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## Introduction

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### Introduction

In early April 2020, as the country went into the pandemic lockdown, CPFT arranged to replace the monthly ED Carers Support Group with a weekly online meeting to provide support and advice. The first eighteen months of summaries have been published as three standalone summaries.

This is a summary of all the discussions from the online Carers Support Group meetings held between September 2021 and April 2022, compiled by Keith Grimwade, including open and specialist led meetings. Presentation slides have been copied into the relevant section. Resources are highlighted.

#### Facilitators:

Keith Grimwade, Carer and Lead Governor, Cambridgeshire and Peterborough Foundation Trust

Dr Sarah Beglin, Consultant Clinical Psychologist, Community Eating Disorder Service (CEDS), Cambridgeshire and Peterborough Foundation Trust.

#### Format

The format is to have a monthly presentation from one of the AED team with a Q&A session, and the weekly sessions to be "Tell and Share".

Each meeting was run in three sections:

1. A general introduction round with everyone to introduce themselves, to give a brief summary of how things are and to say if there are any issues they would particularly like to discuss.
2. The issues raised were grouped during the introduction then Sarah / the Service asked to respond; and give an opportunity for us to respond as well with anything that we have found helpful.

#### Attendance

Was by invitation only, meeting times

1st Tuesday of month: 4.30 - 5.45pm, support group discussion

2nd Tuesday of month: 6.30 - 8.00 pm presentation

3rd Tuesday of month: 4.30 - 5.45pm, support group discussion

4th Tuesday of month: 6.30 - 7.45 pm, support group discussion

5th Tuesday of month: 6.30 - 7.45 pm, support group discussion

**They alone can do it - but they can't do it alone**

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**5th October 2021 – Questions? and Praising the ‘green shoots of recovery’**

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**5th October 2021 – Questions? and Praising the ‘green shoots of recovery’**

Another excellent discussion, thank you for everyone’s willingness to share. I have summarised some of the key points below.

**Why are things going well?**

It's understandable that we focus on the difficulties we and our loved ones are experiencing, but important lessons can be learnt from reflecting on why things are going well; and it is so good to hear that that is the case for a number of our loved ones at the moment. The first thing to say is that there is rarely, if ever, a single identifiable reason why our loved ones recover. When Amy and Ana spoke to us about their recovery journeys neither could identify a 'magic moment' that led to recovery but both talked about a number of things that, combined, helped. Sarah reminded us of Janet Treasure's statement 'Only they can do it, but they can't do it alone': people make themselves well when they are ready, and by being calm, consistent and caring - and by putting into practice all of those good 'dolphin' skills - we as carers can help create an environment in which our loved ones stand the best possible chance of getting better. We have heard on a number of occasions that, 'Stepping back was the best thing'; this takes courage and you have to hold your nerve, which is why it is so important that you have support, too.

**Why does xxxxx take it out on me, but not on my partner?**

This proved to be a common experience and the group came up with some helpful comments. One point made well was that this is common whether our children are unwell or not. It is almost inevitable that one partner is present more, or more involved in making our loved one do the things they don't want to do, e.g. if one partner is at home and one at work. It is very important to remember that it is the eating disorder talking, not our loved one. However, it can still be hurtful and it is right and proper that we say how their behaviour makes us feel. The group's experience is that swapping roles / sharing tasks, if possible, can be helpful. It may also be a case of having to 'step out of the ring' for a few rounds in order to take care of yourself.

**Is setting a curfew being a rhino or a dolphin?**

This question is about setting boundaries, which is a really difficult issue. When is a boundary 'stepping in and exerting control' (rhino) and when is it 'nudging and supporting healthier, more appropriate behaviour' (dolphin)? We can only have boundaries over things that are under our control, e.g. 'their space' is different to a 'shared' space, so you might ignore the state of their bedroom but it is reasonable to expect a bathroom to be left in order. We discussed the example of setting a curfew - it could be 'I am setting a curfew because that is what I expect of a young person, and there is to be no discussion' (rhino), or 'We need to agree a time because it affects the other people in the house and we need to be fair to everyone - what's the solution?' (dolphin). It is important to remember that any

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**5th October 2021 – Questions? and Praising the ‘green shoots of recovery’**

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discussion of boundaries requires empathy - the illness may have drained our loved one's energy levels and what seems a small request to us may feel like a major ask to them.

**Praising the ‘green shoots of recovery’**

We also talked about the importance of praising the ‘green shoots of recovery’ to build confidence. We have to be careful not to miss these because what might seem like a small thing to us can be a really big thing for our loved one, e.g. that extra spoonful of potato, or having a cake with their coffee. I mentioned that if we take a step back, we can often see positives even in worrying situations, and this allows us to communicate in an encouraging way (dolphin) rather than show our anxiety (jellyfish). For example, we might be very worried that our loved one has rung us from university to say they have self-harmed... but the fact that they have told us is a real positive. Seeing this allows us to respond with empathy and encouragement: ‘I can understand how upset you are. It's great that you've rung, tell me about it, perhaps there is something I can help you with’. I mentioned the ‘ABC’ framework as a helpful scaffold for thinking about this (see Janet Treasure's book), which needs a presentation session of its own, so we will add it to the list!

**Reference****Book**

Skills-based Caring for a Loved One with an Eating Disorder by Janet Treasure, Grainne Smith and Anna Crane. Routledge. ISBN 978-1-138-82663-2. 2nd Edition.

## **12th October - Meal Support Presentation - Charlie Middleton, Clinical Nurse Specialist**

This week Charlie Middleton, Clinical Nurse Specialist, gave us a talk on meal support and led a really helpful discussion about some of the issues we face as carers. Charlie's presentation is attached.

Each of us will have our own 'top takeaways' from Charlie's talk. Three messages that have stayed with me are:

- It is not our job to take on the role of food police or food enforcer.
- Only our loved ones can make the decision to get help and decide what help they need.
- We can do a lot to help by being the good 'St Bernard' and 'dolphin' - by staying calm, by providing empathy and validation and by gently encouraging.

We discussed a number of issues that we have faced, or are facing; here is a summary of some of the key points.

### **How can our loved one eat healthily and regularly when they return to work and the demands of the job get in the way?**

A number of the group have had experience of this and offered the following tips:

- Have smoothies / drinks prepared in advance that can be a quick, nutritious snack.
- Plan in advance with 'ready to go meals / snacks' in Tupperware boxes.
- Cereal bars are also a convenient and nutritious snack.

Charlie reminded us that 'healthy vs unhealthy' is an eating disorder division - recovery is the ability to eat normally, which includes biscuits and cakes as snacks. In the past we have heard examples from the group where employers have made 'reasonable adjustments' (as they are required to do by law) to help an employee, e.g. giving them access to a private space for snacks and meals so that they do not have to eat in front of others... although it is important to remember that the goal must be 'normal eating'.

### **What role does praise play in meal support?**

The concern here is that praise can sound very wooden and stilted. When we have discussed 'praise' before we have agreed from our experience some general principles:

- Praise is important because it encourages and builds confidence.
- Praise must not be indiscriminate or it loses its currency.
- It is important to praise what might seem like small achievements to us but are huge successes to them.

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**12th October - Meal Support Presentation - Charlie Middleton, Clinical Nurse Specialist**

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- Praise the process (e.g. the effort they have put in) and not just the outcome (e.g. what they have achieved).
- People like to be praised in different ways; some like a big fuss, some like a quiet word.

It is helpful to think beyond 'praise' (expressing approval) to 'affirmation' (a comment to encourage a positive character strength). For example, compare 'Well done on serving out your dinner' with 'I can see that you are able to judge portion sizes just by looking at your plate, it must be a relief not having to weigh everything. You have come so far.'

**How flexible can snack and meal times be?**

Charlie emphasised that ideally, we would encourage patients to develop a regular eating routine (six eats), although some flexibility is inevitable and not an issue, e.g. if we have to eat earlier than usual because we have a support group to attend. This is the goal for our loved ones and it will be a series of points along a continuum, e.g. a refeeding programme in an inpatient ward will be very fixed. Chloe explained that a snack is incorporated into the MANTRA online group therapy as a deliberate challenge to help our loved ones recover a 'normal' degree of flexibility.

**My loved one requires reassurance every time before eating - is this helpful?**

The short answer is 'no' and there is a real danger of falling into the reassurance trap.

If our loved one keeps asking the same questions again and again (Do I deserve this? Will it make me fat?) our reassurance will be increasingly less effective at reducing their anxiety - they will almost certainly end up asking the same questions even more. It is better to provide some gentle challenge, e.g. 'You've asked me that before, you know what I am going to say', or 'We agreed that I would not answer that question again' (this requires some pre-discussion in a calm moment); and stay alongside them while their anxiety subsides, which it will. However, the longer answer is that if a short ritual of reassurance means that our loved one will eat and it is part of a plan that you have discussed and agreed will not last forever, but will reduce until it is no longer needed, then it can be a legitimate step towards recovery. The group's experience is that withdrawing from a ritual of reassurance needs to be done gradually, with plenty of compassion, unwavering consistency and lots of discussion.

**How can we encourage our loved one to eat with us?**

So many of us have experienced our loved ones withdrawing from the family meal. It is really important to acknowledge how challenging eating with others can be when eating is the thing that really frightens you. The group's experience is that staying calm and being patient is vital - there is nothing to be gained from trying to force the issue. Our experience is that distraction techniques are really helpful:

- TV meals - eating in front of the television, so that there is something to watch / be interested in, and so that there are no embarrassing silences.

**12th October - Meal Support Presentation - Charlie Middleton, Clinical Nurse Specialist**

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- Making up a Spotify playlist - each member of the family has to contribute a track a day, taking it in turns to choose the theme. You can then have a chat about why tracks were chosen and almost certainly the opportunity to laugh at someone's choice!
- Plan a calming activity prior to the meal (e.g. taking the dog for a walk) and having something to do straight afterwards (e.g. a craft activity).

Charlie reminded us that this has to be led by our loved ones, when they are ready to change.

Thank you, Charlie, for such a great session.

And finally, Ann has completed the compilation of summaries April - September 2021, 'Book 3'. It is being added to the Keep Your Head website and I will circulate the link as soon as it is available, but if you would like me to email you a copy, let me know.

**Resources****Web**

Keep Your head

<https://www.keep-your-head.com/adults/MH/eating-disorders/about-eating-disorders-1>

**Presentation**

## MEAL SUPPORT

Charlotte Middleton  
Clinical Nurse Specialist  
12th October 2021



Brief Background about  
myself and experience of meal  
support.

- **What is meal Support?**

- Meal support is a form of emotional support provided to a person struggling with an eating disorder before, during and after meals/snacks in an effort to increase the struggling person's success with meal/snack completion.
- Remember – even though it is frustrating ,only the person experiencing the eating disorder can make the decision to get help and decide what help they need.
- (Motivational cycle , stages of change.)

- **What is meal support not?**

- It is not your job of taking on the role of food police or food enforcer.

**This session will provide you with an understanding of;**

What is meal support  
Meal support guidance /tips, what is helpful/unhelpful.  
Support after mealtimes.  
Ask any questions/discussion.



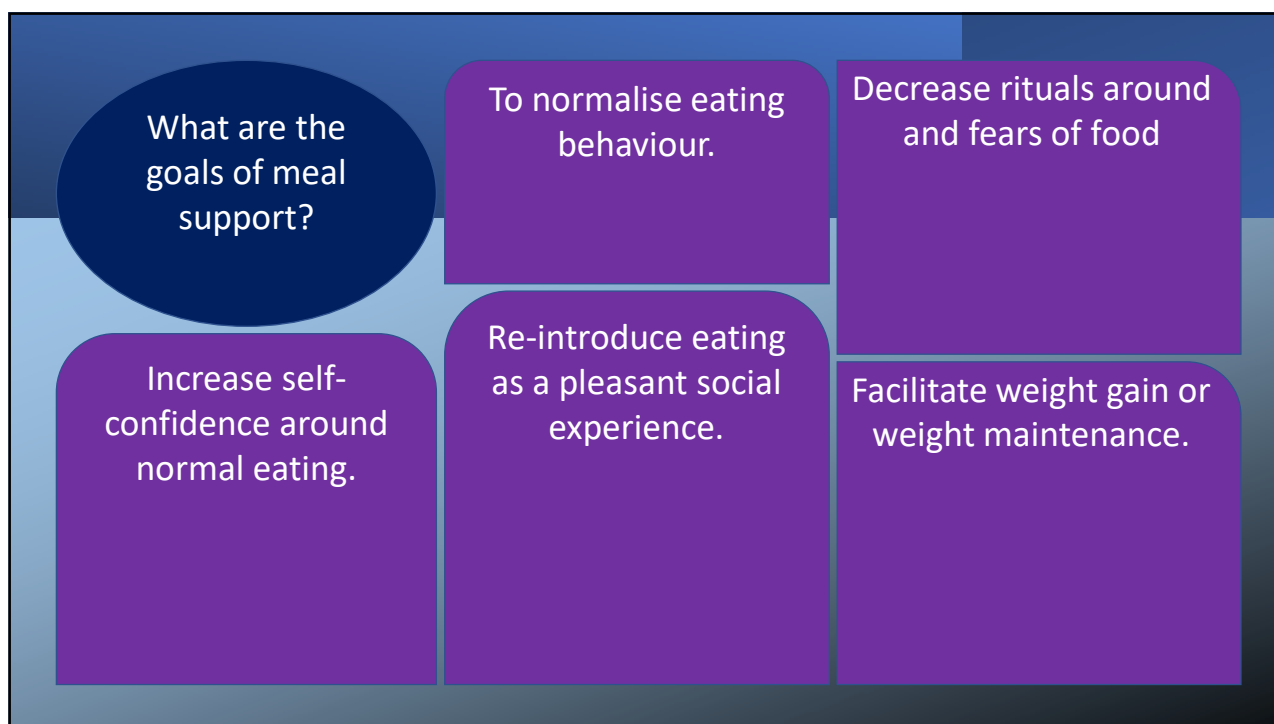
Over to you.....

What are your experiences of meal support?

What are you struggling with?

What would you like help with?

Thoughts and experiences:



## Mealtime tips.

- It can help to ask your loved one what is helpful for them and what is unhelpful . For example, ask them what can I do/ what can I say to help you with your eating.
- Provide encouragement , ' I'm really proud of your hard work'
- Empathise on how they are feeling, ' I know that this is very difficult for you'
- Validate their feelings.
- Making conversation during the mealtime can serve as a form of distraction from eating disordered thoughts .
- Model eating a balanced diet
- Try to keep the atmosphere light-hearted and positive throughout the meal, even if you do not feel that way on the inside!
- After the meal , an activity together can be helpful such as a game or watching TV, this will help to distract from wanting to purge or over exercise.

## Strategies continued:

- Avoid sensitive topics:
  - Food, weight, calories, appearance .
- Try not to bargain with logic.
- 4 c's of meal support – remember, it helps to remain calm, confident, consistent and compassionate.

*" Finishing this snack will be a step towards getting better and showing the eating disorder that you are in charge"*

*" I understand that this meal is incredibly difficult for you. Eating is hard work and I imagine emotionally draining for you. How can I best help you at this moment?"*

*" why don't you try a few more bites? I can see this is a struggle for you, but we're supporting you to get you well again"*

*" your stomach has stopped communicating with your brain, it's no longer saying Hey brain, I feel hungry"*

*" you're doing a great job"*



## Examples of behaviours that you may have observed:

Not eating or eating a very small amount.

Not eating certain foods.

Cutting foods into small pieces.

Stalling mealtime.

Eating very slowly or very quickly.

Eating very small or very large mouthfuls.

Eating foods in a particular order. ( eg. This is called food groups).

Going to the bathroom during meals or immediately after meals.

Exercising after a meal.

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**19th October 2021 – Help with Traumatic memories,**

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**19th October 2021 – Help with Traumatic memories,****Not ill enough for treatment, Assertiveness, Secret exercise,  
Siblings**

We covered some more great issues and questions this week, thank you for being so willing to share your experiences and to offer your thoughts and ideas.

**Our loved ones asking for help to cope with the traumatic memories of when they were ill**

We began with an issue that we have not discussed before, namely our loved ones asking for help to cope with the traumatic memories of when they were ill. The group fully understood the issue and thought that it was really positive if our loved ones talked about this with us and asked for support. Sarah commented that it is our loved ones asking for help with processing emotion in a healthy way and that it is really helpful for us to have this conversation with them. Support can be accessed in the usual ways, through your loved one's GP, or privately.

**Not being ill enough to be accepted for treatment**

One issue that has come up before is 'not being ill enough to be accepted for treatment'. Behind this statement will be a range of individual circumstances but a small number of general points came out of our discussion that may be of help:

- Eating disorder charities may be able to support patients with less severe eating disorders.
- In Cambridgeshire and Peterborough it is possible to self-refer to PEDS <https://www.pedsupport.co.uk>.
- BEAT run a number of telephone and online support groups, including peer support. <https://www.beateatingdisorders.org.uk>
- A small number of private therapists offer specialist eating disorders support; the BEAT website lists some possibilities.

Sometimes when our loved ones have received a lot of psychological therapy, there comes a point where you need to draw a line on further therapy because continuing with it will not result in further improvement and may create an unhealthy dependency. This may be a very worrying time for our loved ones and they may feel that they still need support. However, 'ending' is part of the transition to recovery. Our role is to be a good dolphin and follow the 'three Cs' - stay calm, be consistent and show compassion.

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**Not ill enough for treatment, Assertiveness, Secret exercise, Siblings**

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**'Should we be more assertive?'**

The group's experience is that this is a common question carers ask themselves. However, a better question is **'How best can I communicate with my loved one?'** We know from experience that stepping in, laying down the law and getting into an argument does not work. We know that listening, reflecting and encouraging has a better chance of success. 'Assertiveness' is a communication style in the 'better chance of success' camp and contrasts with, say, 'aggression'. In the presentation Dr Georgina Hurford gave to us earlier in the year she defined assertiveness as 'being clear and open about what you think and feel without being blamey or critical of other people'. She reassured us that it is not easy to do, it takes time and practice. But it is worth the effort. If anyone would like a copy of her presentation, with tips on how to do it, drop me a line.

**Secret exercise**

We have discussed many aspects of the issue of over-exercise in the last 18 months. The group's thoughts are summarised in the FAQ on the Keep Your Head website.

Today we considered 'secret exercise', e.g. our loved one exercising in their room behind a closed door, rather than going out for a run or cycle. Sarah reminded us that we can't make people change their minds. What we can do is pick a calm moment to open up a dialogue to explore our loved one's concerns:

- are they worried about putting on weight?
- do they feel they have to exercise to 'deserve' food?
- is it part of a ritual to control anxiety?

We can ask how we might be able to help and we can encourage healthier behaviours, e.g. group exercise.

**Siblings**

We briefly discussed some of the challenges an eating disorder presents for siblings. This is a big and important topic. Again, some of our previous thoughts are summarised on the Keep Your Head website. That brothers and sisters tease and make comments about each other is nothing new, but an eating disorder unfortunately lends itself to this type of behaviour, e.g. comments about size and appearance. This does require an assertive response:

- I find those comments really upsetting.
- I don't like them and in this family we try not to say those sorts of things.

It is also really important to talk with their brothers and sisters to listen to their concerns and answer their questions.

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**Not ill enough for treatment, Assertiveness, Secret exercise, Siblings**

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And finally, we congratulated Pxxxxx and Rxxxxx for completing the Cambridge Half Marathon. Well, their daughter did the running but Mum and Dad were alongside the whole way, having managed their anxiety, used the opportunity to talk about nutrition and encouraged a healthy attitude towards preparation. I distinctly heard Rxxxxx say that Pxxxxx was planning to do the real thing next year!

**References****Web**

PEDS

<https://www.pedsupport.co.uk> .

BEAT run a number of telephone and online support groups, including peer support.

<https://www.beateatingdisorders.org.uk>

Keep Your Head

<https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder> .

## **26th October 2021 – How do we support and communicate with our loved one**

A number of the group sent apologies this week because you were away enjoying a half term break - thank you, but there is no need to apologise for looking after yourselves! We welcomed Yolande Russell from Eating Matters, a Norfolk-based charity, who is exploring the possibility of setting up a group like ours. Although we were fewer in number than usual, we still had plenty of experience to share and I've pulled out some of the key points below:

### **How do we support our loved one when they are in the 'pre-contemplation' stage?**

i.e. they are not even thinking of changing their behaviour?

This can be a long stage - in their 'Delaying for Years, Denied for Months' report (<https://www.beateatingdisorders.org.uk/about-beat/policy-work/policy-and-best-practice-reports/delaying-for-years-denied-for-months/>) BEAT found that on average it took 91 weeks for an individual to recognise they had an eating disorder. This is understandably an extremely worrying time for us as carers because we can see that there is something wrong, and that our loved one is becoming increasingly unwell, but they will not accept this. The group's experience has been:

- **Hang in there** - it may be impossible to imagine at the time but eventually our loved ones do start to contemplate change and make small steps towards recovery.
- **Don't push too hard** - if they are not ready any resultant conflict will make it harder to discuss worries.
- Don't give advice when it is not wanted, it will be ignored.
- **Do show empathy**, e.g. 'That meeting must be really important for you, I can see why you don't want to miss it' rather than 'I don't think you should go to that meeting, it's not as important as your doctor's appointment'. An empathetic response is more likely to make your loved one feel that you are on their side, which - over time - will make them more receptive to being 'nudged' in the right direction.
- Do provide factual feedback about their health.
- **Do keep the communication bridge open** by talking about non-eating disorder subjects.

And above all, **look after yourself** - you may need to step back and take a break because the effort and anxiety can be exhausting.



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## 26th October 2021 – How do we support and communicate with our loved one

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I was reminded of our conversation with Amy and Ana, who talked to us about their recovery journeys last January. Both talked about the important role their families played and how best we as parent/carers can help:

- **Unconditional love** - being there and listening; being non-judgemental.
- **Showing that you care** - Ana described how her mother put notes under her bedroom door at times when she found discussing her illness more openly was difficult, which demonstrated that she was not blind to Ana's struggle.
- **Connecting - about non-ED subjects / activities**, so that the illness does not define the entire relationship.
- **'Nudging'** - Ana's mother making an appointment for her and telling her about it, but leaving it up to Ana as to whether she attended or not; conversely, speaking about food directly was unhelpful.

### How do we support our loved ones if their recovery falters, or they relapse?

The group recognised the sinking feeling you get in your stomach when this happens. It really is one of those moments when you need to be a St Bernard and stay calm. Think of it as 'lapse' not 'relapse' - it is part of recovery, and it is very common. Acknowledge the situation and be there to offer practical support if it is wanted. Think about 'what worked before' and be reassured by the resilience they have learnt from the challenges they have already been through. And, of course, look after yourself, for your own sake and so that you can give them the best possible support.

### How can we break down barriers and communicate with our loved ones?

'Communication' is at the centre of all that we do as carers. The group's overwhelming opinion was that the 'animal metaphors' in Janet Treasure's book (reference below) are really helpful:

- Don't charge in like a rhino and get into an argument.
- **Do swim alongside like a dolphin** - show empathy, be gently curious and offer support. Communication works best in calm moments. The group described communication being easier when there was a distraction, e.g. doing a jigsaw, or a 'safe space', e.g. a car journey.
- **Listening is a really important part of communication.** It may feel that you aren't doing anything / not coming up with any ideas, but if you listen hard and reflect back your loved one's conversation you can help them sort out a jumble of intense thoughts and feelings.
- **Don't say too much** - let comments hang and wait for your loved ones to draw their own conclusions.

We heard further examples of the group using written notes - texts, emails, letters - successfully. This gives you and your loved one time to think and say what you really want to.

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**26th October 2021 – How do we support and communicate with our loved one**

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**Recruitment opportunity**

And finally, for those of you who live in Cambridgeshire and Peterborough, CPFT's Participation and Partnership Forum is recruiting new members. There is some information about it at:

<https://www.cpft.nhs.uk/participation-and-partnership-forum->

(You may have to paste this into your browser) and here is a message from Anna Tuke who leads the forum: 'Cambridgeshire and Peterborough Foundation Trust are looking to recruit people to their service user and carer forum – the Participation and Partnership Forum (PPF). The PPF meet once a month for approximately two hours. Payment is offered at £10.00 per hour for our PPF members. If you would be interested in finding out more or getting involved, please get in contact with [anna.tuke@cpft.nhs.uk](mailto:anna.tuke@cpft.nhs.uk) / 07929 379950, Associate Director of Involvement and Partnerships.'

Next week's meeting is a '16.30 Support Group Discussion'. I'll get the invites out by the end of the weekend and I look forward to seeing you there.

**Resources****Report**

'Delaying for Years, Denied for Months' report

<https://www.beateatingdisorders.org.uk/about-beat/policy-work/policy-and-best-practice-reports/delaying-for-years-denied-for-months/>

## **2nd November 2021 – Behaviours, Where should I start?, Useful reminders**

This week we discussed a wide range of issues and came up with many helpful ideas drawn from the group's experience. I have summarised the main ones below.

### **How can I stop my loved one scratching and skin pinching?**

This behaviour can be very upsetting for our loved ones, and for us. It is often associated with OCD (Obsessive Compulsive Disorder), a no unusual co-morbidity with an eating disorder. One of the group said that applying coconut oil had helped their loved one because the feel of it gave her a moment to notice what she was doing and a chance to stop. Another said that medication had been helpful. As ever, our role is to stay calm, be consistent in what we say and show compassion to demonstrate that we are on their side; this approach stands the best chance of helping them to manage their compulsions and/or anxieties.

### **How do we support our loved one when they struggle with phoning people up, e.g. the GP?**

A fear of making phone calls is surprisingly common - there is even a word for it, 'telephobia'. For our loved ones, it is easy to understand why phoning someone they might not know about their health could make them anxious. Making the phone call for them will not help in the long run, although if there is a crisis you might need to step in. Showing empathy - acknowledging how hard it is - will help them because it will tell them that they are not making it up. If you can, discuss how the call might go and help plan what they are going to say, e.g. they need to know that they might be put on hold for a long time, and that it is a good idea to write down your key points so that you don't forget them when you do finally get through. Find out if it is possible for them to email, text or write to the surgery instead. Hold your nerve to not step in, and if they do the call use it as an opportunity for affirmation, 'You were so brave to make that call, you showed real strength of character to hang on the line for that long'.

### **Is it normal for someone with anorexia nervosa to eat and eat at the end of the day?**

The short answer is that it is not unusual - 50% of people with anorexia nervosa binge. Sarah reminded us that our loved ones are deliberately mastering hunger all day and that perhaps it is not surprising that at the end of the day, when our loved one is really tired, their resolve cracks and they can't stop themselves. It's great if they can talk to you about this. Be curious - try to understand (and help them to understand) their feelings. For example, there might be an opportunity to raise some 'pros' and 'cons': 'On the one hand you feel guilty about eating loads before you go to bed and on the other you are not eating as much as you would like to during the day'. It may be necessary to agree some boundaries if their behaviour is affecting others, e.g. an empty cupboard at breakfast.

**2nd November 2021 – Behaviours, Where should I start?, Useful reminders**

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**Where should I start - there are so many things I'm concerned about?**

It simply isn't possible to tackle everything at once, we have to prioritise. Dxxxx gave us a great acronym,

**'AH HA!':      Alive, Healthy, Happy, Achieving.**

Sue Young gave us a good example of 'alive' before 'healthy' in her presentation last year when she said 'If our loved one's weight is dropping let them eat the food they want to even if it's not ideal'. Eating disorders are about feelings, not food, so our loved ones' emotional health (happy) should be prioritised over, say, academic achievement. Having prioritised, Sue's advice was 'One battle at a time'.

**How do we reduce our loved one's anxiety at family meal times?**

Joining in with a 'normal' family meal time can be a real challenge for our loved ones, who may prefer to eat alone and/or have complete control over calories and ingredients. The group's experience is that distraction before, during and after the meal is the most helpful thing we can do. This may take some planning - ideally with your loved one - and support from other family members. We have discussed some great 'distraction techniques' over the course of the last year or so:

- taking the dog for a walk
- reading a book
- having music or the television on, quite literally to distract the emotional brain and change the mood, and so that there are no embarrassing silences
- jigsaws
- watching a video on their smartphone
- making up a Spotify playlist - each member of the family has to contribute a track a day, taking it in turns to choose the theme. You can then have a chat about why tracks were chosen and almost certainly the opportunity to laugh at someone's choice!
- a craft activity

**And finally, some useful reminders from our discussion:**

- our role is to be there to support our loved ones, leaving their treatment to the professionals
- the value of small steps - this may be graded exposure to a challenging situation, e.g. going to school, or socialising; or a sequence of steps to achieve a goal such as an aspect of independent living - for example, choosing a few foods they would like for the weekly online order, to sorting out a meal plan and working out the ingredients, to managing a weekly shop on a given budget.

**2nd November 2021 – Behaviours, Where should I start?, Useful reminders**

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- it is important to recognise the positives, for us and our loved ones, because each one is a piece of the jigsaw of recovery
- compassion is really important because it shows our loved ones that we understand how hard things are for them. For example, we may feel furious that they have eaten a whole chocolate cake but count to ten and remember that they will be hating themselves for what they've done. Shouting at them will make them feel worse. Saying how it makes you feel - concerned - and that you want to know if there is anything you can do to help will make them feel that they are not alone in tackling their 'eating disorder bully'.

Next week is our monthly '18.30 Presentation'. Megan Thody, from the CPFT team, will be talking to us about 'Occupational Therapy and Eating Disorders'. I look forward to seeing you.

## **9 November 2021 – OT and Eating disorders presentation – Megan Thody**

### **Plus - Risk of Harm and Denying there is a problem**

This week's session was a presentation by Megan Thody who is an occupational therapist working with the inpatient unit based at Addenbrookes. We welcomed Bxxxxx to his first meeting of the group and then Megan spoke to us about occupational therapy and eating disorders. Megan's presentation is attached and here are some of the key points that I took from it:

- Occupational therapy involves multiple aspects of an individual's care, with the common aim of giving patients the tools to live independently, and with meaning.
- It is a really important part of treatment that addresses a wide range of contexts and issues, e.g. meal preparation, anxiety management, life skills and body awareness.
- We have discussed many times that an eating disorder can make our loved ones' behaviour very rigid and unbalanced - compare slides 5 and 6; occupational therapy aims to redress that imbalance.
- Balance is achieved through small steps, although it is important to remember that for our loved ones what seem to be a small step to us could be a big step for them.
- Our loved ones have to take those steps but there are things we as carers can help them with:
  - Validate and affirm their efforts - 'I am so pleased you enjoyed your morning with the Environment Volunteers Group. It was really brave of you to meet all those new people'.
  - Help them to explore alternatives, e.g. leisure activities that they would enjoy and which would take them away from the eating disorder; and
  - Help them to set meaningful SMART goals - (Specific, Measurable, Achievable, Realistic, Timed);
- Above all, be there when they are challenging themselves by giving gentle encouragement and support.

We discussed the challenge of starting (or returning to) work. Employers are required to make 'reasonable adjustments' to support employees. It is important that the employer is aware of the circumstances and how they could help, e.g. providing regular breaks. Generally, this is a conversation our loved one has to have with their employer. We can offer to help with planning and rehearsing what they need to say, we can listen to their concerns and help them sort their ideas out, and we can give specific help if they request it, e.g. including a range of quick and easy snacks as part of the weekly shop.

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**9 November 2021 – OT and Eating disorders presentation – Megan Thody**

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Megan gave us a fascinating insight into the role of the occupational therapist, and to how important it is to our loved ones' recovery: '**a life worth living for**' is a phrase that has stuck with me. A big thank you from all of us!

We had time to address current issues being faced by some of the group, which Megan and Emma supported us with. I've drawn out a couple of general principles:

**What should we do if we think our loved one is at risk of causing themselves significant harm?**

There isn't a single answer to this question because it depends on a number of factors:

- If there is an emergency, we should ring NHS 111, or call an ambulance.
- If our loved one is in regular contact with medical services, e.g. weekly visits to the GP for monitoring, and their health declines to a critical level, the professionals seeing our loved one will take action, including under the mental health act if there is no other way to keep them safe.
- If you have worries but your loved one has asked the medical professionals not to share information with you it is important to remember that you can still share information with them. They may not be able to respond to you but they will read what you say because the more they know the better they will be able to treat your loved one.
- It is important to know that confidentiality will be breached by the professionals if your loved one's life is at risk.

The group completely understood how stressful this situation is and emphasised how important it is for us as carers to get support and look after ourselves because we need to stay well if we are to give the best possible support to our loved ones.

**A meeting has been set up with my loved one's college but they are going to deny that there is a problem - what can I do?**

A number of the group have experienced this, or a similar situation. You can't argue someone out of an eating disorder and undermining your loved one will damage your relationship, which you need to keep intact for when they are more open to change - and this time will come.

The group's experience is that it is best to present the facts and let the college draw their own conclusion - which they will. Setting these out in writing - together with your concerns - in advance of the meeting was suggested as a helpful way forward. If the college knows how many hours our loved one is exercising, or how much weight they have lost, they will be in a better place to have a conversation with your loved one. It will not be the first time they have met this situation and will have skill and experience of how to deal with it.

Ultimately, it will be up to our loved one but the college will be able to set out the choices, e.g. 'If you want to improve your grades, it will be necessary to spend more time studying,

**9 November 2021 – OT and Eating disorders presentation – Megan Thody**

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and to have more energy'. Colleges can make a number of adjustments, e.g. taking fewer subjects, repeating a year, securing extra time in examinations, arranging for specialist support.

Next week's session is a '16.30 Support Group Discussion' and I will get the invitation out over the weekend. I look forward to seeing you there.

**Resources****Presentation**





## **Occupational therapy & Eating Disorders**

- "Occupational therapy provides practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them. This support increases people's independence and satisfaction in all aspects of life." (RCOT, 2020).

## Key roles for OT in ED service

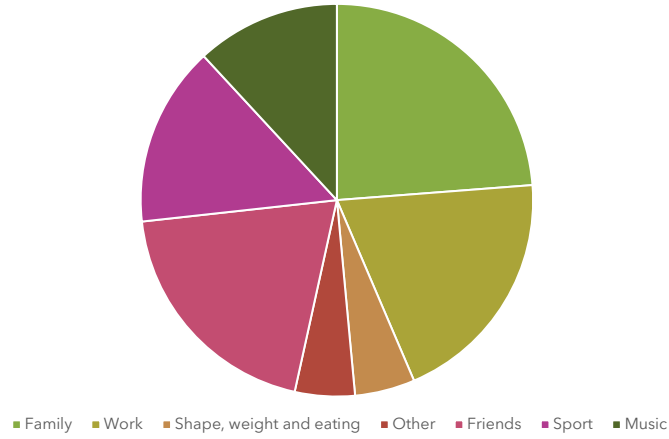
- Meal prep and skills
- Goal setting
- Anxiety management
- Meaningful routine
- Distraction and building new life domains/pie chart
- Group programme
- Vocational support
- Life skills - communication, accessing the community.
- Body image awareness

## Meaningful occupations & Routine

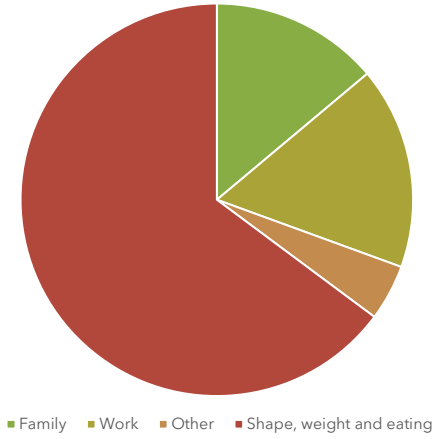
- Meaningful occupations are unique to everyone
- Routines often become rigid and the time given to meaningful occupations dramatically reduces.
- Occupational balance - self-care, productivity and leisure.



# A balanced, meaningful pie chart...



# Life with anorexia...



## *The little things that can help...*

- Achievable, meaningful goals
- Sensory fidgets and tools
- Activities list
- Grounding techniques
- Being there

*Any Questions..?*

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**16 November 2021 – How best to support siblings, Our loved one is stuck, Online and social media**

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**16 November 2021 – How best to support siblings, Our loved one is stuck, Online and social media**

This week we enjoyed another excellent discussion with some great support and advice based on our experiences. We heard that some of the group are having a really tough time; for others, things are going better, which underlines that recovery is not only possible, it is the most likely outcome, although it may take longer than we anticipated.

**How best to support siblings**

One issue that came up was how best to support siblings. This is an important topic that has come up a number of times in our discussions. When we talked about it back in August 2020, this is what we noted:

- **They need to understand the illness as we do**, so some basic information (e.g. from BEAT <https://www.beateatingdisorders.org.uk> > search 'Siblings') is helpful and it is even better if they are able to join in with some of the skills training.
- **Keep talking and listening to them.** This way you will find out what their concerns are and what they think they can and can't do to help. Don't be a 'kangaroo' and protect them from the situation, it will not help them in the long run.
- **Encourage their interactions with their brother or sister to be 'normal'** things such as going shopping, or going to a football match (those were the days.....), i.e. nothing to do with the eating disorder; they are in a good position to do this as they are not the primary carer.
- **There are positives**, too - they will have learnt a lot about some 'tough stuff' and will be more mature for it.

From today's discussion we can add that **it's important siblings have boundaries**. If, for example, their brother or sister is leaning too heavily on them we need to support them establish those boundaries. We can listen to how the situation feels to their sibling, validate those feelings and encourage them to work out a way forward; it's not something we can impose. One of the group found setting up a family WhatsApp group helped keep everyone in touch. If you live in Cambridgeshire or Peterborough 'Centre33' can provide some support for siblings and are definitely worth contacting <https://centre33.org.uk>.

**'Our loved one's recovery is stuck and the support we are giving is exhausting - what can we do?'**

The group recognised this as a familiar but really hard question to answer. At its heart is the often fine line between supporting our loved one's recovery and accommodating their illness. There is the added complication of recovery not being a steady, linear process so there is no fixed amount of time that they will spend in any one stage of recovery. For example, if they have had a number of cycles of weight gain and loss, a period of stability is an achievement but how long that needs to be before further progress is possible will vary

## 16 November 2021 – How best to support siblings, Our loved one is stuck, Online and social media

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from person to person. In the meantime, we and they may get into a pattern of behaviour and support that locks the illness in ... tiring ourselves out in the process. We drew out some general principles:

- **It is essential we look after ourselves** or we will be in no fit state to provide support at all. This is easier said than done, but the group's experience is you have to do something to re-charge your batteries and starting with some small steps in the right direction is more likely to succeed in the long run. What would give you a sense of satisfaction and enjoyment? Do it! Showing how to take care of yourself is also good modelling for our loved ones.
- **Be aware of accommodating and enabling behaviours.** I remember Sarah saying, 'It's understandable and forgivable because as parent/carers why wouldn't we want to alleviate our loved one's distress?' However, it is all too easy to fall into the 'eating disorders trap' - in the short-term we alleviate distress but in the long-term we help to maintain the illness because our loved one does not have to face up to it. I have attached the presentation Sarah gave in August - the 'Four Steps to Change' (slide 10) is a really good framework for thinking about how to get out of this trap.

Discussion and preparation is really important - accommodating behaviours cannot be changed overnight, indeed our loved one could feel that they were being rejected, which would be counter-productive. A gradual process rather than jumping off a cliff edge is likely to be more successful, and the more input they have the better.

### Online material and social media

We talked a little about online material and social media. The group's experience is that some of our loved ones find positive content, e.g. recovery accounts that match their experience very helpful, but there is also a great deal of negative content that can be harmful. Sarah said that this is something that patients are given support and guidance with and we agreed that it would be a good focus for a future presentation.

A big thank you to Sarah and Chloe for your support, and to the whole group for sharing your thoughts and ideas so generously. See you next week!

### Resources

#### Web

BEAT <https://www.beateatingdisorders.org.uk>

Cambridgeshire or Peterborough 'Centre33' <https://centre33.org.uk>

### Accommodating and enabling presentation

  
Cambridgeshire and  
Peterborough  
NHS Foundation Trust

# Stepping out of Eating Disorder traps: accommodating and enabling caring behaviours

Dr Sarah Beglin  
Consultant Clinical Psychologist  
Carers group – 10.8.21



  
INVESTOR IN PEOPLE

  
POSITIVE ABOUT  
DISABILITY

A member of Cambridge University Health Partners



## Before and after....

- Can you remember life before the eating disorder?
- In what way has life changed for you and for the family since the eating disorder arrived? What do you do more of? What do you do less of?

## Examples of accommodation/enabling behaviours

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'I drive across town to Waitrose because she will only eat their organic rye crackers'

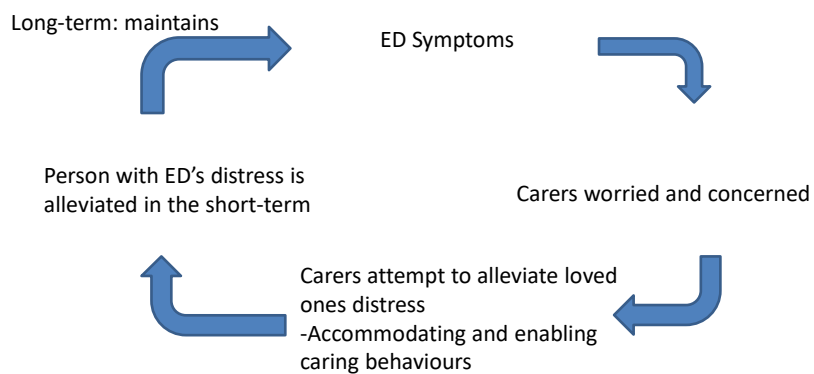
'I have been doing all his washing since he became ill'

'She takes over the kitchen for hours each evening and we are not allowed to go in'

'We haven't been away on a break for years. We don't dare leave him alone'

'We tell her 50 times a day she isn't fat'

## Eating Disorder Traps





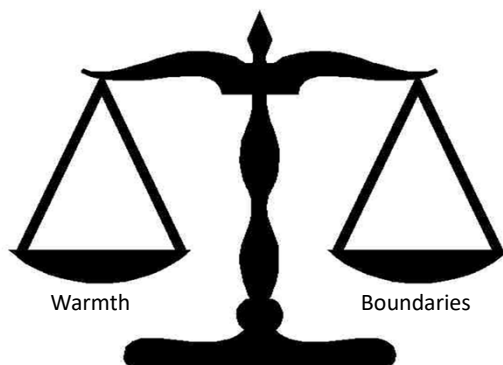
## Ways in which the family responds to eating disorder


- Family adapt around eating disorder
- Invasion/disruption of family routines and rituals
- Change in distribution of time, care, energy (others lose out)
- Narrowing focus of time
- Patterns of family interactions restricted
- Central role of symptoms in family life
- Family habituates to 'new' life
- Loss of agency (feelings of helplessness)

What can we do to help?



# Before we start... Getting the balance right





**PLEASE  
DO NOT  
FEED  
THE  
FEARS**

## Barriers to change?

What might be some of your fears or anxieties about stepping out of the eating disorder traps?

## Steps to change

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Self care all the way (Nod to Anne)	Recognising the traps you are in and the fears you have about changing
Discuss the changes you would like to make with your loved one when you are both calm	Use dolphin skills – E-OARS <ul style="list-style-type: none"><li>• Empathy</li><li>• Open Questions</li><li>• Affirmations</li><li>• Reflections</li><li>• Summarizing</li></ul>

## Tips for stepping out of ED traps

- Accept and acknowledge that change is challenging but that new habits can be established
- Any new approach requires the whole family to 'buy in'
- Recognize possible barriers/ roadblocks to change
- Present the problem – clearly. Ask for loved ones help in generating the solution
- Develop an agreed plan – number of stages if necessary
- Change is likely to be slow
- Treat each stage as an experiment
- Consider communication on an ongoing basis (eg family notebook/regular meeting)
- Aim for a consistent assertive approach
- Recognise behaviours might get worse before they get better
- A new approach takes courage, trust and commitment

**23 November 2021 – Diagnosis, How to raise your loved one's ED with others, Change or not**

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**23 November 2021 – Diagnosis, How to raise your loved one's ED with others, Change or not****Diagnosis**

We began this week by talking about diagnosis. Sarah provided us with useful definitions of the most common eating disorders:

- anorexia nervosa – trying to control your weight by not eating enough food, exercising too much, or doing both
- bulimia – losing control over how much you eat and then taking drastic action to not put on weight
- binge eating disorder (BED) – eating large portions of food until you feel uncomfortably full

The assessment process considers a wide range of factors, not just BMI, and additionally Sarah explained that eating disorders can be transdiagnostic, i.e. starting with one type of eating disorder and becoming another. The Keep Your Head website has some more information about the different types of eating disorders, and their signs and symptoms <https://www.keep-your-head.com/adults/MH/eating-disorders/signs-and-symptoms-1>

**'How to raise your loved one's eating disorder with others, especially close family such as grandparents?**

We then discussed a question that we have touched on before, 'How to raise your loved one's eating disorder with others, especially close family such as grandparents?' The group's experience is that it is really important that our loved ones retain responsibility for who they and we talk to, and what is said. Our role is to ask them what they would like to say (or would like you to say) and to whom, to help them understand why this might be helpful and to encourage and support them. They might not want anything said - if this causes difficulties it is important to say why, and how it makes you feel, but it would be counterproductive in the long run to step in and take over. We know how hard an eating disorder is to understand, so it is not a surprise that friends and family 'don't get it', and it may be necessary repeat conversations and explain the different stages of recovery. Friends and family can be really helpful - BEAT's 'Guide for Friends and Family'

<https://www.beateatingdisorders.org.uk/resource-index-page/guide-for-friends-family/> is recommended.

## 23 November 2021 – Diagnosis, How to raise your loved one's ED with others, Change or not

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### 'How can we tell the difference between our loved one not knowing what to eat to gain weight and them being ambivalent about change, especially if they want to please you / say the right thing?'

Sarah posed this question when we were discussing one of the group's daughters being positive about weight restoration and saying that she was putting more milk in her coffee and having larger snacks. The group's experience is that our loved ones need to eat quite a lot more to weight restore and that small additions make very little difference. Our feeling about Sarah's question was that it depended on the context:

- If the idea came from our loved one and they quickly recognise that they will have to do more, then there is a good chance they are into the 'planning' and 'action' stages of the change cycle - this gives us an opportunity to get alongside them, to support and to encourage.
- However, if they are doing this 'because they have been told to' and/or do not move on from these very small changes, then they are probably still in the 'contemplation' stage. This, of course, may represent really important progress and gives us the opportunity to help them consider the 'pros' and 'cons', e.g. 'On the one hand you would like to gain weight **and** on the other you don't want to increase the amount you are eating', encouraging them to take further small steps.

Along the way we heard some **great examples of our loved ones' resilience and good carer coping**, including:

- Our loved ones saying how they feel to flat mates whose behaviour (e.g. calorie counting) triggers unhappy memories, rather than bottling up their emotions and/or lapsing into unhealthy behaviours themselves.
- Encouraging our loved ones to see the importance of self-care and not to be guilty, for example, about enjoying a day off - and modelling this ourselves!
- Staying calm while our loved ones try new challenges, e.g. a weekend away, asking how we can help and supporting if requested.

### A Recovery journey

And finally, Dxxxxxx shared his partner's recovery journey. The autumn has usually been a difficult time of year and his partner's redundancy at the end of August had the potential for making things worse. However, helping Dxxxxxx's company around the warehouse really improved her mood (a change can be as good as a rest) and she has now secured the job she always dreamed of, as a trainee Children and Young People's Mental Health Practitioner. A telling sign of her resilience and recovery is that it is over a year since she self-harmed. Dxxxxxx reflected that it has taken 5.5 years to get here and although he does not think a full recovery is possible, a good, solid recovery is. Dxxxxxx reflected on the importance of self-care - there were times when he had to go for a walk, or to another room, to look after himself, even though it felt selfish to leave her suffering. He needed to

**23 November 2021 – Diagnosis, How to raise your loved one's ED with others, Change or not**

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do this so that he could continue to support her long-term recovery. My summary cannot do justice to the vitality and enthusiasm of Dxxxxxx 's story; the whole group applauded, it was really wonderful to hear.

Next week's meeting is a '5th Tuesday of the month 18.30 - 19.45 Support Group Discussion'. The group will be continuing to meet over the Christmas and New Year period but there are some changes to the times of our regular sessions.

**Resources****Web**

Keep Your Head

<https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder>

BEAT's 'Guide for Friends and Family'

<https://www.beateatingdisorders.org.uk/resource-index-page/guide-for-friends-family/>

**Book**

Book 3 (April - September 2021) of our summaries is now on the Keep Your Head website at the following link:

[https://www.keep-your-head.com/assets/2/aeds\\_online\\_carers\\_support\\_group\\_summaries\\_book3\\_apr\\_to\\_sep2021.pdf](https://www.keep-your-head.com/assets/2/aeds_online_carers_support_group_summaries_book3_apr_to_sep2021.pdf)

With a big thank you to Ann for editing and compiling.

**30 November 2021 – Long distance support, Fear of foods, Clothes buying and body image**

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**30 November 2021 – Long distance support, Fear of foods, Clothes buying and body image**

We had another great discussion, reflecting on the really positive progress some of our loved ones have made and offering support and ideas for those whose loved ones are having a harder time of it at the moment. The take home message for me was that things do get better, but it can take time and its tough, so it really is important to take care of yourself so that you don't burn out. I have summarised some general points below.

**'How can I best help our loved one who has returned to university but is now ringing us regularly to say that they are struggling?'**

The group's experience is that this is not an uncommon scenario and a really difficult one, especially as you are having to provide care at a long distance. A number of reflections were offered:

- It is important to recognise the positives: they are sharing their concerns with you; they are asking for support; and they have returned to university and got through most of the term. It is important because there are positives character strengths for you to affirm, e.g. courage, determination, endurance, responsibility, being sensible. People who have recovered from their eating disorder invariably say that they found affirmation helpful ... although they probably didn't say it at the time.
- Simply by listening you are almost certainly helping. In all probability they will feel a lot better at the end of the call than at the start.
- Offer to do some joint problem-solving when they come home at the end of term. This might help to keep them going and will certainly help if and when you sit down with a big sheet of paper to record and encourage their ideas.
- Look after yourself - the worry of long distance caring is exhausting and you want to be fit and well when they do return home.

**'There are foods our loved one really enjoys but they just can't bring themselves to buy and/or eat them - how can I help?'**

Again, this is a very common issue. The group's reflection was that there is an important positive here not to lose sight of because at least our loved is wanting to change. Our experience was 'it has to be small steps' and I was reminded of the advice Sue Young, a dietitian, gave us back in June 2020:

*Sue introduced the 'fear food ladder'; a list of foods in rank order from most to least feared. This is a useful tool used as part of treatment to increase variety. It might or might not be that your loved one wants support from you climbing up the ladder. It is important to discuss this. Even if they do not want your active support it is good for you to know the principles. The aim is to move up the ladder. Whether or not you formally draw up a ladder, there are some really useful principles here:*



### **30 November 2021 – Long distance support, Fear of foods, Clothes buying and body image**

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- any discussion has to be at 'low stress' moments; if our loved one is anxious, e.g. at meal times they will resist change.
- if our loved one is making a change, e.g. introducing a food that they would like to eat but find difficult 'wrap around care'. This means, ideally, having a calming activity prior to the meal and something they really like doing planned for after the meal.
- 'nudge' the conversation in a calm moment, e.g. 'I've noticed that you don't have lasagne on your food ladder but you used to really like that'. Be prepared to leave the question hanging - do not insist on a response.
- ask what is helpful and unhelpful to say or do. Be prepared for the first response to be 'nothing'. Let it hang. Very often they will return to the conversation later. (This is a principle for meal times rather than specifically about ladders.)

### **Clothes buying and body image**

We have discussed clothes buying and body image on a number of occasions but a really interesting take on this came up: **'Our daughter is getting married and has asked me to help her choose her wedding dress - how can I best help?'** The group's first reflection was 'congratulations!' What a wonderful positive with the potential to be a real motivator for recovery and/or maintenance. However, we all recognise that this could be a particularly anxiety provoking occasion. A number of ideas were suggested, most of which could be summarised as 'while they are putting on their wedding dress, you need to put on your dolphin costume'... swim alongside, support, encourage and stay calm. It is easier to try on dresses that are too big and will be pulled in, and it is helpful to know that this is quite usual for a wedding dress purchase. Also, there will be plenty of opportunities to boost self-esteem through compliments - because they will look wonderful!

We started to stray into 'Coping with Christmas', which is the subject of Dr Sarah Beglin's presentation on 7th December at 16.30, so I will save my round up of our thoughts until then! I hope to see you then.

### **Resources**

#### **Research opportunity for siblings.**

We have discussed siblings on many occasions. Ann recently received this, an opportunity for siblings to take part in a research study 'What roles do siblings play in their family and how does this affect their help-seeking and coping styles?' Details can be found at this link <https://www.feast-ed.org/uk-research-participation-opportunity/>.

**7 December 2021 – Coping with Christmas – Presentation Dr Sarah Beglin and Ana Bernardo-Gancedo**

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**7 December 2021 – Coping with Christmas – Presentation Dr Sarah Beglin and Ana Bernardo-Gancedo**

A very big thank you to Dr Sarah Beglin and Ana Bernardo-Gancedo for their presentation on Coping with Christmas. Sarah's presentation is attached, together with a copy of the patients' accounts that she read out. Below is a brief summary of the key points, Ana's account and the ideas the group came up with.

Sarah began by reflecting on why Christmas can be such a difficult time for our loved ones. When feelings about food are at the heart of all your difficulties it is no wonder that an occasion that has feasting as a core component is stressful. On top of that there are changes in routine and people's expectations - especially that you should be enjoying yourself - to cope with.

Ana has lived experience of recovering from an eating disorder and gave us a vivid description of Christmas from the perspective of someone in the grips of their illness: imagine the negative emotions around food, the guilt, the shame, the fear of being judged and the feeling of letting people down all screaming at you constantly - and then try to enjoy your dinner and small talk. That is why Sarah's fourth slide says just one thing: 'Our biggest gift is empathy'. Telling our loved ones that we understand how hard it is for them - that we know that they are not making it up - is the foundation for the help we can give.

Ana described some of the things that she found helpful:

- Having some healthy / safe options available so that everyone can participate in the bonding over food.
- Allowing people to serve themselves.
- Finding ways to connect that don't involve food, e.g. a board game, going for a walk, looking through the family photo albums.

Ana also described some things that were unhelpful for her, especially:

- Any comments that are a judgement, e.g. 'Why are you not eating potatoes, are you off carbs?'
- Comments that of themselves are not necessarily bad but that are unhelpful in the context, e.g. 'I'm so full, I'm going to have to go on a mega-diet'.

We discussed how important it is to understand where our loved one is in their recovery journey. For example, in the early stages of recovery serving themselves may be too difficult, or they may not be ready to discuss 'a plan for the day' because they cannot contemplate any change to their current routine. This makes it all the more important that we listen, reflect, and ask how we can help, rather than stepping in and taking over.

**7 December 2021 – Coping with Christmas – Presentation Dr Sarah Beglin and Ana Bernardo-Gancedo**

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Between us we came up with quite a list of ideas:

- Ask everyone 'What is the one thing you'd like to do this Christmas?'
- Organise non-food activities you can do together as a family - board games, films, charades, Desert Island Discs.
- Play some party games not to do with food.
- Plan the day carefully, with timings.
- Discuss with your loved one how they are going to manage the meal itself, e.g. having the chair nearest the door so that they can leave if it gets too much without causing a physical disruption.
- Prepare grandparents, aunts/uncles, friends/family in advance. (See BEAT's guidance for friends and family: <https://www.beateatingdisorders.org.uk/uploads/documents/2017/10/carers-booklet.pdf> ).
- Ask siblings what they are worried about / what you can do to help, do not make assumptions; and involve them in the planning.
- Have contingency plans (plural).
- Include a walk as part of the plan.
- Have a break between courses.
- Play some music together!
- Everyone suggests the food they want to eat.
- And finally... Christmas 'disaster bingo' - think about all the things that could go wrong / be said, make a list... and then tick them off as the day progresses. (This seemed very popular!)

We also talked about the post-Christmas period, and especially the New Year's resolutions around dieting and exercise that flood the media. Ana said that these messages - that we cannot shield our loved ones from - can be very de-stabilising, so it really is a time to remain calm, be consistent and, if necessary, do our best to nudge our loved ones back on track.

Ana offered four final reflections:

- Give unconditional love - respect their challenge, be there for them, listen and be non-judgemental.
- Don't blame yourself, it's not your fault.
- Never give up hope - there is a road to recovery, it's hard, but it's definitely possible.
- And take care of yourself!

## 7 December 2021 – Coping with Christmas – Presentation Dr Sarah Beglin and Ana Bernardo-Gancedo

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Thank you again, Sarah and Ana, for such a great session, and to everyone for sharing your thoughts and ideas. It was really helpful.

### Resources

#### Web

BEAT's guidance for friends and family:

<https://www.beateatingdisorders.org.uk/uploads/documents/2017/10/carers-booklet.pdf>

### Coping with Christmas Accounts

#### Ex service users words

1. Christmas for me was a nightmare and I feel ashamed to say it. I felt I should starve myself in the run up to the big day so that I might allow myself to eat like others – of course, when it came to it, I couldn't do it. I was so aware of how miserable I felt in contrast to everyone else. I couldn't join in with the delights, food, games, alcohol. The only time I had peace was when out walking in the dark streets. I felt very lonely and apart from others.
2. For me Christmas is one of my favourite times of year, all family together with love and laughter in the form of shared company, presents, and all the incredible offerings mum cooks to feed the troops. But there is also a constant undertone of overthinking, calculations, anxiety and guilt about it all. I'm wondering how to appear healthy and not worry loved ones, feeling pressure to enjoy the things I know I used to love and appear fun loving and festive when my normal routines of meals and exercise are lost (and IT is raging as a result). Plus huge social anxiety to take part in all the meals and drinks with friends, work socials etc in the run up to the big event itself....I LOVE Christmas and all that goes with it, but it is one exhausting month of internal battles between the Christmas-loving child inside me and IT (my ED). By the end, I am so grateful for friends, family and the times we've shared, but emotionally exhausted and not really ready to launch into a New Year.
3. Usually a traditional Christmas is all about being together with loved ones, exchanging gifts and seeing the surprised look on family's and friends faces when opening presents! With an eating disorder - this is one of the most difficult times of the year. Anything and everything is about one thing... Food. Advertisements, conversations, shops even Christmas carols and songs, I could hear or see the dreaded fear of food in them all. I felt alone in this, while everyone was enjoying and indulging the Christmas spirit - I only felt fear, upset and stress. I hated anything that stood in the way of my ritualistic fitness regime and restrictive diet. I took every opportunity to stick to my routine as strictly as I could over the usually relaxed Christmas period. I knew I'd be around food ALL of the time, at family/friends gatherings, Christmas day dinner, buffets, gifts and even Christmas shopping. I just couldn't cope.

### Presentation

## Coping with Christmas

Ana Bernardo-Gancedo &  
Sarah Beglin  
8<sup>th</sup> December 2021



Pride in our adults and specialist mental health services

Christmas is a time of peace and joy.....  
Isn't it?

- Christmas for someone with an eating disorder- its challenging
- Being with someone with an eating disorder at Christmas – challenging
- Challenging times (COVID)



## Why is Christmas so hard for those with eating problems?

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- So much food
- Tricky food
- so much emphasis on eating and drinking
- Changes in routine – different eating times/times to exercise
- Visitors + socializing
- Expectations
- General stress

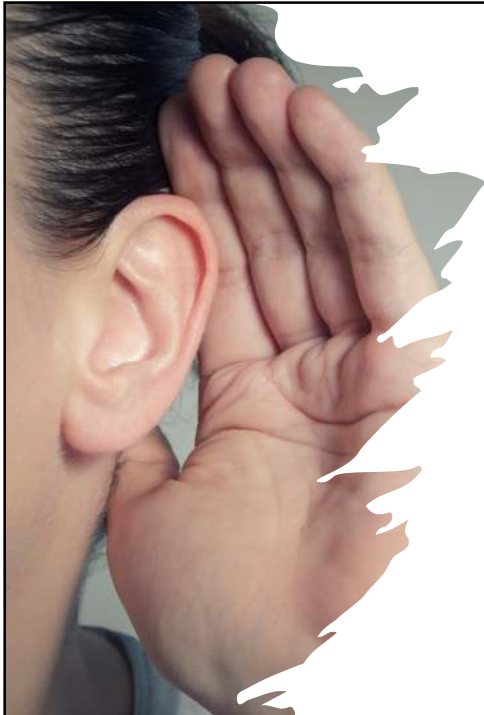


## What can we do to help?

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Our biggest gift is empathy





Lets listen:

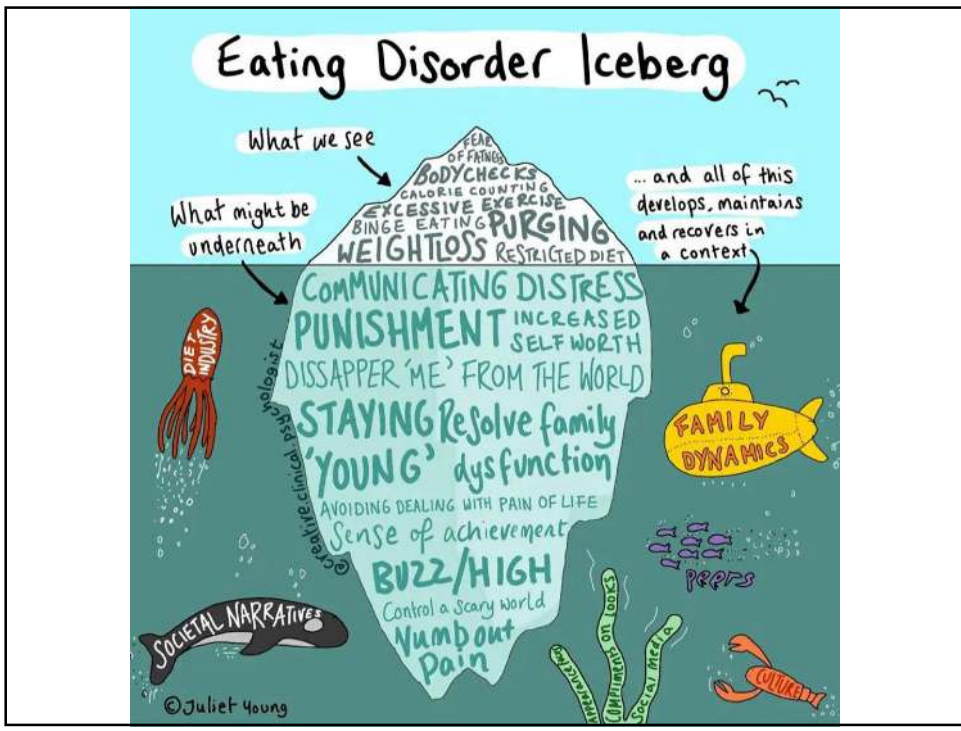
- Ana's account
- Others' account



Over to you...

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- Please share with the group one experience or tip of coping with Christmas that you think might be helpful to others.





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**14 December 2021 – Perfectionism, Self harm, Stepping back, Peer support and Look after yourself**

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**14 December 2021 – Perfectionism, Self harm, Stepping back, Peer support and Look after yourself**

Our discussion covered the full range of 'highs', 'lows' and 'in-betweens'. Some of the group are facing some really challenging situations and we hope that our reflections were helpful. I have summarised key points below.

**Our loved one's perfectionism is causing them great anxiety - how best we can help them?**

This question echoed with many of us. Perfectionism is a characteristic that many people with an eating disorder have. There is an upside - perfectionists are usually high achievers and very reliable - but the downside can include high levels of anxiety, stress, procrastination and depression, which can become a major problem. The group's experience was that you can't argue someone out of perfectionism, this will entrench their view. Showing empathy, e.g. 'It must be so hard for you, I can see how difficult it is to call that piece of work finished' will help because it shows that you care, and that you understand their struggle. As with all anxiety it will pass, so it is really important to stay calm and ride out the storm. If you are able to talk about it with your loved one, in a calm moment, you may be able to find out what would be useful to do or say when these feelings return, e.g. 'When we spoke about this a couple of weeks ago, you said that it would be useful for me to remind you that you have done everything you were supposed to, and that your worries will calm down after you have handed it in, like they did last time'.

**Self harm**

One of the group described a significant self-harm incident. We have discussed self-harm before and I've pulled together some of the key points from those sessions:

- The prevalence of self-harm in people with eating disorders is thought to be about 25% and is particularly high among people who engage in the binge-purge cycle of Bulimia Nervosa.
- Self-harm is an (unhealthy) strategy to manage extreme emotions. For us as carers this means that all of the principles of good caring - being a good dolphin / St Bernard - should guide our emotional response and behaviour.
- Having someone to support you is really important because the physical manifestations of self-harm can be very shocking and will test your 'stay calm' strategies to the limit.
- Be curious about the reason for your loved one's behaviour because it could be serving different functions, e.g. they might be trying to say something that they think they can't express in any other way; this is something we may be able to help them with.

## 14 December 2021 – Perfectionism, Self harm, Stepping back, Peer support and Look after yourself

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- Self-harm isn't an inevitable outcome of extreme emotion. Therapy, and in some cases, medication may be appropriate to help our loved ones to manage difficult feelings and to learn to be kinder to themselves. We can help by discussing alternatives behaviours - other things our loved ones could do - outside of the heat of the moment.
- Sarah mentioned elastic band twanging and ice cubes as less harmful ways of giving the sensation of pain, if that is what our loved feels they need to control their emotions.

There is the ever-present risk of us accommodating these harmful behaviours and of falling into the trap of becoming a kangaroo, shielding our loved one from the issues that, ultimately, they will need to face up to: remember, we cannot treat them. As a consequence there are times, even with such shocking and potentially physically damaging behaviours, that we might support our loved ones to deal with the consequences of their self-harm, e.g. take themselves to A&E. There is a judgement call here because we would not want to do anything that would put our loved one at serious of harm, but we know our loved ones better than anyone and can make this call.

If our loved one is choosing not to take advice, e.g. they have been recommended medication but won't take it, we cannot force them to do so. However, we can be curious about why they won't and we can look for opportunities to create 'cognitive dissonance', e.g. 'You want to lead that training session at work **and** you don't want to take the medication that will help your anxiety?'

### Stepping back

We heard some great examples of carers being brave enough to step back and let their loved ones step forward; trips abroad to visit relations, company dinners (although perhaps not now....), a weekend away with friends. The importance of calm, consistent encouragement, and support with planning, came through loud and clear. Rxxxxx gave us a great line when he was talking about his daughter's recovery and resilience: 'she now has the right tools to keep going, to stay positive and to get on with life'.

### Peer support

We also heard a really interesting example of peer support - one of our carer's loved ones has remained friends with a person they met when they were an inpatient. This month they have set each other challenges using an advent calendar - one challenge a day that they have to follow. Our meeting was Day 14 and so far all challenges have been met. We have talked about 'picking a challenge out of a jar' before but this definitely gets 10/10 for being an innovative, fun and more social challenge!

**14 December 2021 – Perfectionism, Self harm, Stepping back, Peer support and Look after yourself**

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**Look after yourself**

And finally, I make no apology for stressing how important it is to look after yourself. Sometimes it is really, really important to 'step out' and take a break - even a walk round the block will help to clear your head. You need to be fit and well to be a good carer and it may be necessary to seek help for yourself - most of us have, at some time or another.

Next week's session is a '16.30 Support Group Discussion'. Christmas hats, jumpers, Teams backgrounds, your favourite drink and a mince pie are not compulsory but strongly encouraged. See you there!

## 21 December 2021 - Values of a support group, Pack safe foods?, MANTRA, ...

### We are not responsible for treating our loved ones, Examples of our principles in practice

The big question this week was who was decked out most festively. For me, it was Rxxxx's reindeer antlers and the judges decision is final! More seriously, we welcomed Sxxxxx to the group and we discussed, as ever, a range of concerns and successes.

#### Values of a support group

One of the values of a support group is that it can help you see positives in difficult situations. This is important because it gives a sense of perspective - recovery can be a long journey that is rarely straightforward - and it is a reminder that you are doing all you can as a carer, and that you are doing it as well you can. It is really hard when we see our loved one struggling, but if, for example, their determination has got them through difficult patches before; they are still in touch with services, e.g. medical monitoring; and they have a motivation for recovery, they are a long way from being back at square one.

There is a lot we can do as carers when we see our loved one's recovery take a step backwards:

- **stay calm** - work hard to manage your own anxiety;
- **show your loved one that you understand**, e.g. by helping them to articulate their feelings... 'I guess it must be really unsettling that your friend has had to be readmitted to an inpatient unit';
- **be there to offer practical support if it is wanted** (although, be careful not to 'fix' problems that your loved ones can solve themselves);
- **be reassured by the resilience they have learnt** from the challenges they have already been through; and
- **look after yourself**, for your own sake and so that you can give them the best possible support.

#### Pack safe foods when going away?

Should we pack a backup of 'safe foods' if we are going away to family at Christmas or New Year? Sarah encouraged us to think about this question, I suspect most of us have been in this situation. The group's conclusion was that as long as we are aware that this could be accommodating behaviour, i.e. stopping them from facing up to their difficulties, there could be occasional circumstances when this was appropriate, e.g. if our instinct is that their recovery will be more adversely affected if they cannot see the visit through.

## **We are not responsible for treating our loved ones**

Sarah reminded us that we are not responsible for treating our loved one – the responsibility for recovery rests with our loved ones, with the support of professionals; ours is to listen to their struggles, show understanding and if appropriate, gently nudge them in the right direction. An example of this came up with one of the group describing that their loved one's negative self-talk was more pronounced when they were at home. When asked about this their loved one said it was because there was less distraction than when they were at university. It is well known that a daily plan with a balance of activities is much better for mood - we can't make our loved one do this, but we can encourage them and, hopefully, model what 'good' looks like.

## **MANTRA**

We heard a little bit about MANTRA (Maudsley Model of Anorexia Nervosa Treatment for Adults), which is a virtual group therapy provided by the specialist eating disorder service that two of the group's loved ones are currently attending. We heard that some aspects can be quite challenging, e.g. our loved ones having to take their own weight every week, and hearing other's stories, but that there has also been a great deal of positive feedback and some good outcomes. A future presentation, I think!

## **Examples of our principles in practice**

There were some great examples of putting our principles into practice:

- finding a calm moment to have that difficult discussion;
- respecting their decision but saying how it makes us feel, e.g. disappointment;
- asking if and when it would be OK to raise the issue again; and
- stepping back and giving our loved one time and space to think.

## **Some postscripts...**

- Rxxxxx described last week how his daughter had received additional support at university and he has kindly provided these further details: 'Just to let you know the software that was provided for my daughter and a summary of the grant process. Selecting the 'disability' option when applying for student finance via SFE was the hard part. It took some persuasion to convince our daughter that she deserved this help. Supported by a doctors letter, SFE awarded her a grant. Next step was an assessment of her needs via a Teams call and those people were excellent, fully understanding of her lack of confidence, etc. A parent/ carer can do this on their behalf if needed. In our case, she was provided with a new laptop, a microphone to record lectures and 'MindView 8' mind mapping software. She uses it mainly for note taking and loves it. Also allocated a mentor to chat to for 1 hour per fortnight.' Thank you, Rxxxxx, for sharing this really useful information.

**21 December 2021 - Values of a support group, Pack safe foods?, MANTRA, ...**

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- Siblings Support Group. I am delighted to say that this group is really going to happen, starting in the New Year in the Cambridge area. Please contact Helen Eves [helen@centre33.org.uk](mailto:helen@centre33.org.uk) if you would like further details.

And finally, what a year! It has been a privilege to meet with so many brilliant and brave carers throughout 2021; to share experiences; and to support each other. Take care of yourselves over the festive season, and do 'drop in' on the 28th and the 4th if you want a chat, some support or a break from washing up.

All best wishes

Keith



**11 January 2022 –'Social Media and Eating Disorders' – presentation - Harriet Frew, plus Top tips**

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**11 January 2022 –'Social Media and Eating Disorders' – presentation - Harriet Frew, plus Top tips****Welcome to new members**

Welcome to 2022! We began this week's meeting by welcoming new members to the group - Vxxxx, Jxxxx, Axxxx and Axxxxxx - we are really pleased that you have been able to join us.

**Presentation**

I then introduced, and warmly welcomed, Harriet Frew (Highly specialist Eating Disorder counselling practitioner), our presenter for this evening on 'Social Media and Eating Disorders'. Harriet's slides are attached and contain a wealth of detail. Some key points / reflections from me are:

- There are negative aspects and potential dangers to social and there are positive aspects and potential benefits.
- Damaging / triggering content ranges from the more obvious explicit eating disorder triggers, e.g. images of emaciated bodies to the more subtle, e.g. people's fitness journeys, before and after photos and 'love yourself, positive captions' underneath a perfected, slender image; we need to be aware of this.
- Harriet used a phrase that has stayed with me: **'How you look is not your worth'**. Harriet said that she encourages people in normal conversation not to praise weight loss.
- Slide 10 'Positive content on social media' is a really important one to have a look at!
- Harriet said that the current generation is challenging old ideas of diet culture and is more open to valuing all body shapes and sizes - this is encouraging.
- Our role as carers. If we are aware of our loved one spending a lot of time on social media, encourage them to reflect and think about it. However, avoid giving unwanted advice and/or getting into an argument because this will not change your loved one's behaviour and may simply make them more secretive. Slide 13 has some useful pointers for someone who is ready to think about change.

Here are some points that came out of our discussion:

- Harriet recommended <https://thebodypositive.org> as a site that is good for body image, but with the proviso that it's a personal thing and that we should encourage our loved ones to seek out (positive) material that resonates most with them on their platform of choice.

**11 January 2022 – 'Social Media and Eating Disorders' – presentation - Harriet Frew, plus  
Top tips**

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- If we think social media is an issue for our loved one, saying that we have been to this presentation and letting it hang (i.e. not saying any more than that) may open up a conversation - not necessarily immediately.
- Are recovery accounts that include recipes helpful? It is a positive sign if your loved one is wanting to engage with this content. The recipes themselves may, or may not, be helpful. As ever, the motivation for change has to come from within.
- The positive messages about body image on the sites Harriet provided links to can help us to avoid reflecting / projecting any negative thinking that we might have. (This is the link I promised to Hope Virgo's 'Dump the Scales' campaign - <https://www.ncmh.info/2019/02/25/dump-the-scales/> .)

On behalf of all of us, A VERY BIG THANK YOU for an excellent and informative presentation. And I would strongly recommend to everyone Harriet's 'The Eating Disorder Therapist' podcast <https://harriETFrew.podbean.com> !

**Top tips for new members**

We had a few moments to welcome more fully the new members to the group. I challenged the group to come up with their top tips:

- Look after yourself (no prizes for knowing who contributed that!)
- Focus on your loved one's feelings, not food.
- You can't argue them out of it.
- Don't get downhearted if something goes wrong; recovery from an eating disorder is not linear, and if you make a mistake / say something wrong it's part of the learning process.
- Most people recover from their eating disorder, although it can take a lot longer than you ever imagined.
- You are not alone.

**Resources****Web**

<https://thebodypositive.org>

<https://www.ncmh.info/2019/02/25/dump-the-scales/>

**Podcast**

<https://harriETFrew.podbean.com>



**11 January 2022 – 'Social Media and Eating Disorders' – presentation - Harriet Frew, plus  
Top tips**

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**Past Summaries**

Our summaries, FAQs, lists of resources and signposts to support can be found on the Keep Your Head website <https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder>

Next week's session is a '16.30 Discussion Group'. I look forward to 'seeing' you then.

**Presentation**



*Welcome to:*

## **'Social Media and Eating Disorders'**

With Harriet Frew – Highly Specialised Eating Disorder Counselling Practitioner



## **Aims of talk**

- 1) Understand the role of social media in eating disorders
- 2) The positive and negative aspects of social media.
- 3) How to utilise social media helpfully, in an intentional and pro-recovery way.

## Social media's influence as ONE component

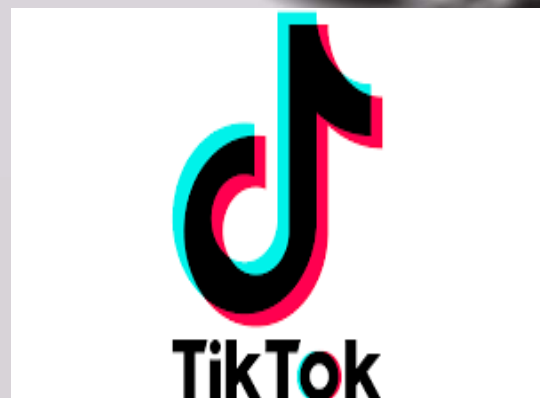


- Eating disorders are complex, psychological illnesses – genetics, trauma, environmental triggers, life events – social media is ONE component.
- If you have an eating disorder, a significant amount of your self-worth will be linked to shape/weight.
- Whereas, someone without an eating disorder will likely derive value for their worth from a broader range of areas including: - hobbies, friendships, work, family, adventures etc.
- With an eating disorder, social media can add fuel to the fire – available 24/7 and much triggering content.

3

## What is social media?

- Websites and applications that enable users to create and share content or to participate in social networking.
- Different platforms: - Tik Tok, Instagram, Facebook, Twitter, You Tube, Snap Chat.
- **Negative aspects:** pro-eating disorder accounts; pro-diet; fitness accounts; idealised bodies.
- **Positive aspects:** body positivity; HAES (Health at Every Size); Intuitive Eating; self-esteem.



4

## Potential dangers

- Social media provides exposure to triggers and is available 24/7. Addictive.
- 'Ordinary people' are posting which makes the images feel more attainable.
- People tend to post idealised and perfected images.
- It fuels social comparisons and feelings of inadequacy. Low self-esteem is often present in people with eating disorders.
- Algorithms show you more of the content you consume.



5

## Research study – FIJI (TV rather than social media, but illuminating in findings)



Study of a rural population of children and adolescents in Fiji.


Psychology researchers – Harvard Medical School (1998) collected narrative accounts – 30 school girls 3 years after introduction of TV.

They found a dramatic increase in indicators of disordered eating after introduction of Western TV programmes.

This overrode the local cultural practices that supported robust appetites and more curvy body shapes, representing wealth and affluence. This was hoped to be a protective factor.

The girls began to equate slimness with economic, social and romantic success. Being in a larger body was an indication of laziness. Very quickly, they had taken on Western values.

6



## The impact of social media on mental health - research

Constants comparisons and negative body image impact mental health: - increased depression, anxiety, low-self-worth, eating disorders and isolation.

Just over one in five adults (22%) and 40% of teenagers said that images on social media caused them to worry about body image (2019 – Mental Health Foundation).

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## Impact of social media on body image

- Research has shown that using FACEBOOK can increase appearance related concerns, particularly for people more likely to compare themselves to others.
- Specific activities like uploading more photos or spending more time on social media are linked with poorer body image.
- In some cases, people with existing concerns about their body might use social media to look for positive or negative feedback on appearance.

- Prevalence of subclinical eating disorders Is influenced by social media.



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## The potentially damaging content on social media

**More obvious** explicit eating disorder triggers – emaciated bodies, small portions, body weights and measurements.

**And the more subtle but equally (if not more dangerous content):**

- Fitness journeys
- Before and after photos
- 'What I eat in a day'; how many calories I eat
- 'Love yourself, positive captions' underneath a perfected, slender image.



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## Positive content on social media



- The Body Positive Movement – promotes and advocates that ALL body types are acceptable – size, race, skin colour, disability, disfigurement, sexuality.
- It challenges how society views bodies; promotes acceptance of all bodies, helps people build confidence and acceptance; addressing unrealistic body standards.
- **Intuitive Eating – 10 principles**
- **HAES – Health At Every Size**
- **Mental health, therapy skills**
- **Helpful** – exposure to all types of bodies; shifts perception of what a desirable body is.
- **Unhelpful** – body positive hashtag taken on by white, thin young women.

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#EffBeautyStandards  
#SlayAllDay  
#SelfLove #GirlBoss  
#Confidence  
#LoveYourCurves  
#BodyPositivity

#bodyneutrality, #intuitiveeating #nofoodguilt #antidiet #dietsuck #allfoodsfit

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**THE PSYCHOLOGY OF EATING DISORDERS - 9 THOUGHTS**

@the\_eating\_disorder\_therapist

**Some helpful accounts - Instagram**

- @the\_eating\_disorder\_therapist
- @the\_binge\_eating\_therapist
- @drjulie
- @thisfoodthingpodcast
- @break.binge.eating
- @isarobinson\_nutrition
- @theintuitivediabetic
- @emilytalksrecovery
- @cazually
- @intuitivelyeaten
- @thefobpodcast
- @realistic.body.therapist
- @diet.culture.rebel

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## Using social media helpfully

- Consider your intentions before scrolling.
- Set a timer.
- Be present.
- Remember that what you see is not reality.
- Don't just scroll, interact or post.
- Avoid the negativity. Unfollow, mute, recognise personal triggers.

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## The role of social media apps

- Effective regulation.
- Protective measures - For You Page; specific content
- Taking a public health approach to body image.
- Our responsibility. Not fuelling the fire. They respond to OUR desires.

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## MORE GENERAL ED RESOURCES TO AVOID Pro ANA websites and 'thinspiration'

- Some online content actively encourages and celebrates unhealthy relationships with food.
- These websites promote strict regimes, obsessions and self-punishment in the pursuit of weight loss or thinness.
- They are dangerous as they promote eating disorders and provide a community of 'support'.
- Thankfully, there is more monitoring and taking down of this type of content.
- They can be highly addictive and potentially dangerous resources.



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## More general ED and mental health resources to seek out

- The Hunger Artist Blog – Psychology Today
- The School of Life – YouTube
- BEAT – National ED Association
- MIND UK
- Intuitiveeating.org
- Tiny Buddha website
- The Bodypositive.org
- Health At Every Size

**Any questions?**



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## **18 January 2022 - It really is OK not to feel OK, Meal planning, DBT**

This was our first full discussion session since the start of the New Year. There was a lot to catch up on and the group pulled together around some really challenging issues. Thank you to everyone for your openness, honesty and care. Here is a brief summary of some of the key points:

### **It really is OK not to feel OK.**

December and January can be difficult months at the best of times and if you are caring for a loved with an eating disorder they can be even more emotionally and physically draining. Everyone in the group recognised this and, whilst knowing that there are no magic fixes, offered some support and reflection:

- **Our feelings are perfectly normal.** It is quite understandable that we would like our loved one's illness to go away, and that we feel bad if we are cross with them or relieved when they return home, or to university. Intellectually, we know it's not their fault, or our fault, and we should not feel guilty. Emotionally, that can be hard to reconcile. That's why it's so important to share these feelings - which is exactly what the support group is for.
- **You really are not alone.** Above and beyond this support group, BEAT and FEAST have carer helplines. Also, many people do not realise that The Samaritans, 116 123 free call, 24/7, is available to carers to ask for support and advice <https://www.samaritans.org>.
- **It really is important to look after yourself** and if that seems too daunting, start with one small thing each day that you can say, 'I did that for me'.
- **You may need to seek professional help for yourself**, I am very confident that at one time or another most of the group have.

### **Meal planning**

We've discussed meal planning on a number of occasions, see the FAQs on <https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder>

This week we considered a different angle, i.e. how best to support our loved one when they are motivated to change. Sarah outlined a clear strategy for support:

- try to build a structure, e.g. three meals and three snacks a day;
- then build up the amount being eaten; and
- then work on the range of things eaten.

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**18 January 2022 - It really is OK not to feel OK, Meal planning, DBT**

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The group gave some examples of where they have successfully 'nudged' their loved one in the right direction, a step at a time. If they are motivated to change, 'push where it moves' - it's too good an opportunity to miss - but don't push harder than a well-behaved dolphin would!

### **DBT - Dialectical Behaviour Therapy**

What is DBT (Dialectical Behaviour Therapy)? Sarah explained that it is a therapy that can help people manage really strong emotions and that at its core it helps people build four major skills:

- mindfulness
- distress tolerance
- interpersonal effectiveness
- emotional regulation.

Some of the group's loved ones are, or have been, engaged with this therapy: 'hard work', 'helpful', 'skills to draw on in the future' was some of the feedback. There is some more information about this on the Mind website <https://www.mind.org.uk/information-support/drugs-and-treatments/talking-therapy-and-counselling/dialectical-behaviour-therapy-dbt/> .

### **Encouraging stories**

Finally, we heard some really encouraging stories of growing independence, of rising to the challenge of having to look after themselves and of accessing professional support after a period of non-engagement, which is really brave. It's so important to remember that recovery is the most likely outcome, although we may have hang in there for some time.

Thank you all for a great conversation.

### **Some notices and information**

1. **Sibling Support Group.** Do you have in your family, or know of, a sibling who would benefit from being part of a support group? I am delighted to say that a group is starting in Cambridgeshire. If 'yes' please contact Helen Eves at Centre33 [helen@centre33.org.uk](mailto:helen@centre33.org.uk), or me, for more details. Please spread the word!
2. A project is seeking **UK research participants** for research into the lived experiences of autistic and non-autistic individuals with an eating disorder, including their carers. Information is available at this link: <https://www.feast-ed.org/seeking-uk-research-participants-lived-experiences-of-autistic-and-non-autistic-individuals-with-an/> .

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**18 January 2022 - It really is OK not to feel OK, Meal planning, DBT**

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3. Rxxxxxx recommended this **book** about autism and eating disorders, and this was endorsed by Sarah who was immediately able to show us her copy onscreen: 'Supporting Autistic People with Eating Disorders: A Guide to Adapting Treatment and Supporting Recovery', edited by Kate Tchanturia.

Next week: is a '18.30 Support Group Discussion'. See you there!

## Resources

### Self care

The Samaritans - 116 123 free call, 24/7, is available to carers to ask for support and advice <https://www.samaritans.org> .

### Web

#### Keep your head

<https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder>

### DBT

<https://www.mind.org.uk/information-support/drugs-and-treatments/talking-therapy-and-counselling/dialectical-behaviour-therapy-dbt/>

### Book

'Supporting Autistic People with Eating Disorders: A Guide to Adapting Treatment and Supporting Recovery', edited by Kate Tchanturia. ISBN: 978-1787754454



## **25 January 2022 – Struggle with routine changes, Change cycle, Too reliant**

This week we warmly welcomed Bxxxx to his first full meeting of the group and offered our experiences and support with regards to discharge from an inpatient unit. It is an exciting time, full of opportunity. It is also a challenging time, made more difficult at the present moment because 'home leave' as preparation for discharge has been affected by covid regulations. Members of the group described their loved one's confidence slowly returning and commented that people can change in six or seven months, which may take some time to get used to. We also reflected that it is really important to remember to be a dolphin and/or St Bernard because it is all too easy and understandable to revert to an unhelpful animal type, e.g. rhino or jelly fish (please see the attachment if this terminology is new to you!) The group unanimously agreed that it is essential to look after, and be gentle to, yourself.

### **Our loved one struggles when their routine changes, e.g. days off work, the end of university term: how can we help?**

We have discussed on several occasions the value of routines. Research has consistently shown that routines help people manage stress and anxiety because they give structure and control. A good routine has a balance of activities and will itself vary - you don't want the routine to become a rut. Not surprisingly our loved ones can find 'forced' breaks in routine, like weekends off work, difficult because they suddenly have nothing organised for them, with the risk that they start dwelling on their eating disorder, or get anxious because 'they are not doing anything'.

- As carers we can encourage them plan an alternative routine that includes activities they enjoy and will give a sense of achievement, however small. I have attached two slides from the presentation that Dr Sarah Beglin gave at our first ever online meeting, about 'activity scheduling'. The context was her son planning his way through the first lockdown but the principle of including a balance of mastery and pleasure activities is a good way of thinking about planning for any unstructured period of time.
- We can also help our loved ones understand that weekends, for example, are there for a reason - people need recovery time from work. Getting up late, watching a few movies on the television and catching up with some friends on the phone is normal and necessary. Validate: 'I'm not surprised you're exhausted after the week you've had'; 'It was a really good idea to watch the rugby on the television this afternoon, my guess is you feel less tired for that'. Also... model good practice!
- It's really good to have non-eating disorder interests to talk about and engage with and 'downtime' can be a good time for these, e.g. a football match, a museum trip. These can be planned into days off, giving structure and something else to talk about.

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**25 January 2022 – Struggle with routine changes, Change cycle, Too reliant**

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**Helping at different stages in the change cycle**

A number of the issues were about how we as carers can help our loved ones at different stages in the change cycle. I've attached the presentation we did about this for new members of the group. In particular, we as carers have an important role if our loved one is contemplating change. We can support their thinking with 'On the one hand, and on the other hand' statements; but don't push the issue, leave the statement hanging so that they can reach their own conclusions. Make connections between the eating disorder and its consequences, e.g. 'You want to go bowling with your friends and you don't think you will have the energy to stay up that late'. Help them plan by discussing what they could do, but leave the decision about what they will do to them.

**Reliance on support that is more than we feel we can continue giving**

A difficult situation we discussed is when our loved one has become reliant on support that is more than we feel we can continue giving and/or is more than is probably helpful to their long term recovery. An example would be us supporting our loved one with their evening meal by joining them on a Zoom call, every evening, at which they are very negative and the conversation is difficult and worrying. The group's experience is that our loved one's mood can be at its lowest at meal times, so it is best if we can deal with an issue like this separate to the meal. However, it is really important that we find a way to say how we feel. That our loved one is engaging in this way, and willing to share their feelings, are real positives to build on. We could combine validation with a suggestion, e.g. 'It is really good that you are telling me about this, can I suggest that I ring back later to talk about it?' Maybe they could write things down in a long text, or email, to allow a more considered response; we could, too. We need to encourage our loved ones to problem-solve with us, e.g. 'I really enjoy having our meal together on Skype but we've got a problem on Thursdays because I need to get your brother to Air Cadets, and also this weekend because we have friends visiting, can we talk through options for what we could do?'

Some other issues we talked about were:

- Seeking permission / reassurance - please see the FAQ at <https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder> for some helpful information about this.
- Long-distance caring - likewise, see the FAQ on the above website.
- Body image - this website, aimed at young people, includes some interesting and useful advice for friends and family about supporting a loved one who is anxious about body image <https://www.youngminds.org.uk/young-person/coping-with-life/body-image/#Howyoucansupportafriendstrugglingwithbodyimage> .

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**25 January 2022 – Struggle with routine changes, Change cycle, Too reliant**

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I'm sure you will agree with me that it was a very full, interesting and useful meeting. Next week's meeting is a '18.30' discussion and I will be sending the invite out at some point over the weekend.

And finally, a couple of notices:

- A study at Imperial College, London, is looking for carers of adult children who have been fed under restraint. If you are interested in being involved, let me know and I will provide you with further details.
- Making Space, the organisation that provides support for carers of a loved one with a mental illness aged between 18 and 65, is holding one of their excellent coffee mornings on Wednesday 9th March 2022. It's going to be held in the Pilgrim Hall, United Reform Church St. Neots from 11.00am – 1.00pm. Two Police Officers will be talking about their role when dealing with someone who has a mental health condition, in particular when Section 136 Place of Safety Order is used and what it means. These meetings are a great opportunity to meet other carers, not just carers of loved ones with an eating disorder; and I would strongly recommend the cake! Let me know if you will be going, so that the organisers can get in the right quantity.

## **Resources**

### **Web**

#### **Keep your Head**

<https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder>

#### **Body image**

<https://www.youngminds.org.uk/young-person/coping-with-life/body-image/#Howyoucansupportafriendstrugglingwithbodyimage>

#### **Activity scheduling**

#### **Animal analogies**

#### **Change cycle**

## Activity Scheduling

**Mastery**

- Planning
- University work
- Tidy room
- Work out
- Wash hair
- Send off application for year abroad
- Write Thankyou card

**Pleasure**

- Xbox
- Netflix
- Bath + music
- Play piano
- Watch TV/movie with family
- Skype friends
- Plan activities for when released

## Activity Schedule

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
<b>Morning</b>	Coffee + cards ☑ 11:30 Breakfast ☑ 11:45 Planning ☑ 12:00 Wash face ☑ 12:25 Plan CHiPs ☑ 13:00 Piano ☑	10:30 Coffee + cards ☑ Breakfast ☑ 10:50 Planning ☑ 11:00 Breakfast ☑ 11:30 Yoga ☑ 12:15 Face wash ☑ 12:30 Grounded theory ☑	Breakfast ☑ 10:45 Coffee ☑ 10:50 Planning ☑ 11:30 Face wash ☑ 11:50 CHiPs ☑ 12:50 Relax ☑	Breakfast ☑ 10:40 Coffee + cards ☑ 11:20 Planning ☑ 11:40 Face wash ☑ 12:00 GT ☑ 12:50 Piano ☑	Coffee ☑ 11:30 Planning ☑ Breakfast ☑ 12:05 Wash face ☑ 12:25 3 <sup>rd</sup> year project advisor ☑	Breakfast ☑ 10:50 Coffee ☑ 11:00 Planning ☑ 11:30 Wash face ☑ 11:45 House tidy ☑	Coffee ☑ 11:50 Planning ☑ 12:00 Breakfast ☑ 12:20 Wash face ☑ 12:45 Relax ☑
<b>Afternoon</b>	13:30 Lunch ☑ 14:00 Walk ☑ 15:30 Workout ☑ 16:30 Hot cross bun ☑	13:15 Lunch ☑ 14:00 Relax ☑ 15:00 Tidy room ☑ 15:30 Workout ☑ 17:30 Football ☑ 18:20 Relax ☑ 19:20 GT ☑	13:15 Lunch ☑ 14:00 Submit application ☑ 15:15 Relax ☑ 16:00 Workout ☑ 17:30 Waitrose ☑	13:15 Lunch ☑ 14:00 Chillax ☑ 14:30 CHiPs ☑ 15:00 Run ☑ 16:00 Relax ☑	13:15 Lunch ☑ 14:00 Project advisor ☑ 14:30 Walk ☑ 15:30 Coffee+ relax ☑ 16:30 Project advisor ☑ 17:00 Workout ☑	Lunch ☑ 14:00 Wash hair ☑ 15:00 Piano ☑ 16:00 Project advisor ☑ 16:30 Afternoon tea ☑ 17:15 Workout ☑ 18:45 Trim ☑	13:20 Lunch ☑ 14:10 Project advisor ☑ 15:20 Football ☑ 16:00 Wash clothes ☑ 16:20 Hot cross bun ☑ 18:00 Advisor ☑
<b>Evening</b>	Make Dinner ☑ TV ☑ Xbox ☑	Dinner ☑ TV ☑ Debate ☑	Dinner ☑ TV ☑ Xbox ☑	Dinner ☑ TV ☑ Boys ☑	Dinner ☑ TV ☑ Xbox + boys ☑	Dinner ☑ Cocktail party ☑	Dinner ☑ TV ☑ Advisor ☑



## Caring styles and responses to the eating disorder: animal models

Eating disorder symptoms frequently lead carers to react in particular ways. It is understandable that responses can be the source of hostile or critical confrontations occurring in all relationship settings. Unfortunately, such responses may result in the sufferer feeling increasingly alienated and stigmatized and retreating into the comfort of eating disorder behaviour even more.

Our team at the Maudsley have devised a series of animal metaphors (jelly fish, ostrich, kangaroo, rhinoceros, terrier) in a light-hearted manner to explain how these automatic reactions can be unhelpful. A veritable menagerie emerges as we metamorphose from one animal state to another in a desperate attempt to remedy the situation. Some 'animals' may be the carer's default way of coping with stress. Each animal analogy may be your default way of coping with stress or part of your natural temperament. Carers frequently swing from over-protection to logic or become overtly emotional or avoidant. In order to change these responses, you may have to challenge yourself and experiment with trying out new responses which do not feel natural or spontaneous. Don't worry if you do not succeed at first. Try and remember to keep looking to the bigger picture. All practice attempts are an experiment. Experiencing you experimenting with change will help your loved one.



### The jellyfish **Too Much Emotion and Too Little Control**

Some carers may be unable to regulate their own intense emotional responses to the ED. Their distress and anger is transparent to all, this gives the message that this carer needs looking after and at the very least needs to be treated with kid gloves. In this sea of emotion it is hard to steer a clear path. Also, like a jelly fish overt anger and anxiety can exert a poisonous sting with the same uncontrolled emotions being mirrored by the sufferer. Unfortunately, this serves to strengthen the eating disorder hold. The downside is that these 'sad and mad' emotions escalate causing tears, tempers, sleepless nights and exhaustion in all parties.

It can be hard to regulate your emotional reaction if you hold some false interpretations about the eating disorder, or have high levels of self blame, or perfectionist expectations about your role as a parent. It is also hard to regulate emotions when you are tired, tense and stressed. Ask yourself the following questions in two ways, as yourself and as if you are a kind compassionate friend looking on at yourself.

- Reflect on your jellyfish tendencies. How do they make you feel?
- What are the effects of these responses on yourself? On others?
- How important is it that you work on your 'jellyfish' responses?
- What message about the world does a 'Jellyfish' response give?
- If you were advising a friend with the same problem, what would your advice be? How would you
- help them take the step to change their jellyfish behaviour?
- What beliefs do you need to work on in order for this change to happen?
- How can you protect yourself from getting total emotional burn out?
- When could a jellyfish response be helpful?

Brainstorm scheduling some fun into your life and ways to nurture yourself. This may be through a hobby, seeing friends or taking a walk whilst listening to music. Try writing your ideas down and

then timetable this relax and recharge time into each day. Another plus side to this approach is the sufferer will learn to find ways of coping when you are away. The fact that you are reading these worksheets shows that you are open to new ideas.



### **The ostrich** **Avoidance of Emotion**

The ostrich finds it hard to cope with the volcanic situation which often arises when trying to tackle the difficult problem of living with an eating disorder. Emotions and the complexities of human behaviour are too chaotic and confusing. The ostrich literally prefers to put his/her head down into the sand. This is something he/she knows he/she can confidently do, avoiding what seems too hard. The downside is that the sufferer may misinterpret this approach, seeing you as uncaring and end up feeling unloved. Self-esteem is sapped away. Additionally, the concealment of emotions sets an unhelpful example for the sufferer to follow. Setting an example of emotional honesty and spreading the concept that having controlled emotions is normal and acceptable human behaviour, will aid the sufferer in coming to terms with their own difficulties with emotional expression. Living with others who can and are able to convey their feelings with words will aid the sufferer in changing their only way of articulating their own emotions which currently is through food.

Ask yourself the following questions and also answer these questions as if you are a kind compassionate friend looking on.

- Reflect on your ostrich tendencies. Have they succeeded in helping you and those you love feel safe and secure?
- Could you take steps to become less of an ostrich?
- What message about the world does an 'Ostrich' response give?
- Who can support you in experimenting with new responses and help you reflect on how you are doing in this non-ostrich role?
- What would you want this person to do/say? A list of suggestions is often useful.
- What do you think about involving others in helping you make the prerequisite changes?
- How do you feel about making these changes? Are you ready to take the baton and run with it?
- Which of your Ostrich tendencies do you feel are helpful?

Change can be difficult and uncomfortable. It may be worthwhile engaging the help of a supportive family member/friend to help you in your quest. Think about your own self-esteem and how role modeling confidence in facing rather than avoiding difficulties might help your loved one experiment with changing their own behaviour. The fact you are reading this sheet and considering these questions is already a huge step. Well done!



### **The kangaroo** **Trying to make everything right**

This type of carer does everything to protect by taking over all aspects of the sufferer's life. They treat the sufferer with kid gloves, letting them jump into the kangaroo pouch in an effort to avoid any upset or stress. The downside of this type of caring is that your loved one fails to learn how to approach and master life's challenges. She/he only feels safe living in this limbo land suspended in a child-like cocoon unable to visualise taking on the world in all its colour or the mantle of adulthood.

Ask yourself the following questions and also answer these questions as if you are a kind compassionate friend looking on.

- Reflect on your kangaroo responses. How are they working for you?
- What difficulties are you encountering? Give an example of what is not working for you?
- What message about the world is a 'Kangaroo' carer giving?
- What aspects of your kangaroo behaviour can you experiment with?
- How important is it for you to address some of your kangaroo responses?
- Think back to one of your kangaroo behaviours in recent weeks. How can you change that behaviour a little? What would be the first step?
- Which parts of your 'Kangaroo' behaviour do you think are helpful?

Change is tough... congratulate yourself after having attempted the change! Taking safe risks is a key aspect of change. You may need to make the change with baby steps.

### **The rhinoceros uses force and logic to win the day**

Fuelled by stress, exhaustion and frustration, or simply one's own temperament, the rhino attempts to persuade and convince by argument and confrontation. The downside is that even when your loved one does obey, confidence to continue to do so without assistance is not developed. In fact the more likely response to a rhino "in a china shop" is to argue back with an even stronger eating disorder voice. An outcome of this is that, for example, the more the ED minx retaliates, the more the Eating Disorder identity is consolidated, embedded and validated.

Ask yourself the following questions and also answer these questions as if you are a kind compassionate friend looking on.

- Reflect on your rhinoceros responses. Are they working for you?
- What difficulties are you encountering?
- What message about the world does a 'Rhinoceros' carer give?
- How can you avoid these obstacles?
- What might be the positive and negative repercussions of changing your rhino response? ,?
- What can you do for yourself to lower your anxiety, stress or anger levels?
- Set a goal for yourself with regards to this. How do you think this will make you feel?
- Which Rhino behaviours do you think are helpful?

Whilst contracts work in a 'crisis situation', try to motivate and encourage your loved one to grow their own garden of independent thinking by letting them make decisions and come up with innovative solutions

Remember that the more you argue for change, the more resistance you are likely to face and you will give the sufferer the opportunity to practice arguments for the statusquo. This allows the eating disorder to embed itself more deeply. A key skill is allowing the sufferer the opportunity to present her/his own arguments as to why change is needed.

### **The terrier uses persistence (often perceived as criticism)**

The terrier persistently , cajoles, nags and tries to wear out the anorexic minx or the bulimic boa constrictor. The downside of this terrier type behaviour is that either the sufferer tunes out to what they perceive as irritating white noise, or gives the opportunity for covert negative counteracting behaviours. Caring motives are misunderstood and everyone's morale is sapped. Your loved one loses the inner resource to face the rich tapestry of life without an eating disorder identity.

Ask yourself the following questions and also answer these questions as if you are a kind compassionate friend looking on.

- Reflect on your terrier tendencies. How do they make you and the family feel? Are they working and helping Edi feel safe enough to leave eating disorder?
- What are the effects of this terrier response on yourself? And on others?
- How important is it that you work on your 'terrier' type behaviour?
- If you were advising a friend with the same problem, what would your advice be?
- How can you develop rewarding communication? A key skill is trying to listen to what Edi might be struggling to say?
- What beliefs do you need to work on in order for this change to happen?
- How can you take steps to be an active listener?
- Speed and timing are factors you can consider. The fact that you are reading these worksheets shows that you are open to new ideas. Well done!
- What specifically can you do now to get started with these different patterns of responding?
- Which terrier behaviours do you think are helpful?

The eating disorder is rather like a terrier constantly criticising your loved one - saying she/he is not good enough, needs to try harder. Role modeling active listening and reflection with compassion and sensitivity directed to the positive will help her/him have the support and encouragement to challenge the eating disorder voice.

Practice praising the sufferers efforts rather than the results.

**Close your eyes and visualize yourself as being kind, warm, compassionate, a good listener, having the best of caring motives—what animal would this be?**

**Create a picture in your mind of a 'ROBUST and RESILIENT' person – what qualities would they need to have to weather the 'Slings and Arrows of Outrageous Fortune'?**

## Inspirational Animals

Of all the animals in the animal kingdom, we want you to aspire to be a St Bernard for warmth and compassion in the face of danger and a Dolphin for its wisdom and hands off form of support.



The dolphin

Just enough caring and control

An optimal way of helping someone with an eating disorder is to gently nudge them along. Imagine your loved one is at sea. The eating disorder identity is his/ her life vest. She/he is unwilling to give up the safety of this life vest whilst living in the frozen wasteland of the eating disorder. You are the dolphin, nudging her/him to safety, at times swimming ahead, leading the way, showing them new vistas, at other times swimming alongside with encouragement, or even quietly swimming behind, showing trust and confidence.



The St Bernard

Just enough compassion and consistency

Another optimal caring response is one of calmness, warmth and compassion. This involves accepting and processing the pain resulting from what is lost through the eating disorder and developing reserves of kindness, gentleness and love. The St Bernard instills hope in your loved one that they can change, that there is a future full of possibility beyond the eating disorder. The St. Bernard responds consistently and is unfailing, reliable and dependable in all circumstances. The St. Bernard has a good antennae attuned to the welfare and safety of those who are lost...calm, warm and nurturing.

### Pearl of Wisdom

Nobody gets it right all of the time – in challenging times it is important to remember the adage, “every mistake is a treasure” and as Martin Luther King said; “You don’t have to see the whole staircase – just take the first step”.


We aren’t expecting carers to be perfect at all times. Just 5 -10 minutes a day of constructive interaction with an emphasis on listening pays dividends.

Good enough care helps the sufferer to tolerate compromise, compassionately.





# The Change Cycle and Eating Disorders

CPFT Adult Carers Support Group, 13<sup>th</sup> July 2021  
Keith Grimwade, Ann Thompson, Renata Dallaway





South London and Maudsley   
NHS Foundation Trust




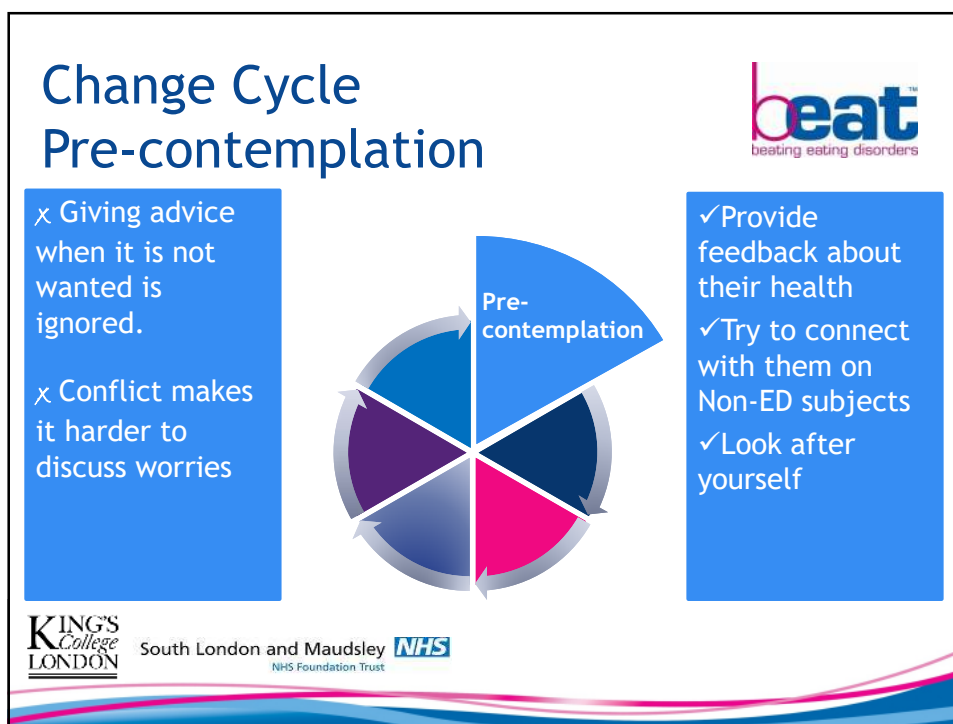
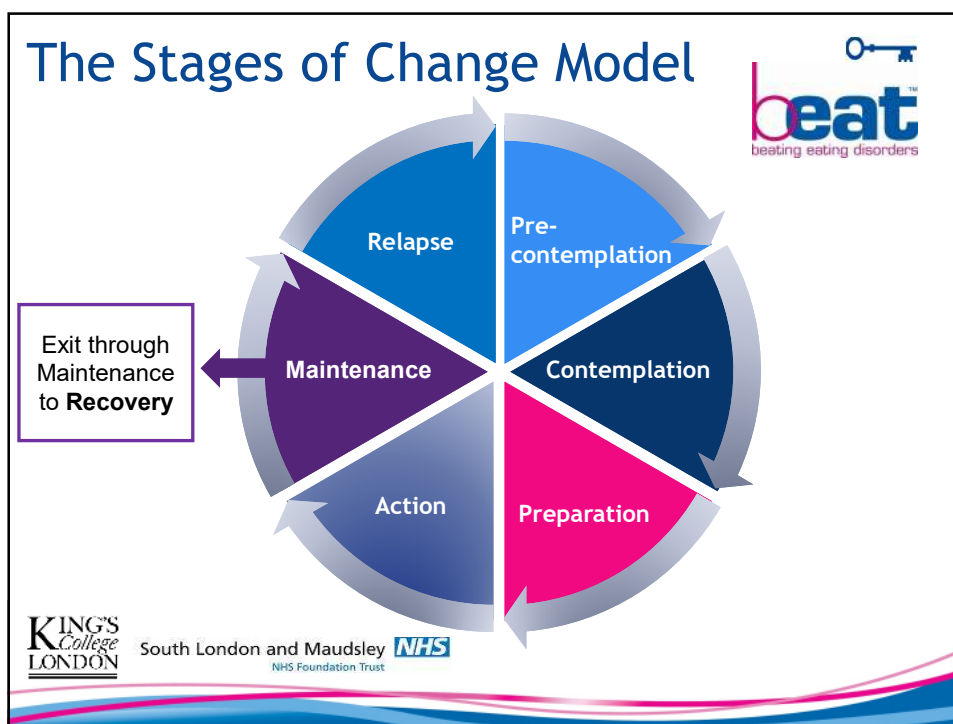
## Aims and objectives

- To know about the change cycle.
- To understand how it can help us support our loved ones.
- To have an opportunity to consider appropriate communication / questions.




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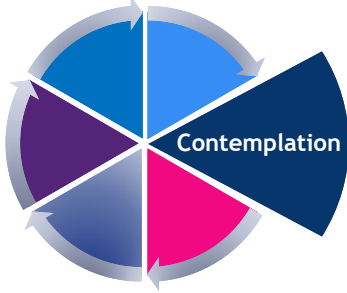




## Change Cycle Contemplation





✗ Arguing for change when person is in 2 minds means they take up anti-change argument



Contemplation


- ✓ Discuss pros and cons of ED, and of change.
- ✓ Make connections between ED and consequences
- ✓ Discuss possible plans of action



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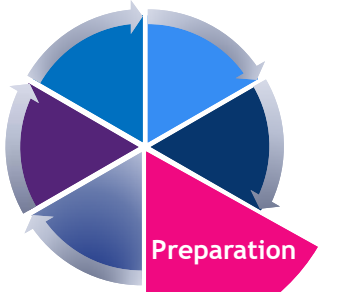
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## Change Cycle Preparation




✗ Ignoring or dismissing change talk means it can fall into stony ground.


✗ Try not to *enable* them to be ill.



Preparation

- ✓ Help make detailed action plans
- ✓ Ask: 'How can I help?' , 'What would success look like?'
- ✓ Build self-belief – Praise is VERY important




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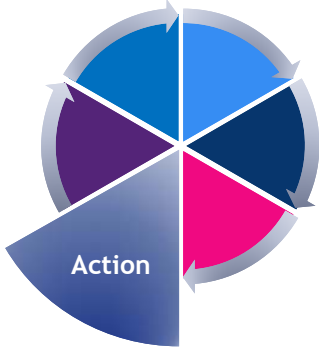
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## Change Cycle Action





✗ Failure to respect the challenge of change can make it falter.



Action


- ✓ Assist with learning new coping strategies
- ✓ Watch for signs of relapse
- ✓ Note and praise improvements & change processes



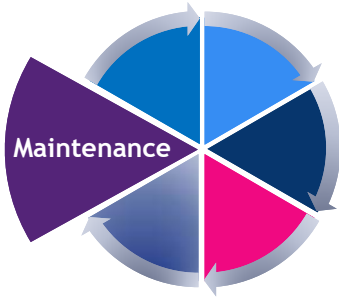
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## Change Cycle Maintenance





✗ Criticism & hostility with a shortfall on goals reduces confidence in change attempts



Maintenance


- ✓ Support efforts
- ✓ Encourage independence and non-ED personality
- ✓ Link healthy behaviour to perceptible life gains



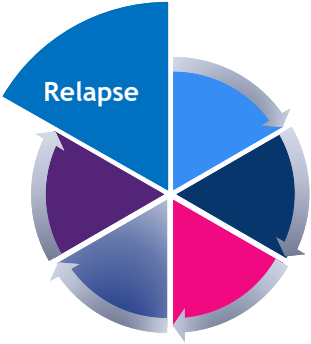
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## Change Cycle Relapse




× Critical remarks, particularly about setbacks, can result in loss of hope & faith, making it harder to pick up where they left off




✓ If relapse occurs, treat it as part of recovery

✓ Every mistake is a treasure


✓ Support loved one to understand and learn from relapses and set-backs



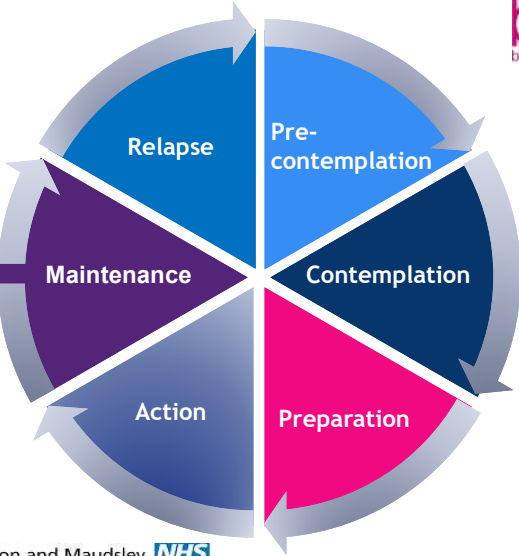
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## The Stages of Change Model



Exit through Maintenance to **Recovery**





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## Model of Change

When in doubt...




# Roll Down

- If the approach you are using doesn't seem to be working, roll right down to the techniques of the earliest stages.
- From this safer stance, you can experiment with which techniques can be used without creating resistance.

  
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## Key points

- The change cycle is not a straightforward progression from one stage to the next.
- Different communication / questions is appropriate for different stages of the cycle.
- It is pro-recovery.

  
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*They alone can do it  
but they can't do it alone*



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**1st February 2022 – Having a tough time, OCD**

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**1st February 2022 – Having a tough time, OCD**

I began this week by asking Emma and Sarah to say a little bit about their roles and how they are! Emma talked about her role as a Clinical Support Worker, which is very varied, e.g. medical monitoring, well-being calls, intensive support, Bulimia Nervosa therapy group. Sarah talked about the changes as a result of the pandemic with almost all therapy and support now online, although there is some 'in person' where it is needed to keep people safe. Sarah also talked about the massive transformation the team has been through above and beyond covid and that the referral rate has tripled. We thank both of you and your colleagues for all that you do for our loved ones, and for continuing to support this group.

**Loved ones having a tough time**

For me, Hxxxxx summed up this week's meeting when he said that more people than usual were reporting that their loved ones were having a tough time. Time of year? Chance? Whatever the reason, this makes it all the more important that we as carers look after our own health and wellbeing so that we can give the best possible care. Sometimes that means taking a break, going for a walk, doing something for ourselves, e.g. a hobby to recharge the batteries. It's essential.

We welcomed Jxxxxx to her first 'full' meeting of the group. Jxxxxx's daughter is having a really tough time of it at the moment, which of course means that Jxxxxx and her husband are too. It is perfectly natural for a parent/carer to want to fix things for our loved ones but the reality is that we can't. That doesn't mean that there aren't things we can do, and the group offered both understanding and a number of suggestions from their experience:

- **Try to stay calm, consistent and caring** but don't beat yourself up if you occasionally 'lose it'; it's pretty much inevitable. If you do, step back and wait for a calmer moment before stepping in again. 'I'm sorry I got angry, what I meant to say was...' is a sentence starter some of us have found useful.
- **Validate** - acknowledge their suffering, e.g. 'I can see how difficult this is for you', 'I see that this is very hard for you, I'm here for you'. This may not seem like much, and it's important to leave it at that and not step in with solutions, but we know from what our loved ones have said in service evaluations that they find it helpful to know that we 'get it' and that they are not making it up.
- Supporting our loved ones to '**name their feelings**' can also be helpful because their emotions can be so overwhelming that they can find them difficult to sort out, e.g. 'It sounds as if you are really angry / upset / anxious / worried...'. We also discussed that our loved ones might respond negatively to this conversation. If that's the case, just leave it; it might be that we've helped their thinking but that it's too raw for them to acknowledge.

Looking back through my notes I am reminded of 'Less is More' as being a helpful approach for a number of the situations that the group brought to the meeting, e.g. when we are not sure what to say or do, when we are the butt of our loved one's anger, when our caring is 'long distance' because they are away from home:

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**1st February 2022 – Having a tough time, OCD**

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- **Listen** - Listening conveys respect for another person's views and emotions. If you are a 'long distance carer', giving the message 'there are other people who can listen if you want to talk to someone else' can be helpful.
- **Empathy** - Empathy means trying to step into the other person's shoes and see things from their perspective. Think how you can communicate empathy in a compassionate, non-confrontational, non-judgemental way. 'We don't know exactly how you are feeling, we do know you are experiencing a very challenging time, we are here for you'. Also, remember you cannot force your loved one to make changes, it must be in their own time and at their own pace.
- **Support** – but carers are not, and should not be, a punch bag. If your loved one hurls an avalanche of abuse and/or hides behind a wall of silence you can feel battered, bruised, and unappreciated. It is important to remember that this is the illness talking, not your loved one. It is equally important that we explain how we feel and that we calmly, but assertively, maintain important boundaries. At a previous meeting, Sarah gave us a framework for this: acknowledge and name their suffering; say that if you could take this away from them you would in an instant; keep giving this validation - generally, if your loved knows you have heard them, they will not feel the need to repeat themselves. For example, 'I can see that you are angry / frustrated / struggling right now. If I could sort it out I would, you know that, but I don't like it when you call me that! It makes it hard for me to listen to you properly'.
- **Share** - in non-eating disorder conversations and activities. Communicate that you know they are more than the ED. Make connections through any route you can that isn't about the ED, e.g. work, their hobbies, friends.

**OCD**

We talked about OCD (Obsessive Compulsive Disorder) as a co-morbidity and how either the eating disorder, or the co-morbidity, can become more pronounced at times of change; the particular example we discussed was when our loved one's medication changes. Sarah reminded us that setbacks are normal. Our role, as ever, is to be alongside our loved one to give gentle encouragement. If our loved one is receptive to change, we could suggest options but we need to leave the decision with them. With regards to OCD, the advice for carers is very similar to the advice for carers of a loved one with an eating disorder, see Resources.

The group also reiterated the importance of finding appropriate ways of communicating. Text / WhatsApp messages, a good old fashioned letter - all are ways of communicating things that can be hard to say and need time to think about. The power of the 'visually validating emoji' was also discussed and illustrated! 😊🔗👏👍

Thank you to everyone for a great conversation. Next week I will be giving the monthly presentation (with a little help from my friends!) on 'Praise, affirmation and positive feedback', from 18.30 to 20.00. I'll send the invite out on Friday.

**1st February 2022 – Having a tough time, OCD**

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**Resources**

**Web**

**OCD**

<https://www.mind.org.uk/information-support/types-of-mental-health-problems/obsessive-compulsive-disorder-ocd/for-friends-family/>

**8th Feb 2022 - 'Praise, Affirmation and Positive Feedback - presentation -Keith Grimwade**

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**8th Feb 2022 - 'Praise, Affirmation and Positive Feedback - presentation -Keith Grimwade**

It was a pleasure to present this week's presentation on 'Praise, Affirmation and Positive Feedback'. I began by explaining why I chose this topic:

- It's important: praise builds self-esteem, confidence and motivation, and affirmation reinforces the positive character strengths that our loved ones need for their recovery.
- It's something we as carers can do that will help our loved ones.
- I'll be honest, I've found it difficult, so I wanted to reflect on my experiences and the ideas I've picked up along the way.

I've attached my presentation with slides 7 and 13 completed following our discussion - thank you for your excellent contributions!

One of the points we discussed was, 'What if our loved one rejects and/or ignores our praise?' The group's experience is that this is a common issue, especially when our loved one is 'pre-contemplation' (not ready to think about recovery) or in the early stages of 'contemplation' (thinking about recovery). There may be other reasons why our loved one receives praise in an unexpected way, e.g. if they are autistic. This doesn't mean that you shouldn't praise - it's really important - but it does affect how, when and how often you praise.

- Sarah reflected that praise is better if you validate first because it shows that you have noticed their suffering, e.g. 'I can see how hard it was for you to attend that therapy session'.
- Rxxxxxx said that face to face conversations are confounded by her daughter picking up on her anxiety, so she has written to her daughter to say how proud she is, with success.
- From my own experience, a quiet word away from the rest of the family was better received than something more public.
- When Ana spoke to us about her recovery journey last January she described eloquently that although she didn't respond to her mother's praise and encouragement when her illness was at its worst, it was still really important to her: 'My mother put notes under my bedroom door at times when I found discussing my illness impossible. I didn't say anything to her, but I'm so glad she carried on doing it because it showed me that she saw how much I was struggling'.



## 8th Feb 2022 - 'Praise, Affirmation and Positive Feedback - presentation -Keith Grimwade

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For those of you who were not at the presentation, the approach to affirmation that we discussed was:

- Think about the positive character strength you want to encourage.
- Plan a sentence that is personal (I / we).
- It doesn't have to be something our loved one has achieved, it can be a process, i.e. the steps they are taking towards the achievement.
- It needs to be current, i.e. now, not in the future.

The more you practise, the easier it becomes (honest!)

Also, it's really important to know that the examples of affirmations given in slides 13 - 16 are not presented as 'best practice'. They are good for stimulating ideas but our discussion showed that we could improve them significantly by applying the criteria given in slide 11.

Thank you for your patience, understanding and involvement, which made presenting this topic a real pleasure!

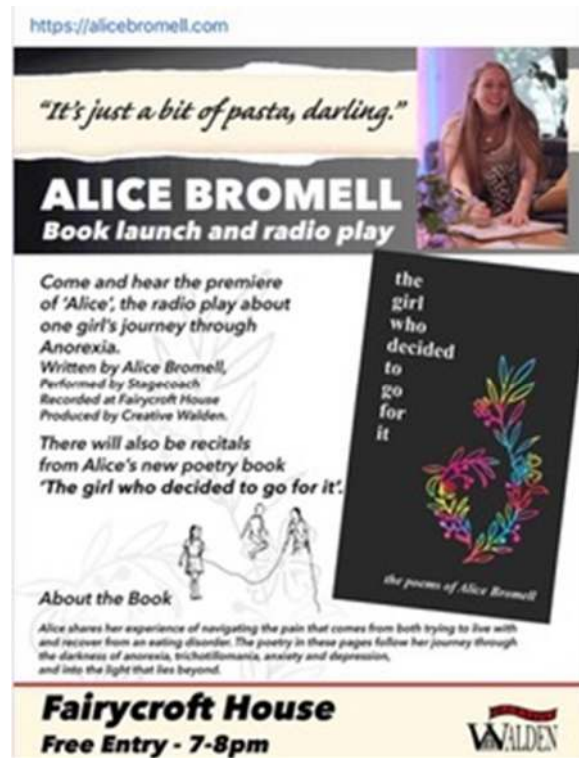
Next week is a 16.30 Support Group Discussion and I'll get the invite out on Friday. I look forward to seeing you then.

### **Four really important notices - please read!**

First Pxxxx, one of our group, has emailed me with some exciting news about her daughter, Alice. Pxxxx says, 'I'm hoping Alice has turned a corner, we're certainly not there yet. She has just started treatment for ADHD, so we're hoping this will help. She has been writing poetry about how it feels being ill and has a book published. She has a book launch next week and I thought the group might find it useful to hear from someone suffering with an eating disorder, and that even those suffering with it know that there is hope'. I've attached a poster about Alice's book launch and a link to a newspaper article about it <https://www.saffronwaldenreporter.co.uk/things-to-do/saffron-walden-recital-for-great-chesterford-poet-8673760>. A couple of Alice's poems are on her website, plus a YouTube video that you might be interested in. Our congratulations go to Alice, and to Pxxxx, and thank you so much for telling us about this. (Fairycroft House, Audley Road from 6.30pm on Wednesday, February 16.)

**8th Feb 2022 - 'Praise, Affirmation and Positive Feedback - presentation -Keith Grimwade**

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Second do any of you have experiences of good support for your loved one (and you) from your GP? If 'yes' it would be great if you could email me a brief description of what was good about your GP's support for a piece of content we are preparing for Eating Disorders Action Week, which starts on 28th February. Please send me your contributions by Friday 18th February.

Third has your loved one been on the Support and Stability Pathway? A task and finish group has been set up to look at establishing a Support and Stability Pathway for the eastern region. They would like one or two carers to be involved. I cannot be definitive about the commitment but it is likely to be a Teams meeting every two to four weeks for about six months. If you are interested I can put you in touch with the programme manager.

Fourth I've attached a poster about the coffee morning I mentioned recently. It's a really supportive general carers group, and I can strongly recommend the cake.

*Editor note: Now out of date, see website*

<https://makingspace.co.uk/cambridgeshire-carer-support>

## Resources

### Presentation

# Praise, Affirmation and Positive Feedback

KEITH GRIMWADE, CPFT ADULT EATING DISORDERS CARERS  
ONLINE SUPPORT GROUP

## Overview

- ▶ Setting the scene
- ▶ Praise
- ▶ Listen, Look and Learn
- ▶ Affirmation
- ▶ Positive Feedback
- ▶ Discussion

## Praise: what and why?

- ▶ What: 'to express admiration or approval of' (The Chambers Dictionary)
- ▶ Why: to build self-esteem, confidence and motivation

## Praise: how?

- ▶ Praise discriminately
- ▶ Praise in the way that your loved one best receives praise
- ▶ Praise 'green shoots'
- ▶ Praise the process as well as the outcome, e.g. if their behaviour has been flexible rather than rigid
- ▶ Praise non-food related behaviours
- ▶ Be heartfelt: genuine, authentic, not just because you want to be nice
- ▶ Be specific

Praise: be careful

- ▶ 'Conversations can be tricky when supporting a person with an ED. The role that control plays in the disorder, means that even well-intentioned comments, like praise, can be viewed as controlling and judgmental.' <https://www.irishtimes.com/life-and-style/health-family/how-to-support-a-loved-one-with-an-eating-disorder-1.4728423>

Listen, Look and Learn

You  
Ears  
Eyes  
Undivided Attention  
Heart



## Listening: barriers and solutions

### What gets in the way of good listening?

- Arguing / disagreeing
- Expressing disapproval
- Making judgements
- Getting upset
- Expressing anxiety
- Being distracted
- Giving a prepared speech

### What can we do to make sure we 'listen well'?

- Remember – eyes and heart, as well as ears
- Undivided attention
- Ask open questions
- Be curious
- Check you've understood
- Ask permission
- Listen differently, e.g. put what you want to say in a letter, email or text

## Affirmation: what and why

Affirm 'to ratify, to give validity to' (The Chambers Dictionary)

In psychology an 'affirmation' is a positive statement that helps challenge and overcome negative thoughts.

It is different to 'praise' where you express approval.

Think of it as a positive comment that gives emotional support.

There is an evidence base stretching back to the 1980s.

## Praise or Affirmation?

Well done on coping with your sister's party.

I could see how determined you were to stick to your plan at your sister's party this afternoon.

## Positive character strengths

Adaptable	Collaborative	Eloquent	Funny	Patient	Sociable
Amazing	Committed	Empathic	Hard working	Persevering	Sporty
Articulate	Compassionate	Energetic	Incredible	Popular	Strong
Artistic	Conscientious	Enthusiastic	Independent	Quirky	Talented
Attentive	Considerate	Expressive	Intelligent	Reflective	Thoughtful
Brave	Courageous	Fantastic	Kind	Resilient	Trust worthy
Calm	Creative	Fearless	Knowledgeable	Resourceful	Versatile
Capable	Determined	Flexible	Level headed	Responsible	Wild
Caring	Diligent	Fortuitous	Loving	Sensible	Wise
Clever	Driven	Friendly	Passionate	Sensitive	Zany

## How to write an affirmation

- ▶ Personal
- ▶ Positive character strength
- ▶ Process or outcome
- ▶ Present, not the future

**I could see how **determined** you were to stick to your **plan** at your sister's party **this afternoon**.**

## Over to you

The list of positive character strengths (slide 10) and the examples (slides 13 – 16) are from Jenny Langley's 'Sidestepping the reassurance trap, giving Edi positive assurance and the power of affirmations', reproduced here with permission. Slide 11 'How to write an affirmation' is mine. **Do the statements about 'Flexibility...' have the 'Characteristics of a good affirmation'?**

### Characteristics of a good affirmation

- ▶ Personal
- ▶ Positive character strength
- ▶ Process or outcome
- ▶ Present, not the future

### Flexibility rather than rigidity

- ▶ You were able to cope well with dinner being unexpectedly ten minutes late – I know you find unexpected delays around mealtimes difficult
- ▶ You showed courage and flexibility when the restaurant had run out of the meal you wanted
- ▶ It is impressive that you have been flexible/adaptable/versatile/reflective enough to...
- ▶ It takes great strength of character to shift from your safe rituals....



## Connecting to others & the world rather than isolating themselves

- ▶ You were determined to go to your sister's baby shower even though I know you were really nervous about people looking at you
- ▶ It was so lovely to see you having such a lovely time with your baby niece and your granny on Sunday
- ▶ I realise it takes patience and thoughtfulness for you to explain your gut reaction to...
- ▶ You seem to notice my efforts to support you for trying to change.....

## Expressing rather than avoiding emotions

- ▶ Thank you for telling me how you are feeling
- ▶ It can't have been easy to be open about your feelings...
- ▶ Wow you really slammed the door, you seem angry/ upset/ anxious/ frustrated

## Flexibility rather than rigidity

- ▶ You were able to cope well with dinner being unexpectedly ten minutes late – I know you find unexpected delays around mealtimes difficult
- ▶ You showed courage and flexibility when the restaurant had run out of the meal you wanted
- ▶ It is impressive that you have been flexible/adaptable/versatile/reflective enough to...
- ▶ It takes great strength of character to shift from your safe rituals....

## Going for bigger picture rather than focusing on the detail

- ▶ I can see that you are able to judge portion sizes just by looking at your plate, it must be a relief not having to weigh everything. You have come so far
- ▶ You were courageous to have a day off your fitbit, you seemed more relaxed and the dog walk was so enjoyable, going at a slower pace and not counting every step

## Over to you 2

### Write your own affirmation!

I noticed that you showed great strength and determination eating that lunch today.

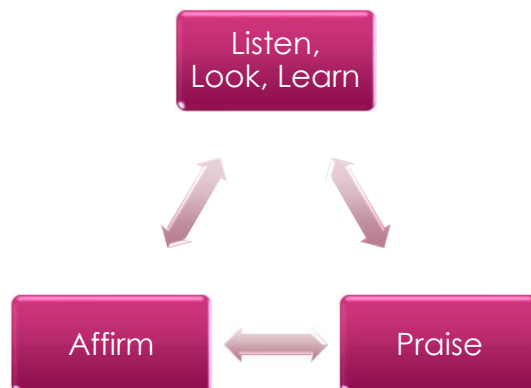
I think you've shown a lot of courage applying for that job earlier today.

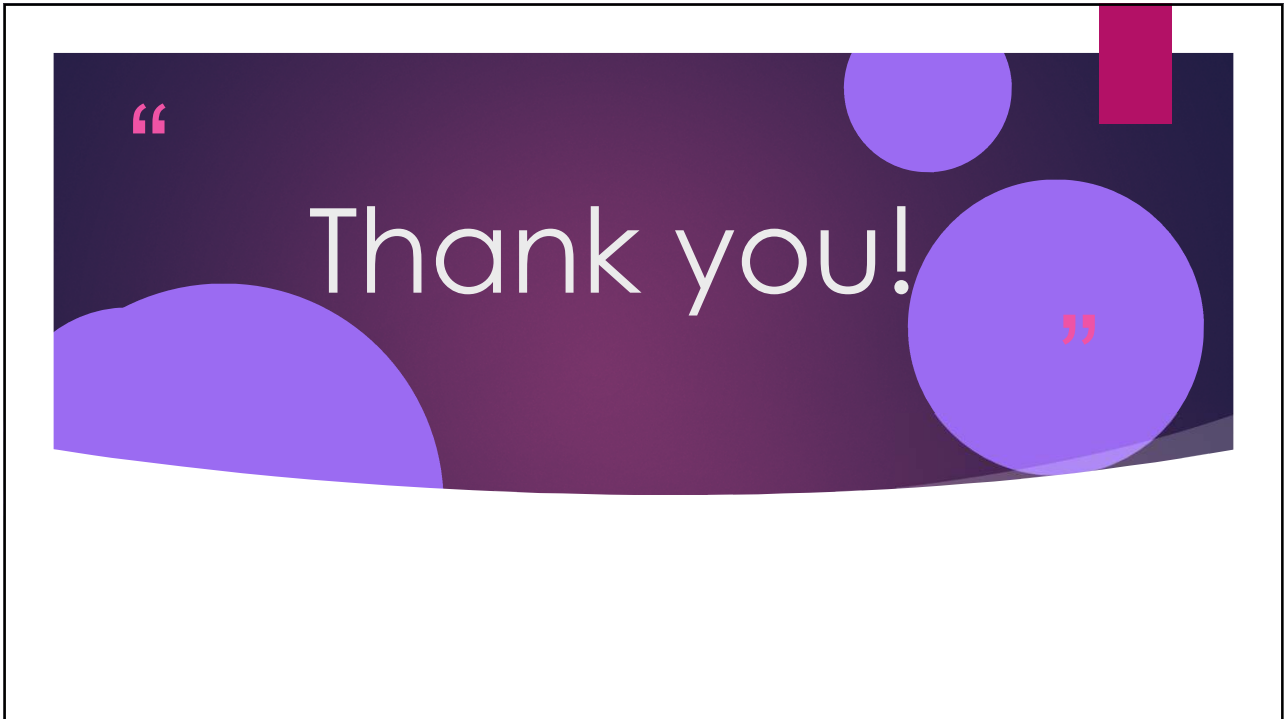
I'm exhausted and you're not even out of breath. *(This is not the standard format but is a good example of how important context is: 'She will know what I mean because of our earlier conversations, this is all I need to say to reinforce the positive character strengths'.)*

We think it was sensible to take that rest when you got home from school today.

## Positive Feedback

'return of part of the output of a system to the input as a means towards improved quality' (The Chambers Dictionary)





**15 February 2022 - Values of the support group, How we step away from 'doing too much'**

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**15 February 2022 - Values of the support group, How we step away from 'doing too much'****Values of the support group**

One of the real values of a support group came through loud and clear this week, i.e. the group can give a sense of perspective and point out things that we can be too close to our loved ones to see. This is particularly true with regards to achievements and 'green shoots'. This week's examples included our loved ones' growing independence, greater resilience and willingness to tell us about their feelings. We should also include our own achievements: from staying calm and managing our own anxieties, to gently nudging our loved ones in a healthy direction, to looking after our own needs, e.g. logging on for this afternoon's call. It was good for us, too, to hear Sarah's reminder that when we see our loved ones distressed we are bound to say some 'rhino-like' things because we are desperate to stop their suffering; as long as we come back with some 'dolphin-like' support it doesn't matter.

We welcomed Sxxxx to her first meeting. Sxxxx's daughter has been accepted onto the MANTRA programme, (Maudsley Model of Anorexia Nervosa Treatment for Adults), which a number of the group's loved ones are, or have been, on. It is a real positive that Sxxxx's daughter is contemplating change and has taken up this offer of treatment. However, she doesn't want to know her weight and she is worried about the requirement to provide this once a week. The group offered a number of reflections based on their experience:

- Emma, who is part of the medical monitoring team, said that most patients who do not want to take their own weight get used to it step by step, with support, until it becomes the norm.
- Rxxxx agreed and said that her daughter doesn't like this requirement but she has got used to it.
- Pxxxx said that for his daughter taking her own weight was part of the recovery process.
- Dxxxx commented that avoiding knowing their weight can become avoiding something else, and then something else, i.e. the anxiety moves elsewhere.
- Previously, we have heard of some very creative ways of addressing this challenge, e.g. Jxxxx's daughter doesn't like talking about her weight but enters it onto a shared spreadsheet once a week that Jxxxx can see.
- Sarah commented that it is very common for some patients to over-monitor their weight and for others to avoid weighing themselves at all, and that both positions are 'eating disordered'; many treatment programmes try to get patients to face it once a week.

Our role as carers, as ever, is to be as calm, caring and compassionate as we can, and to encourage - not force - our loved ones in a healthy direction.

## 15 February 2022 - Values of the support group, How we step away from 'doing too much'

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### How we step away from 'doing too much'

We started - but I'm pretty sure we didn't finish - discussing how we step away from 'doing too much', which can accommodate the illness, slowing recovery, and can also be exhausting for us as carers. There is no easy answer because if we take the scaffolding away too quickly they might fall, if we leave it there too long it might become a prison. The group made a number of suggestions based on experience:

- Motivation to 'take the next step' gives a real impetus, so helping our loved ones find this, and supporting them to make a start on it, is something we can do through discussion, open questions and being curious. A job, going to university, foreign travel, being well enough to return to competitive sport - all were mentioned by the group.
- Being honest about our feelings and encouraging joint problem-solving was mentioned: 'I really want to help but I'm getting exhausted, can we think if there are some other ways of doing this?'
- Some have found jointly planning 'small steps' to be helpful.
- On the other hand, previously we have discussed our loved ones rising to the challenge, e.g. having to prepare their own meal / get to work etc because we have taken a short holiday, or had to attend a sick relative, or been unwell ourselves.
- Janet Treasure writes about this in 'Skills-based Caring for a Loved One with an Eating Disorder'. She suggests the **APT model**:
  - **Awareness** - keep a track of what, when and how 'accommodating' behaviour occurs;
  - **Planning** - plan carefully what you are going to do. This will need to be discussed and agreed with your loved one, so it will require an environment with 'as much comfort, calmness and reassurance as possible'.
  - **Try** - give it a go, reflect and learn; and if necessary, re-plan.

This is one we will come back to.

### Resource

#### App

And last but not least, lxxxx said that her daughter had found the following app helped her to stop picking her skin <https://habitica.com/static/home> .

Drop me a line if any of you can add other suggestions.

Next week is a '18.30 Support Group Discussion', I look forward to seeing you then.

## **22 February 2022 – Big questions, Challenging topics**

I found this week's discussion really helpful. It needed to be because some of the group are having a hard time of it at the moment. Fortunately, we were able to offer the group's experience, some recent successes, and our ongoing support.

### **A couple of 'big' questions**

We discussed a couple of 'big' questions:

#### **How do we help our loved ones when they 'want to want to do more' but can't bring themselves to do it?**

That our loved ones are contemplating change is very much a positive. For us as carers it can be a frustrating time because the solution can seem obvious and straightforward, but it is really important not to step in and take over. Our loved ones may well be scared of what they are going to lose, e.g. being protected from their emotions, or being cared for. The group offered the following thoughts based on their experience:

If they want to talk, seize the moment. Be curious, ask open ended questions, ask how you could help and try to find out what they are scared of... but stay calm and don't be overbearing.

- **Help them find their motivation.** Time and again we have heard the value of 'something worth getting well for'. One way to do this is to explore 'pros' and 'cons', e.g. 'On the one hand you want to be a bridesmaid at your sister's wedding and on the other you are worried about the costume fitting and whether you will have enough energy for the big day'. Let it hang, there is no need for an answer or response, it is all about helping them clarify their thoughts.
- **Make connections between their eating disorder and its consequences on their health, behaviour and activity.** Present these in a factual, not a judgemental, way, e.g. 'If a person hasn't had enough to eat it is difficult for them to concentrate' rather than 'You can't concentrate because you don't eat enough'.
- **Discuss possible plans of action**, i.e. what they could do. If you're anything like me you'll be desperate for your son or daughter to agree to x, y and z and sign on the dotted line, but it is essential that the decision is theirs, and in their own time. It really is a moment to stay calm and patient.

#### **Our loved one is having trouble sleeping, is there anything we can do to help?**

This is a common question because an eating disorder (lack of food, too much food) affect sleeping patterns. High levels of anxiety also disrupt sleeping. The group made a number of suggestions:

- Weighted blankets were mentioned by several as being helpful.
- The NHS has some very useful advice <https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/>.

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**22 February 2022 – Big questions, Challenging topics**

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- Not napping during the day, a regular bed time and getting up time and avoiding caffeine after midday were also mentioned as having been helpful.
- Sarah provided the attached document 'Sleep Hygiene', which is full of advice and tips.

**A number of challenging topics:**

We also discussed a number of challenging topics:

**Medical Monitoring:**

Sarah reminded us that carers are not responsible for managing the physical risk of loved ones and where necessary, medical monitoring provides that medical 'safety net'. We have to hand over the responsibility. More on this topic can be found in the FAQ on the Keep Your Head website <https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder>

*We are worried that our loved one might be slipping backwards but they do not talk to us about their weight, or monitoring results - what can we do?*

Which for those of you new to the group is where (anonymously) our discussions are written up as FAQs and advice for other carers.

**Relapse:**

It is not unusual for our loved ones who have been poorly enough to need inpatient treatment to have one or more readmissions. This is an intensely worrying time for carers - I think it was my most worrying time - so it is really important to hang on to the fact that the vast majority of our loved ones do still recover; the time has to be right. Kxxxx gave us a wonderful example why we must never give up hope by telling us about her son's recovery following eight admissions in as many years. He is doing really well since his last discharge, something has clicked into place and he is reconnecting with old friends, socialising with work colleagues and 'coming back to his normal personality'. He still needs support but it is a different sort of support. Kxxxx's message was 'hang in there'. It is so important to look after yourself to avoid going into a tail spin, and if our loved one is readmitted we must use it as an opportunity to recharge our batteries while they are being cared for by others.

**Support at Higher Education Institutions:**

A number of our loved ones are currently struggling at university. Several of the group reminded us of the support that is increasingly available to students. At a previous meeting, Rxxxx described the process for getting additional support: 'Selecting the 'disability' option when applying for student finance via SFE was the hard part. It took some persuasion to convince our daughter that she deserved this help. Supported by a doctor's letter, SFE awarded her a grant. Next step was an assessment of her needs via a Teams call and those people were excellent, fully understanding of her lack of confidence, etc. A parent/ carer can do this on their behalf if needed. In our case, she was provided with a new laptop, a microphone to record lectures and 'MindView 8' mind mapping software. She uses it mainly



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**22 February 2022 – Big questions, Challenging topics**

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for note taking and loves it. Also allocated a mentor to chat to for 1 hour per fortnight.' We can't make our loved ones access this support, but we can encourage and help them; the hard part for us as carers is that at the end of the day it has to be their decision. Rxxxxx told us about the plethora of 'health coaches' who advertise on Instagram, something else for us to know about. Rxxxxx has helped her daughter find a more appropriate health psychologist - as ever, do let me know if you have any recommendations, it can be a bit of a mine field.

**We also, briefly, touched on two other issues:**

Opening up to foods our loved one used to enjoy, and reassurance seeking. There is information about both of these topics on the Keep Your Head website under these FAQs:

*There are foods our loved one really enjoys but they just can't bring themselves to buy and/or eat them - how can I help?*

and

*Our loved one keeps asking for reassurance – what should we say?*

**Resources****Live Well**

<https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/> .

**Sleep Hygiene**



# sleep hygiene

## What is Sleep Hygiene?

'Sleep hygiene' is the term used to describe good sleep habits. Considerable research has gone into developing a set of guidelines and tips which are designed to enhance good sleeping, and there is much evidence to suggest that these strategies can provide long-term solutions to sleep difficulties.

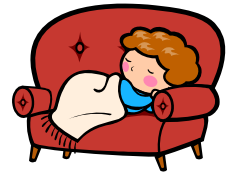
There are many medications which are used to treat insomnia, but these tend to be only effective in the short-term. Ongoing use of sleeping pills may lead to dependence and interfere with developing good sleep habits independent of medication, thereby prolonging sleep difficulties. Talk to your health professional about what is right for you, but we recommend good sleep hygiene as an important part of treating insomnia, either with other strategies such as medication or cognitive therapy or alone.

## Sleep Hygiene Tips

- 1) **Get regular.** One of the best ways to train your body to sleep well is to go to bed and get up at more or less the same time every day, even on weekends and days off! This regular rhythm will make you feel better and will give your body something to work from.
- 2) **Sleep when sleepy.** Only try to sleep when you actually feel tired or sleepy, rather than spending too much time awake in bed.
- 3) **Get up & try again.** If you haven't been able to get to sleep after about 20 minutes or more, get up and do something calming or boring until you feel sleepy, then return to bed and try again. Sit quietly on the couch with the lights off (bright light will tell your brain that it is time to wake up), or read something boring like the phone book. Avoid doing anything that is too stimulating or interesting, as this will wake you up even more.
- 4) **Avoid caffeine & nicotine.** It is best to avoid consuming any caffeine (in coffee, tea, cola drinks, chocolate, and some medications) or nicotine (cigarettes) for at least 4-6 hours before going to bed. These substances act as stimulants and interfere with the ability to fall asleep.
- 5) **Avoid alcohol.** It is also best to avoid alcohol for at least 4-6 hours before going to bed. Many people believe that alcohol is relaxing and helps them to get to sleep at first, but it actually interrupts the quality of sleep.
- 6) **Bed is for sleeping.** Try not to use your bed for anything other than sleeping and sex, so that your body comes to associate bed with sleep. If you use bed as a place to watch TV, eat, read, work on your laptop, pay bills, and other things, your body will not learn this connection.



- 7) **No naps.** It is best to avoid taking naps during the day, to make sure that you are tired at bedtime. If you can't make it through the day without a nap, make sure it is for less than an hour and before 3pm.
- 8) **Sleep rituals.** You can develop your own rituals of things to remind your body that it is time to sleep - some people find it useful to do relaxing stretches or breathing exercises for 15 minutes before bed each night, or sit calmly with a cup of caffeine-free tea.
- 9) **Bathtime.** Having a hot bath 1-2 hours before bedtime can be useful, as it will raise your body temperature, causing you to feel sleepy as your body temperature drops again. Research shows that sleepiness is associated with a drop in body temperature.
- 10) **No clock-watching.** Many people who struggle with sleep tend to watch the clock too much. Frequently checking the clock during the night can wake you up (especially if you turn on the light to read the time) and reinforces negative thoughts such as "Oh no, look how late it is, I'll never get to sleep" or "it's so early, I have only slept for 5 hours, this is terrible."
- 11) **Use a sleep diary.** This worksheet can be a useful way of making sure you have the right facts about your sleep, rather than making assumptions. Because a diary involves watching the clock (see point 10) it is a good idea to only use it for two weeks to get an idea of what is going and then perhaps two months down the track to see how you are progressing.
- 12) **Exercise.** Regular exercise is a good idea to help with good sleep, but try not to do strenuous exercise in the 4 hours before bedtime. Morning walks are a great way to start the day feeling refreshed!
- 13) **Eat right.** A healthy, balanced diet will help you to sleep well, but timing is important. Some people find that a very empty stomach at bedtime is distracting, so it can be useful to have a light snack, but a heavy meal soon before bed can also interrupt sleep. Some people recommend a warm glass of milk, which contains tryptophan, which acts as a natural sleep inducer.
- 14) **The right space.** It is very important that your bed and bedroom are quiet and comfortable for sleeping. A cooler room with enough blankets to stay warm is best, and make sure you have curtains or an eyemask to block out early morning light and earplugs if there is noise outside your room.
- 15) **Keep daytime routine the same.** Even if you have a bad night sleep and are tired it is important that you try to keep your daytime activities the same as you had planned. That is, don't avoid activities because you feel tired. This can reinforce the insomnia.



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**1 March 2022 – Repeatedly asking the same question, MANTRA**

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**1 March 2022 – Repeatedly asking the same question, MANTRA****Medical Monitoring, Discharge from Inpatient, Top tips**

At this week's session we welcomed new members to the group, Jxxxxxx and Lxxxxx. We are really pleased that you have been able to join us and we hope you found the conversation helpful. As ever, we covered a wide range of topics and I have summarised some of the key points below.

**When our loved one repeatedly asks the same question**

The first issue we discussed was when our loved one repeatedly asks the same question, e.g. 'Do I look different?' when they start to regain weight. It is important not to ignore their questions but there is a real danger of falling into the reassurance trap, which is a very common way of over-accommodating the illness. It is understandable that we want to reassure our loved one that they are not fat, that it doesn't matter if they go out for a run etc. However, although this relieves their (and our) immediate anxiety it does not help in the long run. Ideally, discuss and agree what you will say with your loved one in a low stress moment. Possible responses, which show empathy and warmth, include,

- 'I can see you are really anxious, as we discussed it's not helpful for me to answer this question',
- 'I know you are really anxious, I know you can make the decision about this',
- 'I understand you are worried, you know the answer to that question'.

The anxiety will pass and they (and you) will get better at managing it. There is an FAQ about this topic on the Keep Your Head website, based on this group's previous discussions.

**Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA)**

One of the group raised a question about the Mantra group. Their loved one feels that they are being held back by the others because she is in a better state of health than they are. The group's experience evidenced how the response to different treatments is a very individual thing. One commented that their loved one felt motivated by being 'better' than the others. Two reported that their loved ones found group work difficult because they were constantly comparing themselves to the others - their advice was that they should talk to the group leader because, and Emma confirmed this, group work is not for everyone and it may be necessary, and possible, to arrange an alternative therapy. Our role as carer is to encourage our loved one to have this conversation.

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**1 March 2022 – Repeatedly asking the same question, MANTRA**

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**Medical Monitoring**

We talked last week about medical monitoring and this came up again this week in relation to 'waterloading'. Our loved ones may do this to weigh more and/or to depress hunger and appetite. One consequence is that this can seriously affect blood chemistry and a number of the group have had to take loved ones to A&E because this has shown up in monitoring results. Sarah recently reminded us that carers are not responsible for managing the physical risk of loved ones and where necessary, medical monitoring provides that medical 'safety net'; that we/they have been contacted shows that the system is working. However, any trip to A&E is traumatic and it is really important that we as carers look after ourselves - it's one of those times to draw on your support network, including this group.

**Discharge from Inpatient Treatment**

We also discussed our experiences of our loved one being discharged from inpatient treatment. The consensus was that 'losing weight' was very common, which can be very worrying for carers. It is a really important time to stay calm, keep the communication channels open and help your loved one to stay engaged with support (e.g. outpatient appointments, medical monitoring). Experience shows that this is part of recovery, which is more often than not a sequence of snakes and ladders. It can be especially hard when everyone is excited about your loved one's discharge, thinking, understandably, that they must be better... when you know how difficult things still are. BEAT's 'Friends and Family' booklet is worth giving to some 'key' people; it will help their understanding and response.

**Top Tips for new members**

And finally, for the new members of the group, here are the 'top tips' we came up with at a discussion earlier in the year; to be honest, I don't think they are just for 'newbies'!

- Look after yourself. (The need for this came through loud and strong this week, I think most of us are wanting the winter to be over. Some great suggestions were made, from Spa days to jigsaws - everyone needs something, that's our homework for this week!)
- Focus on your loved one's feelings, not food.
- You can't argue them out of it.
- Don't get downhearted if something goes wrong; recovery from an eating disorder is not linear, and if you make a mistake / say something wrong it's part of the learning process.
- Most people recover from their eating disorder, although it can take a lot longer than you ever imagined.
- You are not alone.

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**1 March 2022 – Repeatedly asking the same question, MANTRA**

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Next week is our monthly presentation, with a 18.30 start. I am delighted that Dr Rebecca Ellard (General Practitioner) will be talking to us about the GP perspective, and answering our questions. I look forward to 'seeing you' then.

**Resources****Web****Keep Your Head FAQ**

<https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder> .

*Our loved one keeps asking for reassurance – what should we say?*

**BEAT's 'Friends and Family' booklet**

<https://www.beateatingdisorders.org.uk/resource-index-page/guide-for-friends-family/>

## **8 March 2022 – Presentation -The GP's perspective Dr Rebecca Ellard GP**

This week was our monthly presentation and we warmly welcomed Dr Rebecca Ellard, GP clinical lead for the Adult Eating Disorder Service at CPFT to talk to us about the GP perspective, and to answer our questions.

Rebecca's role is a new one, created in April 2021; she is a practising GP who works 2.5 days a week for the Trust. The purpose of the role is to break down barriers between primary and secondary care, which she does in a variety of ways, e.g. running training and briefing sessions for GPs, liaising between the Service and GPs, preparing information leaflets and agreeing joint protocols and procedures, such as the arrangements for medical monitoring (see below). Rebecca also leads a helpline, a time every day when GPs can ring the Service to ask questions / discuss concerns. Other Trusts are showing great interest in this role and a few are appointing to similar posts, but CPFT is very much a trail blazer. We had a lot of questions! I've summarised some of the key points that Rebecca covered below.

### **Rebecca explained that GPs see very few patients with an eating disorder, even though referral rates have gone up.**

Consequently, there is a role for carers to play in providing information. This is especially true given the importance of early intervention and the reluctance many of our loved ones have to seek help. The question becomes how to do this without taking over and breaking trust?

- Ideally, you will be able to persuade your loved one to visit their GP, to request a 'double slot' and to allow you to accompany them so that you can help them describe how things are.
- The reality is that this might not be possible because your loved one does not want you involved and/or does not give consent for information to be shared. However, you can still contact the GP - ideally you should tell your loved one that you are going to - and provide the GP with information, although without your loved one's consent the GP will not be able to feed back to you, and the GP cannot, of course, force your loved one to attend the surgery.
- Even if your loved one wants you to help them you may find yourself having to dust off your assertiveness skills, e.g. to get a 'double slot' face to face appointment. Rebecca said it is OK for us to say 'this is what we want and need'. For example, if your loved one does not get on with a particular doctor, they/you can ask to see another one.

### **We asked a number of questions about medical monitoring.**

A new system is being rolled out across Cambridgeshire and Peterborough, which will mean much greater consistency. Up until now practice has varied from one GP surgery to another. High risk patients will be monitored at an eating disorder clinic (and occasionally at

**8 March 2022 – Presentation -The GP's perspective Dr Rebecca Ellard GP**

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home) while mild to moderate risk patients will be monitored at GP surgeries with the results being sent to the Service's medical monitoring team for evaluation. If there is any cause for concern, e.g. an aspect of blood chemistry that is significantly abnormal, the patient will be contacted. Transitions between home and university, or a move to a different part of the country, present a challenge to medical monitoring arrangements because systems vary, but Rebecca said that your loved one's community service should take the lead in making the arrangements for a smooth handover.

**We discussed the relationship between A&E, GPs and specialist services.**

Rebecca explained that a discharge summary is always sent to the GP when there has been an A&E admission. If our loved one has a diagnosed eating disorder there will be a plan on the system that A&E will have access to (if it is their local system). There are good links between the community service and the hospitals in Cambridgeshire and Peterborough but, of course, A&E is not the place where an eating disorder can be treated.

**Rebecca explained that eating disorders can be very difficult to diagnose, especially if there are co-morbidities, e.g. Obsessive Compulsive Disorder (OCD), depression or anxiety.**

More is being learnt about autism and eating disorders which is increasingly being seen as significant to diagnosis and treatment. Recent estimates suggest that 35% of people with an Eating Disorder have autism or high autistic traits. I have included an extract from the summary of Dr Pia Thiemann's presentation about autism and eating disorders from May 2021 for those new to the group; Pia identified a number of things that we as carers can helpfully do.

Thank you, Rebecca, from all of us for such an interesting and informative discussion, and for answering our questions so openly and honestly. We look forward to hearing how your role develops, and in the meantime have a wonderful maternity leave!

**Resource*****Extract from the summary of Dr Pia Thiemann's presentation about autism and eating disorders, 11th May 2021***

*There are many ways in which autism can lead to an eating disorder. Often the eating disorder is an attempt to cope with problems that are related to the autistic traits e.g. to cope with anxiety or to connect with others... 'If I was the right weight I would be able to fit in with the other girls'. In addition autistic traits fuel the eating disorder, e.g. sensory issues affect the consumption of food. In therapy it is important to get an understanding of the link between our loved one's autism and their eating disorder because it may not be obvious; for example, the 'classic' reason for not eating a sausage is that it contains too many calories but for our loved one on the autistic spectrum it may be a sensory issue, e.g. disliking the texture or an autistic rule was formed in the past.*

**8 March 2022 – Presentation -The GP's perspective Dr Rebecca Ellard GP**

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*Pia explained that we do not treat autism, it is the person. However, we can help them adapt to a predominant non autistic world and accept themselves. Pia noted that one of the characteristics of autism can be a special interest combined with high intelligence and this can be a really good asset to draw on when supporting them, e.g. our loved ones can learn to use it as an anchor to stay calm in otherwise overwhelming situations.*

Pia explained some things that we as carers can helpfully do:

- If we think autism might be an issue we should push for a test and diagnosis. Even if our loved one's score is slightly below the threshold treatment should be adapted to the individual. Without stepping in and taking over, we can be their champion to make sure this happens. Pia recommended the PEACE pathway website <https://peacepathway.org>.
- We can provide invaluable information to our loved one's therapist because we will be most aware of how they are accommodating their autistic traits. For example, we will know how they try to manage social interactions.
- We need to be aware of - and can take reassurance from, i.e. it's not us - the knowledge that some people with autism can be very spiky (yes, we have a new animal, the hedgehog, to add to our menagerie!). This makes it all the more important to have a range of 'keeping calm' strategies, which is also good modelling for them. Getting into a confrontation will not work, our loved one will simply shut down.
- It is also important for us to know that for most people with autism their treatment takes longer because of a range of factors, e.g. they may need more time to process information and/or to build trust and/or to learn how to control anxiety. This makes recovery an ultra-marathon, not just a marathon, so it is even more vital that we look after ourselves.



## **15 March 2022 – We're doing all the work, They can't see they're ill**

### **What weight is normal, Successes and 'green shoots'**

We had a good, in-depth discussion of some significant issues this week but the group also identified some successes and 'green shoots of recovery'; it's so important not to lose sight of these because although recovery is the most likely outcome for our loved ones it can take a long time and is unlikely to be a smooth process. I have summarised some of the key points below.

### **'We're doing all the work, and it doesn't seem to be making a difference'**

We discussed a situation that most of us are familiar with: 'We're doing all the work, and it doesn't seem to be making a difference'. This is exhausting, physically and emotionally, and does not help our loved one in the long run. At the heart of this issue is the risk of 'enabling and accommodating' the illness. For those new to the group, and as a reminder to all of us, I've attached the presentation Sarah gave about this last August, and here are some of the key points from the discussion we had then:

- Some adaptation to the eating disorder is inevitable but too much may inadvertently maintain our loved one's illness.
- We all had examples of accommodation/enabling behaviours. Sarah used the phrase 'it's understandable and forgivable' because as parent/carers why wouldn't we want to alleviate our loved one's distress?
- However, it is all too easy to fall into the 'Eating Disorder Trap' (see slide 4); in the short-term we alleviate distress but in the long-term we help to maintain the illness because our loved one does not have to face up to it.
- There are things we can do as parent/carers to avoid this trap and to help our loved one's recovery - it's not easy and the communication / dolphin skills need to be in place first.
- The 'Four Steps to Change' (slide 10) is a really good framework for thinking about how to approach stepping out of the eating disorder trap.
- Discussion and preparation is really important - accommodating behaviours cannot be changed overnight, indeed our loved one could feel that they were being rejected, which would be counter-productive. A gradual process rather than jumping off a cliff edge is likely to be more successful.
- As part of your discussion 'naming the problem' is really helpful. Joint problem-solving is also helpful, which could include other family members.
- Remember that this is about your behaviour, which you can control, it's not about telling your loved one what to do.
- Be alert to opportunities, e.g. a move away from home is an opportunity to change behaviours and establish new routines.

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**15 March 2022 – We're doing all the work, They can't see they're ill**

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- The aim is for our loved ones to be responsible for their own health. It is important to respect their choices as they take on that responsibility, even if we can think of 'better' choices - learning from mistakes is part of the recovery process.

**Our loved ones not seeing that they are ill, and having a distorted body image**

We talked about our loved ones not seeing that they are ill, and having a distorted body image. The group's experience is that the move from 'pre-contemplation', when our loved one is not ready to think about changing their behaviour, to 'contemplation' when they are beginning to think about changes that will lead to recovery, is generally a very gradual one. We can help by giving feedback about their health (factual information, not judgements), keeping up a conversation about non-Eating Disorder related subjects so that our relationship is not defined solely by the eating disorder, and by looking after ourselves. Giving advice when it is not wanted and/or getting into a conflict is not helpful. Sarah explained that body image distortion is one of the last things to change in recovery. There are things that we can do to help, e.g. by opening up a conversation in a calm moment to allow them (and help them) to express their feelings, by validating their feelings and by asking how we might be able to support.

**What weight is normal**

We also discussed what weight is normal, and what is healthy. Sarah explained that a normal weight varies but that on the whole it will be a BMI between 20-25. An individual's own 'set point' or health weight range is likely to lie in this BMI range but will depend upon a range of factors, e.g. their weight pre-illness and their body's metabolic rate. With regard to what weight is high risk, weight is not the only risk factor we consider, e.g. blood results, blood pressure, body temperature, tests of muscle strength are all taken into account.

**Successes and 'green shoots'**

It was great to hear about some of those successes and 'green shoots'. A special 'call out' for Fxxxx's daughter for giving a big presentation at university, despite being anxious and being given the opportunity to postpone it; and to Fxxxx on your calm, caring long-distance telephone and text support. And it was really good to hear about your new job and the 2012 project finally being published, Ben; and all that you are doing to support your wife and children.

**Resources**

I have added some attachments with information about initiatives that some of you might like to get involved with.

**The Family Ambassadors Programme** is an NHS England initiative, they are looking for Parents and Carers who have had children or Young people in Mental Health Tier 4 inpatient settings in the last 24 months.

**15 March 2022 – We're doing all the work, They can't see they're ill**

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**Learning About Recovery** is a free six week online course for carers led by Dr Joanna Fox at Anglia Ruskin University; I am aware of at least one of our group who has attended this and gave it very positive feedback.

**Presentation – Enabling and Accommodating**

09/03/2022

# Support Empower Partnership

## Family Ambassadors East of England

The Family Ambassador supports families and carers navigate Health Social Care and Education services, while their child is in a T4 CAMHS Services and enable them to be 'Parents as Partners' in their Children and Young People (CYP) healthcare needs.

The Family Ambassador will champion 'Parents as Partners' with an understanding of the benefits this brings. Parents and carers have a unique perspective on the care needs of their young people and should be embraced as part of the decision-making team with the young person at the heart of the pathway.

The Family Ambassador will assist in improving communication between families and clinical teams. They will provide information and build relationships to support families to be part of the care team. **The Family Ambassadors do not get involved in the clinical process but provide families/carers with the information they need to better understand what happens when their child is admitted to an inpatient mental health unit.** This in turn will provide families/carers with an improved understanding of the system and processes that take place so they can be confidently involved in the processes that follow. They will also act as a source of support to families and carers whilst their Child is in the unit.

They will work alongside clinical teams in the units to support them to build pathways and opportunities to ensure parents and families are treated as partners.

They will provide learning and development opportunities for clinical staff to help them engage, understand and empathise with families and carers through a shared vision of understanding trauma, recognising family/carer needs and active listening.

In the first instance if you would like to talk to someone please contact:

Tracy Thompson

07783818339

[t.thompson12@nhs.net](mailto:t.thompson12@nhs.net)

# Support Empower Partnership

## Support Empower Partnership

### Family Ambassador East of England Focus Group.

We are looking for Parents and Carers who have had children or Young people in Mental Health Tier 4 inpatient settings in the last 24 months.

We want to hear from you, listen to your story and ask you to help shape a service for Families and Carers to feel more supported, empowered and working in partnership with medical teams.

We need your experiences to build a service that YOU would find useful.

In the first Instance please contact:

Tracy Thompson

07783818339

[t.thompson12@nhs.net](mailto:t.thompson12@nhs.net)

## Support Empower Partnership

Are you an **unpaid carer**, over 18-years-old, supporting someone who experiences mental ill-health?



# Learning about recovery: its impact on the caring process

Are you an unpaid carer, over 18-years-old, supporting a family member, friend, or neighbour who experiences mental ill-health? Would you like to attend a free course which focuses on teaching about the recovery concept by combining both virtual face-to-face and independent online learning?


By recovery, we mean that the service user can live a life of purpose despite having a mental health condition. The programme forms part of a research project, undertaken by Dr Joanna Fox at Anglia Ruskin University, to evaluate its effectiveness. Participation in the course may help you to care more effectively and to understand the experiences of the person you care for better.

**To be eligible:** Priority will be given to those attending this course for the first time. You will need access to an internet connection to enable you to take part in the programme. The person you support should experience a serious mental illness such as psychosis, schizophrenia or bi-polar disorder (but not forms of dementia). The person may/may not have a diagnosis or may/may not be accessing services. **You would be expected to attend all the sessions and complete an online questionnaire before and after participation to evaluate the course.** You will be provided with an information sheet and asked to sign a consent form to give your permission to participate in the research.

All sessions will be delivered online. Sessions 1, 3 and 5 will take place via face-to-face virtual teaching and sessions 2 and 4 will be completed as independent online learning in your own time.


Introductory session and meet your peers and teachers online	Monday 25 April 2022, 6.30pm–7.30pm
Session 1: Introduction to recovery	Wednesday 27 April 2022, 6.30pm–8.30pm
Session 2: Carers assessment and recovery	Completed online.
Session 3: A carer's own journey of recovery	Wednesday 11 May 2022, 6.30pm–8.30pm
Session 4: Mental health services and recovery	Completed online
Session 5: The carer's and service user's journey	Wednesday 25 May 2022, 6.30pm–8.30pm

For further information please contact:  
Dr Joanna Fox, Anglia Ruskin University.  
E: [Joanna.Fox@aru.ac.uk](mailto:Joanna.Fox@aru.ac.uk) T. 01223 698939

  
Cambridgeshire and  
Peterborough  
NHS Foundation Trust

# Stepping out of Eating Disorder traps: accommodating and enabling caring behaviours

Dr Sarah Beglin  
Consultant Clinical Psychologist  
Carers group – 10.8.21



A member of Cambridge University Health Partners



## Before and after....

- Can you remember life before the eating disorder?
- In what way has life changed for you and for the family since the eating disorder arrived? What do you do more of? What do you do less of?



## Examples of accommodation/enabling behaviours

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'I drive across town to Waitrose because she will only eat their organic rye crackers'

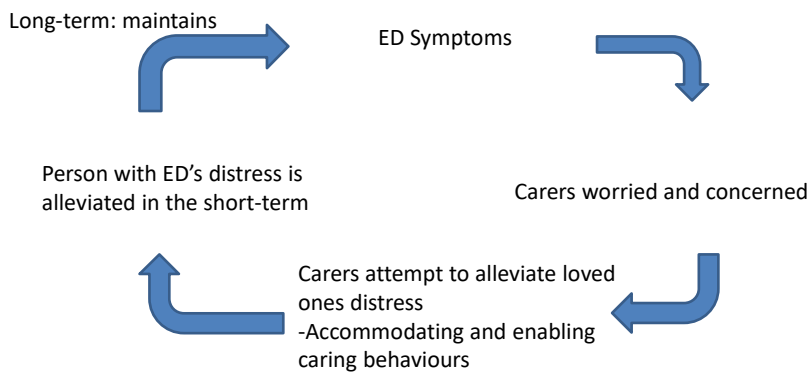
'I have been doing all his washing since he became ill'

'She takes over the kitchen for hours each evening and we are not allowed to go in'

'We haven't been away on a break for years. We don't dare leave him alone'

'We tell her 50 times a day she isn't fat'

## Eating Disorder Traps



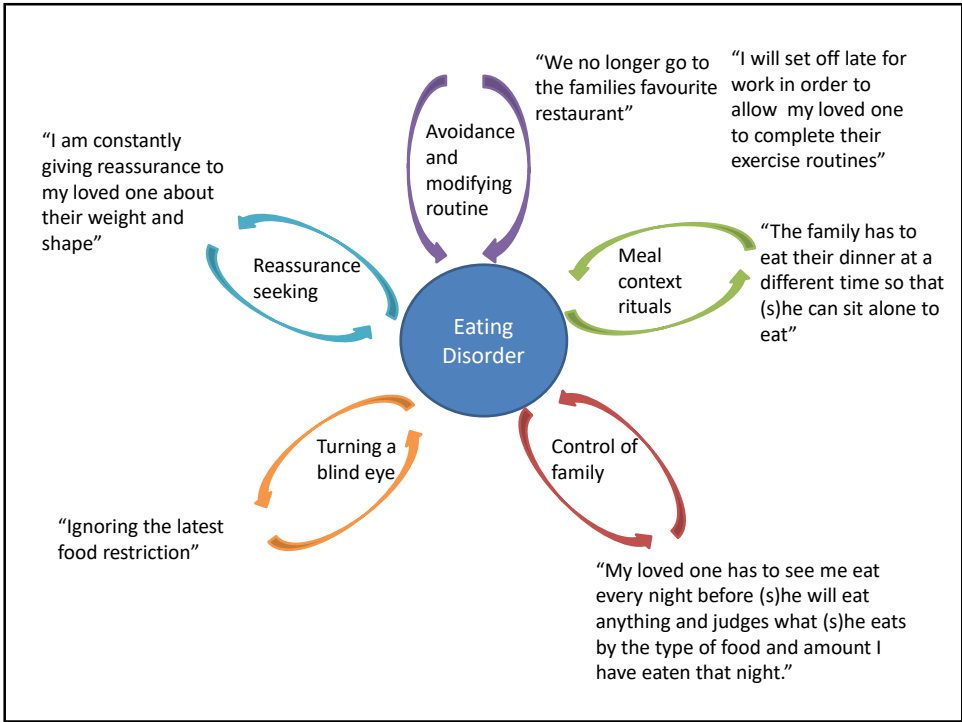
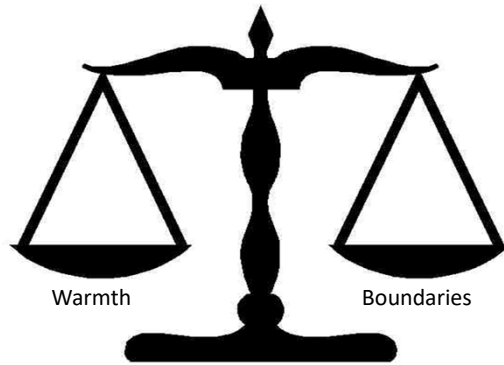
## Ways in which the family responds to eating disorder


- Family adapt around eating disorder
- Invasion/disruption of family routines and rituals
- Change in distribution of time, care, energy (others lose out)
- Narrowing focus of time
- Patterns of family interactions restricted
- Central role of symptoms in family life
- Family habituates to 'new' life
- Loss of agency (feelings of helplessness)

## What can we do to help?



# Before we start... Getting the balance right





**PLEASE  
DO NOT  
FEED  
THE  
FEARS**

## Barriers to change?

What might be some of your fears or anxieties about stepping out of the eating disorder traps?

## Steps to change

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<p>Self care all the way (Nod to Anne)</p>	<p>Recognising the traps you are in and the fears you have about changing</p>
<p>Discuss the changes you would like to make with your loved one when you are both calm</p>	<p>Use dolphin skills – E-OARS</p> <ul style="list-style-type: none"><li>• Empathy</li><li>• Open Questions</li><li>• Affirmations</li><li>• Reflections</li><li>• Summarizing</li></ul>

## Tips for stepping out of ED traps

- Accept and acknowledge that change is challenging but that new habits can be established
- Any new approach requires the whole family to 'buy in'
- Recognize possible barriers/ roadblocks to change
- Present the problem – clearly. Ask for loved ones help in generating the solution
- Develop an agreed plan – number of stages if necessary
- Change is likely to be slow
- Treat each stage as an experiment
- Consider communication on an ongoing basis (eg family notebook/regular meeting)
- Aim for a consistent assertive approach
- Recognise behaviours might get worse before they get better
- A new approach takes courage, trust and commitment

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**22 March 2022 – What if ... we step back and it doesn't work?**

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**22 March 2022 – What if ... we step back and it doesn't work?****Concern when loved one home from uni, Siblings distorted notions about food, How to approach someone who may have an ED**

This week we welcomed Sxxxxxx to her first meeting, we are really pleased that you are able to join us and we hope that you found the conversation supportive. We discussed our usual wide range of questions, and I have summarised some of the key points below.

**What if ... we step back and it doesn't work?**

(For example, from attending our loved one's college, or place of work, to support them at lunch time)

This is such an understandable anxiety because none of us want our loved one's progress to falter, but at the same time we know that 'doing it for them' is neither helpful to their long-term recovery, nor sustainable for us. The group's experience was very much that we should step back, with plenty of discussion and planning. There doesn't have to be a Plan B - if it doesn't work, learn from it, wait and try again. There might be a half way house to step back to, e.g. some of the group have used video calls, for company and support, as a stepping stone from 'being there', to 'not being there'.

**Do you feel nervous when your loved one comes home from university?**

Yes! Our loved ones change while they are away and many of us have found doing the right thing difficult. The question I always try to ask myself is 'What would a good St Bernard, and a good dolphin do?', i.e. stay calm, and encourage - don't panic, smother or charge in. The group's view was that, in practice, this means validation, affirmation and opening up a conversation: 'It's lovely that you are home, you've shown incredible determination to get through a really tough term. Do let me know if there is anything I can do to help. It would be great if we could do some planning together'. It's also important to be honest about how we're feeling - they won't necessarily know the pressures that we've been under, or our concerns.

**Siblings distorted notions about food**

Our eldest daughter's treatment is going quite well but we are concerned that our younger daughter is starting to have distorted notions around food: what should we do?

This is a common question and is part of the wider issue about support for siblings (see Keep Your Head FAQ - How can we best support our loved one's siblings?). The group was unanimous - it's really important to raise your concerns. Eating disorders are a secretive illness and in the early days our loved ones may be very reluctant to admit that they have a problem. It's vital to raise your concerns in a way that they will land best with your loved one, and you know them best.

'I might have got this really wrong, but I need to ask you about how you are feeling.'

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**22 March 2022 – What if ... we step back and it doesn't work?**

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'It's probably just me but I have been worried because.....'

BEAT's Guide for Friends and Families has some helpful advice and I've pasted the key points at the end of this summary.

**A few to follow up:**

- Txxxx recommended 'A Cognitive-Interpersonal Therapy Workbook for Treating Anorexia Nervosa: The Maudsley Model' by Janet Treasure, Helen Startup and Ulrike Schmidt. Chloe explained that this is recommended as part of the MANTRA pathway, (Maudsley Model of Anorexia Nervosa Treatment for Adults), that some of our loved ones are on.
- Harriet Frew's podcasts <https://harrietfrew.podbean.com> were also recommended. Harriet spoke to us recently about social media, we must ask her back! We also briefly touched on bulimia - this is certainly a topic we should come back to. In the meantime, this is the link to the video I mentioned that we looked at back in May 2021 about Susannah Laing's recovery from bulimia, which the group found really helpful [https://www.youtube.com/watch?v=3Q76l\\_4lDsA](https://www.youtube.com/watch?v=3Q76l_4lDsA).
- For those of you new to the group, the key text we recommend is: 'Skills-based Caring for a Loved One with an Eating Disorder' by Janet Treasure, Grainne Smith and Anna Crane. Routledge. ISBN 978-1-138-82663-2. 2nd Edition.
- And finally, the importance of looking after ourselves came through loud and clear: there were some good examples - walking, drinking a bit of wine (or apple juice), gardening, joining a choir, putting your feet up with a nice cup of tea - whatever it is, do something that helps your wellbeing.

Next Tuesday is a 'fifth Tuesday of the month' (it caught me by surprise) so that means it is a 18.30 Discussion Group session. I look forward to another good discussion then.

**Resources****How can I approach someone I think has an eating disorder?**

- Think about what you want to say and make sure you feel informed. Reading this booklet is a good start. You could also look at the information on our website.
- Choose a place where you both feel safe and won't be disturbed. If you're one of several people who have felt concerned, don't talk to the person together as they may feel you're ambushing them. Decide who they are most likely to open up to.
- Choose a time when neither of you feels angry or upset. Avoid any time just before or after meals.
- Have some information with you that you can refer to if you're able to. You could share it with them, or leave it with them to look at by themselves.

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**22 March 2022 – What if ... we step back and it doesn't work?**

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- Try not to centre the conversation around food and/or weight. While it may be necessary to bring this up to explain why you're worried, these may be things they're particularly sensitive about. At their roots, eating disorders are about what the person is feeling rather than how they're treating food.
- Mention things that have concerned you, but try to avoid listing too many things as they may feel like they have been "watched".
- Try not to back them into a corner or use language that could feel accusatory. "I wondered if you'd like to talk about how you're feeling" is a gentler approach than "You need to get help", for example.
- They may be angry and defensive. Try to avoid getting angry in response, and don't be disheartened or put off. Reassure them that you'll be there when they're ready, and that your concern is their wellbeing.
- Don't wait too long before approaching them again. It might feel even harder than the first conversation, especially if they didn't react well, but if you're still worried, keeping quiet about it won't help. Remember, eating disorders thrive on secrecy.
- If they acknowledge that they need help, encourage them to seek it as quickly as possible. Offer to go with them to the GP if they would find that helpful.
- If they tell you there's nothing wrong, even if they seem convincing, keep an eye on them and keep in mind that they may be ill even if they don't realise it. Denial that there's a problem is common – in the case of anorexia, it's considered a symptom of the illness. You were worried for a reason, so trust your judgment.

**Web****Keep Your Head FAQ**

<https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder>

*How can we best support our loved one's siblings?*

**BEAT's Guide for Friends and Families has some helpful advice**

<https://beat.contentfiles.net/media/documents/beat-carers-booklet-1.pdf>



## **29 March 2022 –GP reports blood tests are a concern, Doing it right, Bulimia**

We began this week by welcoming Lily, who has recently joined the eating disorders service as a mental health practitioner, and thanking Emma for coming to the group. We discussed our usual wide range of questions. Some of the group are having a really tough time of it at the moment, hopefully this summary is a helpful reminder of the support the group's lived experience provided.

### **The GP surgery has rung up to say that our daughter's blood tests are a concern - should we be worried?**

This is a common experience and shows that the system is working properly; in that sense it should alleviate anxiety because it shows that the right people are doing the right things to keep our loved ones safe. Of more significance is 'why?' and 'what needs to be done as a result?' Our loved ones may or may not share this information with us - being there and being ready to act if required is the important thing. For example, one member of the group was instructed to take their loved one direct to A&E - worrying, yes, but a clear sign that the problem was being dealt with. If your loved one says something that doesn't sound quite right, e.g. 'Of course my blood tests were bad, I'd been told not to have breakfast beforehand,' be gently curious - who told you, what did they say? - and encourage them to check their understanding with the surgery. Emma was categorical that this is not the advice that would be given, and that something to eat and drink is important.

### **Doing it right**

Rxxxx shared an example of 'doing it right'. Her daughter (who lives nearby) doesn't like her going away, has a melt down and texts constantly. Rxxxx asked three good friends if they would be happy for her daughter to have their number if she needed support, which they agreed to. She then validated her daughter's concerns and offered a solution - 'I realise that this is really hard for you and I am going to put something in place'. Rxxxx gave her daughter the telephone numbers, went on her break and had a really good time. Her daughter didn't panic and all was well. Well done, Rxxxx! You can see how this response was different to a 'rhino' response (I'm going anyway), or a kangaroo response (I'm not going). It was a grade A\* dolphin response - warm, encouraging and supportive. 🐬🐬🐬.

### **Bulimia nervosa**

The loved ones of most of the carers in the group are being treated for anorexia nervosa (trying to control your weight by not eating enough food, exercising too much, or doing both) but some are being treated for bulimia nervosa (losing control over how much you eat and then taking drastic action to not put on weight). We discussed the group's experience of bulimia and the general conclusion was that the similarities with other eating disorders are greater than the differences. For example, anorexia and bulimia are both about great distress and as parent/carers it is important to focus on that rather than how it's

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**29 March 2022 –GP reports blood tests are a concern, Doing it right, Bulimia**

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manifested. As with other eating disorders, our loved ones can be very secretive. At a previous meeting, Sarah noted that about 50% of people with anorexia binge eat and that eating disorders can be considered to be transdiagnostic, i.e. they can move around the categories, so this is something we should all be aware of. There are, of course, differences, e.g. our loved ones feeling 'good' about anorexia but 'disgusted' about bulimia.

We have also discussed boundaries in relation to bulimia (and binge eating disorder - eating large portions of food until you feel uncomfortably full), and in particular the really difficult issue of our loved ones sometimes eating pretty much everything in the house. We know from bitter experience that confrontation does not work. Sometimes tempers flare - we are human after all - and we should not beat ourselves up about this; it will be possible to recover the situation when everyone has calmed down. It is important to raise the issue, choosing a calm moment. We can say 'no' whilst still being sympathetic; it is our house and food and we can (and should) have boundaries. We need to be assertive, saying how we feel and stating calmly what the boundaries are, and why; all the while recognising, and empathising with, the challenge our loved one is facing.

**Is it normal for someone with anorexia nervosa to eat and eat at the end of the day?**

Is it normal for someone with anorexia nervosa to eat and eat at the end of the day? is another common question. The short answer is that it is not unusual - as I've noted above 50% of people with anorexia nervosa binge. When we talked about this back in November, Sarah reminded us that our loved ones are deliberately mastering hunger all day and that perhaps it is not surprising that at the end of the day, when our loved one is really tired, their resolve cracks and they can't stop themselves. It's great if they can talk to you about this. Be curious - try to understand (and help them to understand) their feelings. For example, there might be an opportunity to raise some 'pros' and 'cons': 'On the one hand you feel guilty about eating loads before you go to bed and on the other you are not eating as much as you would like to during the day'.

**Waiting for an inpatient place**

One of the hardest times for carers is when our loved one is waiting for an inpatient place to become available. By definition, they are very poorly. We desperately want to help but feel powerless to do so. Lily reminded us that just being there is supportive, and we know from when Amy and Ana spoke to us about their recovery journeys how much they valued 'unconditional love' - being there and listening, and being non-judgemental, even if they didn't say so at the time. It's a reminder that this illness has many ups and downs and it is definitely a time to 'hang in there' - getting support and looking after yourself.

And finally, Ann reminded us that 19th April is the second anniversary of this online support group, and invited ideas for how we should celebrate it! In the meantime, our meeting next week is a '16.30 Support Group Discussion', I look forward to seeing many of you there.

## 5 April 2022 – Calories on menus, Discharge from CEDS, Avoidance

### 'Every mistake is a treasure', Binging at the end of the day

#### Calories

We began this week by hearing from lxxxx about the letter her daughter has had published in the Guardian about the new legislation requiring calories to be displayed on menus. It is an excellent letter - clear, well-argued and succinct - and a really valuable contribution to this important debate. Here is a link to the letter

<https://www.theguardian.com/society/2022/apr/04/calories-on-menus-will-do-more-harm-than-good> ,

you can see why they published it! lxxxx, congratulations to your daughter and it is really positive that she is engaged in this way.

#### Discharge from CEDS losing weight and motivation: what should I do?

Our loved one has been discharged from Community Eating Disorders Service but they are starting to lose a bit of weight and seem to have lost motivation: what should I do? The group's consensus was that 'losing weight' was very common following any discharge, which is understandably concerning for carers. It is a really important time to stay calm, keep the lines of communication open and encourage your loved one to stay engaged with any support that was part of their discharge plan (e.g. outpatient appointments, medical monitoring). We have heard from patients who have described their recovery journeys how much they have appreciated us simply being there - not stepping in with ideas but validating their experience, e.g. 'I guess it must be really hard for you'. In this way we normalise their fear; it really is helpful for them to know that they are not making it up. If possible, open up a conversation. It may be that there is something we could do to help, from reminding them that they've come through difficult patches in the past, to helping them access a therapist privately. As one carer found out it might be that they think they can get through it without help. This is when the good dolphin swims away but keeps a watchful eye in case their loved one get into more serious difficulties.

#### 'Every mistake is a treasure'

There were some good examples of 'every mistake is a treasure'. One that struck a chord with me was when you feel under pressure to be ready for the possibly rare moment when your loved one wants to talk to you... but that moment coincides with you being exhausted / rushed / distracted and you handle it badly.

Sarah reminded us that no-one gets it right all the time, even if you could define what 'right' is and that the important thing is that you return to the conversation if you thought it could have gone better and explain why. It is good modelling to say, 'I'm sorry, I was really tired and what I meant to say was...'

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**5 April 2022 – Calories on menus, Discharge from CEDS, Avoidance**

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**Binging at the end of the day**

We returned to the discussion we had last week about it not being uncommon for people with anorexia to binge, particularly at the end of the day, when they are really tired, their resolve cracks and they can't stop themselves. What can we do about this? We can't force our loved ones to change their behaviour, but we can help their motivation, e.g. with the 'EOARS' framework. The five components add up to 'good motivational communication'. They don't have to be in this order but they do all need to be in the mix. (This is also a very good structure for 'long distance' caring, on the phone in particular, because it makes you listen really hard.)

- **E - Empathy.** 'I can see how hard this is'.
- **O - Open questions.** 'What' and 'how' questions are better than 'why', which can sound critical.
- **A - Affirmations.** Praising to build confidence.
- **R - Reflective listening.** Demonstrating that you have understood by reflecting back to them what you've heard, e.g. 'So, it sounds to me as if...', 'Let me check I've understood correctly...', 'So, from your point of view...'
- **S - Summarise.** Pull the key points of the conversation together to make sense of the whole. Summaries don't have to be at the end.

**What if our loved one avoids doing things, like showering, because they are disgusted at how they look?**

This is a very common, and very complex, issue. Sarah explained that exposure therapy can help our loved ones have a more realistic view of themselves but this is a skilled process and something that therapists, rather than carers, would help with. Harriet Frew in her presentation about social media recommended:

<https://thebodypositive.org>

as a site that is good for body image, but with the proviso that it's a personal thing and that we should encourage our loved ones to seek out (positive) material that resonates most with them on their platform of choice.

This website, aimed at young people, includes some interesting and useful advice for friends and family about supporting a loved one who is anxious about body image:

<https://www.youngminds.org.uk/young-person/coping-with-life/body-image/#Howyoucansupportafriendstrugglingwithbodyimage>

And, as ever, we can help by opening up a conversation in a calm moment to allow them (and help them) to express their feelings, by validating their feelings and by asking how we might be able to support.

**5 April 2022 – Calories on menus, Discharge from CEDS, Avoidance**

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Next week is our monthly presentation. It's at 18.30 and is being given by Steph Casey on the subject of Perfectionism, one of the key topics we asked to hear about. I look forward to seeing you there.

**Resources****Web****Body image**

Body Positive <https://thebodypositive.org>

<https://www.youngminds.org.uk/young-person/coping-with-life/body-image/#Howyoucansupportafriendstrugglingwithbodyimage>

**12 April 2022 – Presentation – Perfectionism - Steph Casey**

This month's talk was an interesting and thought provoking presentation on 'Perfectionism' by Steph Casey, who is about to complete her training as a Clinical Psychologist. I have attached Steph's slides and here is a summary of some of the key points, and of our discussion.

- Perfectionism is complex and many faceted - you can see from slide 3 the large number of words we came up with in a very short space of time!
- Perfectionists may not only set themselves high standards but may also expect high standards from others.
- It can be considered a lifelong personality trait, i.e. it may be present before, during and after our loved one's illness.
- The evidence suggests that the cause is partly genetic (perhaps 30 - 40 per cent) and partly socio-environmental, e.g. a belief that family expectations, social media, and a culture of competitiveness and accountability requires us to be perfect to avoid harsh judgement and failure.
- There are some 'pros' to perfectionism, e.g. perfectionists may get excellent results at school and college, achieve their goals and do well at work.
- However, there are many more 'cons' and perfectionism is considered a vulnerability factor for a range of mental health conditions. 'Perfection' does not exist and continuing to strive for it can lead to stress, feelings of self-failure and burn out. Perfectionism can also lead to procrastination, e.g. putting off a job application because of a fear of rejection or failure, and then missing the application deadline.
- Perfectionism and eating disorders are commonly associated: slide 9 has some important information about this. It may have delayed our loved ones seeking help in the first place because this would mean going against expectations they have set themselves, e.g. about appearance.
- Steph explained that the underlying factors are low self-esteem and self-worth, and she described how clinical psychologists address perfectionism as part of our loved one's recovery (slides 10 and 11).

Steph identified developing self-compassion as an important way of addressing the 'cons' of perfectionism. Self-compassion exercises can help tune out the critical voice and turn up the compassionate voice, which is something that a lot of perfectionists can struggle with. She suggested that we should start with ourselves and for those of you who weren't at the presentation, slide 12 tells you how to do this! Have a go, it took me out of my comfort zone but helped me see how perfectionist traits could be 'dialled down'. The questions to ask yourself were particularly helpful, e.g. 'What do I need to hear to express kindness to myself?', or 'Is there a phrase that would help me to be compassionate about myself?' These are the questions our loved ones need to be able to ask and answer for themselves, so this is something we can support and encourage.

**12 April 2022 – Presentation – Perfectionism - Steph Casey**

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Some of the key points that came out of our discussion were:

- Conversations about perfectionism, and skills development, are for calm moments; if our loved one is in a stressed or fearful state they will not be receptive to developing self-compassion. But in a calm moment exploring, 'What if you didn't get the perfect grade?' would at the very least mean that you had introduced a conversation to model flexibility.
- Validation and affirmation are important ways we can help our loved ones address perfectionist traits. For example, 'I can see why it was so important to you to get that application right. You were really realistic about what you could include' (bold = the characteristic you want to encourage).
- As a life-long trait it is something that we may need to continue to support our loved ones with after recovery from their eating disorder.
- Modelling self-care is important, as is being aware of any perfectionist traits in your own character and their consequences.
- Being there and sitting with our loved ones as they experience negative emotion, without stepping in with solutions, can be very helpful. You may feel that you are not doing very much, but that is not the case. Helping them to name / articulate these emotions can be invaluable.
- A number of us noted that our loved ones can swing between extremes of 'perfectionism' and 'not caring at all'. Steph explained that the latter is a tactic to avoid failure, which is why the aim is to move people more towards the centre of a continuum between 'perfect' and 'worse than bad'.

Thank you, Steph, for an excellent presentation and we wish you all the best for the future!

# Perfectionism

Stephanie Casey  
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## What Is Good Enough?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10

Horrible    Bad    Below Average    Okay    Good    Excellent    Perfect



[www.menti.com](http://www.menti.com) and use the code 7738 8251

Go to [www.menti.com](http://www.menti.com) and use the code 7738 8251

## What is perfectionism?



## Perfectionism- what is it?

- Can be considered a lifelong personality trait
- Individuals may:
  - Set themselves very high standards
  - Expect high standards from others
  - Perceive others as having high expectations from them
  - Engage in certain behaviours despite them consistently having negative consequences

## How might perfectionism impact day to day life?

- In the workplace or at school
- Relationships
- Home life and environment
- Sports
- Physical appearance
- Health

## What causes perfectionism?



### **Genetics**



### **Environment**

- Societal and family expectations
- Social media
- Western culture and competitiveness
- Increase in accountability of mistakes



## Perfectionism and eating disorders

- Perfectionism is high across eating disorders, particularly in Anorexia and Bulimia
- A focus on eating may offer a sense of control with low self-esteem seen in perfectionism or when standards in other areas of life are not met
- Eating disorders may also present as an extreme expression of perfectionism in wanting to portray a perfect image to others
- The effect of starvation on the brain makes it much harder to think flexibly and can maintain difficulties
- Perfectionism is not only a vulnerability factor but also may maintain eating disordered thinking and behaviours

## Perfectionism and recovery from eating disorders

- Letting go of the perfect recovery
- Engaging in treatment means going against standards they have set themselves previously
- Engagement may also initially be “perfect”
- Set backs are normal and recovery looks different for everyone, there is no “perfect” recovery

## What can we do to manage perfectionism?

- Moving towards the middle of the continuum
- Recognising the downfalls and becoming more aware of expectations
- Recognising successes even when not “perfect”
- Developing self-compassion
- Positive self-talk

## Self-compassion exercise



Accepting uncomfortable emotions



Useful for when developing a compassionate voice and choosing to listen to this over our critical voice