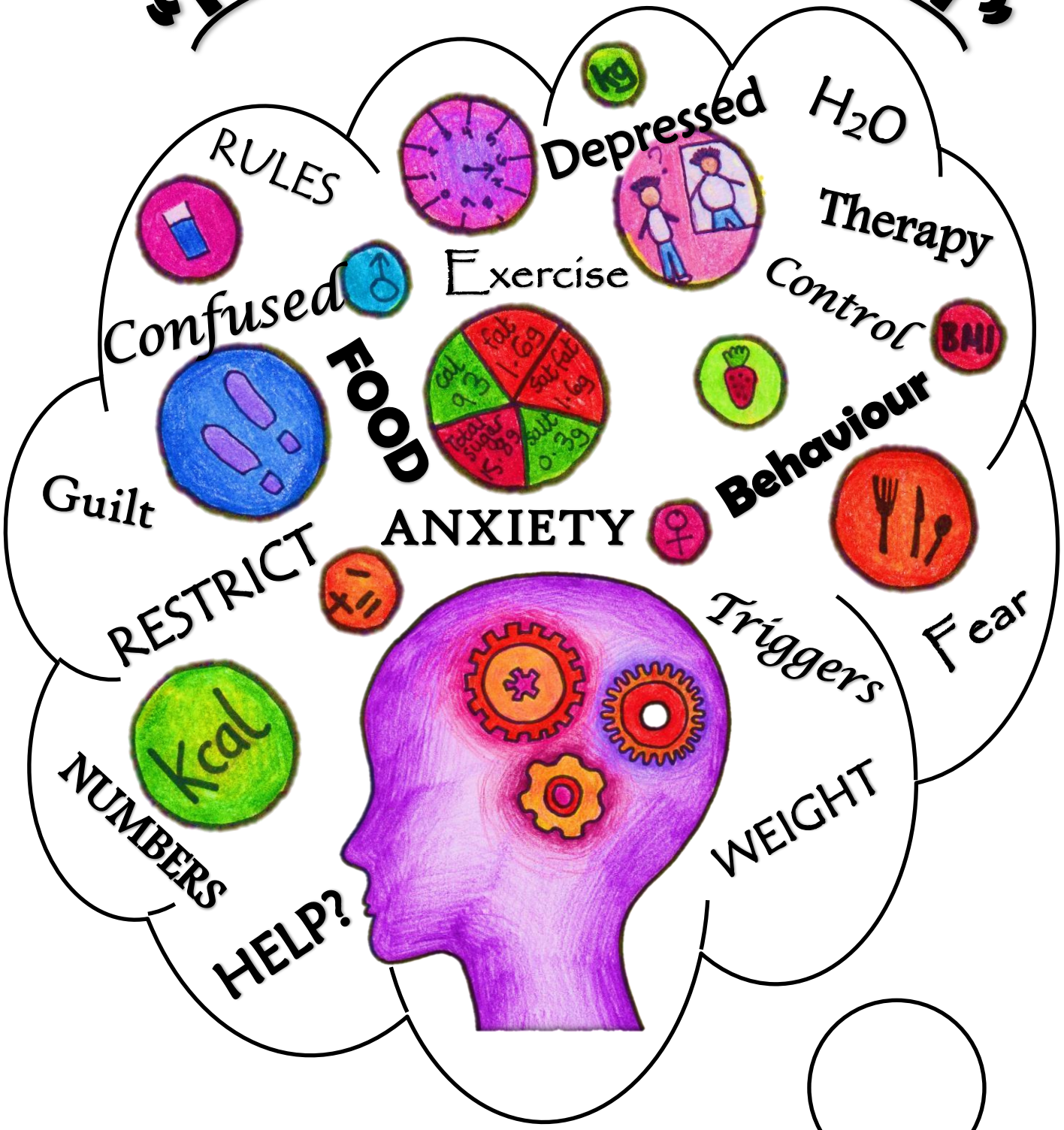
"FOOD FOR THOUGHT"



"A Glimpse into the World of Eating Disorders"
A Patient Guide for Those who work with them

"FOOD FOR THOUGHT"

"A Glimpse into the World of Eating Disorders"

A Patient Guide for Those Who Work With Them

The term **"eating disorder" (ED)** is used here to refer to eating difficulties. This is a term which is used in treatment settings and in society at large. In the treatment of eating disorders the term is generally split into diagnoses of Anorexia Nervosa, Bulimia Nervosa, and EDNOS. Many view severity in that order due to the more obvious physical effects of Anorexia therefore, currently inpatient settings mainly focus on the treatment of this. The reality is, however, no category is in itself more severe than another and the distinction between categories misses the fact that eating disorders belong on a continuum they are incredibly fluid and sufferers will often experience all of the categories at one time or another.

Using the term can also be problematic as it becomes a label of identity rather than a diagnosis – **"You are anorexic"** rather than **"You suffer from anorexia."** It is also weight focussed, rather than thought focussed. Commonly, treatment tackles the illness as if it is the same for everyone when this is not the case. The eating disorder is a set of symptoms. Severity of difficulties and underlying causes will be different for each sufferer (although may share some commonalities). This will affect the treatment needed for individual sufferers and prognosis. Eating Disorders are the solution to a problem but morph into a problem in their own right. This can mean the real illness/difficulties are hidden even from the sufferer themselves and, therefore, hard to treat. It is easy to treat the symptoms and not the cause because it is the symptoms which lead people to hospital admission and these which cause the threat to life and, therefore, require attention. This can then miss the point. The term eating disorder may, therefore, be in itself is a disguise, nevertheless this is the term commonly used (after all terms are necessary regardless of their flaws in order to provide a way to communicate) and so is used here despite its complexities.

✶ OTHER TERMS USED IN "FOOD FOR THOUGHT"

✶ **Patient/sufferer** – I have yet to meet someone with an eating disorder who likes to be called a "service user". It suggests "wants", "needs", "asking for help", "opportunities" and "choice". Using the term completely misunderstands the fundamental feeling within the illness so immediately creating barriers for treatment adding to the guilt they already feel. Patient/sufferer of an illness feels a more helpful description and can help engagement.

✶ **ED** – Eating disorder, generically used to be inclusive of all presentations of an illness around eating.

✶ **Ward Principles** – These refer to the boundaries, or aspirations which an inpatient setting may put forward in order to create a "safe enough" environment for patients to be helped and supported with their illness. Different settings, and treatment ethos may have differing principles by which they wish to operate but most will use this type of ideology.

✶ **Community Meeting** – A meeting where the patients and staff come together to problem solve, to discuss issues, support each other, present requests and ideas, negotiating the shared space in which the community is living and working.

✶ **NG** – Nasogastric Feeding

✶ **HCA** – Health Care Assistants

✶ **MDT** – Multi-disciplinary Team. . All those who are present on the ward and involved in delivering treatment OT, Dietitian, Therapists, Psychologists, Consultants, Doctors, Nurses, HCAs etc

✶ INTRODUCTION

An eating disorder is a very complex, multifaceted illness which affects people differently. Treatment is not straight forward and no one approach works for all, mistakes will always exist. Life on an inpatient ward is hard both for staff, patients and carers. It is an illness of an unusual nature in that sufferers may "appear" to be ambivalent in regards to treatment and collaboration can prove to be a difficult obstacle for both patients and those who care for them. Therefore, the treatment of sufferers may not follow the pattern that might be expected in physical or other mental health illnesses. It requires the use of different language, different encouragement and support, different types of validation and care to the "norm".

This document came about through the observation and experience of the treatment of eating disorders on an inpatient ward. It was a way in which Eating Disorder patients could provide insight into their world and what may help them without experiencing a conflict within themselves that they were directly collaborating in their own personal treatment. This can be difficult for sufferers. Secondly, it came as a response to tangles patients and carers can find themselves in unintentionally, but ultimately damaging to patients producing feelings of helplessness in carers leading to a difficulty in staffing units. Thirdly, it seemed that those who work with sufferers were somehow meant to know how to help and negotiate the complex interactions without ever being exposed to how sufferers feel, how to interpret and understand the behaviours and the complex interaction between the psychological and the physical. In no other area of life would people expect to be able to treat illness, write essays, take exams without giving people the material to learn, however in eating disorder treatment this so often happens. Staff arrive on the ward never having seen someone with an eating disorder and are some how magically meant to know what to do, say and how to support. Not only is this unfair on patients who can sometimes feel like "guinea pigs" and have to tolerate unhelpful interactions, but it is also unfair on those staff members who through no fault of their own get thrown in at the deep end. The fear and anxiety of getting it wrong becomes overwhelming and their first experiences of the ward are negative, potentially stunting the learning of those staff members as well. This ultimately leads to staff disillusionment and staff leaving inpatient units and so the cycle begins again.

However, it does not have to be that way, and, therefore this document was written to provide some insight into what it is like to have such an illness and possible ways patients can feel supported. It is not a short document but the hope is that staff will gradually read it and remind themselves of it from time to time in order to help patients and staff work together in an effective way. The aim would be that new staff would be given it, but as staff become more experienced they would remind themselves of it. At this point staff will gain a greater insight because they will have a greater basis experience to interact and learn from it.

Acknowledgements
L.S - Help with front cover
P.W - What not to say and positive alternatives sheet.

CONTENTS

❖ "PERSON & ILLNESS"

✶ "Jekyll & Hyde"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ People with ED's often find it hard to separate their own identity from the ED. They become entangled and intertwined.	⇨	✶ Enforcement of the "ward principles" need to be in a firm, sensitive and non-judgemental way. Any perceived criticism of a person's ED behaviours can become to feel like a direct criticism of their own very being & therefore, reinforcing self-hatred. ✶ It may be helpful for staff to help patients to separate their illness and their identity so that patients feel less ground down with the day to day work of battling the illness.
✶ Around food patients become very anxious, and, therefore, they may behave in ways they would not otherwise do (eg. Shout, swear) and feel compelled by their illness to do certain behaviours. Patients feel guilty about this adding to their own self-loathing as a person.	⇨	✶ Clearly it is never "ok" for staff to be treated in any type of abusive way. When there has been a conflict & emotions on both sides have calmed down it may be helpful to find time for a quick chat between the staff member and the patient as this can allow a relationship to be repaired for both. This may also help the patient move away from creating extra self-loathing, helping patients to be able to face the idea that they do not always need to be perfect and it is ok to make a mistake and say sorry.
✶ Sufferers often experience a lot of self-blame for their ED. They feel much guilt about it and the effect it has on friends and family.	⇨	✶ Encouraging patients to *"do it for your family"* as an approach will generally be unhelpful:- 1) Patients already feel acutely guilty about this so such comments just burdens the sufferer further. 2) It increases the self-blame guilt. ***What sufferer would want to make everyone around them suffer too?*** Therefore, staff could help by removing guilt.

❖ "WANTING VS NOT WANTING"

✶ "Catch 22"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ The concept of ***"wanting"*** in ED patients is complex. ***"Wanting"*** suggests a desire to the outside world which they may not feel worthy of, or feel able to engage with.	⇨	✶ **Staff can try to avoid using this type of ideal, particularly around food:-** ✶ Asking for things like food & medication produces an internal battle within patients, so wherever possible it would help if this was avoided *(eg which flavour do you want?, Just say "which flavour"?).* ✶ If a patient plucks up the courage to express a want & is turned away, it reinforces that they should not want. Of course staff may not be able to do what is requested (eg. It may not be safe), however, if they are aware that patients agonise over such things then they can help the patient feel responded to so that it is worth asking. It is these little glimmers of asking which ultimately allows patients to trust and feel understood.
✶ **Wanting help and not wanting help: -** - This is a constant dilemma within those who have EDs. They are desperate for help, while wanting to be left alone, feeling unable to ask for help, or indicate what they are struggling with, but at the same time wanting someone to notice. When people are then given the help or the situation is taken out of their hands they may feel relief but at the same time resist the help. - EDs are very complex and it is part of the illness to not want help and to not want to be stopped. Their thoughts and feelings lead them to resist & not co-operate. Some may feel resentful that treatment is being forced. Some may feel it should not be, others later in their lives will be grateful for the intervention. (A continual dilemma for those who treat them) - People with EDs may not be "psychotic" but their illness does drive their choices. It is worth remembering that it has the highest death rate of all the mental disorders. - The assumption that informal patients are somehow **"more well"** than formal patients is not a truth.	⇨	✶ **No one wants to have an ED it is not a choice.** - This can be frustrating & difficult for those trying to care for patients. The idea people may not be able to control their ED and their thoughts is difficult for those around them as it is easier to think that they are choosing not to get better rather than acknowledging that may be they can't. - Even patients themselves might avoid thinking this way as it is easier to think you want the ED and you could stop if you wished, rather than the frightening alternative that may be they cannot. ✶ **It should not be assumed that people get stuck through a lack of motivation.** - It is not possible just to ***"will"*** yourself better as if it can be produced by magic. People with EDs are often very motivated people in terms of their lives. - It can be unhelpful to talk to some patients in terms of *"why don't you get better for your family or children", "what about the starving children of the world", "look at what you have in your life and don't' you want X things in the future"*
✶ **Wanting to want things to be different: -** - Some patients may feel guilty & will judge themselves harshly because they feel they do not want it enough.		

❖ "CHAOS VS CALMNESS"

✶ "The calm in the storm"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ The inner world of those suffering with an ED is chaotic, so sometimes the ED is the solution to this; a way to gain some control.	⇨	✶ **The ward atmosphere, particularly around protected meal times, needs to be one of calm:-** - so patients own internal battles are not reflected externally. - So patients feel more contained, especially around food where anxiety is high.
✶ The correct practical aspects of treatment (eg. correct food & portioning, food being on time, having the suitable equipment.) help to reduce feelings of being out of control for patients.	⇨	✶ **If the practical aspects are not consistently completed, patients then do not feel safe enough to really engage with the psychological work.** Instead:- - Their thoughts are consumed with the next meal or snack. - It sends patients into safety behaviours *(eg. continual checking, performing rituals, which then become a problems in themselves.)* ✶ These things going array destroys trust and can contribute to a feeling that staff do not understand, and that if the practicalities cannot be right then it feels hard to trust the staff with the emotions.

❖ "CONTROL VS OUT OF CONTROL"

✶ "Method in one's madness"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Control is a key issue in the function of an ED. It provides:- - a way to feel in control when many life events are uncontrollable. Such events leaves people feeling chaotic, therefore, the ED provides a way to create order in one's life. - a way of controlling emotions. ✶ In EDs the *"being in control"* and the *"mastery"* over food and emotions becomes "being out of control", the ED gradually takes over *(without total awareness, like a thief in the night.)* It then becomes difficult to stop and the person finds that the ED controls them. Sufferers may not see it this way as they may feel it is part of their identity. ✶ Others deciding on your food sometimes allows people to engage in treatment as they feel it is not their choice to eat. Eating can become easier to accept. Others will just find eating unbearable full stop.	⇨	✶ Staff recognising and understanding that taking the control of food away represents much more than just that to the patients. It is traumatic.
✶ Handing over control of eating and weight *(as occurs in treatment)* is extremely stressful and anxiety provoking for patients, it is much more than just not having the control over eating. This is because it takes away their way of controlling life and emotions. Patients will feel vulnerable, unable to cope, they will start to face intolerable emotions and feel chaotic. They may even feel violated. It is not, therefore, surprising that patients don't necessarily want or feel able to do this. For some people although it is hard somewhere inside they are relieved that they don't have to do it anymore.	⇨	✶ Staff being aware that the handing back control can be extremely difficult for patients. They may on one level be pleased *(sometimes because it means they can use behaviours more easily)* but on another level find the onus on them very difficult. This is of course magnified because of their new weight which they hate. It is at this time when the battle is on and patients need a lot of support with it if the transition is going to work.
✶ Being given control back in treatment is also very stressful. Taking responsibility for eating is scary and the sufferer may start to feel like they are giving themselves the food. It can be a time where the ED very strongly kicks in. Not only do people have to face the trauma of their new weight but also having to eat.	⇨	✶ Sometimes patients are thrown back control the moment they get to the agreed weight. This is very unhelpful as this is the time when the patients feel most vulnerable because their physicality and their mind are poles apart. Therefore, the transference of control needs to bare this in mind and needs to be a very gradual process. It can start before people get to target, but it needs to occur in a slow way so that there is time for difficulties to be worked through.

❖ "SAFE VS UNSAFE"

✶ "A safe pair of hands"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Patients need to feel *"safe enough"* in order to engage, make changes and face fears.	⇨	✶ No one can ever feel totally safe when making changes they fear, this is inevitable. If this is recognised and talked through it can help people feel **"safe enough"** to try. ✶ Ask individual patients what helps them to feel safe as this will vary between patients.
✶ Patients feel safe when:- - The right food, portions & equipment is provided. - The daily structure is clear and a program happens, allowing people to feel supported. - They can build trusting & therapeutic relationships with staff.	⇨	✶ If the practicalities are not right then the patient's minds are overburdened by continual anxiety just by trying to survive this. ✶ **The atmosphere around eating needs to be therapeutic.** The practicalities of eating need to be consistently correct. If this occurs then:- - patients are more likely to trust staff with their emotional world. - patients are more likely to feel understood, as it would feel like staff knew how difficult it is and thought it was important enough to get right.
✶ When appropriate support structures are not in place patients start to feel:- - unsafe & use their eating disorder to cope. - resentment as patients feel like the only thing that matters is weight, again making it hard to make therapeutic relationships.	⇨	✶ Groups & daily support structures need to be as consistent as possible.
✶ Patients need to feel they are being communicated with when changes are made. (Any type of change food or otherwise)	⇨	✶ It is hard to hand over the control around food and if patients are suspicious that this is tampered with then the team lose their trust. Therefore, patients should be told about changes.
✶ Room changes can be very stressful to patients as to cope with all the other changes they need a safe place where they feel in control.	⇨	✶ Patients realise that sometimes rooms need to be altered for practical reasons. It would help patients if:- - they could be given some notice about the change so they can adjust themselves. - staff showing understanding regarding how stressful it is and talk to patients about this after it has occurred.

❖ "POLICING VS ENABLING"

✶ "Authority without wisdom is like a heavy axe without an edge, fitter to bruise than polish"

➔ GENERAL COMMENTS

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Patients are ill, they are not criminals. It is easy for people to feel like they are being punished, rather than cared for. They haven't done something wrong to be in the position of needing inpatient treatment. (Even if this is what they feel like themselves).	⇨	✶ It is very easy for staff to slip into policing rather than supporting patients in order to enable them to combat the illness.
✶ If patients are spoken to in an unsupportive way, not acknowledging their distress, & in a way that suggests suspicion, it can really damage further a patient's self-worth. It reinforces the idea they are to blame & are a deceptive bad person. When patients feel this way it blocks their ability to engage.	⇨	✶ Staff should keep boundaries and be firm (as it is this that keeps patients safe), while at the same time be firm in a way which can help people to move forward and feel cared for.
✶ Living with an eating disorder is extremely tiring and **"never ending"** hard work. Being in treatment is equally as hard just in a different way.	⇨	✶ Wherever possible treatment should be made as easy as possible, *(this will vary from patient to patient.)* Barriers need to be removed to make eating and weight gain as tolerable as it can be.

➔ THE DINING ROOM

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ This is an extremely anxiety provoking place for those with EDs. ✶ *Timings:-* - Patients have to psychologically prepare themselves for every meal & snack; therefore, if meals are delayed anxieties quickly heighten in order to keep their mind in a place where they can try to eat. Delays prolong the distress. - Keeping to a structure is important so when at home the same can be followed. It is very easy for ED patients not to have a structure and skip food.	⇨	✶ Staff can help by prioritising the timings of meals & snacks to reduce delays as often as possible
✶ *Choice:-* - Some patients find choice difficult, partly because choosing suggests a **"want"** for food. - Some fear their choice may be scrutinized by staff & patients. - Some just may not know what they would prefer.	⇨	✶ Commenting on patient's food choice is generally unhelpful. It emphasises they have made a choice which increases a patients guilt and inability to have it again. This is especially so if people are trying new foods or they are having an item they may feel is not a ***"proper ED choice."*** (eg. cheese, chocolate) Drawing attention to this can be awful for a patient.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ *Correct food & portion:-* ✶ If the food is not correct then anxiety shoots up. It is very hard for patients to psychologically prepare themselves for certain foods, to then have to swap is extremely difficult.		✶ Checking food in advance is helpful, so there is time for problems to be rectified. It would be best to:- - Firstly, solve the problem without involving the patient to avoid unnecessary anxieties. - Secondly, if the problem cannot be rectified then the patient concerned needs to be approached to discuss what could be done instead. This needs to occur as soon as possible. The longer they know this the easier it is to prepare for the swap. **There is nothing worse for patients to get to the food trolley and be faced with a decision.**
✶ Having different sized plates, cups, bowls etc. can be very difficult for patients, particularly at the start of treatment. This is because the portion sizes, although may be the same, look different which leads to anxieties that things haven't been measured or aren't correct. ED patients find it hard to feel safe when this is the case.		✶ Having consistent implements is helpful. Where this is not the case it may help patients who find this difficult to be shown the same amount in the different eating utensils as this helps them to see that the portions are the same.
✶ *Self-service:-* ✶ Some patients will find this hard because it feels like it is giving yourself the food, so suggesting that you **"want"** it. This can create guilt in the eating process. It can be hard just being in close proximity to food.		✶ Self-service is stressful. It would help if staff:- - focussed on that one patient at the trolley, supporting them. - insist that other patients and staff are not standing near this area at this time. ✶ Chaos around this time is very anxiety provoking for the patient. It can become hard to put the correct portion on if no one is looking. This can make patients feel greater guilt as they know they could have given themselves less.
✶ Some may find it very hard to give themselves the correct portion size. It can create anxiety about there being enough food left when you get to the trolley or being left with corner pieces, which can create safety behaviours.		✶ Staff need to say if a portion is too little or too much. If patients feel they can just give themselves whatever amount then it is not containing. Patients feel safer with staff who will ask them to do more but also say if there is too much. ✶ The language staff use at this time is very important. Rather than saying repeatedly *"It is not full"* or *"more, more, more"*, it would be better to say *" you have done well but it is not quite at the line"* or *"The portion requires a little more on the spoon, how about you try to be a little more on that part of the spoon."*

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Some find it easier to self-serve etc. because they feel like they have more control.	⇨	✶ Staff need to be consistently firm about portions *(whether they are self-served or staff served)*, but in a quiet way staying calm even if the patient is shouting. If the server keeps their voice quiet & calm then it will lower anxiety & perhaps stop a big show down. It is hard for a patient to continue to shout if the staff are very calm & speaking in a normal non aggressive fashion.
✶ Others may not find it stressful as they may be used to doing it for their family *(although perhaps not for themselves).*	⇨	✶ It should not be assumed that all patients find any sort of self-service hard. Some will not, and if it is not an issue then it is better not to make it an issue.
✶ Washing up can be extremely stressful for patients because:- - there is no distraction of what has been consumed. - it prolongs the eating process as it can feel to patients that the meal has not ended until this has been completed. ✶ This can leave patients with high anxiety levels for a longer time and an inability to use the post meal support time.	⇨	✶ It would help if staff were aware of this so that they understand the importance for some patients to wash up.

➔ REPLACEMENT PLANS, FORTISIP & NG FEEDING

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Naso-Gastric (NG) Feeding, restraint, and replacement plans sometimes have to be use to enable a patient to take in some calories *(sometimes to save life)*. When people are very unwell this may be the only answer. Patients find these interventions extremely traumatic & may do anything to avoid it, some will find it very traumatic but at the same time relieved it has been taken out of their hands, but will still resist it because they are so frightened and their illness is so strong.	⇨	✶ **Support after this type of intervention is vital.** ✶ Patients are scared and that is why they behave as they do. ✶ Patients will need to talk with someone who can understand. ✶ Sometimes because nursing and permanent health care assistants (HCA) have other pressures on their time, these interventions occur but then are not able to support the patient afterwards *(a bank staff member is not appropriate support).* Even if staff cannot give support right away patients who are going through this need proper support & talking time daily *(patients may not actually want it immediately as they may be very angry with staff, or feel at that moment too traumatised to speak & share their feelings.)*
✶ It can be very difficult for patients to stop resisting such interventions as they feel like this indicates they ***"want"*** it, and this is uncomfortable & may not be the case.	⇨	✶ If patients do stop resisting commenting on this is unhelpful. Drawing attention to such changes can be counterproductive and lead patients to feel compelled to resist more.
✶ It is very hard for patients to express a ***"like"*** or a ***"preference"*** in life in general never mind with food. It is hard then for patients to express a wish for a particular flavour of fortisip.	⇨	✶ It would help patients for their wishes to be taken into account whenever possible. It helps patients feel listened to. If their requests are often refused then it can reinforce the idea that it is wrong for them to have a preference.
✶ Patients sometimes eat & drink things they don't like in order to punish themselves for taking in of the calories or because they think they don't deserve it.	⇨	✶ Allowing flavour choice removes some of the difficulties around punishment & nourishment.

➔ FLUIDS

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ For some patients fluid is not part of their eating disorder.	⇨	✶ Where fluid is not an issue (unless for physical reasons) then making it an issue can lead to the creation of a new problem, eg. it can plant the notion that they should not be having them.
✶ Some patients may over drink others may restrict fluid.	⇨	✶ Talking to patients generally about why either of these can be dangerous
✶ Some patients will be terrified of all fluids (some, just drinks with calories.) Even water can feel unbearable. Reasons will vary between patients.	⇨	✶ Avoid assuming that water is "just water" (ie. no calories). Many struggle with having anything inside them.
✶ Others will over drink for a whole host of reasons eg. Use it as a way to fill them up or to alter their weight etc.	⇨	✶ Some patients may use over drinking or under drinking as a punishment.

➔ POST MEAL SUPPORT

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ It gives some patients the opportunity to sit down & rest. Many will find this hard as resting is often difficult for ED patients.	⇨	✶ **It is worth thinking about what post meal support is for and what patients find helpful in this space.**
✶ Patients may feel strong urges to use coping behaviours *(cleansing rituals, vomiting, exercising, pacing etc)* at this time, & so it can be difficult to come to post meal support.		✶ Note the word is post meal ***"support"*** rather than *"supervision"*. *"Supervision"* is merely **"policing"** whereas it is support that is needed is to help with feelings, acknowledging how difficult it is to eat & not carry out behaviours.
✶ Some patients find this hard as they find it difficult to be around people after they have eaten.		✶ There needs to regular opportunity for patients to talk, otherwise they will not perceive that there is any support or understanding & acknowledgement of the trauma. *(This can make them feel more guilty about eating.)* and will feel like it is a waste of time.
✶ Some have difficulty about talking about meals they have just had and need distraction.		
✶ Some may need room to talk to someone about how they feel.		

➔ IMPORTANT CONCLUDING COMMENTS

✶ Enabling patients to try treatment is not necessarily about changing the "principles"; it is about the way these are enforced and the flexibility to respond to the individual.

✶ Providing a structure & atmosphere in order to enable patients to combat the illness has a two way interaction:-

1.) If the ***psychological work*** is not occurring *(therapy, key work, groups, post meal support)* then the atmosphere moves from one of **support & enabling** to one of **"policing"**.

2.) If the ***practical things*** *(food, meal times etc.)* are not functioning as they should then psychological work, even if available, cannot be effective because patients have such anxieties around the practical things they have no room left to engage in anything else.

3.) If the "principles" & structures are not enforced regularly & consistently, then the patients will not be safe enough to change any behaviours.

✶ It would be helpful if staff thought about how they speak to patients and whether they have slipped into unhelpful communication styles during the busyness of the day. Practicing using different styles will help staff to talk in a constructive way more often because it will gradually become second nature.

✶ Sometimes when patients are very unwell decisions will have to be made which patients may not want or agree with or perceive as a punishment. It is possible to be firm with patients but do it in a sensitive way with explanation & empathy, understanding while allowing patients to be angry about such things and give them space to talk.

✶ It should be encouraged to respond to patients in a way that is not defensive, things patients may say may not be direct criticisms but be just helping to find a better way. All people however much experience can learn new things and being willing to do this shows patients they are heard. (*ED patients are an expert resource, many people will be able to see how things could be done more helpfully. Why would people not want to learn from the experts?)*

✶ It is always ok to say sorry, or I got this wrong. No patient expects staff to be perfect, what is more frustrating and hard, is the lack of acknowledgement of this, or the pretence it has not happened. This can then damage relationships. Saying sorry when appropriate is a much better way to build relationships. It is a sign of strength not a sign of weakness.

❖ "PUNISHMENT VS REWARD"

✶ "Carrot and Stick; the Facilitation of Change?"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶This can be a very complex issue for ED patients:- - Some may feel that food is a reward rather than a necessity and, therefore, feel they don't deserve it. - Some may use food as a punishment and, therefore, may spoil food, eat only the things they don't like, or only eat things that are rotten.	⇨	✶ It is unhelpful to attach food & eating with the notion of reward or punishment as these concepts can be very skewed in ED patients. ✶ There are a number of issues staff could think about in relation to this:- - Clear targets which have to be met in order to be able to have home leave, walks, sits etc. may help some patients eat, gain weight and engage with treatment. It may feel it is a means to an end & so easier to comply with. - For other patients such an approach will feel like coercion so will not respond at all, and even move them in the other direction. - Some people will just feel they cannot do what is required, therefore, they will be unaffected by such rewards or so called punishments. They then just feel distressed and it adds to their torment. - If patients feel like they are unworthy of reward then they will find such things difficult to accept & so may find it difficult to interact with this approach. *The trick is knowing which patient you are dealing with, and adapt accordingly. (This is hard of course!)*
✶Patients frequently perceive what happens in treatment as rewards & punishment. This can be very negative because it leads to patients feeling like they are to blame for being ill and should be able to change their behaviour.	⇨	✶ Rewards & punishments can change behaviour, however, it is less likely to be permanent change, but one in which it just becomes easier to "play the game". The emotional problems remain unchanged. ✶ Staff may not intend for patients to see things in this way & it could be avoided by using different language & terms where there isn't this type of straight forward link. Eg. *"We are worried that you are struggling with weight gain & behaviours so we thought that just for the moment we will alter the stage you are on, in order to give you more appropriate support & we can then review it next ward round and see how things are."* Note that it may be helpful not the use the word **"back"** a stage as this suggests **"punishment & failure"** rather than **"safety & support" (of course patients cannot really view it like this if there is no extra support!)**

PATIENTS THOUGHTS & FEELING		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Patients can feel like they are being threatened by the removal of privileges, or the move of a stage. Therefore, sometimes patients feel desperate so they resort to behaviours to *"seemly comply"*. They can feel humiliated & feel like they have done something *"wrong"*.		✶ Discussions about treatment as:- - involving ups & downs rather than linear progression. - changing plans to help people cope better & keep them safe. (Rather than punishing them for not coping.) - aiming to break a pattern of unhelpful behaviour in order to create restabilisation and then have a safer base to try again. - Helping people engage more with the process. **If this is made clear at the start of treatment it will normalise these types of alterations in care and, therefore, patients may not feel as bad when these things occur.** ***(Especially if they see these things happening with people all the time.)***
✶ If patients feel if they admit or are honest about behaviours they are using then they are automatically going to get things removed then patients will be less willing to say. They will feel shame & misunderstood.		✶ Encouraging openness is helpful. Therefore, sometimes it may be better to respond *"what can we do to support you now, these are the teams thoughts*". Some patients may require a firm line because this can help them to stop behaviours but it should still be made clear that it is not because they have not heard what the patient feels but to enable them to combat aspects of the illness.

❖ "DOING WELL VS NOT DOING WELL"

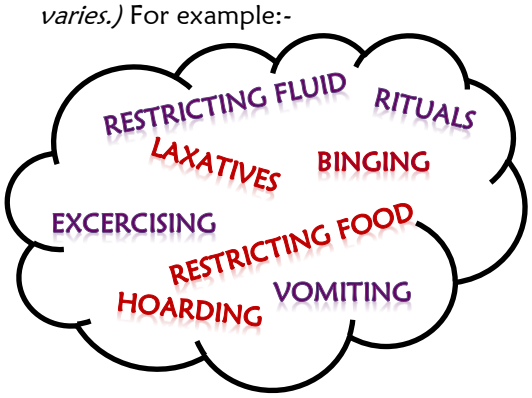
✶ "Winning or Losing"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶The idea of "*doing well"* and not "*doing well"* is a bit of a minefield with those who suffer with EDs:- There is a gap between how people are physically and how they feel psychologically. It is the worse time for patients when there is a mismatch between body & mind. Much support is needed at this time.	→	✶ Staff should be aware of the difficultly of this concept and hold it in mind when they are talking to patients. - Staff can ask patients outside the dining room how they can be best supported. - Staff could ask the patients who they are supporting at the start of the meal how they feel they can be best supported.
✶Some patients do not want to hear they are doing well. - They may feel people are saying they are getting better when they don't feel like that. - They may also relate this to their body so perceive people are saying they are fat now. - Patients can feel conflicted about going against their feelings and the ED. Anything that draws attention to this can be difficult & counterproductive.	→	✶ No patient expects people to automatically know what helps them and would see it as a positive thing to be asked this and then to be understood. ✶ Some people may not initially know what they will find helpful, and what they find helpful may alter over time, therefore, keeping an open dialog about this for patients may be helpful.
✶It can be difficult to give up behaviours as it can feel that everyone will now think they are no longer distressed. This then may trap a patient in a behaviour they no longer wish to do but are scared that if they don't do it is signalling they are ok. ✶Some may feel if they do not do such behaviours then staff and fellow patients think they are not eating disordered or that they "want" to eat. ✶Others may want to hear that they are doing well, and find it easier when people praise them for difficult things, such as completing meals. *(whereas for some this will cause distress)*	→	✶ If staff notice that a behaviour has changed, it may be appropriate to think about whether it will be helpful to mention it:- - Drawing attention to such a change may start the need for a patient to start this behaviour again as the patient may hear it as staff thinking they are no longer distressed and are better. - Patients may be desperate to be able to stop a behaviour but feel disloyal to their ED, therefore, not mentioning the change can sometimes make it easier. It allows the patient the space to stop without confronting the issue directly. - If it is thought helpful to discuss changes then this should be done privately at a time outside of the time when they would be doing such behaviours. This can remove some of the shame around it. If a key worker and patient are wanting to try and alter a behaviour patients may find it easier if everyone else does not know, and does not bring it up, unless the patient themselves want others to know.
✶ Sometimes patients are able to do something at one time in treatment & cannot at a later date. It will continually vary.	→	✶ Recognising this is helpful; sometimes things get harder to do, particularly when patients are gaining weight.

✶ *Most patients do want it recognised how hard it is and will need encouragement & empathy, but will still feel conflicted about it.*

❖ UNDERSTANDING ED BEHAVIOURS

✶ "Our fears always outnumber our dangers"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ EDs are not the problem they are the patient's solution to the problem. It is the symptom; however, it very quickly takes over and then becomes the problem by bombarding people's physical and psychological state. Sometimes patients won't even know what the problem was. The ED becomes all-consuming so the once effective coping mechanism morphs into something which sucks the life out of people. ✶ Just because the ED was not the problem does not mean the patients are not absolutely terrified of food, eating, & weight gain. ✶ ED treatment is tough because it requires people to do very difficult things without a copying strategy. ✶ Patients **feel shame** about their behaviours. They fear letting people in. ✶ They **fear judgement** by others and by their own self. Patients can then feel isolated. ✶ Behaviours are **coping methods**. They help the patient to control their environment and act to distract from their emotions.	⇨	✶A culture of openness is needed to enable a patient to not feel alone with these behaviours. They need to feel like they will not be punished for disclosure. ✶Many patients will think that they are the only person who does such behaviours so in the right environment it is important to talk about these. If they remain shrouded in secrecy *(where the ED thrives)* and is unspoken then this only creates further shame.
✶ Behaviours are **also anti detection devices**. They are used to avoid detection of, and to protect their ED. Eg. *They may where baggy clothes, hide weights when being weighed, leave a bowl with milk to look they have eaten etc.* and many others. ✶ There are many behaviours which may be involved in an ED. *(individuals behaviours varies.)* For example:-  	⇨	✶It is important for staff to be aware of such devices. Staff may have to confront a person about them but with the awareness that they are not about deceitfulness (patients are not deceitful by nature) they are just desperately trying to cope and feel compelled to do them. They, need to be dealt with empathy, sensitivity and without judgement. ✶Patients have very different ED behaviours. They will be individual and have different reasons behind them. Thus, to help plans need to be made for each individual to tackle them as different solutions and approaches will be needed.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Other Issues can also be around. For example:-  		
BEHAVIOUR DEVELOPMENT ✶ ED patients develop behaviour **rules**. They cover all aspects of daily life and they feel like they must follow them. - They often have strict rules around food, exercise and weight. These rules develop over time. - They tend to become stricter and stricter. - Patients feel a greater and greater need to complete them and are very anxious if they cannot perform them. - They become exhausting and move from manageable behaviours to ones that are totally out of control which consume virtually every working hour. ✶ The developing rules encroach on other parts of life eg. Spending money, Treats etc. ✶ The behaviours are very driven and sufferers end up in a place where they no longer have time to do anything else.	⇨	✶ ED behaviours have a purpose, sufferers may not know what this is, as the behaviours become multi-layered over time and the links become less clear. These then become harder to change. Staff can help people explore what the behaviours are for and how they have developed pulling back the layers. Helping a patient to understand may help a patient to change them. ✶ ED sufferers tend to have rules particularly around food, therefore it is more helpful for the ward to put as few rules around eating as possible. Many inpatient settings place many rules around the eating process (eg. mixing foods, spoon size, food combinations). While some rules are necessary to keep patients save it is questionable how helpful endless rules around eating are, firstly because it doesn't make eating a therapeutic process but one of greater anxiety. Secondly, exchanging one set of rules for another whether or not these are felt to be more "normal" is not mirroring eating without rules. Thirdly, such rules create a punitive atmosphere.
BEHAVIOUR SHIFTING ✶ EDs demand more and more behaviours. ✶ In treatment:- - New behaviours develop due to the replacing of a lost coping mechanism. Eg. Having to eat may make a patient harm themselves instead.	⇨	✶ The behaviours an ED person may have will change over time, they may get worse, they may change, new ones may be added. A behaviour that had been tackled may reappear at a later date. The staff, therefore, need to watch out for this and always give opportunity for patients to talk about this. It would help if staff asked regularly about behaviours and whether others had developed.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
- Different behaviours are needed on the ward. Eg. Being first in the food cue, being last to the finish the food, and so more develop. - There can also be behaviour learning when on an inpatient ward. **BEHAVIOUR BREAKING** ✶When one behaviour is stopped, it is hard not to substitute another. ✶Behaviour breaking leaves a patient highly anxious. ✶The ED mind is always working out how it can get round any of the protective boundaries. It becomes a constant battle. **BEHAVIOURAL COMPLUSIONS & OBSSESSIONS** ✶These types of behaviours are always around in EDs eg:- - Excessive cleanliness may feel like it is cleaning the mind. - Ordering items may reflect a need to control the world. ✶The psychological side of the illness demand such behaviours. ✶The physical side of the illness also perpetuates them further as the starved mind leads to this.	⇨	✶ Merely forcing people to stop may be effective in the short term but it may lead to further escalation, or a swap to a more dangerous behaviour. Where possible it is better to work with the patient and try and tackle them in a time frame they can manage. ✶ Suggesting that food not being correct on trays, or wrong portion sizes etc gives the patient opportunity to see what it is like in the "real world" is unhelpful. It is not meant to be like the real world because sufferers have been unable to eat there. Behaviour experiments only occur and can only help break behaviours if they are set up and agreed, suggesting that mistakes are this often destroys possible behavioural experiments at a later date.

CYCLE OF DISORDER:- ***The ED creates behaviours and the behaviours further fuel the ED. It is a viscous circle which deepens, creating a more complex disorder.***

❖THE USE OF LANGUAGE

✶"Whatever words we utter should be chosen with care for people will be influenced by them for good or for ill."

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ It is easy for patients to feel guilty about their illness.	⇨	✶ Comments attributing blame, lack of motivation, comparisons to those less fortunate, do it for your family, don't you want to get better etc. should be avoided. Such comments only fuels patients despair & guilt further.
✶ Patients can be very sensitive about what they perceive to be criticisms.	⇨	✶ Ward "principles" should be implemented in a sensitive way. They are not there to punish people but to keep them safe enough to try to eat.
✶ The language used around eating can change whether a patient feels able to eat.	⇨	✶ Commenting on people's food while eating is not helpful. Eg. asking whether people **"want"** something, **"like"** something, or commenting on the quantity of food they have. Giving people verbal encouragement *(although not over board)*, and avoiding picking on the way in which people are eating is more helpful.
✶ Patients find it hard outside of the dining room to be spoken to as a child, as this further removes their own autonomy.	⇨	✶ Speaking to patients as adults with valid opinions helps patients keep a sense of themselves.

✶ The way in which language is used on the ward, especially when talking with patients, is one of the most important things and its importance should not be overlooked. It makes a significant difference to how people feel, their ability to accept help and make steps towards recovery.

✶ It can be hard for staff to alter the way they say and present things, as the mind of an ED patient is complex. Therefore enclosed with this document is a hint sheet which shows how language can be used more effectively to help. *(Please read this sheet)*

❖ COMMUNICATION

✶ "The single biggest problem in communication is the illusion it has taken place"

COMMUNICATION BETWEEN STAFF & THE WIDER TEAM

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Patients can find themselves going round in circles between the different staff members in their team because it is unclear who is able to make which decision, therefore, patients end up going backwards and forwards between staff. The consequences of this are:- - it is hard to get an issue sorted in a reasonable time frame. - Patients give up because it becomes too difficult to keep asking. It can be hard to ask in the first place & patients are acutely aware of being a pest so it creates a lot of anxiety.	⇨	✶ It helps to get very clear responses on feedback sheets of the outcome of what the patient has asked & having clear ways to make sure these things are communicated to the rest of the team. ✶ It easy for staff not to discuss the things the patient is worried about as they may seem to be of less importance. However, to answer requests allows the patient to feel what they think is important has been dealt with too. It can help the patient to trust the team & feel supported by them.
✶ Patients can find that things get misrepresented to the MDT, leading to unhelpful changes and more importantly produces feelings of being misunderstood.	⇨	✶ Carefully enquiring whether some things are accurate is helpful. It may help if ward round decisions or plans are reviewed at the next ward round to reduce the problem of thinking something has happened which has not.

➔ COMMUNICATION BETWEEN STAFF & PATIENTS

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ **There is a need for transparency & trust:-** - Many patients will have experienced broken trust in a fairly catastrophic way; this may be in their history or in previous treatments. It cannot be overemphasised how important maintaining trust is in enabling people to change. - ED's are often in their nature a secretive illness and this is how it thrives. If patients are to allow people into this private world they need to see that it is ok to be open.	⇨	✶ It helps patients to be able to have an open dialog with staff. Patients need to be in the loop. This is both in their individual care and in ward changes. It is hard for patient to trust the staff if they feel they are not involved. It damages the relationships, creating a "them & us". ✶ It would help if the staff mirrored what they encourage patients to do, if staff do things without bringing it to the community then people will feel like things are being hidden from them creating resentments. It may also leave the patients thinking why they should be open. ✶ This can be done in very simple ways. For example, staff may say "the nurses are finding it hard to find time to write their notes so they wish to have some protected time" instead of just putting a poster up.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Patients need to feel like they are being listened to.	⇨	✶ In eating disorder treatment patients have to give up their control over food. However, they are still adults and they do know when people are not giving them the full story. ✶ Responding to things bought up in community meetings helps this. It is easy in the busyness of the ward to forget to find out or sort out the issues that have been highlighted by patients. Follow up helps people feel they are being acknowledged and it matters. If this does not occur it can lead to patient disengagement and possible reinforcement of not voicing their needs. ✶ Writing down on a separate piece of paper *(as well as the community minutes book)* by the staff in the meeting and ensuring they find out the answers and write the responses to be talked about in a future community meeting is helpful. Even if the issues bought up cannot be solved quickly, a rough time table could be given, or a time at which it will be discussed. It may be that responses can be written on a patient board.

➔ KEY WORK

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶Providing a way for patients to be able to communicate with staff about what is really happening in regards to eating, eating behaviours, other behaviours, what is happening on home & community leave etc. is very important	⇨	✶ Staff may be able to help patients to use key work more effectively:- -Creating a space where people can be open and honest is hard. Regular meetings with key workers help this. - The space needs to be non-judgemental, where people can be honest without fear of being penalised, and not forced into a change they cannot yet manage. An atmosphere of acceptance of where that patient is at, at that time, allows the possibility for patients being able to reach for support in their own time frame when they feel safe enough. *(Assuming these things are not vital to a patient's survival.)*
✶Some patients may find it hard to bring things to key work as they fear vulnerability, shame, and also feel conflicted of wanting help with behaviours and wanting to keep them so they feel safe.	⇨	✶ Having some structured sheets for different issues *(leave, food feelings, behaviours)* that patients could fill in and then take to key work and make a folder out of may:- - help patients to be able to voice things which they find hard. - give more structure for key work. Plans to deal with an issue can be written down on the sheet and then followed up in the next session, rather than each session standing alone.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
		- stop issues being lost, and help people to actively move forward. Help key work to not get totally side tracked in ward based issues. - help newer staff, or staff who find key work daunting as it may help them to be able to see what key work could be used for and therefore, lessoning staff anxieties of knowing what to do. *(Clearly patients don't always need to use such things; some patients may find it easier not to, some might like a mixture of approaches at different times during their treatment.)*

➔ PATIENTS EXPERIENCE OF MEETINGS WITH THE TREATMENT TEAMS

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶In most inpatient units there will be a time once a week or once a month etc. where the whole team will meet to discuss care of a patient. The structure of this will differ across units and change over time but however it occurs (with the patient present all of the time, part of the time or not present) it is still clearly a time where communication between the wider team and the patients can occur. The experience of such meetings, however, is a complex one for patients:-	⇨	✶ It is important to recognise that it is a high stress situation and patients may be entering fearing what is going to happen.
✶Anxiety is often high ✶Patients may find it hard to say what they really feel due to the number of people that are present, particularly when some of these people are not part of their team. ✶Patients feel very vulnerable when they go in. They may feel shame & judgement. They may feel they are going to be criticised and may well be on the lookout for this, especially when patients illness and identity feel meshed.	⇨	✶ When difficult things need to be challenged & addressed, it may help patients if this done with language which patients do not feel is threatening, but in a supporting way. Knowing that patients may interpret things as punishments. The availability of staff post ward round to find time to talk and explain when patients are calmer, so patients aren't alone in dealing with it may help.
✶Rather than a joint process it can feel that as a patient you are on your own facing staff who are all together and so can feel like it is going into battle without the correct equipment. ✶Patients may feel they have been misrepresented *(this could be accurate or not)*. They may feel that decisions are made before they get there, and so a joint discussion where patients are involved does not really happen.	⇨	✶ The team finding some time to talk to patients on a one to one basis helps those who find ward round particularly difficult to be able to say more easily what they are feeling. It also allows patients to fix misunderstandings.

✶ Sometimes what is agreed in ward round gets lost, patients can get frustrated when the plans don't happen or go wrong. It needs a robust system with a way for the patient to show other staff what has been agreed. What is agreed needs to be followed up at a later date to check whether these things have actually happened. The whole team is then in the loop rather than assuming that ward round decisions have occurred.

❖ CONFIDENTIALITY

✶"Discretion is the better part of valour"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ It is incredibly hard for people with EDs to let people into their world. They have spent much time hiding behind a mask. They feel shame about even having the illness let alone the behaviours the illness drives them to do. Sufferers need to feel safe enough to let people into their behavioural and psychological world. Safety cannot be gained if people feel that the information they talk about does not remain confidential. ✶ Many patients will have previously had an abuse of trust. Therefore, they are slow to trust again. A lack of confidentiality can make them feel violated and they will then not feel able to share. This then makes engaging in treatment hard.	⇨	✶ Sharing information in a team needs to be done within the knowledge that they should not be telling others about it *(other patients, family members, & depending what it is not the whole team.)* ✶ There need to be boundaries where information is shared on a need to know basis, in order to allow a person to build a trusting relationship. Everyone does not need to know everything. ✶ Where information has been shared with staff, staff members who were given this information in notes or handover should not be asking patients directly about it. Patients to not see this as helpful support they see it as a break of trust. Staff instead can just offer people time and then if a patient then brings the issue up it is then ok to talk about it with them. ✶ On an adult ward breaking confidentially to parents and family members should not occur unless there has been prior agreement. Patients need to ok exactly what information would be passed on. This needs to be done every time because patients may feel differently in regard to different information. Therefore, consent should not be assumed. ✶ Some may be ok about sharing some information but not all. Staff should not be talking about meal plans, or snacks with people other than the patient unless they have given this permission. *(This does not mean that involving family members is not sometimes helpful but there still needs to be consent given).* ✶ Staff need to be mindful of communication between members of staff and communication between patient and staff that information is not spoken about in the ear shot of others, whether this is about medicines, care plans, meal plans etc

❖ "ASKING"

✶ "The most important thing in communication is hearing what isn't said"

ASKING FOR TREATMENT

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ **It is hard for patients to ask for treatment because:-** - Some may not see anyone about their ED until the illness is at quite a severe level until then the ED helps them cope. Many think they can stop whenever they want to. They think they are in control. - Some are in denial of how ill they are. They think that none of health issues which stem from it will happen to them. - They may feel shame both of their behaviours, and of having the illness; they should be able to cope and they should be able to stop.	⇨	✶ Underneath some do worry about these things but it is easier to deny them as they may feel there is nothing they can do about it. ✶ Staff can encourage patients by repeatedly saying that the illness is not their fault & it is not easy to deal with it, and there is no "should" about it. This can help people to accept this. If patients feel the staff feel this then it is easier for them to engage with treatment.
✶ Many patients can function at a high level even when very physically unwell, and, therefore, they see no need for it to be treated. ✶ Some when they can no longer function at the level they will see a need to be treated, but the moment they can start to be able to function well again they then no longer see the need to be treated. The ED thoughts and feelings kick in intensively.	⇨	✶ Just because people are seemingly functioning well does not mean they are many just feel driven to keep going
✶ They may fear being forced to stop. ✶ They worry about asking for it & being rejected. ✶ Some feel unable to stop unless they are forced to. ✶ Some want treatment while at the same time not wanting treatment (or not want what treatment involves), some want treatment but can't accept, so when it is offered they refuse.	⇨	✶ This feeling will be increased if patients are told:- - *"You are not getting better because you are not ready", "you need to think about whether you want this" "you are not motivated enough"* etc. as if people can just suddenly decide. This approach does not really make sense it is rather like saying it is ok for you to be depressed & have an ED but you shouldn't have any symptoms. Of course depressed people are going to lack motivation this is one of the signs. Just as one of the signs of having an ED is ambivalence.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ They may not feel worthy of treatment. (They can even worry about people giving them time and the cost). They may feel that others are more in need of it.	⇨	✶ Avoid saying things such as*;* *"You have been here a long time", "you have had therapy for a long time, why aren't you better".* Patients hear a lot of these comments from the outside world, and inside their head, they don't need to hear it in treatment as well. It just makes it harder.
✶ They may not feel ill enough for treatment, and worry that people will see them as too fat for treatment. ✶ Some are so unwell they can't see anything outside of ED world and so the ED cognitions & compulsions don't allow any space in their mind for treatment.	⇨	✶ Avoid asking questions such as:- "*when are you going to be discharged?" "Don't you want to go home?" "You've been here a long time." "Wouldn't you rather be somewhere else?"* ✶ Avoid statements such as:- "*Your weight is not as low as some of the patients we deal with." "You should be able to do it by now".*
✶ **It is a fault in the system which is currently in place, both in terms of outpatient & inpatient treatment that people are not given treatment (whether asked for or not) until their weight is 'low' enough which encourages patients to do this.**		

➔ ASKING FOR FOOD

PATIENTS THOUGHTS & FEELINGS		
✶ **Patients find asking for food very difficult:-** - They may find it hard to go against their ED thoughts around this. - They may feel they don't deserve food. - To ask suggests a ***"want"*** & patients may not want to eat.	⇨	✶Staff can help by:- - making sure, that food plans are correct and changes in plans are clearly written down in an appropriate place. - Having a workable system which enables all staff to know the changes. ✶The computerized food plan updated immediately, old plans removed immediately. ✶ A list of changes that have been made that day could be stuck on the office wall (this would have to be regularly changed.) If the master copy somehow is wrong then the staff can quickly check, rather than having to trawl through Rio which at the time when the discrepancy is happening.
✶ To ask for food can make patients feel guilty, and this feeling is heightened further if they feel they could have not had some food.	⇨	✶If a patient asks for food when something is missing (eg. forgotten butter) then it is better for staff on the table or who are serving not to comment about the item and just give it to the patient in a quiet manner. Drawing attention to the asking heightens guilty feelings. To ask and to be given it in front of the other patients is hard.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Some patients will feel they can't ask for missing food, then they can get into a mess as they are not having what they have been set down to have. ✶ Patients often feel guilty too if they don't ask for what they should have creating a confusing, ***"no win",*** situation for them.		✶ Staff could help by providing an opportunity for patients to say the plan is not being followed. For example, staff in key work could ask their patients whether there are any difficulties where food is not being given. This allows patients a way to tell someone without feeling too guilty, as they haven't actually asked for it themselves.
✶ Plucking up the courage to ask for food they are meant to have & then be told they cannot have it leads to patients feeling even worse.		✶ If a patient asks for food and it doesn't say it on the plan, and it cannot be easily solved at that very moment, it is important for staff to recognise how difficult it was to ask for the patient, and respond in a sensitive way. Eg. *"The plan doesn't say that but I realise it is hard for you to ask and is anxiety provoking for it not being correct. I am sorry but on this occasion I cannot give it to you but I will see if I can find out about the change after and get back to you."* (making sure they do then do this) If the mistake is not then sorted and keeps happening the patient will stop asking as they feel like it was not important enough (they also may feel relieved that they don't have to have it).
✶ Trying something different whether that is an individual challenge or optional change of food is very difficult. Some may wish to do this but need encouragement, in part because it is hard to opt in to some of these things as patients fear judgement from both staff and the other patients. *"They are not a proper anorexic", "They are more well".*		✶ Avoid making assumptions about what as staff you think an ED sufferer might fear (It is possible to create more fear foods by doing this). **People's thoughts and emotions around food types are very different. There is not an ED hierarchy.** ✶ When their might be a special menu *(Christmas, Easter, pancake day etc)* then instead of putting up a sign up sheet where patients have to suggest a want, it would help patients if what was proposed is placed up on the patient board, and announced in the community meeting discussing about how people feel and issues which may be around. Then approaching individuals about whether they would like to have it and talk with them about their anxieties.
✶ Choosing a menu, and asking about different sorts of food is hard for patients. Patients often want to choose so they feel more in control and they can have the food which they are happy with. At the same time this is stressful because it is suggesting a preference, and so suggesting they want it. It can be particularly hard for patients to ask for foods that they might like but their eating disorder has made it hard to have. They feel the staff will think they are better, and are not bothered about such things.		✶ When planning a menu with a patient it is important not to give the opportunity to feel they can choose *"bad"* foods, but not forcing people to do so. If people feel forced to constantly eat food they cannot tolerate when they leave hospital they will cut these things out. As treatment progresses patients may start to feel able to opt for these, and then they may be more likely to eat them when home. This should be an open dialogue as treatment goes on as people may become more open to other food choices.

➔ ASKING FOR TIME

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ There are a number of issues that patients may feel about this, for example:- - Patients can feel unworthy of it. - They may feel that others need that time more. - They may find it hard to approach busy people as they don't want to bother them.	⇨	✶ Staff approaching patients and asking people how they are, even if is only 5 or 10 mins helps people to feel someone does care about them. If patients are not asked then their feelings of unworthiness will be reinforced.
✶ They may fear asking and then being rejected. If this happens it can reinforce their need to keep their world private and reinforce that they should not be asking. ✶ Asking for time implies they *"want"* treatment. - Patients may feel a conflict between wanting help to stop behaviours but worried at the same time if they say they may be stopped and fear whether they could cope with this.	⇨	✶ Offering people time can help those who find it hard to ask and may enable them to reach out. Also from the patient view point they are not saying that they *"want"* treatment. ✶ If staff see that a particular behaviour is occurring then it is better to speak to them quietly, and where possible talk briefly about why they should stop. Eg. If a patient is pacing instead of saying *"stop pacing please"*, *"it is a ward rule that you should stop"*, *"you are upsetting the other patients"*, it would be better to say, *"I can see you are struggling as you are pacing, it is ok to stop, and if you could stop, it would be safer for you."*
✶ Knowing when someone may see you helps a person feel more contained and safe as they know that someone is interested and that they will have an opportunity to address issues. ✶ It also gives patients time to think about what it is they wish to talk about and what needs to be done. This means they will feel more able to use key work. When it is purely ad hoc it makes it harder for patients to think about issues they wanted to discuss.	⇨	✶ Where possible it can help patients if they know when they are going to have key work or "time" in advance. Staff may arrange a time earlier in the week for a slot later on in the week. A staff member could say at the start of a shift they hope to give a person time later in the shift. Patients do understand that sometimes uncontrollable events may mean the time cannot be offered, but it is helpful for a staff member to come & explain the situation, so they know they are not forgotten. ✶ If patients knock on a door, it is helpful if the staff look up and acknowledge the knock and signal they will respond in a minute. ✶ If patients ask for time and this cannot be facilitated at that moment, rather than ignoring their knock, or saying *"I am busy"*. It would be better to say *"It is good that you are asking, I don't have time right now but I will come to see you at X, if I cannot do it I shall ask in hand over for someone to come and see you."* (making sure it is put in handover!). ✶ It is more helpful for a patient to be given only a small amount of time than nothing at all. It is fine to say *"I only have 10 mins but is there anything I can help with."* Patients won't mind this if it set out at the start, and they can judge themselves which issues they discuss knowing the time restriction, it still makes them feel cared for.

It is worth noting that patients may find it extremely difficult to receive any help, and so resist, it does not necessarily mean they actually don't want it. They may oscillate from view to another.

➔ ASKING FOR PRACTICAL THINGS

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ It can be hard to ask for such things because it can feel humiliating for people, especially if they have to be supervised	⇨	✶ Wherever possible patients should be given autonomy, as they are adults and outside of eating they can make sensible decisions, and should be spoken to as such.

❖ THE PATIENT MASK

✶ "Looks can be deceiving"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Some patients find it difficult to show their emotions outwardly, therefore, they can appear they are coping, when inwardly they are not.	⇨	✶ Finding ways of helping an individual patient remove their mask (discussing a way which is helpful to them, as this will vary between patients). Being aware that people do put on a mask is important. ✶ This can be helped by staff not attributing feelings to a patient. *Eg. "It nice to see you smiling, you have been less distressed lately"* etc. as it makes it difficult for a patient to say otherwise. ✶ Ask how people are, ask if they need support with something, but at appropriate times, ie. not in the meds queue, or during a meal. Do not write notes based on the outward appearance.

❖ WEIGHING

✶ "Food for the body is not enough. There must be food for the soul."

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ *The overwhelming emotions that patients feel around weighing are fear and anxiety.*	⇨	✶ Staff being acutely aware that these are some of the feelings around (everyday, but acutely on weigh days) can help them to be sensitive about it.
✶ It is a ***"no win"*** situation for patients, especially when in treatment, as there is no good result. They fear it going up, but also fear it going down as for example, they then may face an increase. They fear the "***knowing"*** and the "***not knowing"*** of their weight.		
✶ It feels humiliating to patients & affects their self-esteem. It feels an invasive intrusion into their private world.	⇨	✶ Discretion and confidentiality around weight needs to be high. While staff need to know what is happening in order to support the patient, patients would find it more helpful to talk about their specific weight and how they feel about it with their own teams at a suitable time, rather than any member of staff randomly talking about it.
✶ Patients fear the interpretation and the misinterpretation of their weight. For example:- - The assumption of suspicion increases self-loathing. If patients feel like this, whether or not they are doing behaviours, it becomes harder to admit difficult behaviours. - The inference of behaviours, which may or may not be, accurate. - The higher the weight the more "well" they are.	⇨	✶ Patients find it hard to be automatically viewed with suspicion, it increases their self-loathing. If people feel like their weight has been interpreted in one way it is hard to say that actually it is something completely different.
✶ Patients may feel that staff will judge them. Some fear that staff are thinking that they are fat and greedy when they put on weight because this is how they feel.	⇨	✶ Staff may not realise that patient may feel this as they don't see how it would be possible for someone so underweight to think this. However, some do.
✶ Patients fear what will happen to their weight, so on weighing days and the night before they may feel like they have to do certain routines and prepare themselves for the agony of their weight.	⇨	✶ Staff being aware that weighing is a very stressful thing especially when patients will feel bad whatever the scales say. Weighing should be done in a calm way, not too rushed with sensitivity, calmly waking patients rather than shouting down the corridor. Keeping the atmosphere calm and quiet means the process does not reflect the chaos the patients feel inside.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Patients sometimes feel compelled into doing behaviours to make their weight different to what it is, whether that is doing behaviours to alter it during the whole week, or trying to manipulate it at weigh in time. They only do this because they are so scared & anxious and may often feel guilt about it.	→	✶ Supportive, sensitive help is needed. This may involve putting in some boundaries, but it needs to be in a way which does not leave the patient feeling worse about themselves. It is also hard to admit things and be honest if they fear they will be punished.
✶ Patients are scared that their weight might not do what they expect it to do & fear the uncontrollability of this. This feels chaotic for people. ✶ Self-loathing is high due to the new body shape (some of which is real & some of which is not real but nevertheless is still distressing).		✶ Rather than ignoring the topic of weight it may help for it to be discussed in a safe environment with staff and patients. *(Clearly not patients' actual situation this is confidential)*. However, never discussing it makes it feel like the "pink elephant" in the room. Patients think & worry about it all the time. If these things are not discussed it leaves patients to deal with their feelings on their own, meaning the ED is unchallenged. ✶ This fear could be addressed by discussing the mechanics of weight, weight gain, the effects of different things on it, the effects on the body, why weight may not do as they expect & discussing the myths that patients may think. Discussing how they feel about weight in a contained way allows patients to know they are not alone.
✶ Patients fear the weight target. Often whatever the target is it will feel too much and they will want & need it to be less to feel they can cope. At the same people are afraid of being labelled as "chronic"/"SEED".	→	✶ Sometimes it may be best to have a target weight while keeping an open dialog about. People who get labelled as "SEED" or "CHRONIC" can feel like everyone has given up on them. It may be that for some of these patients there is a limit to what BMI they can manage and focus on life quality is helpful. However, in the labelling of such patients and giving them a low BMI may also not enable them to ever go any further. This may be because they feel like they are not allowed to as the team are judging it is not necessary for them. It is also impossibly difficult for patients to ask to have a higher target. It may help some patients to set a target but with open dialogue about it. Sometimes a higher weight decided early feels to overwhelming and so they cannot begin but then when they get further along they may feel they are able to go a little further.

❖ CHANGE

✶ "Change is hard because people overestimate the value of what they have and underestimate the value of what they might gain"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ ED sufferers often find change particularly hard. It feels uncontrollable and chaotic. Anxiety of change and anticipated change is high.	→	✶ Staff can help creating a secure environment.
✶ Change tends to need an atmosphere of relative safety, where anxiety levels can be contained. Of course this often cannot happen in life. However, in treatment this should be a prime aim.	→	✶ For some patients and for different types of changes, change needs to be planned for and anticipated in order for people to get their head round it, and try to work out what support they might need and what difficulties there might be in order to enable a change. ✶ There are some patients and certain types of change which if not done quickly prolongs the agony and creates greater distress and trauma.
✶ It is hard to feel safe when a lot of changes come together.	→	✶ Staff need to consider which type of patient and what type of change is occurring and involve where possible the sufferer in the planning of the change.
✶ Fear is the common difficulty. In treatment patients may worry whether they will be able to do it and whether they will be able to cope.	→	✶ Sometimes change requires very small steps which over time will move people forward. If too large steps are set out then sometimes patients feel unable to start to try as they feel overwhelmed by the task. Staff sometimes want the change to be too rapid because they feel there is urgency or think it will take too long in small steps. However, making steps too large often paralyses any change. It is better to have a small change which builds up over time than no change at all. ✶ If a change is urgent then there are times when change will need to be forced in order to break dangerous behaviours. This needs to be done sensitively and with as much involvement with patient as possible.

❖ MEDICATION ISSUES

✶ "One man's meat is another man's poison."

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Some patients find it hard to take medication, some fear weight gain, others feel they don't deserve it, some find it difficult in terms of purity, and a host of other reasons.	⇨	✶ It may help for staff to be aware that patients may have some of these cognitions and encouraging and helping them to take them.
✶ Asking for meds can be difficult for some as it implies a **"want"** or a **"need".**	⇨	✶ It can help for some that the medicine is given rather than asked for.
✶ For some medication is hard to take because they may feel that their ED thoughts may reduce so will resist taking them. They may not be in a place where they feel able to allow that to happen. The illness may require them not to allow the potential for any change of thoughts.		✶ Patients can feel bad when the word **"refusal"** is used as it feels like a negative judgement & misunderstanding.

❖ LEAVE

✶ "One more step along the world I go"

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ Some may find it hard to ask for time and help in regards to home leave:- ✶ Asking for a plan suggests a **"want"** for food patients may feel uncomfortable with this. ✶ Patients may think they **"should"** be able to do it so may feel unable to ask. ✶ Leave has positives and negatives about it. Patients will want to go on leave but this does not mean the experience is necessarily going to be good. - The taking over the responsibility for food is stressful and difficult. For example, how are people going to contain restriction, exercise, vomiting, bingeing etc. particularly when they are likely to be uncomfortable and unhappy about weight gain? Deciding & buying of food can be difficult.	⇨	✶ Where possible it would help if staff prioritised seeing someone before and after going on home leave to make it as successful as possible:- - *Meal planning* - How many meals & snacks - What foods - How patients are going to acquire the food - What support is needed (eg. talking with family or ward support by checking in etc) - Taking food from the ward - Going out to buy the food needed with support - How to deal with timings being different or eating in different environment.

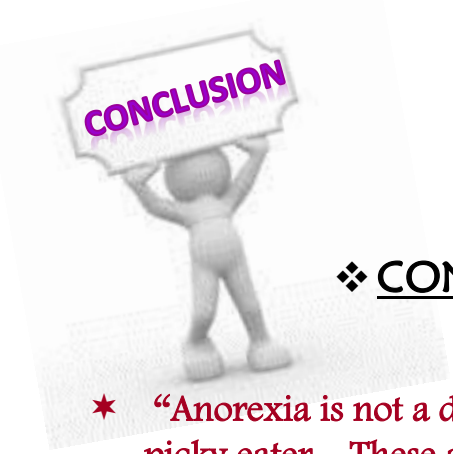
PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
- Patients who live with family may have to deal with this and may or may not be able to use them to help. Others may live on their own requiring a different type of preparation. - Home may have difficult memories. - Home may be triggering as it is the environment where they have been unwell. - There can be many things to sort out (bills etc) which can be overwhelming. - Thinking about structures, activities and time can be hard. - Seeing people you have not seen for a long time, is particularly stressful when you may look more physically better but not feel that way inside. Many people you might see do not understand this. They assume you are pleased to have your weight up. - Patients take themselves and their problems with them on leave.		- *portion planning* - How to portion - What equipment is needed - Practice before - Looking at the exchange lists etc. - *activity planning* - Thinking through possible difficulties - Thinking about distractions - Strategies in avoiding behaviours etc ✶ This does not necessarily need to be directly before, in fact planning it last minute is likely to be less helpful as it can be harder to fit in everything that might need to be done which will raise anxiety and make it harder for the patient to get their head around it.
✶ Coming back to the ward can be stressful eg:- - Leave may have been difficult. - It may be hard to start back on the same plan. - It may be a relief to come back - It can be difficult juggling being at home and in hospital, it can be stressful and unsettling.		✶ Reviewing what has happened enables:- - patients to feel like they are still on the programme even if they are at home which may help them be able to stick with plans. - time to reflect on difficulties and successes and how difficulties might be solved in the future. - If this doesn't occur the knowledge a person gains from leave is lost, and behaviours which may occurred are not addressed producing the possibility that these will just continue to escalate further in future leaves. ✶ It is helpful for staff to see leave as a learning curve, one which has peaks and troughs. Leave does not just become easier in an upward linear pattern they oscillate. It is important the patient feel unjudged and not feel they will be "punished" about what has occurred otherwise it is hard for patients to discuss and disclose.
✶ Community Leave also has positives and difficulties. - It can be a very needed a helpful break from the ward environment which may help patients to keep engaging with treatment. ✶ ED behaviours often appear to help people cope with what has happened on the ward. These behaviours may not emerge immediately but can start small and escalate very quickly. Eg. A small walk may occur, this then builds, then it is impossible to do any other route and if for a reason it then cannot be done anxiety levels can soar.		✶ Reviewing & thinking about community leave is also helpful. Staff should not assume it is always a nice time.

❖ BEING AN INDIVIDUAL

✶ "There is more than one way to skin a cat."

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ **Patients are not a set of symptoms which fit neatly into a box** *(eating disorders are not the same for all)*. For example:- - Patients struggle with different behaviour - find different sorts of food easier or hard - the driving force of the illness and people's ability to overcome the illness will vary.	⇨	✶ **Patients can be helped by encouraging them to have a voice as an individual, and to respond to them as such.** ED patients have often got used to not using their voice, but their ED instead, therefore, listening to their individual needs and attempting to address these enables treatment to be as easy as possible. ✶ Treating people as individuals does not mean that patients will always be given what they want, as clearly what they may ask for may be unhelpful to them. If this occurred then patients would feel unsafe as for some it will make it harder to change behaviours and to go against their feelings as they feel the onus is on them.
✶ It is easy for patients to feel impersonalised, when those treating them assume certain attributes to them because ***"that's what all ED patients do***". Patients feel judged and misunderstood, which can make it hard for patients to get the actual support they feel might help.	⇨	✶ It would help if staff did not assume that all of what patients do or say is **"just their ED".** Some requests are driven by the illness, they are bound to be, how could they not be *(this is also the same in physical illnesses)* but just because a request may be due to that, doesn't mean that it should be disregarded. **Patients will only get better if they are worked with where they are at, at that current time not where you might like them to be in the future. Accepting this, acknowledging this *(both patients & staff)* and working with this is actually the most likely way that sustained change will occur.**
✶ Many people arrive on an inpatient ward because treatment elsewhere has not been successful. This is often because of the rigid nature of this treatment and the unwillingness to work with complex cases. They have often spent time in treatment where professionals have been trying to shape a patient into their treatment hole. This can leave such patients feeling more awful about themselves and more despairing, less able to engage and find trusting staff hard.	⇨	✶ Tailoring treatment allows such patients to be reached by embracing their misshapenness and changing the hole.
✶ The "rule for all" can never totally work. ✶ Patients do need rules to feel safe, safe to eat, safe to make changes. If a "rule for all" is always applied some patients will feel and be unsafe.	⇨	✶ It would help patients if staff held in mind that imposing a "rule for all", while may seem easier, can never completely work as it will inevitably lead to some patients not being able to engage. Therefore applying such rules needs to be done with discernment, sensitivity and flexibility.

PATIENTS THOUGHTS & FEELINGS		SUGGESTIONS FOR HOW STAFF COULD HELP
✶ What is helpful to patients is varied. ✶ Individualised planning is not about being fair or not fair. *(sometimes patients will feel like this is the case)*	⇨	✶ Staff can help by being prepared to think about what may help an individual, adapting menus, plans and therapy, can all be adapted without giving patients too much unhelpful control or being too burdensome to staff. It can help patients to engage in the treatment. Sometimes staff are scared to do this because they fear it will become too complicated and other patients will resent it. However, individualised planning doesn't mean that everyone has radically different things, it is often very small things that can be done to help and if this is happening to different degrees, at different times, for all patients then this can remove resentments. In the end everyone wants to make treatment as easy and less traumatic as possible.
✶ Different EDs take different forms, dual diagnosis complicates things further, patients will all have different underlying reasons for developing the illness, and differing histories within the illness. In the end it is just about helping individual people who are unwell.		



❖ CONCLUSION

✶ "Anorexia is not a diet…Bulimia isn't a bad habit…EDNOS is not just being a picky eater…These are horrible disorders not life choices"

- ✶ *Helping those with eating disorders is about coming alongside sufferers, sitting with & accepting their distress, encouraging people to express their feelings and share their inner world without fear of judgement, but with understanding & empathy.*
- ✶ *The solutions to such things are very often unclear & therefore, treatment is about trying to find a way through. However, the key is that this is done on an individual basis.*
- ✶ *It is ok to not know whether things can be better for someone and to express that. It does not take away hope. It allows the person, as they are, to be accepted and worked with in a realistic way where knowing all the answers is not the key but instead being with people in their pain.*
- ✶ *Sometimes treating people as individuals actually creates an atmosphere where everyone can be included.*
- ✶ *Having an eating disorder does not mean that all people are suffering in the same way. Just like a physical illness there are different presentations and different responses to the illness. It may not be possible for all people to live without having an eating disorder, but this does not mean the sufferers have control over this & neither does it mean that they cannot be helped.*

Patients will not care about how much staff know about eating disorders and how they be helped if they are not shown through staff behaviour how much they care.

APPENDIX

✶ FURTHER RESOURCES

✶ Helpful Hints Crib Sheet ➔ A sheet to show how to use language when speaking to eating disorder patients to help them

✶ Snap Shot of the Dining Room ➔ An image to show the kind of experience eating is for patients

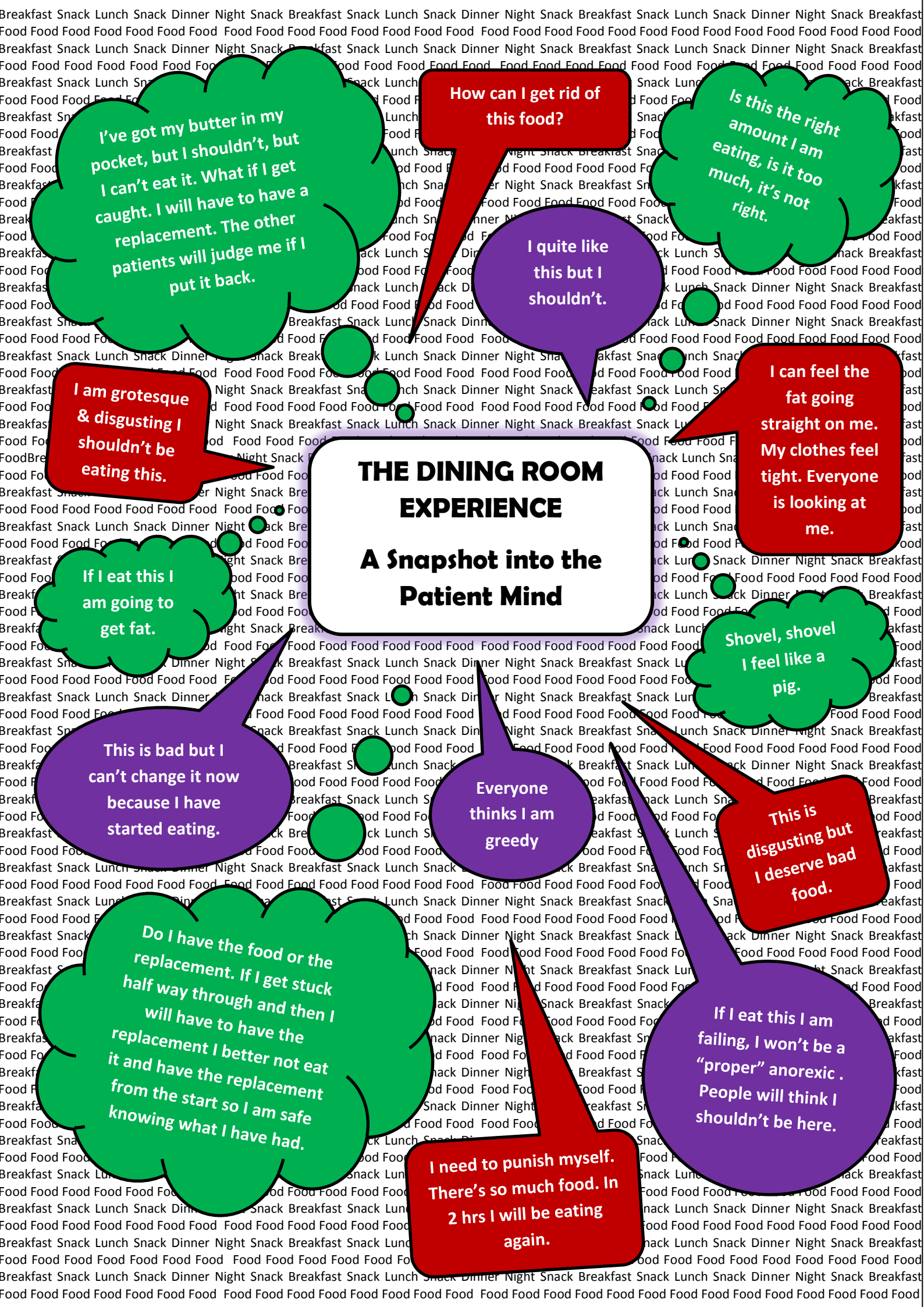
✶ Talking to an Eating Disorder Sufferer ➔ A brief sheet of what not to say and some positive alternatives

HELPFUL HINTS ON HOW TO SUPPORT PATIENTS

Helpful Hints		Practical Examples of How to Help
Every person's eating disorder is different.		Ask individual patients what they find most helpful, both at the table and also generally in regards to living on the ward.
The kind of words you use when talking to patients about their meal plans is very important.		When discussing food choices, avoid *asking* ***'do you want?'*** or ***'would you like?'***; Instead, carefully check the patient's meal plan, and if you are still unsure, ask the patient ***what is on their meal plan***, or what they **should** have.
Be careful of making unhelpful comments when talking in general to patients.		Avoid comments such as: 'You're looking '**well/healthy/better**' 'Did you **enjoy** your meal?' 'Don't you **want** to get **better/go home/get out of hospital?**'
When enforcing boundaries at mealtimes, be mindful of the language you use.		Instead of saying ***'Scrape your plate!',*** say **'I can see you've tried really hard; let's see if we can manage this last bit.'** Instead of saying ***'5 minutes left!'***, say ***'I can see you're trying hard but try and keep an eye on the time' or 'I know it's difficult but can we all try and finish within the next few minutes?'***
Wherever possible, try not to comment on patients' food choices.		Unless there is an obvious problem with the patients' meal, please don't comment on the food that is being eaten. Eg: ***'That macaroni cheese looks nice'*** or ***'Ah, you've chosen branflakes this morning'.***
If you are serving, check that the meal is complete before the patient enters the dining room (and utensils!).		▪ Check that butter/Flora is served with jacket potatoes. ▪ Check that all food groups are present (Protein, carbs & veg) ▪ If you are overseeing breakfast tray prep, ensure that the patient has everything on their meal plan on their tray before leaving the kitchen. ▪ Check the fluid ▪ Check the correct utensils are there.
When supporting patients who self-serve: 1) try to use appropriate language 2) do not leave the patient midway through serving 3) ensure there is space around the trolley.		1) Instead of saying ***'Not enough!' or 'More, more, more'*** when a patient is serving their meal, say ***'you're almost there, but you need to try and put a bit more on the spoon.'*** Equally, if a patient has too much on the spoon, sensitively ask them to take some off. 2) Whilst a patient is self-serving, you need to ensure you are not distracted by other things eg. Patients who have a problem with their meal. Finish supporting the self-server and then deal with any other requests. 3) Try and minimise the number of people stood around the trolley when a patient is self-serving.
Try to keep in mind that a patient's distress extends further than meal times, and may not be immediately obvious.		Patients are likely to feel distressed throughout the day, not just at meal times, but they may not always show it. Try to let patients know that you are there to talk if they need to. Problems can't always be solved but simply being listened to will often be enough for the patient.

THE DINING ROOM EXPERIENCE

A Snapshot into the Patient Mind



Talking to an Eating Disorder sufferer

*What **not to say** and some **positive alternatives***

DON'T

'You're Looking Well'

- Is often interpreted as 'you're looking *'fat'*
- ***Any*** comments around food, weight and appearance e.g. *'It's great to see some colour in your cheeks', 'Glad to see you looking less bony'* are misinterpreted negatively and as a failure on our part.
- Despite maybe *looking* better, we are likely feeling a lot worse - fighting feelings of guilt, shame, anger, sadness.

DO

'How are you?'

- Although we may not be able to articulate an answer, knowing that you care (e.g. *'I'm here if you want to talk')* is key.
- If we can talk please listen even though you may not understand how we're feeling.
- Don't expect consistency. Inside our head is a battle between the 'self' and 'anorexia'. We can't always tell them apart.

DON'T

Congratulate us at mealtimes

- Maybe you noticed we tried a new food, or ate more than previously.
- Meal times are stressful and acknowledging efforts will halt us in our tracks. We may be trying hard but the anorexic voice is ANGRY with us.

DO

Keep quiet and mention it casually later

- Mealtimes need to be as stress free as possible – 'small talk' is safer.
- If you do want to acknowledge an effort mention it at a less anxiety-inducing time: away from meal times. You don't need to go into huge detail as this can induce anxiety.

DON'T

Make a big deal about what we won't eat

- We are likely to have a lot of rules around food. Don't try to coax us out of these.
- Don't assume because we didn't eat pasta last week we're not eating it this week.
- Putting pressure on us to broaden our repertoire before we're ready will likely induce panic and hamper 'progress'.
- Don't question strange food combinations.

DO

Provide us with options and respect our choices

- Let us eat the foods we feel able to tackle.
- Leave the options open for us don't make a fuss if we try something different.
- Respect our choices and let us get on with it (unless your role is to ensure we are following a specific meal plan).

DON'T

Say 'Get well soon' or 'You'll be fine'

- Can indicate a lack of understanding of Eating Disorders and the enormity of the task of trying to get better.
- Can be misinterpreted as desire for us to stop bothering you with our illness or can put pressure on us to make progress more rapidly than we're capable of.

DO

Recognise this will take time and commit to being there

- When we are first ill we might look really ill. As we get better these visual cues diminish and people think we're fine. We're not.
- Our bodies will be ahead of our minds - knowing you understand this and will continue to offer their support even once weight is restored is essential.