

New Maudsley Skills Workshops for Carers

Capsule – Menu of Options around Meal Support for a 17 Year Old
Mention “meal support” to a group of carers of a loved one with a restrictive eating disorder and you are likely to be met with a collective sigh, groan, moan or even a tirade of terrible tales of woe, uneaten meals, broken plates, furious arguments and exhausted and depleted families.

There is no doubt that meal support is extremely hard! Carers do their absolute best when instructed by the eating disorder specialist team that they must take control and feed their child. The specialists will warn the family about the incredible risks that come if weight is not regained quickly and will reassure the carers “of course you know how to feed your child”. Of course, the carers do know how to feed their healthy hungry child, what they are not sure about is how to feed their child struggling with an incredibly complex mental and physical health disorder, in which there is a voice in the child’s head instructing them not to eat.

The level of support offered by the specialist eating disorder team also varies greatly. There may be a detailed meal plan or no meal plan. There may be supervised family meals, or in some cases a trained nurse might visit the family at home to help support the early stages of refeeding. More commonly the family is left to their own devices and are required to check in every week for the dreaded weekly weigh in. If their child has not gained the required ½ kg the family feels inadequate and disempowered by the ED.

Not only is the family expected to feed their child they are expected to deal with the trauma that the child gaining weight is likely to be experiencing. The approach is also “one size fits all” so the instruction to parents of a 12 year old are likely to be the same as those to parents of a 17 year old. Of course families often find that what worked last year or even last month, doesn’t work so well today simply because their child is growing up into a more independent young adult.

Having painted this awful picture of trauma and distress, I would like to remind readers that the power of families is incredible, and most families do get through this awful experience, with a great deal of grit, determination and unconditional love, and their loved ones emerge from their eating disorder able to eat a range of foods and ultimately to look after their own nutritional health.

In this short capsule we will consider different approaches that a family might take to support their loved one through a refeeding programme.

Let us consider this scenario:

Rachel is 17 and has been battling her anorexia for the past 18 months with the support of her mum Jane and dad David. Early on in her treatment Jane and David gave Rachel a great deal of support, preparing and supervising her meals including going to school every lunch time to support her to eat her lunch in the car. Whilst there were inevitable difficulties the family managed to find a good balance and Rachel stabilised her weight at around 50 - 51 kg for around six months. Ideally her weight will need increase a little more to regain full health, but the family were happy to acknowledge the huge progress that had been made to get this far. They also acknowledged that it is very common for weight to stabilise at a sub optimal level whilst the sufferer develops new more healthy coping strategies and so Jane and David were not too concerned.

Recently however, as Rachel has been pushing for more independence her weight has fallen sharply and she is now back at her lowest weight since developing anorexia. The family are struggling to find the right balance between allowing 17 year old Rachel to be responsible for her own destiny, or stepping back in and taking complete control. The family therapist at the eating disorder unit seems to be erring on the side of allowing Rachel more autonomy. An important part of treatment is allowing the sufferer to reach an appropriate level of adolescent maturation after all.

Jane feels they should let Rachel take full control. If it doesn't work out they can always step back in as parents and take over.

David feels they should step in and exercise total control over Rachel including taking away all her "anorexia driven " rituals including her favourite bowls and cutlery.

Having suggested to Rachel that these are the two options Rachel has pointed out that these are extreme polar opposites and that neither approach is helpful. It is often the case when carers are thinking about what the next options are that it seems like a black and white decision - option A or B. A third option (let's call it option C) is to change nothing and carry on and just wait and see what happens. This is rarely helpful, what is more helpful is to think of any possible options in between. If you can enlist your loved one with the eating disorder to contribute (or indeed any other family member) then that can be most productive.

Menu of Options

In one of our carer support groups we tried to come up with as many different options as possible:

- A) Jane feels they should let Rachel take full control.
- B) David feels they should step in and exercise total control over Rachel including taking away all her "anorexia driven " favourite bowls and cutlery.
- C) Carry on with a halfway house - the status quo
- D) Apply the principles of LESS is more, with the aim that things will calm down and then Rachel will get some of her past confidence back and be able to tolerate the distress of

gaining weight. Within this a first step would be to ask Rachel what she would find helpful. See example LESS is more below.

- E) Remind Rachel and rest of family of past successes
- F) Include siblings in the conversations, as they resented being left out in the past, ask them what they think might help
- G) Help Rachel to start to think about her future in a more positive way by identifying her own behavioural experiments. Remember to strike when the iron is cold
- H) Identify helpful mealtime distractions (watching TV). Create a list of other possible distractions - anything that can help quieten the ED voice
- I) Listen to Life Hurts audio book at mealtimes (story of a GP who battled her own anorexia and came out the other side)
- J) Identify other young adult buddies that might provide Rachel with motivation (Tabitha Farrar, Laura Hearn)
- K) Never talk about food, weight, shape issues at the meal table
- L) Recognise any progress even if it is tiny
- M) Always use Rachel's name at meal time so that Rachel knows you are really trying to support her as an ally against her bullying ED voice
- N) Develop Discrepancy - on the one hand we know you are excited about leaving home, going on holiday with your friends, going to university, and on the other hand you know that you weight is too low for you to be able to do these things
- O) Show Rachel you believe she has the strength of character to fight her ED voice - Rachel you know what you need to do, we believe you have the resources to do it. We are here to help.
- P) Remind Rachel of the science behind proper nutrition - Rachel your brain needs fuel and we know how much you want to do really well in your exams. Rachel remember what the nutritionist said about your brain needing oil to work properly. Rachel I read that you need to eat carbs to create serotonin in your brain. You need serotonin to feel happy. Answers to Anorexia by James Greenblatt can be useful.

Before reading on write down any other options you can think of that might work in your own family setting.

Let us imagine that Jane and David decide to put options A, B and C on the back burner for now. Instead they decide to try to work alongside Rachel so as to become her allies in her battle with her ED voice.

Looking at the other options they quickly decide that they are not mutually exclusive and so decide to adopt an approach that lets Rachel guide them in choosing helpful strategies.

As a first step they revisit the LESS is more approach and phrases that might be useful to help the family to become calmer and regain some of their past confidence.

A reminder : talking to your loved one using the principles of LESS is more

The concept of LESS is more conveys the spirit of our communication approach using motivational interviewing techniques. It provides a useful checklist when things seem to be going off track:

Listen; active and reflective listening without judgement

Empathy; Understanding with compassion (not sympathy/pity) Step in to Edi's (the sufferer's) shoes.

Share; non-eating disorder parts of life – the bigger picture

Support; providing a calm safe environment: The St. Bernard's unconditional love

is MORE

In simple terms less talking and more listening.

Learning:

The Less is more approach helps carers to let go of their natural "fixing" instinct. By listening more and talking less carers learn to curb their rhino and kangaroo caring responses. Instead carers allow their loved one to have a platform from which to experiment and to express what he or she wants, in a warm, non-judgemental and supportive environment.

Visualising a conversation between Jane and Rachel

Listen: Listening is fairly easy when Rachel is prepared to talk. Jane can use non-judgemental listening skills to reflect back what Rachel has said in a current or previous conversation.

Even in a situation in which Rachel is so agitated she is finding it difficult to talk, Jane can still make it clear that she cares and is interested to know how Rachel is feeling and what Jane can do to help. The concept of reflective listening means that you can notice what is going on even if Edi won't talk to you – "Rachel I notice you have gone very quiet and you

don't feel like talking. I would like to help, you know I am here for you. These are difficult times and things will be different for a while"

Empathy: "Rachel I can see you don't want to talk. I know this is really difficult for you. You made so much progress on gaining weight last year. With hindsight I realise how traumatic it was for you when your periods came back, and I can see you were relieved when they stopped as you lost weight again. I can see now that your ED voice was screaming at you about how fat you were, and the only way you could see to shut the voice up was to lose weight again. I am sorry I didn't recognise how difficult that was for you. I know that you want to be independent and make your own decisions and I am wondering if we should let you take more responsibility for your meals. You could show us you are ready to fight your own battles against the ED voice. I know it is really hard and we are here to help you. Let me know if you would like to try that."

Share in non eating disorder related parts of life: "Rachel let's make some plans for the next few months so that things seem easier and you have more certainty about what you want to do next so you have an idea of what the days look like. We could look at things you can do at home to help you feel more confident and also things you can do to increase your confidence about mixing with your friends at school and even eating lunch with them."

Support: "Rachel we love you unconditionally. We are here for you whatever happens. These are difficult times for you, we are a strong family and we have already come so far together. You have shown so much determination and courage to get this far and we are all here to support you through the rest of your recovery journey.."

Having tried the Less is more approach with Rachel, Jane and David may find that Rachel is much calmer, and more able to think about next steps. Rachel may be able to reflect on the progress she has already made.

The key step in any experiment is the review and reflect.

Giving Rachel More Responsibility

Let's assume that Rachel says she is not ready to take full responsibility and that she still would like her mum and dad to support her, but in a more age appropriate way for a 17 year old. She might have a conversation with her dad David along these lines:

Rachel : Dad I know you think that it would be easier for me if you just tell me what to do, and that you should just make me stop my mealtime rules and rituals. I just don't think that would work. It is too overbearing for me and I would find it too stressful.

David: Ok that is fine. Help me to understand what would be helpful. We talked with that new family therapist and I got the impression he believes you should be taking more responsibility. What would be helpful?

Rachel: Well first off, I know you hate my special crockery and cutlery but I need them at the moment. When I use them I feel so much calmer. It is like a security blanket. I won't always need them but I do need them at the moment.

David: No problem let's stick with the crockery and cutlery for now. I am interested to know if there are any other things that help you to be calmer. Let's think up some ideas together.

Rachel: Watching TV can really help.

David : That's ok - anything else?

Rachel ; Well there is something that isn't helpful. Don't take this the wrong way but I hate it when you and mum keep telling me to take one more bite. It used to work at the beginning. Now though, however calmly you say it, it just makes me mad. In fact, any talk about food at the dinner table makes me mad.

David: Fair enough. Thank you for explaining that. You know what mum and I are like, Creatures of habit. We wouldn't have worked that one out on our own

Imagine you are having this conversation with your 17 year old. It could go in a number of different directions. You could jointly write a list of helpful and not helpful things, or you could jointly create your own menu of options. The idea is that you are encouraging Rachel to take more and more responsibility whilst at the same time being there to guide her when things are not going according to plan.

In a worst- case scenario Rachel might find it is simply too difficult to gain weight with her parents watching over her. Her weight is likely to drop further and in this instance in patient treatment might be beneficial and can really help to kick start sustainable refeeding. This is what happened with my son. Once he had become accustomed to the refeeding programme in the unit, he was then able to carry on at home, very quickly taking more and more responsibility himself.

I have also known many 17 and 18 year olds who have been on the brink of being admitted to an in-patient unit, and then have drawn on their own resources as emerging young adults and managed to take responsibility for their own weight gain. Very often a peer type buddy can be helpful and many young people really connect with Tabitha Farrar and her recovery story.

Harry's Story

Harry was treated as an inpatient when he was 12 years old and regained weight and returned to school. However, his mum was worried that he hadn't really had any therapeutic support to build better coping strategies. The treatment had dealt with the physical medical emergency but not the psychological issues.

Sure enough, Harry had a dramatic relapse age 17 and the family had several terrifying emergency trips to A&E. It became clear that the NHS was unable to provide Harry with the support he needed so his mum decided to "look outside the box". She took Harry to see a very professorial nutritionist who talked to Harry about the science behind nutrition and

recommended a book *Answers to Anorexia* by James Greenblatt. The nutritionist suggested Harry should aim to gain 1 kg a month. His mum felt this was not enough but didn't say anything as she had learnt that Harry needed to be given some autonomy at the age of 17. She knew from experience she couldn't make him eat. Harry was very motivated by this more adult approach and was very interested about the science.

Harry agreed he would try to gain a kg a month, but he didn't want his mum to be standing over him. Instead his mum found a personal trainer who had recovered from anorexia. The personal trainer came every week to help Harry to write a meal plan. To start with this just included Harry's safe foods, very gradually new things were added in. Harry would then give his mum a shopping list. Harry took charge of making his own meals and with the personal trainers support he gained a kg a month for 40 months. Harry is now in his early twenties, is 6ft 4in and weighs over 80kg. He and his mum now train together in the gym with the personal trainer who has become a firm family friend.

Useful Videos Around Meal Support and the Challenges of Re-feeding

These videos might give you some more ideas for useful phrases and ideas to navigate the stormy seas of mealtimes and endless battles over the yoghurt or the pudding!

1. New Maudsley SUCCEED meal support video
I have just uploaded this to Youtube and you might find the attached meal support capsule useful (ignore reference to Clip one) <https://www.youtube.com/watch?v=9j3Ww6AA58Y>
2. Eva Musby has made a series of animated video clips that can help re-energise exhausted parents and give you some new ideas to try out. See her website <http://evamusby.co.uk/>. In particular this video is particularly helpful for parents who feel their child is stuck. "Stuck & not eating! Anorexia/restrictive eating disorders: parents' meal support tips by Eva Musby"
<https://www.youtube.com/watch?v=BVhKXh0gLGc&feature=youtu.be&list=PLVgyQbyKQSBHUbIDLlc7t3v7bN0ImLcve>
3. [KeltyMentalHealth](#) - Eating Disorders Meal Support: Helpful Approaches for Families
<https://www.youtube.com/watch?v=pPSLdUUITWE>
4. Laura Hill TED talk – eating disorders from the inside out
This one isn't about meal support per se but it really helps you understand the power of the eating disorder voice: <https://www.youtube.com/watch?v=UEysOExcwrE>

Remember our golden rule – never ever get drawn into endless discussions around food, weight and shape. You will not win that argument. The eating disorder voice will be louder than you are!

A young person with an eating disorder is more likely to respond best to a firm, clear but gentle and empathic approach. At times it can be difficult to be with a young person who is

struggling through a meal. It is essential to their progress however that they are made to feel safe however difficult it gets. Make up your own “broken record” phrases to use over and over and practice saying them calmly, even when you are feeling pretty desperate when at the table.

Summary

Less is more and the menu of options approach are among the many principles that we use in the Carer Skills Workshops. There are many more communication techniques such as OARS, ALVS, DEARS which many carers are already familiar with and you can download worksheets and watch videos on these from www.newmaudsleycarers-kent.co.uk The beauty of LESS is more is that it is a very simple easy to remember tool that can be used in any situation in which emotions are running high and/or things seem stuck.