

Collaborative Care New Maudsley Skills Workshops for Carers Additional Capsule - Addressing the Challenges of Returning to School

These workshop capsules have been created from scenarios considered in previous workshops and are designed to help carers to review and reflect on specific areas that can prove extremely difficult.

In this capsule we review and reflect on the challenges that carers often face when their loved one is returning to school after a period of absence. Eating disorders often emerge and/ or re-emerge at key times of transition and when stress levels are raised for whatever reason. In this capsule, we consider

- Contingency planning for returning to school
- A scenario in which Edi has started back to school but very quickly decides it is too tiring.
- A scenario in which a student profile proves really helpful
- Managing school lunch and communication about eating & exercise in school

Contingency Planning for Returning to School

Returning to school after a long period of absence can be a daunting experience and it is well worth spending the time to consider all aspects of being back in school. This might be due to treatment, or it might just be going back after the long Summer holidays.

Things that your loved one might be thinking/feeling:

- Fear of the unknown
- Fear of being judged
- Fear of being able to fit in
- Fear of failure

As carers it is important, we also acknowledge the joy and excitement that comes with going back to school. Getting my life back, seeing my friends, freedom, lots of joyful activities. Not being stuck at home with mum and dad.

From the caring perspective there is a balance between being protective (Kangaroo), emotional (Jellyfish), directive (Rhino) and the gentle nudging of the Dolphin and the calm compassion and unconditional love and support of the St Bernard. Reflecting on your caring response can be useful. If your current caring style is working, carry on that way. If things feel stuck and/or there is lots of tension think about small changes you might be able to make to give your loved one more autonomy so that they can naturally start to become more resilient.

Visualisation: It is well worth spending time with your loved one to consider all aspects of being back in school.

This might include (this is by no means an exhaustive list):

- Travelling to and from school
- Eating at school (especially if returning whilst in recovery from an eating disorder)
- Dealing with large numbers of students and adults at the same time
- Timetable management (is it realistic for the student to take part in the full timetable from day one?)
- Homework management (is extra time required, or reduced levels of homework?)
- Having to take time off for any reason (eg appointments)
- A free pass to take a break if anxiety levels are high
- A safe place to go if anxiety levels are high (eg student support)
- A buddy who will look out for the student (peer and/ or empathetic member of staff)
- One off events (eg a theatre group visiting the school and hosting a large noisy event)
- School trips (might be one day trips and/ or longer residential trips)
- PE (will the student be fit and comfortable to join in with all PE sessions?)
- PSHE (are there any subjects in which the student might feel overly sensitive or upset, or feel everyone is looking at them)
- Friendship issues (if a new school does the student find it difficult to make friends. If an existing school were there any friendship problems before the period of absence?)

It is also useful to make a list of specific things that might trigger a lapse or relapse for your loved one:

- Ongoing FEAR of weight gain/ being FAT
- COVID or other infectious illnesses sweeping through the school
- Unexpected events
- Disappointments
- Relationship breakdown
- Exam stress, any stress
- Transitions changing school, moving year, choosing subjects
- Increased activity leading to energy deficit (REDS)

Of course, sometimes we don't know and lapses/ relapses can occur at any stage of the journey.

It can be really useful to help your loved one make a list of behaviours and strategies they have used in their recovery so far

For some young people a charter/ contract agreed with parents and/or care team can be helpful – depending on the stage of recovery. For example:

- Gain a minimum of 0.25kg per week/ stabilise weight
- Stick to a rigid meal plan
- Finish all food given to me
- Take all my vitamins
- Eat what is given at home, same as the family
- Eat school lunch and snacks at school
- Let Mum cook and dish without interfering
- Continue to engage in all therapy and do as the therapist says
- Continue not to exercise, until at safe BMI to do so
- Continually challenge fear foods until they aren't a fear anymore
- Make decisions
- Stick to appropriate portion sizes even if eating by myself
- Report back on any problems to parents/therapist immediately
- Plan ahead for the day
- Tell someone when I'm struggling, so they can help

Also think about warning signs that your loved one might be struggling:

- eating alone,
- solo exercise,
- weighing person/ food,
- body checking,
- shame around eating

Crisis card:

Some young people find this useful. Make a list of healthy alternatives to ED behaviours that you can refer to in a crisis (poster or crisis card)

When I am feeling anxious/ angry/ frustrated/ tired, rather than turning to my ED behaviours I will:

- Strategies I can use at school
- Strategies I can use at home
- Strategies I can use when out with friends

Write a list of people/ helplines you can call on in times of crisis

Plan ahead for setbacks:

For example:

If I start to lose weight then I will sit down with my mum and plan my meals to make sure I am eating enough for my levels of activity

If I feel ashamed about eating in front of other people then I will

If I start to over exercise then I will

Time spent going through these issues with the school and young person will be invaluable. After a long period of absence, it is natural that the student will find the return to school exhausting and scary, whilst also feeling positive and excited about getting on with their lives away from home.

It is not uncommon for weight gain to stall, or weight to drift downwards once school is resumed. This may be due to energy deficit caused by skipping snacks and/or lunch at school, or may simply be caused by the increased activity levels. Vigilance is required to help a student manage both. Also watch out for growth spurts which can also trigger energy deficit. My son needed to be consistently eating 4000 to 4500 kcals a day when he returned to school.

Scenario – Too Tired To Go To School

Peter, who is 15 years old, has been absent from school for almost a year and has been doing online school and achieving really great results throughout. However, he decided that he was starting to get bored and lonely so at his request he has started at a new school. A great deal of thought and planning has gone in to this process and so Mum is confident that he will settle in quickly. After all, he has chosen to go back.

However, on day 3 of the new term he claims he is too tired to go. Understandably Mum is frustrated and gets cross. Peter gets even more cross back and retreats into his room slamming the door in anger. Everyone is upset. Mum has to cancel all her plans for the day. Peter is not going to school today.

| Antecedents | Behaviour | Consequence |
|-------------------------------|-------------------------------|-----------------------------|
| Peter is too tired (or upset) | Mum gets cross when Peter | Peter gets upset and |
| to go to school. | says he is too tired to go to | retreats to his room. |
| Mum is bewildered and | school | Peter doesn't go to school. |
| disappointed that Peter | | Mum feels terrible and |
| doesn't want to go to | | wishes she had reacted |
| school. | | differently. |
| Mum is exhausted from | | Mum is worried Peter will |
| years of looking after sick | | never want to go to school |
| children. | | again. |

The ABC model of behaviour can be used to consider the antecedents and consequences of Mum's reaction.

On reflection Mum realises that whilst there had been a great deal of thought and planning in to the logistics for Peter getting to and from school, and the structure of the day at school, she hadn't prepared herself for the scenario in which he would not want to go.

In addition, in the heat of the moment, she had reacted crossly, rather than calmly and gently exploring with Peter what was behind his tiredness and not wanting to go to school. Easier said than done of course!

An alternative response therefore might have been to use our MI communication skills to roll with resistance, with a little empathy and affirmations thrown in:

"So, you are too tired to go to school? Why don't you go back to bed for an hour or so and then we could take the dog for a walk. I can imagine it must be exhausting for you doing full days at school after such a long period of absence. I imagine many boys wouldn't have coped so well and I am impressed at how you handled the first two days. On our walk we can talk about what went well and perhaps what didn't go so well and see if there is anything we can do to help you get through these first few weeks without feeling so tired"

Peter might still slam the door when retreating to his room, but not because Mum has been cross. Mum has shown that she empathises with the challenges he is facing going back to school and that she is prepared to help him review and reflect on the first few days and support him in any way she can.

Mum also knows that when Peter says he is bored and/ or tired it usually means something has upset him and sure enough on the walk he describes the chaos of the first few days, the whole school assembly and then a whole school fire drill, the bun fight at lunchtime, and the scrabble for the school bus at the end of the day. On a positive note he says he likes his form tutor and he has made friends with a couple of really nice boys and he has signed up to go to chess club with them next week.

Mum enquires as to what might be helpful and Peter expresses the wish to be able to take a break or have a little bit of time out when he is feeling stressed in the school day. In addition, he asks if he really needs to have school lunch in the dining room which is really loud and noisy. He has noticed that several boys bring a packed lunch and there are several quieter places you can go to with a packed lunch. It also becomes apparent that maybe the school bus is a step too far in these early days and Mum agrees to drop him at school in the mornings. In turn Peter says he is happy to get the train home as he knows one of his chess club friends does this because he can't stand the school bus scene.

Mum and Peter agree that they will spend a few minutes at the end of each day having a conversation to review and reflect on the good and not so good things that happened at school on that day.

Student Profile

A student profile can be really helpful. These can be created by a student on their own, or with help from a trusted adult. It is useful for all staff who teach the student to have access

to the profile. In this way, the staff are more likely to empathise with the challenges the student is facing, and work alongside them to encourage and boost confidence, rather than punishing what might, on the surface, look like bad behaviour in the class room setting.

In this scenario Clara who is 17 years old, has been making good progress in her recovery from bulimia, and she has a good relationship with the school counsellor. However, she is finding the school environment really challenging and some teachers have been quite dismissive and critical of her in recent months. This can trigger eating disorder behaviours. Together with the school counsellor she creates this student profile:

My name is Clara. I live with my Dad but he is often away. My Mum doesn't see me much. Thank you for taking the time to read this.

| I have had some difficulties recently. They | These are my strengths: |
|---|---|
| are | I am most proud of being lacrosse vice- |
| Academic issues | captain and house sports captain |
| Relationship issues | I am especially good at lacrosse and |
| Feeling lonely | gymnastics |
| Feeling depressed | I also like drama because it gives me an |
| Recovery from an eating disorder | escape |
| | I really like it when people say I have |
| | performed well |
| These are my worries: | Types of learning: |
| Falling behind academically | I struggle in exams |
| Getting bad exam results | So, it would help if you reassure me |
| That my friends don't really like me | I feel nobody notices my efforts |
| Nobody really cares about me | So, it would be helpful if you gave me more |
| Being seated right at the front of the class | feedback |
| as that makes me feel really exposed | l often feel stupid |
| | So, it would be helpful if you could help me |
| | keep things in perspective |
| People Friends and Social Situations | Learning Environments |
| I feel really nervous in class and shy | In difficult subjects, I sometimes cannot |
| On the sports field, I feel alive and skilful | concentrate |
| My close friends are | It would be helpful if I sit near the front but |
| I think they worry about me. I think this is | not right at the front |
| awkward for them and maybe they need | In difficult subjects, I give up easily |
| to talk about that with someone | It would be helpful if you gave me feedback |
| | noticing things I am doing well rather than |
| | letting me always dwell on what I get wrong |
| | |
| How I feel (there can be several of these | Helping Myself |
| eg sad, angry, tired, depressed) | I sometimes feel like I am two people in one |
| When I feel depressed sometimes I act in a | body. |
| certain way: | In sport, I feel talented, alive, determined |
| Daydream | and a good leader. |
| Just go all numb and quiet | In academic subjects, I feel useless much of |
| | the time. |

| I might put my head on the desk if I am | I will try to remember my strengths when I | |
|--|--|--|
| feeling tearful | am feeling down | |
| I find it hard to focus | l have a six step plan | |
| So, it is helpful if I can have a minute | Identify what is worrying me | |
| outside or go to talk to the school nurse. | 2. Talk to somebody about it | |
| The school nurse knows about my | 3. Work out some options | |
| problems and is a good listener | 4. Try one with SMART baby steps, not | |
| It is helpful if you notice that I am | great big giant ones | |
| struggling in a subtle way, rather than | 5. Review and reflect with someone | |
| being annoyed with me for not | 6. Celebrate my successes and learn | |
| concentrating. That makes me feel 100 | from setbacks. | |
| times worse. Not noticing and saying | In school the best person to help me with | |
| nothing also makes me feel that you don't | that is the school counsellor. | |
| care. | | |
| My goals | My goals | |
| Soon | In 2 years | |
| I want to feel happier | I want to be at Loughborough or Durham | |
| I want to get good grades but they don't | University studying sport | |
| have to be perfect | I want to be in a better place emotionally | |
| I want to enjoy my sport and drama and be | I want to be more confident in myself | |
| able to celebrate my achievements | | |
| | | |

Managing school lunch

When recovering from any eating disorders there are three distinct phases around restoring regular nutrition:

- 1. Eat sufficient for the body's basic needs
- 2. Eat flexibly and with variety. Stabilise eating patterns.
- 3. Eat socially with food being a normal part of the bigger picture of life

Returning to school is a challenge in itself and as we have reviewed in this capsule careful planning is required. Eating school lunch is undoubtedly one of the biggest challenges, as it requires the confidence to eat in front of peers in a noisy and chaotic setting. Other students might inadvertently make inappropriate and unhelpful comments around Edi's weight, shape and/or how much food they are eating. It is likely that Edi will need to eat significantly more than the other students, especially if in the later stages of recovery from anorexia nervosa.

On the other hand, we know that regular nutrition is essential for a young person recovering from an eating disorder. Skipping school lunch is often the first step towards the development of an eating disorder. Skipping school lunch in the later stages of recovery can lead to significant relapses.

Within the workshops we often discuss the benefits of building up confidence around social eating very gradually. This might start with Edi sitting with the family, but not being expected to eat, it might be a series of trips to small coffee shops, gradually building up to a meal in a restaurant. All carefully thought out and planned. The same approach can be useful in building up to the return to the school lunch hall.

Scenario - Molly, age 15 is recovering from anorexia and is hoping to return to school full time in September. At the moment (assume it is early in the Summer term) Molly is going to school three days a week and Dad drives to school every day so that Molly can eat her packed lunch in the car with his support.

Planning for a return to the school lunch hall

The ABC analysis can be useful in understanding the challenges of returning to the school lunch hall. Every behaviour has antecedents (triggers) and consequences.

| Antecedents | Behaviour | Consequences |
|------------------------------|------------------------------|-------------------------------|
| School lunch hall is really | Currently not eating school | I miss out on all the social |
| chaotic and noisy | lunch in the dining room at | aspects of having school |
| My ED escalated when I | school, instead having lunch | lunch with my friends |
| started avoiding eating | with mum or dad in the car | It is not normal for students |
| lunch at school | | to have lunch with a parent |
| Lots of my friends don't eat | | in a car |
| much at lunch time | | It is time consuming for my |
| My ED voice gets really loud | | parents |
| in the lunch hall | | It does mean I can eat lunch |
| I feel really panicky about | | |
| the thought of eating in | | |
| front of so many people | | |
| | | |

The decisional balance could also be useful.

Menu of Options: the anxiety hierarchy can be a useful way to start to visualise the steps that might be helpful in achieving a seemingly impossible goal. In this case Molly's expected anxiety at the prospect of eating school lunch in the main dining hall from September is extremely high 99.999999999

The idea is that by gradually increasing the goal from the current stage, which is depicted at the bottom of the hierarchy, Molly starts to be able to face her fears and sit through waves of anxiety. The next time she repeats this new stage the level of anxiety feels lower and therefore more manageable. By the time September comes Molly's actual anxiety of going into the school hall may be much lower, perhaps 40 - 60 depending on who she is sitting with and what the lunch is.

| Goal- School lunch in the main dining hall from | Expected | Actual |
|---|--------------|-----------------|
| September | Anxiety | Anxiety |
| Menu of Options: | | |
| School lunch in the main dining hall from September | 99.999999999 | |
| | | |
| | | |
| Smaller less chaotic dining room | | |
| Sit in a classroom with a couple of friends (having a | | |
| few friends who know that Molly is recovering from an | | |
| eating disorder can be really helpful) | | |
| Sit in an office with a member of staff eg school nurse | 60 | First time this |
| | | triggered |
| | | anxiety of |
| | | 99.999 so go |
| | | back a step |
| Having a few friends having a picnic in the park at the | 60 | 30-40 after a |
| weekend or ask school and a family if they could do | | few times |
| this, one lunch time at school | | and this could |
| | | be repeated |
| | | through the |
| | | summer |
| | | holidays |
| Have a really close friend over for a snack | 40 | 30 |
| Introduce concept of going to cafes and restaurants in | 99.9999 | It is dropping |
| the evenings | | say 40 - 50 |
| Gradually increased the range of food being eaten for | 80 - 90 | 40 after a few |
| lunch eg Subway/ pizza and might sit outside the car or | depending on | times |
| in the park | food | |
| Mum or dad drives to school and Edi has packed lunch | 50 - 60 | 30, it feels |
| in the car (just after she came home from hospital) | | normal now |
| repeat as much as needed. | | |

Another idea might be that Molly starts to go into the lunch hall for a few minutes at the beginning of lunch, with her pals, and then meets her mum or dad in the car park to eat lunch. This exposure to the noise and chaos of the lunch hall could gradually be increased over time, maybe building up to Molly having a drink with her friends in the lunch hall having had her lunch in the car.

Careful planning in which families can visualise a staged approach to things like this can be really helpful. The key is to be flexible. If an idea doesn't work out as planned (such as sitting with the school nurse in the example above) take a step back, maybe repeat an earlier step before coming up with a new next step.

A question that often comes up is around how carers can know what is being eaten in school and what the activity levels are?

It is very tempting for carers to ask their loved one – what did you eat today? Most teens will find this infuriating and in any case they can lie. Of course, if they are restricting food intake and being more active, their weight is likely to start to drop. Carers who can keep lines of communication open and empathise with all the challenges of being back in school are more likely to be able to judge if this is a temporary slip, or a more serious relapse.

A few tips from other carers:

- Try not to panic, there may well be good days and bad days. It is the overall trajectory that is important rather than day to day detail. Your loved one may well lose a little weight to start with purely because they are more active.
- 2. Agree boundaries before the term starts. We agree not to ask you every day about food/ exercise. We will need to check in with you once or twice a week. Agree a specific time and place to do this.
- 3. Keep lines of communication open with the school in a positive solution focused way. Again, you might have one member of staff who is your main contact for a weekly check up to start with.
- 4. Make sure you pay lots of attention to what is going well and the character strengths your loved one is displaying every day, and the joy they are experiencing being back in school
- 5. Be curious about all the other things your loved one is doing in school, and don't just focus on academic progress.

Conclusion & Resources

For many young people recovering from eating disorders, returning to school is exciting and filled with joy. For others it can be utterly terrifying. Each young person will have different experiences and challenges.

Families can support this process with empathy and unconditional love and support.

There are many other ideas in Pooky Knightsmith's excellent book <u>Self-Harm and Eating</u> <u>Disorders in Schools: A Guide to Whole-School Strategies and Practical Support:</u> <u>Amazon.co.uk: Pooky Knightsmith: 9781849055840: Books</u> Pooky did her Phd on this topic at the Maudsley and all of her ideas fit very neatly within the New Maudsley Model.

There are also very useful practical tips at <u>Schools:Practical measures to support pupils with</u> <u>an eating disorder (anorexiafamily.com)</u>

If your loved one is struggling to cope with school there are of course many options now around home schooling, which might be a temporary or permanent measure. This website has lots of really useful resources <u>Not Fine in School - Families, Information</u>