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Highfield Unit Eating Disorder Program

Parent and Carer

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**Case team**

Primary Nurse:

Secondary Nurse:

Care Assistant:

Link Worker:

MHW:

Current Weight Deficit:

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**What is an Eating Disorder?**

There are many eating behaviours which are typical of eating disorders. You do not need to meet all the criteria to be diagnosed with an eating disorder and there are different types including anorexia nervosa and bulimia nervosa.

If someone has **anorexia** they are likely to:

* deny they feel hungry, despite not eating
* be obsessed with losing weight
* count calories meticulously
* hide food or secretly throw it away
* completely avoid high-calorie foods
* make themselves sick
* exercise excessively
* use drugs that reduce appetite or speed up digestion
* wear baggy clothes to cover up any weight loss, or to keep warm
* believe that they look fat, although they are considered underweight by other people.

Anorexia can affect every aspect of life: the way you think, your concentration and your ability to move around. Anorexia is a serious, life threatening illness.

If someone has **bulimia** they are likely to:

* eat in binges (excessive quantities all in one go)
* starve themselves after eating
* make themself sick or use laxatives (known as ‘purging’)
* think constantly about eating
* eat in secret
* have irresistible cravings for certain foods
* think of themself as fat.

If someone has bulimia their weight may stay roughly the same, so it is not so visible. Because of this, people are less likely to notice the illness or offer help without someone asking. This can make it harder to get support even when someone feels ready to try to get better.

*Some of the examples and advice provided in the in this booklet are taken from the book “skills based learning for caring for a loved with an eating disorder” by Janet Treasure, Grannie Smith and Anna Crane (2007) and the Young Minds website (www.youngminds.org).*

**Who experiences problems with eating?**

While people may feel that a problem with eating is unusual or shameful, it is actually very common.

* Eating disorder charity beat has estimated that at least one million people in the UK are affected of which around 11% are male.
* It can develop in boys, girls, men and women, regardless of background.
* As many as 1 in 20 women will have some form of eating problem.
* Compulsive eating seems to be a problem for both men and women, equally, at all ages.
* It’s possible for people to experience both anorexia and bulimia in the course of their lives.

Eating disorder behaviour can provide short term and relatively quick relief from distress. It can seem to an individual that the benefit of relief from distress, increased sense of well being, and control over difficult emotions far outweighs the costs of their eating disorder.

The initial stages of treatment on the Eating Disorder Service focus on supporting the individual and their family, to develop healthy distress tolerance strategies necessary in order to **accept** and **tolerate** food. We focus on making the behavioural changes needed to overcome the illness, only then can young people make cognitive changes.

It is important to remember, that there is **no single cause** of an eating disorder.

**Highfield Unit Eating Disorder Program**

It has been found to be helpful to highlight with young people admitted to Highfield on the Eating Disorder Programme that the Highfield staff team are here to support the Young Person in their **recovery** from an eating disorder and to promote more “normal” eating behaviours.

We aim to assist young people to regain both physical and mental health. We can help **advise** on how to continue with aspects of the programme after discharge into the community. It is important to note that the programme is **time limited** and both parents and young people need to be motivated and actively involved in order for it to be effective in treating the eating disorder. Strategies learnt as an inpatient can be used in the community to support long term change which is why HFU an emphasis on **family involvement**. This has been demonstrated in research to be the most important part of a teen’s recovery (Ivan Eisler, 2010).

We continue to treat young people as individuals and recognise that in turn there will be **differences** in different staff approaches. Recovering from an Eating Disorder involves **accepting** those differences whilst balancing with a fair approach. The team have drawn up these expectations to assist us all to work together in a **fair** and **consistent** way.

**Assessment and Period of Treatment**

Ideally prior to admission each young person will be assessed and motivational work commenced, although this is not always possible. The **case team** will be at the forefront of everyday work on the unit with a young person and will provide support throughout the admission. Your child’s PN and CA will aim to meet with them on a weekly basis. The SN will maintain contact with you and give updates regularly on your child’s care.

Regardless of the stage of the EDP, the focus will initially be upon weight stabilisation and gain, establishing eating patterns, and giving you and your child the opportunity to attend the Multi Family Workshop. You will be able to meet new families experiencing similar situation to you and engage in activities.The young person will be assessed in a number of areas (physically, nutritionally, standardised questionnaires, educational/vocational and nursing). Regular Case Team meetings are to be held and the young person will have a **CPA review** as per policy.

When first admitted, a young person will generally be on a low meal plan which they and family will be given a copy of. Activity level and meal plan will be **reviewed** regularly on Thursday mornings with the dietician. There are 9 meal plans and Highfield also uses supplement drinks however every young person’s treatment plan is individual.

**Stage 2** of the programme enables young people to have more control, independence and confidence. This normally happens once young people are 10-15% weight deficit and only if the team feel they are motivated enough for the stage to work. It is a collaborative step involving negotiation and compromise where the young person must work together with nursing team and family. It is important these steps are used at home too to ensure consistency. Young people have the option to prepare their meals and breaks with staff support and guidance. This will include measuring out drinks and choosing correct number or type of snack in line with current meal plan. For lunch, young people will be expected to arrive a few minutes early in order to choose their options. Young people may also go on to reduced supervision (refer to supervision section for times).

Highfield is also able to cater for **day patients** on the EDP. Times of attendance will be discussed with your case team. Prior to discharge young people may spend time as a day patient as a transition to community services.

**Meetings and Groups**

Attendance at morning and afternoon meeting is expected and if the young person has not yet finished or has yet to start a meal, they are to attend the meeting and then return to the kitchen.

Attendance to other groups (e.g. 16+, HUG, Eating Disorder Group etc.) will depend upon the physical state of the young person and activity level and will be discussed within the MDT. Attendance at any therapy sessions is expected regardless of activity level or diet completion.

**Eating Disorder Group** runs every Thursday 10-11am. During this time young people will get the opportunity to ask the medics and dieticians questions. Young people will also do activities and have discussions with your peers about thoughts and feelings.

Please try and avoid visiting during meal times and group times. Expected visiting times are 6.30-9pm, weekends are 2-6pm.

**Weighing**

Weighing normally happens on a Monday and Thursday morning between 6-7am.

All young people will be weighed in their underwear after voiding urine. If they do not void urine they will not be weighed. Bathrooms will also be locked the night before to support with this.

Excessive fluid should not be drunk before weighing; if staff suspect that excessive amounts have been taken to falsify weight young people will not be weighed.

This weight will be recorded on the weight chart and graph and the young person can see this being charted (a record is also be made in the nursing notes). Staff are to ensure they feedback to the young person if an incentive has been achieved or lost (e.g. prepping breaks), on the morning the young person was weighed.

It is also required at times to do ‘spot checks’ of weight on different days in the week whereby the young person will not be aware of the plan to measure their weight.

**Meals & Diet Plans**

**Breakfast:** 8.30-9am

**Morning Break:** 11-11.20am

**Lunch:** 12.30-1pm

**Afternoon Break:** 4pm-4.20pm

**(Mondays & Thursdays:** 4.30pm-4.50pm due to HUG/Skills Group**)**

**Dinner:** 6-6.30pm

**Evening Break:** 9.30-9.50pm

**Expectations**:

1. Nursing staff will serve all meals and breaks following a diet plan specifically given to each young person for their current requirements.We will honour existing diet requirements eg long standing vegetarian & long standing dislikes but these must be agreed with case team and parents (maximum of 3 dislikes).

1. Young people will stay out of the kitchen area whilst meals are being prepared. This is relaxed during **Stage 2** of the programme when young people will have the option to prepare their meal/break with staff support and guidance. Patients will be given supervision at meals and breaks at all stages of EDP.
2. There is a high expectation that meals will be finished in **30 minutes and breaks within 20 minutes**. If young people refuse to start or are unable to finish the meal, young people must remain seated at the table supervised until the next meal or break. The unfinished meal/break will then be taken away and replaced with the next and re-presented after finishing. All periods of sitting out will be done at the table in the dining room.
3. Portion may vary slightly; it is up to the individual staff member preparing the meal to decide. If young people have any individual requests they must let staff know 5-10 minutes before meal times, if not staff are to decide. Once served this will not be changed.
4. If food is out of stock young people are to choose from the exchange list. YP/parents must not bring in substitutes.
5. Young people are allowed to make changes to sandwich or breakfast choices. Normally case team will support with this to ensure a **balanced diet** is chosen and variability within choices, eg, 3 different fillings for sandwich choices. Options are sent to the kitchen on Tuesdays so YP are required to do this in time to ensure correct choices are delivered.
6. Young people and their families are not to bring in any food items to eat when on the EDP (eg fruit, jams, bread, milk and biscuits), unless an exceptional case and agreed by case team.
7. For those who have a cake bar at afternoon break; if a cake is made for a leaving tea young people will be expected to have this as a replacement instead of your normal cake bar.
8. Young people are only allowed fluids stated on your meal plan. An extra 300ml water is allowed at main meals (breakfast, lunch, dinner) at staff discretion. Diet coke, diet drinks and chewing gum are not allowed.

**Supervision**

**Standard: Main Meals: 1 hour, Breaks: 30 mins**

**Extended: Main Meals: 1 ½ hours, Breaks: 1 hour**

**Reduced: Main Meals: 30 mins, Breaks: 15 mins**

Supervision is required during and after every meal. Young people are required to sit still and not get up and move around. Young people will be given feedback if they are moving too much. Levels of supervision are dependent on what stage a young person is at on the program. It may be helpful to engage in distractions during supervision (examples below). Staff can support with this.

**Expectations:**

1. All young people are expected to attend meals on time.
2. Young people need to be **seated and still** during meals and supervision.
3. Young people are to use the toilet before meals or after supervision; if they need to use the bathroom during supervision a same sex nurse will accompany them to the nearest toilet. The nurse needs to be able to see them whilst in the toilet to ensure no secreting of food or purging.
4. Young people must eat all meals appropriately and in a normal way. For example: not pulling cake/sandwiches apart or taking small mouthfuls. The nurse supervising will support all young people to do this through modelling him and herself and reflecting back when they feel that diet is not being eaten in a normal way.
5. It is important young people eat everything on your plate so it is clear. Staff will give feedback for this if unsure.
6. Young people must eat with the appropriate cutlery. For example: not use teaspoon for cereal. Again the nurse supervising will help young people if unsure.
7. If young people do spill/drop any of their diet the nurses supervising will replace this with a drink/food considered by the nursing team as a sufficient amount (Young people can ask to see a copy of the replacement list). Hot food will also be replaced from 1.30pm.
8. Young people must not have any food/drink in their bedroom, as staff must be able to monitor dietary intake. Additional fluids need to be drunk at the table or with nurse knowledge so this too can be monitored.

*The Highfield staff team accept that this is not an exhaustive list of expectations and that expectations may change depending on the individual persons difficulties. Please feel free to discuss any aspect with the team.*

Distress tolerance skills and anxiety management skills can be especially useful after a meal. Staff will be more than happy to guide you with this. Examples of **distress tolerance skills** include:

* Gentle soothing or motivational music
* Journaling
* Arts and crafts
* Deep breathing
* Meditation
* Progressive muscle relaxation
* Reminders about the reasons to get better
* Origami
* Card games
* Conversation

Some **helpful suggestions** that YP have used here at Highfield include:

* Making cheerleading cards
* Colouring
* Reading
* Bananagrams

**Supported Meals**

After a few weeks into admission, the team will start to book supported meals with you and your family. This is a time to support both you and your family with meals when you are on leave and after discharge. You will have a meal assessment initially to see what you may find useful then have at least one meal booked a week.

Meal support aims to:

* Normalise eating behaviour
* Involve and support all members of family that young people would like
* Facilitate weight gain/weight maintenance
* Re-introduce eating as a pleasant social experience
* Increase self confidence around a healthy food intake
* Decrease fear of food
* Decrease disordered eating rituals and routines i.e. decrease rule bound eating
* Help young person and family prepare for leave

**Activity Levels Information**

|  |  |  |
| --- | --- | --- |
| **Level** | **Title** | **Description** |
| 1 | Bed Rest | *Stage 1:* Meals in room, up for toilet and baths  *Stage 2:* Up for meals |
|  |  |  |
| 2 | Couch Rest  2.1  2.2 | Wheelchair use. Feet up when in living/social areas. Meals in the lounge. Baths limited and monitored. OT involvement if appropriate. Only upstairs access for therapeutic meetings (e.g. 16+, EDP CBT group) and then only in lift/wheelchair  Wheelchair use only for longer distances (e.g. corridor), able to eat at the table. Baths; as above. OT or teaching involvement as appropriate. Only upstairs access for therapeutic meetings (e.g. 16+, EDP CBT group) and then only in lift/wheelchair. |
|  |  |  |
| 3 | Chair Rest  Home Leave | Able to walk without the use of the wheelchair (if physically stable).  To remain for the majority of the day in living/social areas or patio if warm.  *Stage 1:* Up for meals, toilet, and bath/shower. Only upstairs access for therapeutic meetings (e.g. 16+, EDP CBT group) and then in lift.  *Stage 2:* One trip up to school/OT (in lift)  Home leave, dependent upon physical state and as negotiated with family |
| 4 | Chair Rest  Home Leave | Full school attendance/OT and scheduled therapeutic activities  Movement to Level 4 when physical observations are stable  Home leave, dependent upon physical state and as negotiated with family |
|  |  |  |
| 5 | Gentle Activities **on** Unit  Home Leave/Time off Unit with Family | Examples: pool, table tennis for 10 minutes at a time, about twice per day,  after school/Unit structure (including pottery but no use of wheel)  Able to have time in room  No off-Unit activities/trips with peers/staff  Home leave, dependent upon physical state/as negotiated with family  10 minutes gentle activity at home twice a day at weekend |
|  |  |  |
| 6:1  6:2  6:3 | Gentle Activities off Unit | *Stage 1:* 10-15 minutes PE/activities; short walk **in grounds** on days there is no  other outside activity. Examples: relaxation swimming (10/60 if swimming; 15/60 if less active) able to do PE warm-up/stretches. Pottery, (able to use wheel)  **No** attendance on school trips or OT activities off of the unit.  Home/weekend leave to be negotiated dependent upon physical state and ability to manage diet/activity appropriately; activity as above (e.g. 10-15 minutes of gentle (e.g. walk) twice per day).  *Stage 2:* Attendance on most school trips allowed (apart from those longer in duration or more active). Able to walk down to the Cowley Road (dependent upon other activity that day).  Activity level and amount of participation to be determined by staff; guidelines of;15-20 minutes PE/swimming, walks of 15 minutes in the grounds, accompanied by staff/parents, 2-3 times per day (dependent upon other activities in the day). Home/weekend leave expected; similar activity allowed as above (e.g. 15-20 minutes 2-3 times per day of gentle activity).  *Stage 3:* Walks of 15-20 minutes on own or with peers, 2-3 times per day  Longer period of time in PE and swimming (20 minutes)  Home/weekend leave expected; activity on leave 15-20 minutes of moderate activity 2-3 times per day unsupervised if appropriate. |
|  |  |  |
| 7 | Moderate Activities | Can participate in moderate activities, including all school trips, PE,  general swimming, and games; same expectations for weekend leave  Continue to be monitored by staff and family |
|  |  |  |
| 8 | Full Activities | *Stage 1:* Full range of activities, but monitored |
|  |  | *Stage 2:* Full range of activities, not monitored |

**Notes:** These are guidelines, which have some flexibility. However, there needs to be a clear reason why an individual would be on a higher activity level than expected according to the chart.

1. The activity level depends upon physical fitness/state, which is assessed by physical examination, current weight, and rate of weight gain. Activities on a particular day may be dependent upon physical/medical status at that time.
2. Safety/care plan restrictions may overrule these activity levels.
3. The frequency and nature of activity in Levels 5 and 6 are to be decided by the case team.
4. At greater than 35% deficit, with low pulse and blood pressure, the individually will generally be on bed rest.

**Home Leave**

Once the medical team feels that a young person is physically stable and managing their diet on the unit, their case team will arrange home leave. This is a very important part of any admission, as the main aim is to **normalise** eating behaviour **so young people can manage at home** with community support and eventually independently.

Home leave will usually follow several supported meals, and may start with day leave to see how just one or two meals at home are managed. This will build up to weekend leave or longer. Prior to discharge, young people may go on a period of extended leave (4 or more nights).

At home, the expectations of young people are very similar to those on the unit. Many young people find it helpful to stick to the same meal times at home as on the unit, although there should be some flexibility around family life (for example; many people have hot dinner instead of hot lunch). Meals, and periods after them, should be supervised as on the unit (see above section).

As the meal plans are very specific it is a good idea to make a **shopping list** of everything you will need for the period of leave. Some parents find it useful to try to match the food at the unit at home exactly, but some flexibility is fine as long as the calories are roughly the same (for example, a small cake instead of cake bar). It is useful to **plan main meals in advance** as young people on the EDP often find uncertainty around food difficult to manage.

Here is an example shopping list:

* Apples
* Bananas
* Preferred cereal choice
* Bread
* Fillings for sandwiches
* Cake bars
* Rich tea biscuits
* Chocolate digestive biscuits
* Juice
* Hot puddings
* Ingredients for any hot meals to cook:

usually one meat/vegetarian main dish, some vegetables, and one form of carbohydrates; e.g. potato, pasta, rice.

**Managing Difficult Leave**

One of the most difficult aspects of leave can be sticking to the **boundaries** of the Eating Disorder Programme as it can feel harsh, but in reality most young people find being **firm but fair** is the most helpful approach.

It is good to remember that sometimes things go wrong on leave, and this is normal. It is always absolutely fine to **contact** the unit to get support. Very often nursing staff will encourage parents and young people to **try to continue with leave** as planned, even if it is very difficult. This is because eventually young people do return home, and so it is best to face these issues during admission with the support of the unit. Usually leave does become **easier over time** for both parents and young people.

Specific problems may include:

* Young people missing diet encourage them to have it then and there, or make a plan to make it up with another meal later.
* Young people leaving supervision encourage them to return, or supervise them where they are, suggest distractions.
* Family arguments try to keep meal times calm, but if needed take some time out (both young person and family) to calm down, or try an ice dive
* Disagreements over portion size/diet be firm and keep the boundary, try not to doubt yourself.
* Slow eating offer kind but firm encouragement

More important than occasional mistakes, is that parents have an overall understanding of the programme and how it works so that there is **consistency** for young people, which can continue into their recovery and their discharge from the unit!

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