrenched in colluding with the anorexia and feel disempowered by the strength of resistance they are met with when attempting to get their child to eat. Consequently it is not unusual for parents to appear to support the young person in their attempts to negotiate their way out of eating certain foods.
Reluctance to begin the meal.	The child/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	This reluctance is driven by extreme anxiety and the longer the child/young person sits in front of the