

**CPFT ADULT EATING DISORDERS
SERVICE
ONLINE CARERS SUPPORT GROUP**

Summaries – April to September 2020

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Introduction

Introduction

In early April 2020, as the country went into lockdown, CPFT arranged to replace the monthly ED Carers Support Group with a weekly online meeting to provide support and advice.

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 was 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.
3. To finish on a positive note, the group asked all to share any tips for brightening up the day!

Attendance

Was by invitation only.

This is a summary of all the discussions from the online Carers Support Group meetings held between April and September 2020, compiled by Keith Grimwade, including open and specialist led meetings.

Presentation slides have been copied into the relevant section.

Resources are highlighted.

Additional resource files are included in the appendix.

21st April 2020 – Presentation - Coping with lockdown - Dr Sarah Beglin


21st April 2020 – Presentation - Coping with lockdown - Dr Sarah Beglin

Please find attached Dr Sarah Beglin's presentation 'Carer coping in Covid-19 Times' from yesterday's online support group meeting.

A big thank you, again, to Sarah for putting this together.


Fifteen carers joined the meeting and the feedback has been invariably positive.


Don't forget, Sarah's presentation includes some really useful links and references.



Carer Coping in COVID-19 Times

Dr Sarah Beglin
Consultant Clinical Psychologist
21st April 2020





Pride in our adults and specialist mental health services

Focus of today...

Part one:

Carers coping with COVID-19

Part two:

Carers living with loved ones coping with COVID-19

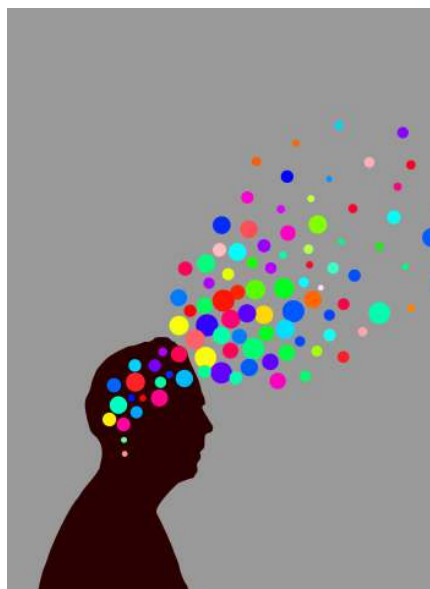
We are all at sea.....


But not necessarily in the
same boat....



Unprecedented times: Emotions are normal


Anxiety
Stress
Feeling overwhelmed
Angry
Frustrated
Lonely
Low
Fearful
Helpless
Guilty
Lost
envious





We are in threat mode

Our chimp is out of its box



Concentrate on what you can do..

<p>Things I can't control</p> <ul style="list-style-type: none">• The virus• The government's decisions• Other people's behaviour• The duration of lockdown• Social media	<p>Things I can control</p> <ul style="list-style-type: none">• My actions• How I deal with stress• Following government guidelines• My response to others
---	---

Managing your stress levels..



Observe thoughts
and feelings – accept
them



Focus on body –
breathing, posture,
grounding



Engage fully in what
you are doing – use
your senses



Take committed
action

A note on over- monitoring

- Over-monitoring increases anxiety (ask someone with an eating disorder..)
- Try not to spend too long on social media
- Don't watch too much COVID-19 related news
- Try not to check repeatedly for symptoms

Take action



Importance of
routines



Importance of
balance



Activity scheduling
- Pleasure
/mastery list



Include self care,
soothing, calming
activities

Activity Scheduling

Mastery

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

Pleasure

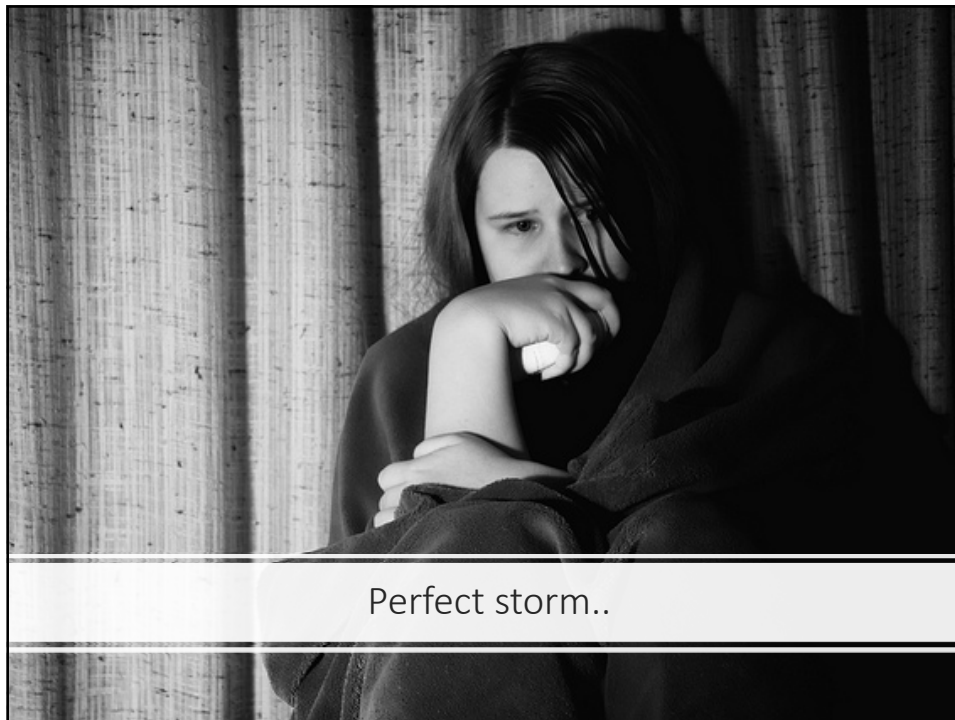
- Xbox
- Netflix
- Bath + music
- Play piano
- Watch TV/movie with family
- Skype friends
- Plan activities for when released

Activity Schedule

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	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 rd 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 ☑
Afternoon	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 ☑
Evening	Make Dinner ☑ TV ☑ Xbox ☑	Dinner ☑ TV ☑ Debate ☑	Dinner ☑ TV ☑ Xbox ☑	Dinner ☑ TV ☑ Boys ☑	Dinner ☑ TV ☑ Xbox + boys ☑	Dinner ☑ Cocktail party ☑	Dinner ☑ TV ☑ Advisor ☑

Part Two – lockdown with someone with an eating disorder

- Impact of increased anxiety – global and local
- Impact of isolation
 - Increased contact with family (or decreased)
 - Reduced contact with friends/others
 - Loss of structure – hobbies, education, work
- Restrictions on activity
- Difficulties getting hold of food items



What can we do to help?

- Look after yourself
- Be kind and empathic
- Take a break if you can't be kind!
- Accept distress – don't try to ignore or fix
- Listen (when you can)
- Try to keep your routine steady and not over accommodate the eating disorder
- Try not to be bullied by the eating disorder
- Model good (enough) coping!



Over to you...

- What is working for you and your loved one?
- What are you struggling with?
- Remember that this will pass
- Beat resources – extra chat rooms + support
<https://www.beateatingdisorders.org.uk/coronavirus>

References and links:

- <https://thewellnesssociety.org/wp-content/uploads/2020/04/Coronavirus-Anxiety-Workbook.pdf>
- FACE COVID: How to respond effectively to the Corona crisis. Dr Russ Harris, author of The Happiness Trap
- Free Online Meditation Resources for Times of Social Distancing / COVID-19 by The Awake Network
- Coronavirus Anxiety - Helpful Expert Tips and Resources from the ADAA
- The free e-Book FACE COVID: How to respond effectively to the Corona crisis by Dr Russ Harris
- Free Guide To Living With Worry And Anxiety Amidst Global Uncertainty from Psychology Tools
- The Framework, our deeper dive into understanding, transforming and reducing stress, autostress and anxiety
- The Mental Wellbeing Toolkit, our comprehensive set of practical tools designed to help you improve your mental health and wellbeing
- Our online guide to accessing therapy. There are many therapists currently working via video chat. If you start to feel too overwhelmed emotionally or physiologically, we strongly encourage you to seek the support of a trained professional
- The free online course Coping during the pandemic from Recovery College Online (click log in as guest)

28th April 2020 – Long distance caring and Challenging situations

28th April 2020 – Long distance caring and Challenging situations

One of the main issues we discussed was ‘**long distance caring**’. Some of the general principles that came out were:

- keep the line of communication open, don’t push it, eventually our loved ones will open up
- our role is to be there to listen, don’t try to fix things
- do help our loved ones to find their own way forward - lots of open questions, check that you’ve understood what they are saying (that will help them to sort out their own thoughts, too), listen, listen, listen, pull it all together and don’t give an opinion unless asked

We discussed some other really **challenging situations** that reminded us all to ‘stick with now’ (get through tomorrow - even today - before worrying about the future) and that we must trust the people who are supporting our loved ones professionally.

Resources**Books**

‘**Skills-based Caring for a Loved One with an Eating Disorder**’ by Janet Treasure, Grainne Smith and Anna Crane is a mine of inspiration.

It sets out the carer’s role in the ‘New Maudsley Method’, which is what CPFT bases its family support on. It’s a must (and has a dolphin on the front cover). A google search indicates many suppliers with copies available for mail order.

Videos

There are many helpful videos but these two will cover a lot of what we talk about. One is Dr Sarah Beglin talking from a professional’s perspective and the other is from a carer’s perspective, and features our very own Naomi! Copy and paste the full links below - I know they can be abbreviated but experience has taught me that this is the most reliable way to connect everyone’s browsers to these resources!

A Carer’s Perspective

https://player.vimeo.com/external/269177912.hd.mp4?s=8b7a5b34b34d51877cf1d4309184955b976a41f3&profile_id=175&download=1

A Professional’s Perspective

https://player.vimeo.com/external/269159983.hd.mp4?s=3ea549895b12e5b21d3197abd8994163649e3f56&profile_id=175&download=1

5th May 2020 – Regret and Guilt

5th May 2020 – Regret and Guilt

Thank you to everyone for another really good session. When I look through my notes, I see that we covered a great many issues but two that we focused on were:

Our loved ones regretting the years they have wasted not being ill and/or not 'the right size'

- reminding / reinforcing what they have achieved, but not making a big thing of it, emerged as a good approach for the former; and
- reflecting / listening / asking open questions was felt to be the most helpful for the latter, for example 'what makes you think like that?', rather than going into 'contradiction' mode.

Our loved ones feeling guilty / bad about falling short

- the 'reflection + praise' principle is the one to try here, for example 'it sounds as if it has been really hard and you are doing so well'.

And remember, **'You can't go too far wrong with a reflection!'**

12th May 2020 – Self Care, Listening and Staying Calm

12th May 2020 – Self Care, Listening and Staying Calm

I found yesterday's discussion so helpful, I hope you did too. Although this did not apply to all of us, it was noticeable that more of us had had a '**rough**' week and that more of our loved ones '**had had a bit of a dip**'. We discussed both of these and some general principles emerged:

It's not selfish to self-care

- We reminded ourselves how important it is to look after ourselves.

We all need a list of things that we find pleasurable and we have to make sure that we include them in our daily plans.

Some great examples were shared:

- an online guided meditation course,
- decorating,
- craft activity,
- crocheting really scary animals (and mixing cocktails).

Listening is a massive gift

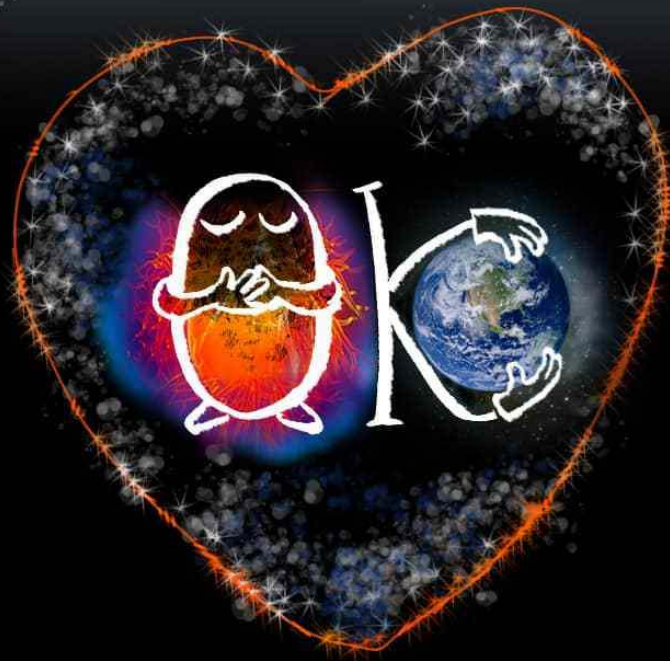
- People are allowed to suffer.

Calmly listening is really helpful to our loved ones, although we might not think so and might want to step in and sort things out.

Stay calm

- This can be easier said than done but we can prepare by thinking about our coping strategies in advance.
 - How have we stayed calm before? Again, some great examples were shared, for example not replying to a phone call straight away but sitting with the concern and giving yourself space to think it through and/or long, deep breaths. (I find this works although I never thought it would - so I guess being open to new experiences is also a good principle!)
 - Be empathetic when we respond: 'I see you're having a really difficult time' acknowledges the situation and tells our loved ones that we are listening, not ignoring.

Resources**OK – Observe with Kindness**



bserve
with

indness

www.evamusby.co.uk

Two steps to being OK when your child has an eating disorder

What can we parents do when we are hurting – when we're in the grip of fear, hate, anger or despair? It's so hard to support a child with an eating disorder when we're not OK. It's so hard to do anything. So what to do?

We can make it 'OK'.

- O is for Observe
- K is for Kindness

I have researched and tested out many ways we can take care of our wellbeing, and I'm offering you some of the best bits with this 'OK' acronym.

It can change your mental state within minutes and all you have to remember is two letters. Try it and tell me if you like it.

Start with O for Observe.

Make a mental pause to step back and observe what's going on for you. You're looking for thoughts, emotions and most importantly, physical sensations.

For example you're pressing the 'Pause' button on the thought "I'll never get my child to eat", and as you do so you're recognising fear and you're noticing how tight your chest is.

'O for Observe' allows you to be aware of the burden you're carrying. Before taking that step back, you probably didn't even notice your chest was knotted – you were too caught up in an endless chain of thoughts. Before 'O for Observe', if you noticed you were scared (or angry, or distressed), you were probably judging yourself for feeling that way. 'O for Observe' invites you to turn off the autopilot, be present, and allow whatever is there right now.

Now you've done 'O for Observe' you've nicely interrupted your internal chatter, but perhaps your chest is really hurting and now you're also conscious that your breathing is irregular and you're getting nervous.

'Observing' seems like a daft thing to do. And it probably is, unless you also bring in 'K for Kindness'.

'K for Kindness'.

What's needed now is kindness towards yourself and your experience in this moment. The most natural way of doing this is to distract yourself. If you're in a horrible mental state and you're very alone, I recommend you stick to that while you seek professional support.

The way I'm proposing here, though, is to actively invite kindness into you. This route is usually more healing and frees you from constantly having to distract yourself or exert self-control.

Ask yourself what kindness means for you right now. With the feelings you're experiencing, what do you most need? Perhaps it is a sense of being held, or loved or understood, or maybe you're longing for peace or rest. Perhaps what would nourish your soul right now is a sense of light or warmth.

So send kindness – or peace, or light, or whatever you most need – send that inwards now. You can help yourself by voicing your wish: "May I have kindness", "May I be peaceful". Or by placing your hands on the part of your body that most needs comfort.

Kind companions

Kindness towards yourself can be tricky if you're locked inside in a small, tight me-me-me. Before things got really tough you might have gotten through life by pulling yourself up by your bootstraps. Self-reliance might have deprived you of a greater quality: interdependence. Connection is crucial to being OK. So when you do 'K for Kindness', bring to your aid the kindness of others.

Imagine all the parents who are in the same boat as you. Their story might be different, but they know what it's like to suffer as you are suffering, and their deep needs are just the same. You could imagine parents in general, or even take in the whole of humanity or the whole of life. Or you could bring to mind a specific being – real or imagined – who dearly cares for you and will hold with you – or for you – what is too much to hold on your own.

Expanding the kindness

So in your mind you're now giving yourself kindness and receiving kindness from others. See what it's like to expand outward, sending kindness out to specific people or to the world in general, including yourself: "May we all have kindness", "May we all be peaceful". You can include your child in these wishes, if it feels good.

More than a trick of the mind

'OK' is a low-tech but effective way of changing your biochemistry. It can shift you from a state of fight or flight into a compassionate and resourceful state. You are allowing your limbic brain to halt its frenetic work on your behalf, you're halting the production of adrenalin and cortisol and you're producing feel-good hormones like oxytocin. And because the brain rewires itself with use, the more you consciously do 'OK', the more likely your brain will do it for you spontaneously.

When you've drifted away from being 'OK'

You can do 'OK' for a few seconds while you're in the middle of a stressful event, and you can take time to do it later, addressing your feelings in the 'now' as you recall the event. You can be sure that your mind will regularly wander off, because that's what minds do. As soon as you notice this, you're already doing 'O for Observing' – how great is that?! Add 'K for Kindness' and keep going until the current wave of suffering subsides.

Kind action

And that's it. Being OK through Observing and Kindness. It doesn't change your external reality but it may change how you relate to it. Which will then allow you to make wise choices and take wise actions. For instance, you might be moved to go and get the kindness you need from friends or professionals. The 'OK' visualisation, I hope, will not just give you instant relief, but will help you make great use of real connections – for a shoulder to cry on, for a listening ear, for shared laughter.

For more on eating disorders, mindfulness and compassion, see Eva Musby's book "Anorexia and other eating disorders – How to help your child eat well and be well."

Eva Musby has also produced audio resources guiding you with the process described here.

<https://anorexiafamily.com>

For more on compassion, see the work of Kristin Neff and of Paul Gilbert.

For more on compassionate mindfulness practices, look up Buddhist loving-kindness ('metta') meditations.

19th May 2020 – Presentation - Eating Disorders, the Medical Perspective, Dr Melanie Bruneau

19th May 2020 – Presentation - Eating Disorders, the Medical Perspective, Dr Melanie Bruneau

A big thank you again to Dr Melanie Bruneau, Consultant Psychiatrist, for her excellent presentation on Tuesday about the medical perspective on eating disorders, which addressed all of the questions we raised in our introductions. I found it really interesting and useful. Below are my notes - drop me a line if anything fails to make sense! I am working on the best way to share the link to the recording - there are a couple of options for 'guests' on Teams and I need to try out which is best.

Questions**Prescribed drugs**

In general, we don't prescribe a lot, therapy is main treatment. Can be helpful if there are other issues, for example depression and anxiety. High dose of antidepressants, especially fluoxetine helps with cravings associated with bingeing. Clinicians may try high dose to see if it works, 60mg c/f 20/30 mg. May prescribe for months or years, won't rush to stop it but will regularly review. May use anti-psychotic at a lower dose, which reduces anxiety and desire to exercise... weight gain is not a side effect for someone with low weight, but helps with weight restoration because anxiety is lowered. Mostly, the drugs prescribed are not addictive.

Long term effect of being low weight

Osteoporosis - most complications are reversible but this is more concerning - we check bone density at least every two years - up to 30 years of age can still reverse process, at least to some extent, with treatment, which is weight restoration, no real alternative. Mechanism leading to osteoporosis is different than for older people. Happens quite rapidly, for example after only one year. Avoiding osteoporosis can be a motivator.

Blood tests

Frequency depends on health of individual. If monthly and deteriorating will up frequency to fortnightly or even weekly. Medical monitoring is more than just bloods, for example squat test. Important thing is seeing the trend. Tests are an indicator of particular behaviours and can be a way in for discussion, for example purging behaviours show in blood test results.

Long term consequences

Concern is effect on organs, especially heart. Infection is a risk, too, for example UTIs - could be related to not drinking sufficiently. Purging can lead to low potassium and dehydration. Enamel on teeth affected - depends on duration of purging behaviour and how much enamel has been eroded - may be a point where it's irreversible but specialist dentist opinion needed. Anyone who is vomiting is advised to rinse mouth with water immediately. Dentist has advised particular toothpaste and not to brush after coffee or for

19th May 2020 – Presentation - Eating Disorders, the Medical Perspective, Dr Melanie Bruneau

too long. Over drinking of diet coke - anything highly acidic - is also an issue. MB is going to ask a dentist friend and get back to us!

Impact on voice

Yes, it's a risk. Purging may cause damage. Pro-recovery - lovely story re daughter who couldn't stand to sing being back in the chorus.

Co-morbidities

For example, depression, bipolar (BP), OCD, personality disorder, anxiety disorder. BP has clear criteria with manic episodes and depression. With an ED you can go through phases of low and high (quite common) without being BP. Is risk of BP greater in someone with a history of depression? Not a given consequence.

COVID-19

Too early to say if people with an ED are more at risk. Not proved in the literature that low weight, although it suppresses immunity, means a greater risk. BMI over 40 = high risk and on the shielding list. Up to now been surprised that patients are doing OK, patients who have had the infection have responded OK. The severe reaction to the infection - possibly low weight has meant the body adapting its immune system so don't have such a bad reaction BUT it's early days.

Responsibility

Who oversees all the different medications where there are a significant number of co-morbidities? Do drugs act against one another? (Yes.) If discharged from specialist services, GP should review and will take advice from specialists as appropriate.

Resources**Web links**

Here is the link to the article in the Guardian that R---- emailed to me. Those of you who have attended the Saturday Workshop will remember Dave from one of the videos we showed you:

<https://www.theguardian.com/society/2020/may/17/like-losing-control-fears-eating-disorders-on-rise-amid-lockdown>

26th May 2020 – Carer Coping, Boundaries and Transition from lockdown

26th May 2020 – Carer Coping, Boundaries and Transition from lockdown

We covered so much ground on Tuesday it's difficult to summarise it all succinctly but I will give it a go! I found it a really helpful - albeit at times an emotionally challenging - discussion. I am sure we will return to these themes again. Thank you so much for your contributions, for being there and for listening.

Carer coping when our loved one is overwhelmed / angry / bad tempered

We discussed some useful strategies:

- **Grounding** - exercises / actions to calm ourselves, so that we are best able to support
- **Step back** - we aim to be good listeners but we are not there to be a punch bag; withdraw and come back to the discussion later when they (and we) are calmer

Boundaries

This is a huge topic, and undoubtedly one of the most difficult. We considered it in relation to meal times and 'family rules'. All families have boundaries and they are constantly being re-negotiated (remember when you wanted to stay overnight with your friends, go to a night club, get your nose pierced [not me, that one]?!)

- **Family problem-solving.** Agree together outside the heat of the moment.
- **Shuttle diplomacy** - talk to individuals, for example siblings before bringing everyone together.
- **Roll with it** - so what if there is the occasional boundary breach; you've tried, try again - it's better to try than be an ostrich.

The transition from lockdown

It's going to happen. None of us know how it is going to go. As with any challenge - **remember to be a dolphin!** Keep your bag of self-help tools packed and ready to go - take the oxygen first.

Resources

Here is the link from A---- re siblings:

Web links

<https://www.anorexiabulimiare.org.uk/family-and-friends/siblings>

2nd June 2020 – Coping

2nd June 2020 – Coping

Coping with setbacks

We began by discussing **coping with setbacks** - anticipated and actual. There was a wealth of experience and advice in the room. Some of the key points were:

- **Reminding** ourselves that setbacks are almost inevitable - it is the nature of this illness; recovery is rarely a linear process.
- **Remembering** how we coped before... and that 'all things must pass'.
- **Trying** not to be oversensitive - everyone has a bad day, which may be independent of the eating disorder.
- And the golden rule '**Look after yourself**'.

Coping with the long duration and the impact on us as carers

Our discussion then developed to consider how we cope with the (often) long duration of this illness and the impact it has on us as carers, especially with regards **to our mental health and wellbeing**. Again, there were lots of suggestions:

- **Talking** to someone who can listen in a reflective way can be really helpful.
- It's important to **express our feelings** (not bottle them up) - ideally to someone we trust, but if that's not possible to a diary, or in a painting, for example.
- It can be very sensible to seek **professional help** - your GP is the usual start point.
- **Support groups** are also a good place to offload, too!

We concluded with a reminder that if you have a question that you don't think has been fully covered, drop me a line and I will find the right person to respond.

9th June 2020 – Transition from lockdown and over exercise

9th June 2020 – Transition from lockdown and over exercise**The transition from lockdown**

We began by discussing **‘the transition from lockdown’**.

This is an understandably anxious time for all of us. Some people with an eating disorder have been comfortable with the lockdown because it has validated their social isolation. Others have been anxious because it has meant, for example, that ‘favourite foods’ are not available and that opportunities for exercise have been reduced. Of course, the chance to see our loved ones if they have not been living with us is a real positive.

Our conclusion was plan in advance. This is not totally straightforward, but as with a family event, or Christmas, that is going to happen we need to look for opportunities to **discuss calmly our loved one’s thoughts and feelings, and what they (and we) can do / put in place to reduce anxiety**, for example thinking through the commute to the office - even doing a trial run on the bus.

Over exercise

More opportunities to exercise led to **a discussion of over exercise**, which is a big issue for so many of our loved ones - and therefore for us. We discussed that it is important to see this as a behaviour that our loved ones are using to control thoughts and feelings.

When the opportunity arises, **gently exploring their feelings** could be very helpful to them, and it shows you care: ‘You seem upset that you have to go out for such a long bike ride, tell me about it because it is hard for me to understand and I really want to help if I can’.

Give information about their health, but without judgement, for example, ‘It looks as if you are still carrying that calf injury’; it may stimulate a discussion.

Ask permission to ask a question, and don’t pursue it if permission is not given.

Be assertive and say what you’d like to work towards with regards exercise - you will be **modelling ‘normal’ behaviour** and looking after yourself. Sarah asked if we would like an education session on this from the team’s physio and there was a resounding ‘yes’.

We ended with a timely reminder that in Carers Week of all weeks we should follow the golden rule and **Look After Ourselves**.

Resources**Web links**

<https://www.good-thinking.uk> - it is a site for London Boroughs but has some useful stuff on it and is NHS / Public Health England approved.

General information about Carers Week <https://www.carersweek.org>

Managing Role Strain

Carers:

Many people in this role report negative effects on their health, family life and on other areas of their life. Common feelings are confusion, self-blame, guilt, exhaustion, a sense of loss, hopes and dreams fading, fear and anxiety, resentment, anger and feeling rejected.

Manage Role Strain:

People who are devoting a lot of time and energy to a caring role commonly find that they have difficulties managing their other commitments. Dealing with this problem is an important part of reducing the stress of the role.

Boundaries and Limits:

It may be helpful for you to set limits and boundaries on the amount of time you spend being with or worrying about your relative/partner. This may not be easily achieved, but in reality, these constant efforts to offer support may not make a substantial difference and may reduce your capacity to support a sufferer effectively by wearing you down physically and mentally. It may also mean that you neglect your other relationships and commitments. Many people find that looking after a loved one with an eating disorder can distort family life through the effect on relationships and activities and that this is usually unhelpful and often isolating. It is important that you try not to spend all your time with the sufferer as this may have unintended consequences. A lot of time spent together may encourage unhelpful dependency and undermine the sufferers' belief in their own capacity to manage their affairs and make important life decisions. The shifting balance of responsibilities may also lead to high levels of resentment in you the carer as you take on more and more responsibility for your loved one. What is important is that time spent with your relative is balanced, effective and retains a sense of healthy relationship with the whole person with all their strengths and weaknesses and not a relationship to the illness.

Clarify Roles:

You may also find it helpful to reassess and clarify your roles with others by negotiating what you can and cannot do.

Accept being a 'Good Enough' carer:

It can often be helpful to lower the pressure you put on yourself. Thinking that you have to be perfect and do everything right is unrealistic and will probably leave you feeling stressed and unhappy with yourself. One of the challenges of caring for a loved one with an eating disorder is that it can highlight issues in how you manage stressful situations and your beliefs about life in general; so for example you may have to confront that a loved one who has lived independently is back at home and old patterns of relating may be activated in unhelpful ways for example trying to take control by applying sanctions "if you don't finish your meal, you can't come to the shops with me at the weekend". An important message for you as a carer is to realise that you are human with your own frailties and weaknesses and you are not empowered to solve and sort out all that is thrown at you.

Manage Contact Time:

Reducing the amount of contact time with the sufferer

Respite breaks:

It is vital that you feel you can set limits on the amount of time you spend with the person suffering from an eating disorder. If possible, get support from others to allow you to have time to yourself and for other activities.

Make time for you and your hobbies and interests:

It is not selfish or indulgent to take time to look after yourself, to "come up for air" regularly; it is essential for both you and the person you are trying to support. It can often be tempting to give up your own interests and hobbies so that you can devote yourself to helping your relative get better. Remember a consequence of this is that you may quickly become exhausted and resentful.

Look after yourself and get support:

Living under extreme long-term stress has recognised physical and emotional effects. To be able to survive let alone support someone else, it is necessary to find strategies which help that survival. It is important to be kind to you and to avoid wasting time blaming yourself for the eating disorder. Blame will accomplish nothing and will only make you miserable. It can be more helpful to gather information and review your options, then decide what to do next. Most importantly, finding ways of strengthening your inner resources will help YOU get through the ups and downs.

A personal haven

Consider where you can retreat to for peace, consider setting up your bedroom or spare room as a haven. Consider the shed...

Regular Breaks:

Perhaps a coffee, a meal out of the house every week? With friends or in a café accompanied by a good book? An overnight stay once a month? A weekend away?

Walk the dog:

Consider borrowing one if necessary...

Talk to friends and family:

Talk about how you feel, share your sorrows as well as joys. Then friends will feel able to share their own too. Sometimes you need to off load, sometimes you need distraction. Be willing to share and ask for support.

Make time to attend a support group (if there is one in your area):

Support groups offer a mutually supportive and confidential environment to share experiences, including difficulties and frustrations; to learn from others and to share ideas.

You are not alone!

Exercise:

There are different kinds of yoga and tai chi to try, dance classes, Pilates, judo as well as tennis, badminton, golf, football, walking and cycling. Lots of different types of massage – you could try them all.

Hobbies:

What did you used to enjoy when life had a smoother path? What new hobby do you fancy trying? Any interesting evening classes nearby, anything from conversation Spanish to upholstery, painting to...?

Music:

Try different types of music for different moods and to help express different emotions – look for what suits and helps you.

Writing:

You may like to keep a journal, write letters to an imaginary, very supportive friend, make up stories or plays about imaginary, or renamed, characters. All sorts of things can happen when you are writing...and it doesn't need to be for publication or sharing. Shaky spelling and gruesome grammar don't matter if it's to be shredded, but the writing puts feelings into a new perspective, out of your head and onto more manageable paper!

16th June 2020 – Presentation - Nutrition

16th June 2020 – Presentation - Nutrition

We began by welcoming new members; Pia Thiemann (Clinical Psychologist) and Sue Young (Dietitian); and hoped that Sarah Beglin was enjoying a well-earned break! Having introduced ourselves, Sue Young gave a presentation based on the questions we had raised about nutrition. Here is a summary of the key messages:

If our loved one's weight is dropping let them eat the food they want to even if it's not ideal. **'One battle at a time'** and in this situation weight stabilisation / recovery is the priority.

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:

- **any discussion has to be at 'low stress' moments;** if our loved one is anxious, for example at meal times they will resist change.
- if our loved one is **making a change**, for example 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**, for example, '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.)

Sue talked about how difficult it can be to unravel what is a medical behaviour (for example food intolerance) and what is an eating disorder behaviour (for example avoiding particular foods because of the calorie content). This is where professional help is important - carers are the first line of support but we cannot make our loved ones better by ourselves. If possible, have a discussion with a professional about issues such as food intolerance. Gently remind your loved one, when you see that they sometimes vary what they can tolerate/not tolerate, that this could be an ED avoidance tactic.

Supplements

With regards to supplements, vitamins and minerals for someone with an eating disorder are recommended. A dietitian can advise, but 'over the counter' are fine. What our loved ones do not need is supplements designed for athletes / professionals - our loved ones, whatever they think, are not in this category.

16th June 2020 – Presentation - Nutrition

Binge eating

It is very important to establish a routine. If you can support a regular eating pattern - breakfast, lunch, dinner and then snacks - what was the binge becomes the snacks in between meals and they are not as significant. This has to be achieved in steps, starting with breakfast. The 'nudge' conversation is 'I'm not asking you to stop your binge but I am going to ask you to have breakfast'.

Food related behaviours

The more starved our loved ones, the more they think about food and engage in food related behaviour, for example cooking, collecting recipes. They are the experts and will use the internet to justify their opinions.

Try to steer them towards websites that give safe messages about eating and that are meant for people of low weight, for example BEAT

Pia emphasised that **discussions need to take place in calm, quiet moments**. In therapy, nutrition is rarely a priority - it's all about motivation and changing behaviour. When we are **calm**, we are best able to help.

Resources**Web links**

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

23rd June 2020 – When should I say something and Understanding treatment

23rd June 2020 – When should I say something and Understanding treatment

We began by discussing one of the really big questions:

When should I say something about my loved one's weight/appearance?

The specific context was meeting a loved one for the first time since lockdown and being shocked by their appearance, but this question is relevant to many situations. The experience of the group was:

- in this situation the 'St Bernard' needs to kick in - **stay calm - find a positive**: 'It's lovely to see you', 'Well done on getting through lockdown'
- **discuss the big questions in a low stress moment**, not when emotions are highly charged
- use **open questions** and try to help your loved one understand their feelings and remember, it's '**feelings not food**'

To summarise, it's important not to ignore the big questions for ever - that's what an 'ostrich' would do, but don't charge in like a 'rhino' - pick your moment and support like a 'dolphin' (see Janet Treasure's 'Skills-based Caring for a Loved One with an Eating Disorder' for a full explanation of the animal metaphors!)

Understanding our loved one's treatment

Our second question was about **understanding our loved one's treatment**; for example, them saying to us that they had been given an ultimatum, 'You are not allowed to lose weight, or we will not continue with treatment'. Comments from our experience were:

- it is common for our loved ones to push back against treatment - its aim is to take away the very thing they have been using to control their unbearable thoughts and feelings. This may affect their account of their treatment to us.
- Our loved ones will not be abandoned by the Service, but willingness to engage will affect the kind of treatment that can be offered.
- It is really positive if our loved one talks about their treatment, whatever spin they put on it - that it is to be encouraged, 'I really appreciate you telling me about it and if there is anything I can do to help, do say'.
- Our role is to be there, to listen and to encourage our loved one to explore their thoughts and feelings; and to acknowledge that they are building up for another treatment session.
- 'Roll with it' - such good advice to keep calm and avoid unhelpful confrontation.

23rd June 2020 – When should I say something and Understanding treatment

- It's very common for initial sessions to be the source of considerable anxiety. This often improves as the relationship between the individual and therapist develops. Encourage your loved one to share their anxieties with their therapist.

In summary, our loved one's reaction to treatment can be placed in the Change Cycle (see Janet Treasure's book for a really good account of this - I do not have shares in the book, by the way!); if they are engaging in treatment they are at least in the contemplation stage, but they may well be ambivalent about change.

Green shoot

And finally, we heard a great example of a 'green shoot', a loved one who has decided to try to make changes to a behaviour of over-exercise.

We heard the power of the open question, 'What can I say if I am worried?' It might not always work but when it does it is gold dust and exactly what good carer support is.

30th June 2020 – Contacting the professionals and First discharge from IP

30th June 2020 – Contacting the professionals and First discharge from IP

We discussed some big issues and raised a number of others that we did not have time for.

Contacting the professionals

The first we tackled was ‘**contacting the professionals**’ - should we contact our loved one’s GP / therapist / nurse with information whether or not we have our loved one’s permission? This is a complex issue, but from our experience:

- If you have information that is important to your loved one’s recovery you can always pass it on - you might not get a response, but it will be taken into consideration; the team supporting your loved one’s recovery would rather know than not.
- The principles of planning in advance, in low stress moments and of asking permission can be very helpful: ‘What would you want me to do if....?’
- If safety is an issue, do not hesitate.
- There is a difference between ‘acting for and on behalf of’ your loved one and ‘contacting with important information to help their recovery’; the former does have to be agreed and recorded in your loved one’s file.
- Confidentiality is, of course, an important issue. What your loved one is willing to share with you, and what they are not, will be discussed and recorded at the start of their treatment and regularly reviewed. Confidentiality should be breached if your loved one’s life, or someone else’s life, is at risk. The attached leaflet explains CPFT policy.
- Families and carers are seen as a vital part of the treatment for eating disorders, so the aim will always be to involve you.

First discharge from inpatient treatment

We then discussed our experiences of ‘**first discharge from inpatient treatment**’. The consensus was very much that ‘losing weight’ was very common - this can be dramatic and consequently 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 (for example outpatient appointments, medical monitoring). Experience shows that this is part of recovery, which is more often than not a sequence of snakes and ladders. That’s why it’s so important that carers look after themselves.

We didn’t have time to discuss our loved ones being obsessed with preparing food that they expect us to eat but that they don’t eat themselves - this is also common. We can pick this up next week as part of our Education Session on ‘Assertiveness and non-enabling behaviours’ to be led by Dr Georgina Hurford; I will let Georgina know in advance.

30th June 2020 – Contacting the professionals and First discharge from IP

We also identified **transition** (for example home to university) and **crisis management** as big issues that we must return to as part of our peer group discussions and/or as education sessions.

Resources

Common Sense Confidentiality

See next page ...

Principles of Best Practice

Staff should seek service users views on sharing information with informal carers / family as early as possible. This will usually be during assessment or admission. This is the time when it is most likely the service user will refuse permission. This may be because they may be very unwell, feel betrayed by their carer, or be very angry about the carer's role in their assessment or possible detention.

There needs to be a clear understanding that sharing information will need to be re-visited during the care episode. Regular review of the situation by the care team is essential. The care team should always seek to understand the reasons why a service user may be declining to share information.

Even if permission to share information is refused at this point staff must still give general information about mental illness and treatment options, discuss the carer's concerns or fears and signpost them to carer's support services. If permission is given to share information with the carer it is essential that it is shared.

Any decision made must be always be made in the best interest of the service user and to achieve the best possible outcome for them. It is essential that staff explain how and why the decision to breach consent is their best interest'.

The carer may need help and support to understand their relative's decision to exclude them. Deciding what information is general and what is personal will be a clinical judgement in each case.

The same principle of confidentiality applies to information given by carers. Staff must clarify the carer's expectation as to who the information can be shared with.

Where the service user withholds consent or lacks capacity and cannot express their wishes clearly, personal information will only be shared on a strictly 'need to know' basis.



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Common sense Confidentiality: A guide for employees, carers and service users accessing adult health services

“It is important to bear in mind that the care professionals “are not prevented from talking to carers about facts they already know; a breach of confidentiality only occurs when personal information is newly disclosed.”

Leaflet published: March 2019

Leaflet review date: **March 2020**

Patient Advice and Liaison Service

For information about CPFT services or to raise an issue, contact the Patient Advice and Liaison Service (PALS) on Freephone 0800 376 0775, or e-mail pals@cpft.nhs.uk

Out-of-hours service for CPFT mental health service users

Please call **NHS 111** for health advice and support.

If you require this information in another format such as braille, large print or another language, please let us know.



A member of Cambridge University Health Partners

Who is a carer

AT CPFT we believe that carers and family members should be seen as working in partnership with those who provide clinical services. They provide important information that may help doctors, nurses, social workers and therapists to have a better understanding of the needs of service users.

In order to be effective partners, carers and family members need clear information about the service user's care and treatment, their medication, potential side effects and any circumstances that may put the service user at risk.

Confidential health-related personal information is shared between care professionals such as doctors and nurses involved in a service user's care, so that they get the safest and highest possible quality clinical care. In addition, staff need to include carers in the extended care and support team.

Carers' roles require them to be well informed to be able to provide the essential support that service users need.

Effective care and better clinical outcomes rely on this three-way partnership (triangle of care) between people who experience mental health problems, their families and carers, and our staff.

Who is a carer?

'Carers are people who provide help and (unpaid) support to a family member, friend or neighbour who would otherwise not be able to manage. We use the term 'carer' in its broadest sense to include the most significant people in the life of the service user, including spouses, parents and young carers. It is also important to note that the carer is not always the "nearest relative". The term "nearest relative" is defined in the Mental Health Act.

The person they care for may have a physical or learning disability, dementia, mental health problems, may misuse drugs or alcohol or may be ill or frail.' Consent to share information.

Young carers are children and young people who often take on practical and/or emotional caring responsibilities that would normally be expected of an adult.

Consent to Share Information

Duty of confidentiality

Service users have a right to expect that information about them will be held in confidence. Carers can expect that the information they provide will be held in confidence by the professional care team. Crucial to this process is the building and maintaining of trust between service users, professionals and carers which is the foundation of good care.

Duty to share information

Doctors, nurses and other members of the care team have a duty to share information about the care treatment, medication and other important information about a person's health, in order to provide the safest and best clinical care possible. This means that sharing information must be discussed with service users early on in their care and where there are difficulties in sharing information that is crucial to care this should be seen as a major problem that requires intensive work. Even when there are problems with confidentiality this should not be used as a reason for not listening to carers or for not discussing fully with patients the need for their carers to receive information and support. Further where service users do give consent for information to be shared this must be done

Consent to share information

Confidential information about a service user should only be shared with their explicit permission. If the service user doesn't give permission, confidential information can only be disclosed in exceptional situations, such as where the service user's, or others' health and wellbeing is under serious risk, or where there is a public interest or legal reason for disclosure without consent. In the absence of consent it is good to share non confidential information with carers. The care team should always revisit a service user's refusal to share information with their carers. The support carers can offer is invaluable in supporting individuals recovery. The care team should seek to understand the reasons why a service user may be declining to share information; the best outcome is always that they do agree to share at least some information. Detailed documentation of any conversation related to consent and family or carers is imperative.

Consent to Share Information

Consent to share Information

Many service users often agree to sharing information with carers when their condition improves. Any decision made must be always be made in the best interest of the service user and to achieve the best possible outcome for them. The provision of general information about mental illness, emotional and practical support does not breach confidentiality. General information can include: Information about the condition and behaviour it may cause. Advice on managing, particularly in a crisis situation. Contact details of the team responsible for the service user / patient's care.

Case Study

Andrew is an inpatient who is known by staff to be close to his family, who are supportive. He instructs staff that he does not wish to see any member of his family and does not want any of them to be invited to a multidisciplinary team meeting for a review of his care.

Tracy, his sister, is aware of Andrew's instruction but asks to be invited to the meeting as a representative of the family. Arrangements were made to see the sister separately from her brother. She was given the opportunity to express her concerns about the frequency of Andrew's readmission recently, and wondered if he is being treated with appropriate medication.

She reported that he had responded well to a particular depot medication in the past, but that he had been given different types of medication in his recent admissions which in the family's view, resulted in early relapse and readmission.

She was aware that professionals believe that Andrew's preoccupation with his bowel was delusional. However, she was able to confirm that there is a significant history of death from bowel cancer in his family, thus reinforcing the team's plan to investigate his physical complaints more assertively, which reassured both Andrew and his family.


It was agreed that Andrew will be encouraged to write an advance directive when he is well, to make sure that his family continue to be engaged with the professionals in his care.

7th July 2020 – Presentation - Assertiveness and non-enabling behaviours, Dr Georgina Hurford, Clinical Psychologist

7th July 2020 – Presentation - Assertiveness and non-enabling behaviours, Dr Georgina Hurford, Clinical Psychologist



Georgina's presentation is below. Here are some additional points that came up in discussion:

- **Boundaries are important**, and they have to be accompanied by warmth: we need to show empathy, understand where our loved ones are coming from and help them 'name the emotion', for example 'You seem angry / worried / frightened'.
- **Praise the green shoots** of recovery to build confidence.
- **Falling into the reassurance trap** is one 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 et al. 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.
- The overarching goal is to **keep family life as normal as possible**. This is hard and we may need support from outside the family; from friends, colleagues at work, other carers, professionals. Look after yourselves!


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

Dr Georgina Hurford
Clinical Psychologist

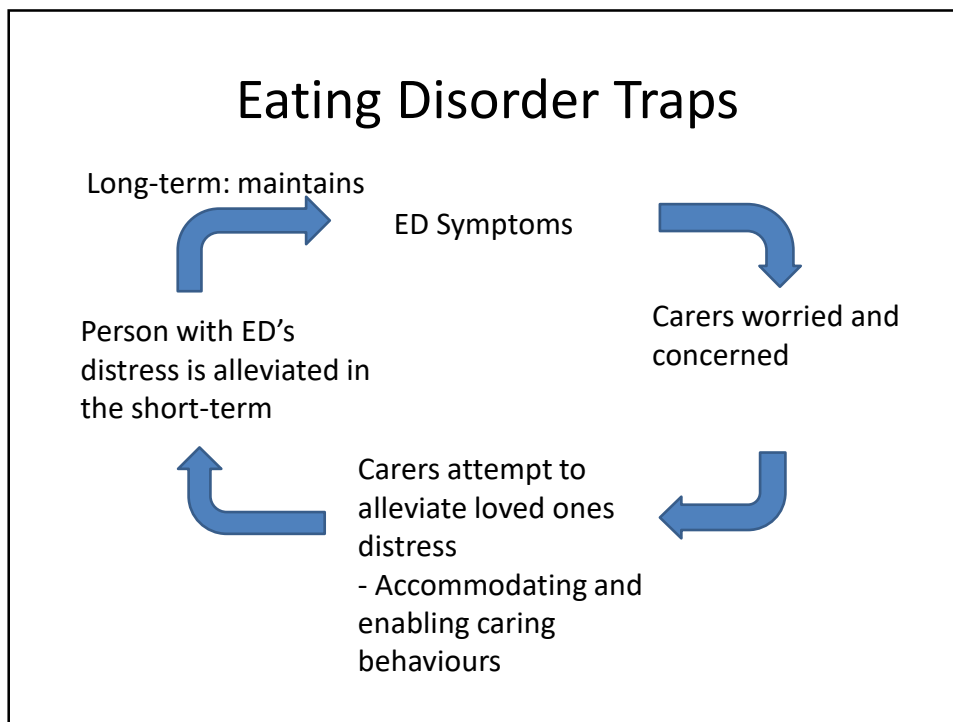

A member of Cambridge University Health Partners

Reflection point

Before and after....



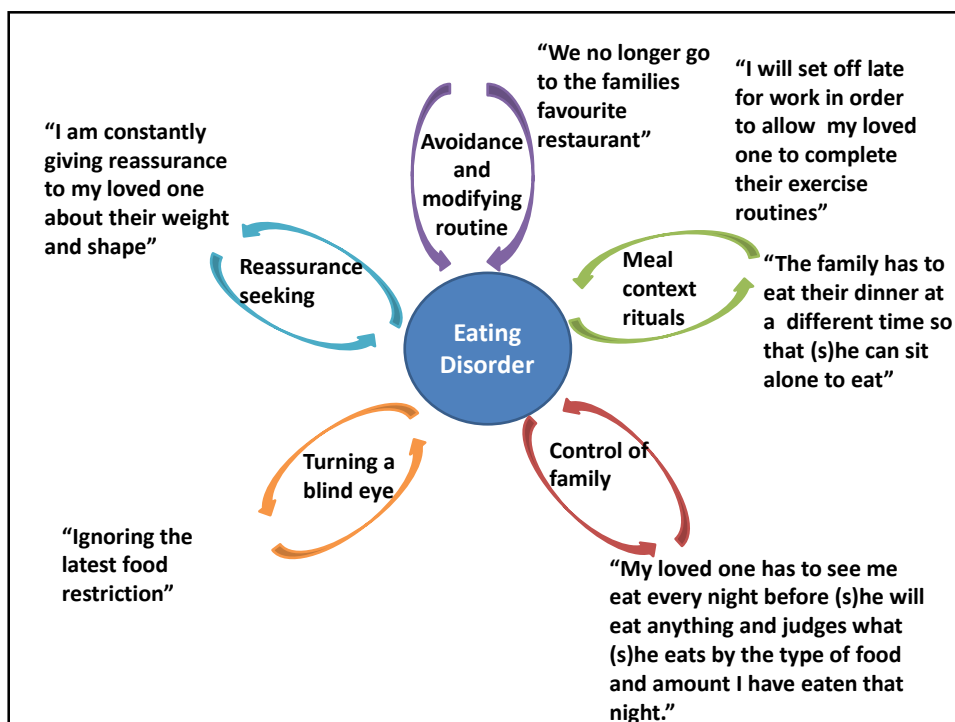
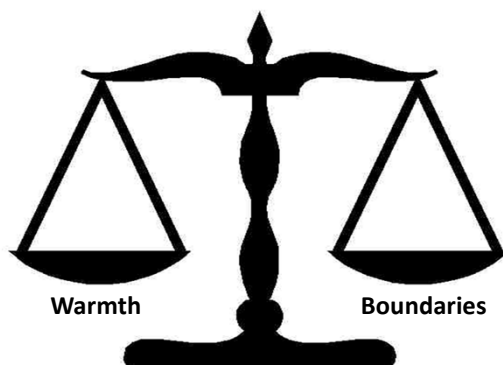
- Can you remember life before the eating disorder?
- In what way has life changed for you and for the family since the eating disorder arrived?
- What do you do more of? What do you do less of?



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)

Before we start... Getting the balance right



Barriers to change?

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

Steps to change

1. Self care all the way!
 2. Recognising the traps you are in and the fears you have about changing
 3. Discuss the changes you would like to make with your loved one when you are both calm
- Use dolphin skills – E-OARS
 - Empathy
 - Open Questions
 - Affirmations
 - Reflections
 - Summarizing

Tips for stepping out of ED traps

Accept that Change is Challenging...

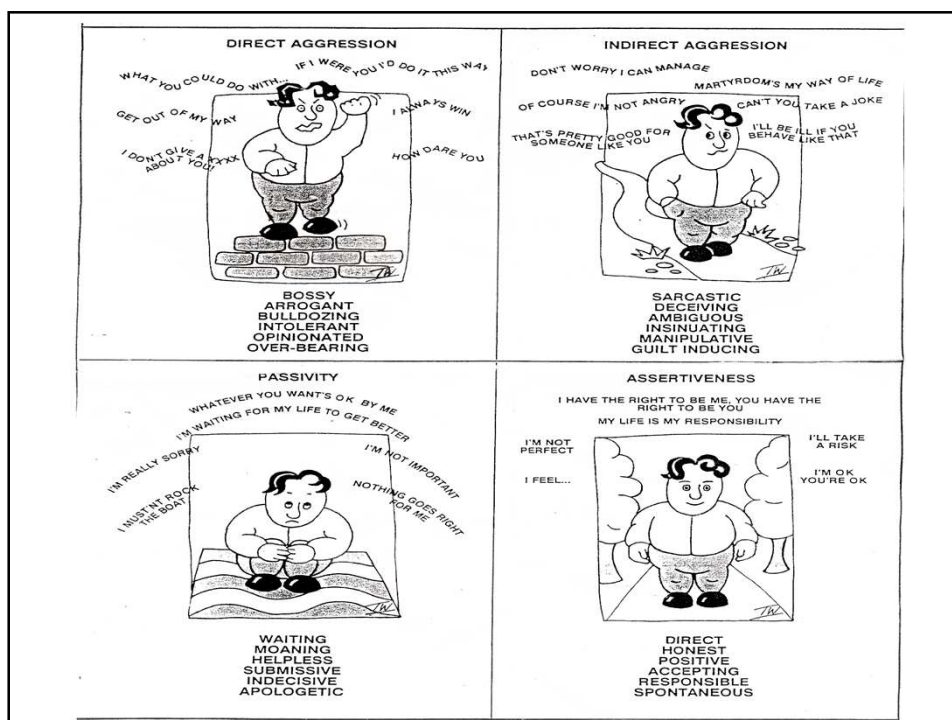
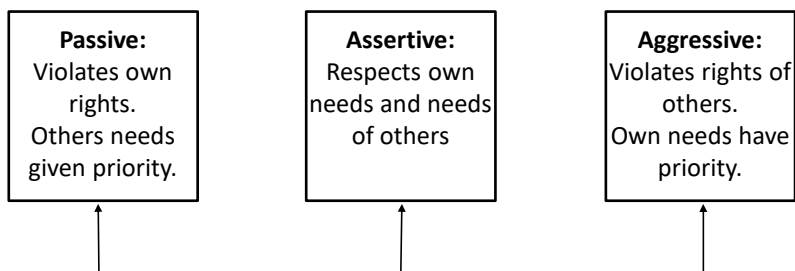
Any new approach requires the whole family to buy in and recognition that:

- Change is likely to be slow
- Treat each stage as an experiment
- Recognize possible barriers/ roadblocks to change
- Consider communication on an ongoing basis (e.g. family notebook)
- Aim for a consistent assertive approach
- Recognize behaviours might get worse before they get better
- A new approach takes courage, trust and commitment

What is assertiveness?

- Communication style.
- Ability to express your feelings, thoughts, beliefs, and opinions in an open manner that doesn't violate the rights of others.

The three communication styles



Strategies for saying no

- Assertive body posture
- Decide on your position before you speak
- Wait for the question
- Decide on your wording
- Don't apologise when it isn't necessary
- Don't defend yourself or make excuses when it isn't necessary
- Don't ask permission to say 'no'
- Strengthen your position
- The broken record technique
- Don't wait for acceptance
- Accept the consequences

Making requests

- What would you like to happen?
- What would be reasonable?
- Don't apologise for asking
- Avoid putting yourself down as part of the request
- Before making your request, define the situation
- Express how you are feeling in the situation
- Use "I" statements
- Be clear but brief
- Frame the request positively
- Focus on behaviour
- Describe the outcome

Providing corrective feedback

- Watch the ratio
- Think before talking
- Talk one to one
- Be precise
- Include the positive in the message
- Cement the relationship
- Give information and advice
- Focus on the behaviour, not on the person

14th July 2020 – Transitions

14th July 2020 – Transitions

The focus for our discussion this week was **Transitions**, particularly from home to university and from sick leave to return to work. Looking through my notes I think we covered almost every aspect good caring, so I am restricting myself to three summary points on the grounds that that is as much as I can ever remember!

- **Any transition is a big change** and is almost certainly going to make our loved one (and us) anxious. So, all the principles of good caring need to kick in. Get alongside your loved one to understand their thoughts and feelings; help them articulate these; and nudge, but don't direct, their decision making, for example they might be planning to go to university against professional advice, but might still be in two minds about this, so conversations to explore the discrepancy could be helpful: 'On the one hand you really want to start your course, **and** on the other you are worried that you might not have the energy for a full day's study, or be able to join in with the other students'. Let it hang, let them draw their own conclusions.
- **The team supporting your loved one, the place of work, the college - all want to put measures in place so that things go well.** They should welcome any information you can provide that will support them in this goal. There is no harm in contacting them and although this is better done with your loved one's consent it could be done in confidence. If your loved one is receiving treatment and is transferring to another university/college, the ED service will, with the consent of your loved one, be in touch with the GP / ED service they are being transferred to, so there should be a plan to monitor and support your loved one's care. If returning to work, the Service may make contact with occupational health (with consent/discussion).
- In the same way that **planning ahead** with your loved one in less stressful moments is important, make your own plans in advance, for example how will you react if the return to work fails (answer calmly and learn from it!); how are you going to keep in touch.

And the fourth of my three points is:

- **Our loved ones have to learn to manage their illness themselves;** they have to take their own decisions, even if it is against professional advice. It was striking how many of us shared experiences of our loved ones failing at university initially, but succeeding subsequently, often on a different course and/or at a different university.

We were also reminded that '**other stresses are available**' when our loved ones move away from home and it may not be the eating disorder that is the problem.

21th July 2020 – Resilience and Holidays

21th July 2020 – Resilience and Holidays**Resilience**

The first issue we discussed was **resilience** - how we keep going we feel like giving up, or when we feel overwhelmed by the pressure of 'being here again'. I think most, if not all, of us have been there. There were some really helpful suggestions:

- remembering that you've got through it before
- thinking of the illness as a third person so that you can still see your loved one
- writing things down / keeping a diary - many carers find this a good way to relieve stress
- remembering that recovery from an eating disorder can be like a game of snakes and ladders
- Seeking help for yourself, for example through your GP

Holidays

We then discussed **holidays**, both going away with and without our loved one. Going away 'with' is bound to be stressful for our loved one because it is a change of routine. There are things we can do:

- discuss in advance - what will make it easier?
- research places to eat online
- explain to the staff in restaurants - the vast majority will be very helpful
- be realistic - the illness cannot be left at home
- our loved one will be experiencing challenges not faced at home and will almost certainly succeed at some - so there should be some green shoots to praise and, hopefully, some good memories, too

If we go away and leave them at home, it's about planning and 'long distance care'. Do you have a family member or friend who could support if there was an emergency? Have you discussed how you will keep in touch - it's a perfectly reasonable discussion to have and an opportunity to demonstrate trust (whereas over-monitoring can raise anxiety and damage trust).

We may worry about leaving them behind but we do need respite: small breaks can be as beneficial as longer ones.

There was one piece of advice common to both of today's issues: **small steps can lead to success.**

21th July 2020 – Resilience and Holidays

I have pasted the links A---- has researched for us below.

I've also attached two documents to help with the transition to university, which are very relevant to last week's discussion. See [Appendix](#):

Planning for University is written for carers by Jenny Langley, who provides carer support in the South East. Jenny's website is definitely worth looking at.

Preparing for University is written for students and supports an early intervention programme called 'FREED'.

And don't forget Charlie Mackesy - <https://www.charliemackesy.com> !

<https://pbs.twimg.com/media/EcgBwYbXQAIXDTt?format=jpg&name=medium>

Resources

Web links

Jenny Langley, who provides carer support in the South East

www.newmaudsleycarers-kent.co.uk

Mental Health Matters <https://www.mhm.org.uk/>

Resources <https://www.mhm.org.uk/Pages/FAQs/Category/helpful-resources>

Moodgym <https://moodgym.com.au/>

Relate <https://www.relate.org.uk/>

Self Help leaflets (Cumbria, Northumberland, Tyne and Wear NHS FT)

<https://web.ntw.nhs.uk/selfhelp/>

Including Anxiety, Eating Disorders and Stress - A---- drew attention to this page in the Stress leaflet:

Challenge your stress thoughts

The following questions and answers might further help you to **challenge your stressed thoughts**:

Q: Are you expecting too much of yourself and aiming to be perfect? Perhaps trying to achieve the impossible?

A: Aim for good enough. Don't compare yourself with others in an unhelpful way.

Q: Are you focusing on your weaknesses and ignoring your good points?

A: Write a list of all your strengths and achievements and keep it close to hand. Remind yourself of what you are good at. It is easy to forget this when feeling stressed.

Q: Are you taking responsibility or blame for something that isn't really in your control?

A: Just remind yourself 'I can only do my best, it's out of my control'

Q: Are you worrying about something that might never happen?

A: Use your mindful breathing, and just let the thought go.

Q: Are you underestimating your ability to cope if the worst did happen?

A: Remind yourself of how you have coped in the past and got through other difficult situations.

Q: Are you focusing on the negative all the time and starting to feel quite low?

A: Keep a **Gratitude Diary** by your bedside, and every night, jot down three things which have gone well that you are grateful for that day. This simple act which shifts our attention to the positive has been found to improve mood and reduce stress.

What goes on in our mind when we are stressed not only involves our thoughts and feelings, but also has a huge impact on our behaviour. So to control our stress it helps to have a good look at our behaviour and see if there is anything we can change to reduce our stress.

28th July 2020 – The Government's obesity strategy and Difficult communication issues

Government's obesity strategy

We began by discussing **the government's obesity strategy** and in particular the way it was being presented in the media, which can be very challenging for our loved ones. Advice from the group - it is not a new issue - included:

- Be as open as possible.
- Explain that it is aimed at people needing to lose weight.
- Explain that the aim of the strategy is for people to be a healthy weight and that for some people that means gaining weight.
- Present some of the medical facts.
- There is a positive because it is a potential opportunity to discuss your loved one's health with them. But remember 'it's feelings not food' that is the underlying issue.

As I said, we are not the only group concerned about this. BEAT's response is on their website <https://www.beateatingdisorders.org.uk/get-involved/campaign/current/public-health-not-public-shaming>.

I am in touch with other carer groups and one emailed me shortly after our meeting with this statement, which you may find helpful:

'On Monday Boris Johnson introduced new measures to curb the obesity epidemic in the UK with the introduction of nutritional information on menus, advocating calorie counting apps and other measures to help people with their fight against obesity. Of course, as carers of a loved one at the other end of the spectrum, this will inevitably make our role harder. When you consider that in the UK 68% of people are either overweight or obese and only 2% of people are below normal on the BMI scale you can see why the government are keen to focus on obesity as a major health crisis. This new raft of measures will however, likely impact your loved one.'

Difficult communication issues

We then shared experiences of some of those **really difficult communication issues**; for example, when our loved one puts the phone down and doesn't respond to a follow-up text or call. We also considered **how we manage our own emotions** when this happens.

The group had a lot of experience - if you find yourself in this position you are not alone. Some of the key points that came out of the discussion were:

- Just because they don't respond to a text doesn't mean that it hasn't helped and been appreciated. It communicates your concern and love for them, which is really important for them to know. The issue is how we manage our own emotions at not getting a response - it comes back to 'looking after (and out for) ourselves'.

28th July 2020 – The Government's obesity strategy and Difficult communication issues

- You could explain your concern and you may be able to come to an agreement, for example to phone every other day.
- Our loved ones have different 'preferred' methods of communication - some respond better to text, some to email, some to a phone call. Use their preferred method even if it is not yours and although there is no guarantee you will get a response there is a greater chance of success.
- It may be best to step back, letting your loved one know that you are there if they need you; this shows trust and is a good way of looking after yourself, too.
- Ask what you can do to help. You might not get a response but you are sending a message that you think help is possible.

And remember that **it takes time to become a dolphin!**

4th August 2020 – Presentation - Excessive Exercise and Eating Disorders - Dr Pia Thiemann

4th August 2020 – Presentation - Excessive Exercise and Eating Disorders - Dr Pia Thiemann

First, a big thank you to Dr Pia Thiemann for her presentation on 'Excessive Exercise and Eating Disorders'. Pia's presentation is attached and here are a few points that I noted down by way of a summary:

- Normal exercise, whether formal (for example team sports) or informal (for example gardening) provides physical, psychological and social benefits.
- Excessive exercise has none of these benefits. 'Excessive' is less about 'how much' and more about 'the reason', for example exercise being used to compensate for what has been eaten, or to control feelings.
- Treatment has to be tailored to the individual. There are three stages:
 - Preparation (for example creating an awareness of the problem),
 - Change ('cold turkey' or 'stepped') and
 - Recovery (for example the introduction of normal exercise).
- We cannot make our loved ones stop exercising, but we can support them.
- For example, and in relation to the change cycle:
 - Pre-contemplation (not thinking about change). We can work towards creating an awareness of the problem. Ask yourself what are the costs for them so that you can feedback to them, for example are they very tired, or in pain. You can try to share observations in a calm moment, for example 'I've noticed that you are very tired'.
 - Contemplation (beginning to think about change). Create ambivalence, for example 'On the one hand you want to go running but on the other you've not enough energy to do as well as you would like to'. Use open questions 'Why is exercise so important to you?'. Targeted support is often difficult in the pre-contemplation and contemplation stage. What you can do is work on your relationship, trying to have quality time with no eating disorder related topics. Look after yourself because you don't know how long this stage will be.
 - Planning and Action. When your loved one is preparing for and taking action you can be more directly involved if they want you to and remember to validate their feelings, for example 'I see that this is very hard for you, I'm here for you'.
 - Relapse - if your loved one relapses help them to get back on track by reminding them of their past successes and that you are there to support them.

4th August 2020 – Presentation - Excessive Exercise and Eating Disorders - Dr Pia Thiemann

It is important to remember that our loved one's behaviours should not dictate our behaviours, for example the benefits of normal exercise can be a very important part of carer coping.

Other matters!

You will have received the invite to next week's meeting and to the Carer Engagement Event on 18th August.

Resources

For those who find Mindfulness techniques and practice helpful, A---- saw this in the Daily Telegraph recently:

Using Cues to trigger Mindfulness by Linda Blair (Clinical Psychologist)

- You probably know how to practice Mindfulness, but so often it's difficult to feel ready to let go of your worries and judgments. Yet these are usually times when you most need a Mindfulness break.
- That's where a cue will help, both to trigger readiness to practice and to 'remind' yourself how good it will feel to set aside those five minutes.
- If you have a garden or take walks, look for a natural object that appeals—a pebble, stick or leaf. If you must stay inside, choose a small knickknack. Whenever you practice Mindfulness, pick up your object first, and during your practice describe the object to yourself. Don't judge or compare it with anything. Just describe it.
- Getting to know that object well means after about six sessions, simply seeing it will trigger the desire to allow yourself five minutes to refocus and refresh yourself.

Exercise and Eating Disorders

Carers Group 4th August 2020; Dr Pia Thiemann (Clinical Psychologist)

Overview

Your experiences

Exercise

What is exercise? Why are we exercising?

Exercise and eating disorders

How does exercise in eating disorders look?

How does exercising keep eating disorders going?

How do we treat excessive exercise?

What can I do as a carer?

What is your experience of exercise in eating disorders?

What do you want to know?

Normal Exercise

What is exercise?



Icons downloaded from freepik.com

Normal Exercise

Benefits of exercise

- physical
- improves heart and lung function
 - improves muscle and skeletal strength, joint flexibility, helps maintaining a healthy weight
 - improves sleep pattern
- psychological
- improves confidence
 - improves mood
 - helps to let go of stress
 - can provide a support system
- “150 minutes of moderate exercise or 75 minutes of vigorous exercise per week”**
(Government guideline for health levels of exercise for individuals with BMI > 18.5)

Excessive Exercise in Eating Disorders

What is exercise?

- Regular exercise
- Covert exercise
- Persistent restlessness
- 
- compulsive or excessive exercise**

Icons downloaded from freepik.com

Excessive Exercise in Eating Disorders

“I use exercise to compensate for what for I have eaten”

“Exercising allows me to eat”

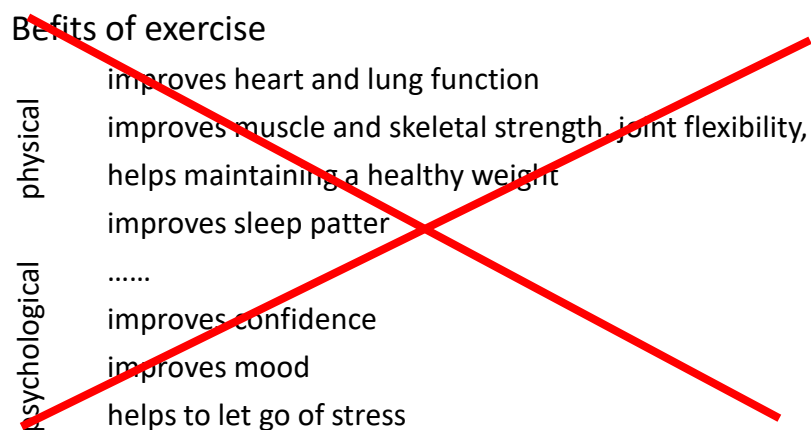
“I think about exercise a lot and avoid social or work commitments if it would mean I couldn't exercise”

“I exercise even when I am tired, ill or injured”

“Exercise is the only way that I feel better about myself”

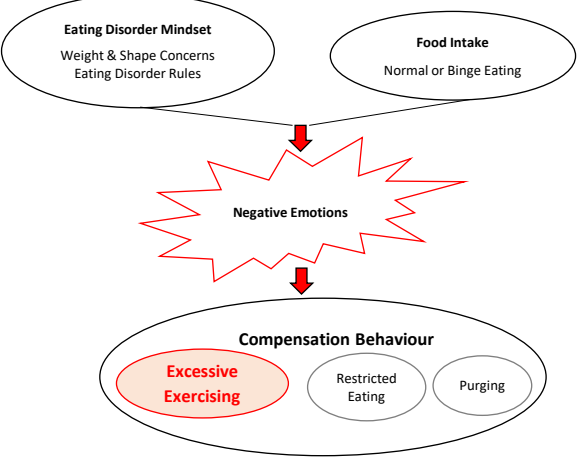
Excessive Exercise in Eating Disorders

Benefits of exercise

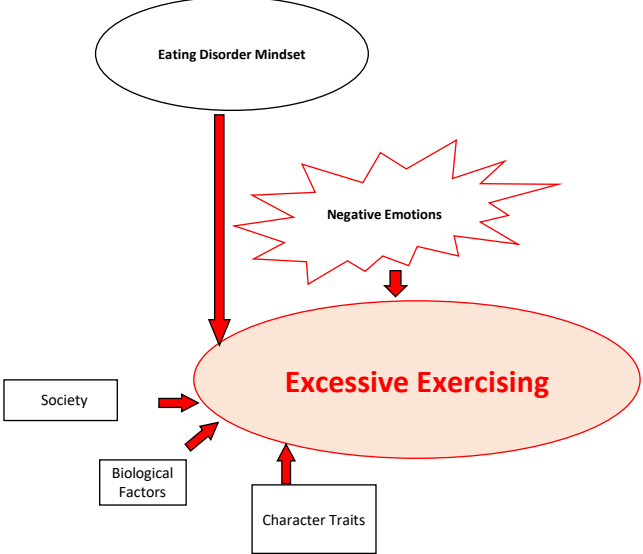


physical	improves heart and lung function
	improves muscle and skeletal strength, joint flexibility,
	helps maintaining a healthy weight
	improves sleep patter
psychological
	improves confidence
	improves mood
	helps to let go of stress

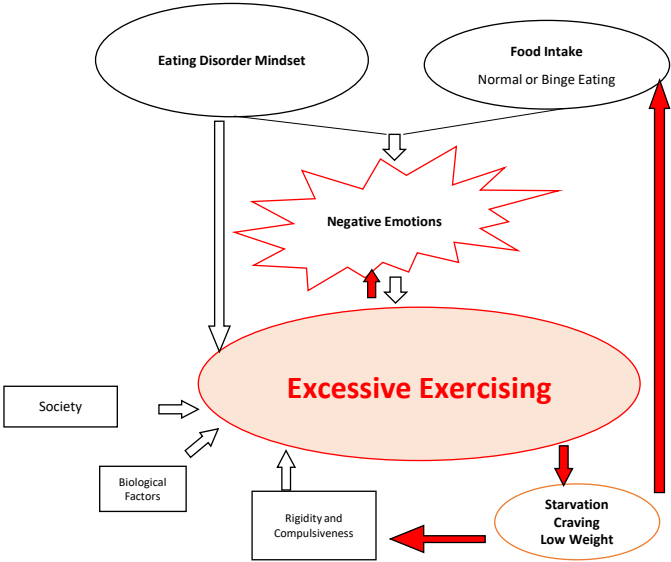
Excessive Exercise = Compensation Behaviour



What makes Excessive Exercise more likely?



How EE keeps the ED going



The Exercise Trap



adapted from The Reassurance Trap BEAT, Kings College London South London Maudsley

Excessive Exercise and Emotions



How we treat Excessive Exercise:

Preparation

- Psychoeducation
 - Monitoring
- Create awareness of the problem and motivation for change

Change

- "Cold turkey" or stepwise reduction
- Cognitive work
- Emotion regulation skills

Recovery

- Introduction of healthy exercise
- Relapse prevention

What can I do as a carer?

You can not make your loved ones stop exercising,
but you can support them.

What can I do as a carer?

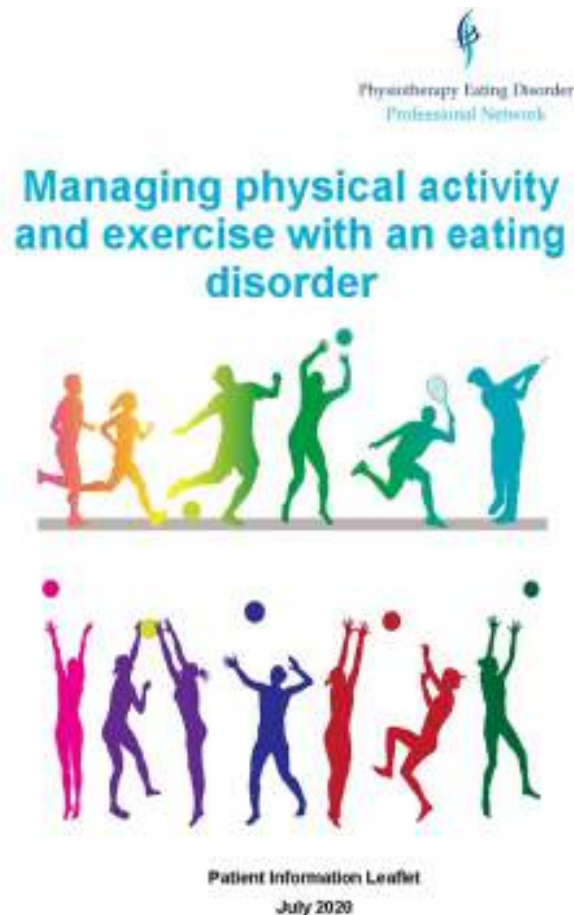


Adapted from Prochaska and DiClemente's Stages of Change Model

4th August 2020 – Presentation - Excessive Exercise and Eating Disorders - Dr Pia Thiemann

Links to Further Reading and Resources

Managing physical activity and exercise with an eating disorder



[https://cpmh.csp.org.uk/system/files/documents/2020-07/managing physical activity and exercise with an eating disorder pedpn july 2020.pdf](https://cpmh.csp.org.uk/system/files/documents/2020-07/managing_physical_activity_and_exercise_with_an_eating_disorder_pedpn_july_2020.pdf)

7 warning signs that your exercise is becoming destructive

<http://www.rethinkyourbody.co.uk/blog/2017/08/31/7-warning-signs-that-your-exercise-is-becoming-destructive>

Exercise and Anorexia: The Case for Cold Turkey (patient experience)

<https://tabithafarrar.com/2017/05/exercise-anorexia-case-cold-turkey/>

Research paper

Meyer, C., Taranis, L., Goodwin, H., & Haycraft, E. (2011). Compulsive exercise and eating disorders. *European Eating Disorders Review*, 19(3), 174-189.

11th August 2020 – Really challenging thoughts and feelings

11th August 2020 – Really challenging thoughts and feelings

Thank you for another supportive discussion, I think it's so helpful that we can be open about some really challenging thoughts and feelings. Here is my summary of the three main ones that we discussed on Tuesday:

Gaining weight more rapidly

Our loved one **gaining weight more rapidly** than you would expect from what they are eating. This can cause a range of emotions for our loved one and for us. It can be upsetting to think that their body is not responding normally. Sarah Beglin explained that starvation and overeating disrupt our body's metabolism but it does recover with a normal eating regime. There is a lag but the readjustment takes weeks rather than months. Some medication has weight gain as a side effect. The group found this knowledge useful and reassuring.

The tough discussion

Having the '**tough discussion**', especially when you prefer to avoid conflict. Some key principles came out of us sharing our experiences:

- **Be curious rather than judgemental.** For example, if our loved one is threatening to discharge themselves from hospital, ask 'How are you going to manage at home?' rather than saying 'I don't think that's a good idea'.
- **Refer to the higher authority.** 'Your doctors have agreed what's best for your treatment, we're here to support you with that'. The 'higher authority' can be something you've read or something that you've heard, for example at this support group.
- **Arguing doesn't work**, our loved one will come up with more ideas for why they are right and you are wrong, making the problem worse.
- **Pick a calm moment** - if emotions are high it is unlikely that any discussion will be productive.
- Tough discussions need **lashings of empathy**, for example 'I see that this is really hard for you to talk about'.
- **Do be a dolphin/St Bernard but don't be a rhino/ostrich**, i.e. don't avoid 'tough discussions' but do be supportive and calm.

11th August 2020 – Really challenging thoughts and feelings

Relationships with people with an eating disorder

Our loved ones' **relationships with people with an eating disorder**. We discussed both sides of the coin. Such relationships can be supportive and pro-recovery. They can also be 'toxic' - we heard of one experience where a friend made in an inpatient setting encouraged one of our loved ones to regress. Reflecting on my notes I can see that the experiences we discussed lead to the same principle whether the friendship is positive or negative:

- **Do be curious:**
 - What do you enjoy about each other's company?
 - What are you doing together?
- **Don't be judgemental**
 - 'I don't think you should be seeing / talking to them.'

The latter will drive friendships underground... and may remind some of us of relationships we had in our youth when our parents said that?!

18th August 2020 – Boundaries, Managing emotions and Supporting siblings

18th August 2020 – Boundaries, Managing emotions and Supporting siblings

A special thank you to Suzanne and Will for keeping us on track this week and for checking this summary, which I hope you find helpful. We discussed three main issues:

Food hoarding / state of bedroom / personal space.

The group had a number of helpful observations from experience:

- There is **often a correlation with the illness** - with recovery this becomes less of a problem.
- **Boundaries are important**, for example '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.
- Any discussion of boundaries requires **empathy** - the illness may have drained their energy levels and what seems a small request to us may feel like a major ask to them.
- Our loved ones **may feel shameful** about the situation, so encouragement is much more likely to succeed than challenge.
- **Do be a dolphin, don't be a rhino and don't be an ostrich!**

Managing the roller coaster of emotions that our loved one expresses.

I think everyone recognised this as a major challenge - one day things are OK, the next they are not; one day you have a great conversation, the next day they are upset / challenging. How do we cope with this?

- **Accept that it is a roller coaster** - remind yourself that downs are followed by ups.
- Try your best to **appear calm** - take a step back, count to ten, say the third thing that comes into your head, not the first.
- Remember that **it is the eating disorder talking**, not your loved one.
- If you don't feel up to dealing with it at the time, acknowledge what they are saying, explain that you are, for example, tired and offer to come back to it.
- **Discuss 'side by side' not 'face to face'** - it really does seem to make a difference.
- Try to **steer the conversation to non-eating disorder issues**.
- **Look after yourself** - being on a roller coaster is physically and mentally demanding.

18th August 2020 – Boundaries, Managing emotions and Supporting siblings

How best to support siblings

Not surprisingly this was another issue that most of us had experience of:

- **They need to understand the illness as we do**, so some basic information (for example from BEAT > search 'Siblings', leaflet attached) 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 maturer for it.
- There are **dedicated support groups for young people**, for example all local authorities commission young carers groups, and the BEAT leaflet, attached, gives further details.

Resources**Web links**

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

BEAT Young Carers leaflet



**I'm worried about someone
with an eating disorder...**

Talk eating disorders with Beat.

**Eating
disorders
are mental
illnesses.**

**Eating
disorders
can be hard
to spot.**

**Recovery is
possible.**

What is an eating disorder?

Eating disorders are mental illnesses. They aren't the same as changing your diet – they can take over someone's life and the lives of those around them. While unhealthy eating behaviour is involved, they aren't about food. Instead, they are about feeling in control or coping with something else. People with eating disorders are often secretive about their eating, and may feel guilty and ashamed. All eating disorders are very serious, and everyone who has one deserves care and support. The good news is that recovery is possible.

In this booklet, we'll talk about different eating disorders and the treatment someone might have. Eating disorders differ from person to person – there are common signs, but someone with an eating disorder doesn't have to have them all. This is part of why eating disorders can be hard to spot, and it may take some time before someone is officially diagnosed. There's lots more information at beateatingdisorders.org.uk.

What is anorexia?

People with anorexia may eat very little food, or binge (eat lots of food all at once) and then exercise or make themselves sick so they don't gain weight. Someone with anorexia is likely to be a lower weight than expected for their age and height.

Signs may include:

- Worry about gaining weight.
- Not seeing their body the way you do.
- Being secretive about their eating.
- Doing lots of extra exercise.
- Feeling dizzy or faint.
- Wearing baggy clothes to hide their body shape.
- Feeling cold.
- Isolating themselves from others.

Learn more
about anorexia at
[beateatingdisorders.org.uk/
anorexia](https://beateatingdisorders.org.uk/anorexia)

What is bulimia?

People with bulimia may binge (eat lots of food at once) and then make themselves sick, exercise obsessively, or take laxatives because they feel guilty about what they've eaten, worry about their bingeing, or because their stomach is so painful. This is known as purging. Often someone with bulimia will stay a "normal" weight, which can make it even harder to spot.

Signs may include:

- Yo-yo weight changes.
- Secrecy around food.
- Exercising lots more than usual.
- Going to the toilet after meals.
- Isolating themselves from others.
- Poor skin.
- Scars on fingers, knuckles, or backs of hands, and bad breath from being sick.
- Feeling bad about their body image.

Learn more
about bulimia at
[beateatingdisorders.org.uk/
bulimia](https://beateatingdisorders.org.uk/bulimia)

What is binge eating disorder?

People with binge eating disorder may binge on a regular basis. Bingeing isn't just eating a bit more than usual – it might be days' worth of food in one sitting. Usually the food is what we might call "unhealthy". Binges will often be planned in advance and the food eaten in secret. Someone might feel "better" while bingeing, but afterwards they'll feel guilty and anxious about what has just happened. Their way to cope with this may be to plan their next binge.

Signs may include:

- Eating in secret.
- Hiding food packaging.
- Gaining weight.
- Spending lots of money on food.
- Self-conscious about eating in front of others.
- Loss of confidence and low self-esteem.
- Isolating themselves from others.

Learn more about
binge eating disorder at
[beateatingdisorders.org.uk/
BED](https://beateatingdisorders.org.uk/BED)

What is OSFED?

OSFED stands for "other specified feeding or eating disorder". If someone is diagnosed with OSFED, it means that their symptoms don't quite fit with what doctors expect of anorexia, bulimia, or binge eating disorder, though it is just as serious.

What is ARFID?

ARFID stands for "avoidant/restrictive food intake disorder", where someone avoids certain foods or limits how much they eat. This can be for a number of reasons, for example, they might be sensitive to certain tastes or textures, have had a bad experience with food, or not be interested in eating due to other reasons.

Learn more about
OSFED and ARFID at
[beateatingdisorders.org.uk/
types](https://beateatingdisorders.org.uk/types)

Why does someone get an eating disorder?

We don't know the exact answer, but research is leading to better understanding. We know it could be down to someone's genetics or biology – there's lots of research into how the brain works that's starting to tell us more.

Eating disorders can be triggered by many things. These might be significant life events, like moving house or school, parents splitting up, or someone close to the person passing away. They could be things like stress from school work or trouble with their friendship group. People may also experience pressure from classmates, social media, and things like adverts, that makes them worry about the way they look and feel the need to change. These aren't the only reasons – we'd run out of room if we tried to list them all!

Anyone of any age, gender or background can have an eating disorder.

What happens when someone is diagnosed with an eating disorder?

Depending on their eating disorder and other factors, a person will need to see their doctor, school nurse or other healthcare professional to access treatment. For bulimia and binge eating disorder, self-help may be recommended first – for example, keeping food and mood diaries. If someone is diagnosed with anorexia, they will probably be advised to access outpatient treatment such as therapy first of all. Sometimes they may need inpatient treatment, and during this they will usually stay in the hospital full time.

Full recovery from eating disorders is possible.

How can I help?

Eating disorders don't just affect the person involved but their family and friends too. Here are some ways you can help:

- 1. Talk to them.** Ask if things are okay, if there's anything they want to talk about, and if there's anything that would help, and remember they are still a person and more than just their eating disorder.
- 2. Learn about eating disorders.** Having knowledge can help you understand why the person is behaving like they are, and lets them know you care. Beat's website contains lots of information about eating disorders.
- 3. Stop the body talk.** We can all be guilty of talking about body shape and weight, but it can be an extra sensitive subject for someone with an eating disorder.
- 4. Make sure they know you're always there to listen and support them.** But don't feel you have to make every conversation about their eating disorder. It can be helpful to both of you to take your minds off things with the same conversations you'd usually have.

When you care about someone, it's understandable to want to fix things.

Remember eating disorders are complicated, and your friend or family member might need support from doctors to get better.

Sometimes the person doesn't think they need help or just isn't ready to talk. Remember that's not the person you know but the eating disorder taking over. Trust your instincts – if you're worried, tell a parent or another trusted adult what's going on.

Talk to them...

Stop the body talk...

Learn about eating disorders...

Be there...

Don't forget to look after yourself

Supporting someone with an eating disorder can be exhausting. It's important to look after yourself too, because you can't help them if you are not well yourself.

Sophie struggled when her younger sister was diagnosed with anorexia at the age of 14.

" I was lost. No one would talk about the real issues. Everyone avoided the topic. I felt like I had lost my best friend. I was never really allowed to be fully involved because my parents decided it was "better" for me. I was distraught and empty. My friends didn't truly understand the anguish I was going through. After a few years I found Beat, and just knowing someone out there felt the same way I did made me feel like I was "normal" again. With other people's support, I finally realised the only way I could help my sister was to first take care of myself. I was no use to anyone

when I was so depressed. It's completely understandable to feel the way I did, but I needed reassurance that I was allowed to take time for myself. I sought the help of counselling services and found even just talking about everything that bothered me made me feel so much better. The main thing anyone can do for a sibling or friend who is suffering with an eating disorder is be there for them. It sounds simple, but anyone who has supported someone through an eating disorder will know it is anything but. Eating disorders affect everyone close to the sufferer, and I think a lot of people forget that it's normal for siblings or friends to feel lost, depressed or helpless. The main thing is to ask for help if you feel like this. Despite how you may feel, you are the most important person, you are your number one priority, and you deserve help. **"**



Don't forget to look after yourself

Lots of people who know someone who is suffering with an eating disorder feel the way Sophie did. Here are some ways you can take care of yourself:

1. Take time for yourself: relax and spend time with people who care about you.

2. Write about what's happening in a diary, or creatively through poetry or music.

The eating disorder is changing everything

It's natural to feel negative emotions about the eating disorder. You might feel it's taking over everything – your relationship with the person and other people around you. If it's your brother or sister, it might seem like your parents are focussing all their attention on them. Don't keep these feelings bottled up – talk about them.

Even though things can get very difficult, remember the person isn't doing any of this deliberately, and with the right treatment and support they can get better.

3. Make sure there's someone you can talk to, like a trusted adult. You can also call or email our Youthline.

Glossary

There are lots of medical terms you might hear about eating disorders. We've explained some of them below.

AMHS: "Adult Mental Health Services" – the specialist mental health services that are accessed as an adult, usually over the age of 18.

Antidepressants: Medicine used to reduce symptoms of depression. A doctor might (but not always) prescribe these to someone with an eating disorder.

BMI: Body mass index is a measure that uses your height and weight to work out if you're healthy.

CAMHS: "Child and Adolescent Mental Health Services" – the specialist mental health services accessed under the age of 18.

CAT: Cognitive analytical treatment is a therapy used to treat eating disorders. A therapist will work with a person to help make positive changes. Sometimes it will look at how someone has coped with problems in the past.

CBT: Cognitive behavioural therapy is one therapy used to treat eating disorders. It helps people link thoughts, feelings and actions with their eating disorder behaviours.

Day patient: If someone is a day patient they might visit the hospital during the day and then go home at night before returning again.

Diagnosis: A doctor will look at someone's signs and symptoms and give them a diagnosis. Eating disorder diagnoses might include anorexia, bulimia, binge eating disorder or EDNOS/OFSED.

ECG: Electrocardiographs are a test that records the activity of the heart.

Electrolytes: Vitamins and minerals in the blood often measured or monitored with a blood test.

Glossary (cont.)

Family therapy: Family therapy involves the whole family and not just the individual with an eating disorder.

Inpatient: If someone is an inpatient they will stay in hospital full time. Sometimes this can be over weeks or months.

Mental Health Act: If a doctor thinks someone is too unwell to make decisions about treatment, or if someone refuses treatment, they can be treated under the Mental Health Act, which means someone else will make decisions about their care.

Outpatient: Someone who attends hospital appointments but doesn't have to stay overnight.

Section: If someone is sectioned, they are being treated under the Mental Health Act.

Directory

Here are the details of helplines and websites that provide further help and support

Beat's services

Call or email our Youthline, 0808 801 0711 • fyp@beateatingdisorders.org.uk. Find help and support in your local area at helpfinder.beateatingdisorders.org.uk. Follow Beat's Support services on Twitter: @BeatEDSupport 📱 BeatEDSupport

actionforchildren.org.uk – Action for Children work with and support young carers across the UK, providing practical and emotional support.

barnardos.org.uk – Barnardo's runs 20 services across the UK, which work to support young carers and their families in a variety of ways. Search for their services online.

childline.org.uk – Childline is a free, private and confidential service to help anyone under 19 in the UK with any issue they're going through. You can contact a Childline counsellor by phone 0800 1111 or get in touch via online chat or email.

themix.org.uk – The Mix offer support to anyone aged 13 to 25. You can chat with people going through similar experiences to you online or speak to one of their advisors online or by free phone 0808 808 4994.

Looking for support?

Youthline: 0808 801 0711 fyp@beateatingdisorders.org.uk

Studentline: 0808 801 0811 studentline@beateatingdisorders.org.uk

Visit beateatingdisorders.org.uk for more information and online support services

 [@BeatEDSupport](https://twitter.com/BeatEDSupport)  [BeatEDSupport](https://www.instagram.com/BeatEDSupport)

Beat, Unit 1 Chalk Hill House, 19 Rosary Road, Norwich, Norfolk, NR1 1SZ

0300 123 3355 • info@beateatingdisorders.org.uk

 [@beatED](https://twitter.com/beatED)  [beat.eating.disorders](https://www.facebook.com/beat.eating.disorders)

With thanks: Beat is grateful to the funding from BBC Children in Need to create this leaflet and the contributions from volunteers.

Last reviewed: February 2020.

Sources used to create this information are available by contacting Beat. We welcome your feedback on our information resources.

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25th August 2020 – Inpatient Treatment

25th August 2020 – Inpatient Treatment

The challenge we focused on was **inpatient treatment** and I have summarised our discussion below:

- Sarah Beglin explained that **the vast majority of people are treated as outpatients** which means that people get to practice recovery skills in their home environment. The decision to offer inpatient treatment is based on a range of indicators that mean our loved one's health cannot be managed safely in the community. These include physical factors, for example rate of weight of loss, abnormal blood results, blood pressure, core temperature and strength tests, as well as psychological factors, i.e. our loved one's state of mind.
- **Inpatient treatment is not a quick fix.** It is part of a process of recovery that can take a long time. As carers we should be reassured that our loved one is getting appropriate, specialist care but it is important to accept that the reality is that for most people it is a stage in a marathon.
- **Inpatient treatment has advantages and disadvantages** for our loved one and for us, for example it is more intensive, but it is more disruptive of normal life. Carers should be reassured that it will not be offered unless it is the right treatment for our loved one at the time.
- As carers we should take the opportunity of a reduced caring responsibility to **recharge our batteries: this is really important.**
- Being worried about our loved one's return home is quite understandable. However, this will be a managed (usually staged) process. We are never left on our own without a number to ring. **There is always a discharge plan** and this will involve us as carers unless there are exceptional circumstances.
- **Some patients are unable to maintain their health on discharge and require a second admission.** This is a very worrying time for carers. It is really important to remember that most people do recover, recovery can take a long time and it is a roller coaster with ups and downs. This is why it is so important that we look after ourselves.
- **Inpatient admission can have practical implications for our loved one**, as can their illness for us as carers, for example time out of work, additional expenses. The inpatient unit will support your loved one and they can also arrange a **formal Carers Assessment for you that may be able to provide support such as respite care.**

25th August 2020 – Inpatient Treatment

Previously, we have discussed '**long distance caring**', which is very relevant to talking to our loved one on the phone when they are an inpatient. Here is our summary from 28th April!

- keep the line of communication open, don't push it, eventually our loved ones will open up
- our role is to be there to listen, don't try to fix things
- do help our loved ones to find their own way forward - lots of open questions, check that you've understood what they are saying (that will help them to sort out their own thoughts, too), listen, listen, listen, pull it all together and don't give an opinion unless asked

1st September 2020 – Presentation - Distress tolerance and managing strong emotion in the context of eating disorders - Will White, Trainee Clinical Psychologist

1st September 2020 – Presentation - Distress tolerance and managing strong emotion in the context of eating disorders - Will White, Trainee Clinical Psychologist

Will's slides are attached and here are a few additional notes summarising some of our conversation:

- Will stressed that **negative emotions are not inherently bad**. They warn us when there are threats or challenges. However, too many can feel overwhelming and the danger is taking action on the basis of raw emotion that we are sorry for later.
- It is better to **regulate rather than repress** emotions - see Will's slide about this. When emotions are high it is not a good time to work out solutions.
- We discussed **ways to tolerate distress**. Some of the 'top tips' were
 - to distract ourselves (although I'm not sure that the example of cleaning and hoovering would reduce my personal stress levels);
 - contribute to something outside of ourselves, for example a volunteering activity, helping a friend with their garden; engage with something the opposite of your current emotional state, for example if you are feeling low, watch/listen to a comedy; and
 - treat yourself to enjoyable sensations, for example a hot bath. Will's message was, 'Give some a go, try some out, see what works for you!'
- If we find ourselves **in a fog of emotion**, it can be hard to know what to do next or disentangle emotions and thoughts. It can be helpful to write them down, or talk to someone outside of the stressful context or crises about what you are experiencing, to help make some sense of what is going on.
- **If our loved one is distressed** many of the ideas we discussed can be 'flipped', for example helping our loved one learn how to recognise and name their feelings, and find ways of managing them. The most helpful thing is to show **empathy** ('I can see that you are at the absolute end of your tether') and to **listen** so that our loved can express their emotions and let them out.
- Will emphasised **how hard managing strong emotions is**, but that we can learn to be better at it and that being a good role model for our loved one is something very positive we can do to support their recovery.

Distress tolerance and managing strong emotion in the context of eating disorders

Will White
Trainee Clinical Psychologist



10/09/2020



A member of Cambridge University Health Partners



A quick bit about me...

10/09/2020

Plan for this presentation

- Show you some of the strong thoughts and feelings that we have all experienced in response to crises.
- We are going to talk about the importance of these emotions and thoughts
- Will cover some distress tolerance strategies



10/09/2020

Crisis – “a time of intense difficulty or danger”

- My loved one didn't eat anything at the meal
- My loved one took lots of slimming pills
- My loved one has lost a lot of weight
- My loved one has hurt themselves
- My loved one made themselves sick
- My loved one has had another binge
- My loved one is still over exercising
- My loved one doesn't want to get better
- My loved one is isolating themselves from me
- My loved one is shouting at me, we had a huge argument

10/09/2020

What EMOTIONS have you experienced that you have found hard to deal with following a crisis?

- Despair
- Frustration
- Impatient
- Anxiety
- Sadness
- Guilt
- Fear
- Confused
- Painful
- Exhaustion
- Panic
- Depression
- Inadequate
- Angry
- Hopeless
- Bewildered
- Hurt
- Sense of loss

10/09/2020

What THOUGHTS have you experienced that you have found hard to deal with following a crisis?

- Is this going to go on forever
- I want to escape
- How can I fix it
- Are we helping
- I can't anymore
- Will we ever be happy again
- Why did I never notice it
- Why could I never stop this
- Why didn't medical professionals notice it
- This is too much for this person to bear
- Where can I/we get help

10/09/2020

The importance of emotion



- Feeling emotions are a part of what it means to be human
- Negative emotions aren't inherently bad, they warn us when there are threats or challenges (e.g. fear responding to danger)
- So raw emotions aren't dangerous, however they can feel overwhelming
- The danger lies in taking action on the basis of raw emotion in the moment, as often we do things in the moment that we are sorry for later and can make the situation worse.

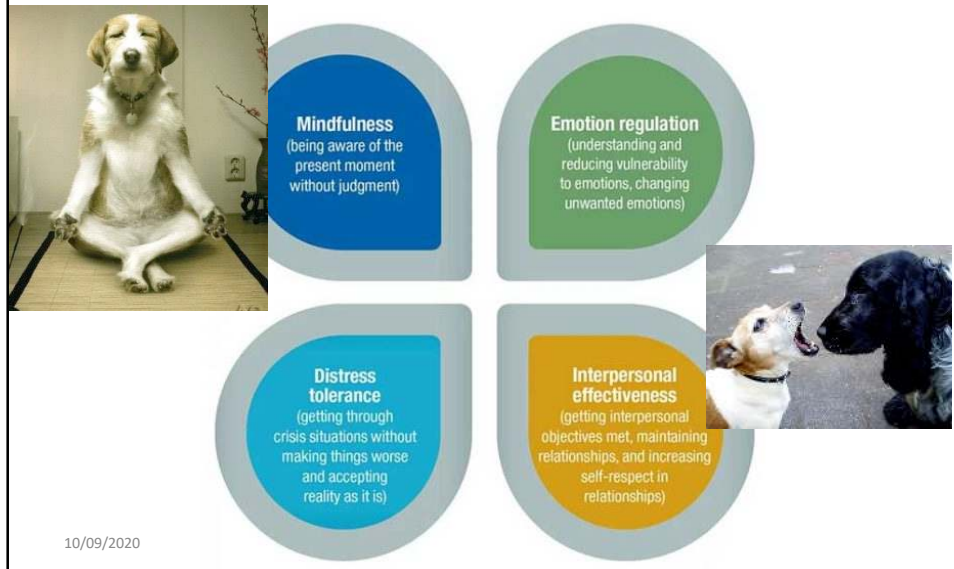
10/09/2020

So what can we do in the moment when we are experiencing distressing emotions?

10/09/2020



Managing stressful and challenging emotions



Emotion regulation

- the ability to exert control over one's own emotional state
1. Allow all feelings, yours and your loved one's
 2. Notice the feelings that come and go
 3. Don't take feelings personally
 4. Notice how you defend against vulnerable emotions
 5. Resist the urge to act on feelings
 6. Notice that whilst feelings are real, conclusions drawn in the heat of the moment might not be true
 7. Instead of acting on feelings, use them as information
 8. Take time to get out of the fight flight, freeze response

10/09/2020

Distress Tolerance

- Learning to tolerate negative emotions or crisis situations without responding in unhelpful ways
- Radical acceptance
- Distraction (ACCEPTS)
 - **A**ctivities, **C**ontributing, **C**omparison, **E**motions, **P**ushing away, **T**houghts, **S**ensations



10/09/2020



10/09/2020

8 September 2020 – Plans for Uni, 'Dips' and Independence

8 September 2020 – Plans for Uni, 'Dips' and Independence

It was good to hear that many had had a good week.

Uni

Plans for starting or returning to university are well underway and the group shared useful information about support services. Sarah said that the Community Eating Disorders Service is developing its 'university transition checklist' and if there is anything that you think would be a useful inclusion please email it to me and I will pass it on. Some links and information from our discussion, and from A---'s daughter, are included at the end of this summary.

Dips

Not everyone had had a good week and we spent some time discussing **how we can help our loved ones when they have a 'dip'**. This is almost inevitable because recovery rarely, if ever, goes in a straight line. A number of suggestions were made based on our experience:

- **What have they learnt from therapy?** The more our loved ones learn, the more resilient they become. It can be helpful if we support them to think things through, for example 'What did you find helpful the last time you felt like this?', or 'What has your therapist suggested you should do if you find yourself feeling this way?'
- **Offer support, with empathy**, for example 'I'm really sorry you are struggling like this again. I would like to help if I can, let me know what you would find helpful'.
- **What worked before?** Can you spot any patterns? Are there any triggers that you can anticipate? Have you noticed things that help your loved one find their way back up after a dip? You can then use these as the basis of a conversation, for example 'I noticed that the last time you felt like this you really benefited from (a day out on the Norfolk coast). What about us doing that this weekend?'

As ever, there are no guarantees of success, but these are things that we can do as carers that might help.

Independence

We then discussed **the issue of independence**; to what extent do we trust our loved one to take responsibility for themselves? There are many contexts for this understandable concern, for example discharge from an inpatient unit, being left at home while we take a break. That there is often so much evidence of our loved ones not being able to make healthy choices adds to our anxiety.

- The consensus was that being a 'kangaroo' - protecting our loved one and doing almost everything for them - was unhelpful because they will never learn to look after themselves, they will never have to face up to the illness.

8 September 2020 – Plans for Uni, 'Dips' and Independence

- As ever, it's much better to be a 'dolphin' - being there to nudge them along and support them if they start to sink. So, for example, it can be helpful to 'be around' so that they can ask for support if they stumble.

In practice there is a transition, a shifting balance as our loved one takes more responsibility. To quote Janet Treasure, '**They alone can do it, but they can't do it alone**'.

Thank you for this really supportive discussion.

Resources**Suggestions re University**

University Health Service GP

IAPT Services

Some Halls have Student Resident Mentors who can signpost resources.

Student Groups

Mental Health Matters	https://www.mhm.org.uk/
Nightline	https://www.nightline.ac.uk/
Student Minds	https://www.studentminds.org.uk/
Sane	http://www.sane.org.uk/
The MIX	https://www.themix.org.uk/

Plus

The Samaritans

BEAT

Mind

Headspace

15 September 2020 – Physical and Interpersonal Distance

15 September 2020 – Physical and Interpersonal Distance

Sarah chaired today's meeting in Keith's absence - we all hope that he is having a well-earned break!

We began as we always do by going round and checking in with everyone, and it was lovely hearing some good news from some of you. One of the key words to summarise some of the difficulties that talked about today could be **distance**; whether that be physical distance from our loved one when they are on S3 or transitioning to university, or more interpersonal distance when we feel as if our loved ones are not sharing things with us concerning their eating disorder.

Physical distance

Coping with university transitions and providing support from afar – physical distance

- We reflected that many of us are **concerned and worried** about our loved ones either attending university for the first time or returning following the holidays. We raised specific concerns around:
 - uncertainty,
 - the practicalities of organising medical monitoring,
 - registering with a new GP,
 - accessing therapy and having to go to the bottom of the waiting list again,
 - being able to judge how our loved one is doing from afar.
- We explored how helpful it is to know that our loved ones have **someone local to them** when at university, to act as a source of support. Whilst they can provide another set of eyes and ears, we felt that they cannot take full responsibility for our loved one, as this would be cruel and unrealistic. Whilst we tend to look to professionals and university support services to help (see next bullet point), we can also consider the **wider support network**.
- We felt that it can be helpful to **explore the range of support services available** to students, including
 - out of hours care,
 - phone lines,
 - counselling, both academic and pastoral support.

All this information can be found out on the university websites.

15 September 2020 – Physical and Interpersonal Distance

- We reflected on the **Preparing for University** - A guide for those recovering from an eating disorder document shared within this group in July 2020. A helpful suggestion was that we can all **plan ahead**, whilst things are calm, for a time when things go wrong, and when things go right. Another key theme of today's session was that **recovery is like a roller coaster**, there are ups and downs. Maybe if we can plan for both the ups and downs in advance, we will feel better prepared when we get there?
- It was shared that when we experience **acute stress or anxiety**, it can be helped to **have a day out**, to do something that you find **enjoyable**, to **look after yourself**. We also spoke about sharing our difficult thoughts and how we are feeling with others whom we trust, which often results in us feeling better. However, there are difficulties with this when our loved one doesn't want others to know about their difficulties, and we have to be mindful about confidentiality. A good idea might be **to be upfront with your loved one, to explain your intentions and reasons for needing to share**, and to come up with a shared compromise.
- Finally, we tackled the challenging subject of **what to do with worries**, when you are being kept up at night, for instance, ruminating. One strategy was to engage in mindfulness, focussing on remaining in the present moment, dealing with the here and now, rather than projecting into the future and predicting what might happen. Useful resources were suggested either for engaging with mindfulness, or for providing your mind with something to focus on and get lost in when dealing with anxious thoughts.

Interpersonal distance

Coping with **secretiveness and feeling as if we are not being involved** – interpersonal distance.

- We explored how many of us feel that **information is withheld** by our loved ones, especially concerning their eating disorder and the care that they are receiving, and that this is a common difficulty when supporting adult children.
- **One of the hardest things can be when a loved one doesn't seem to recognise or acknowledge that they are unwell, and that we get embroiled in pretending that everything is fine when we know it isn't.** Can our loved ones really change and recover if they don't recognise their difficulties?
- We shared how sometimes it can be that a **different form of communication needs to be established**, so that our loved ones feel more comfortable sharing information. Many of you talked about how useful you have found it to **write** to your loved ones in the form of letters or notes, and how helpful it has been for your loved ones in return to communicate in this way. Letter writing can have a dual purpose: to help you to get difficult feelings and emotions off your chest, and to foster more meaningful communication.

15 September 2020 – Physical and Interpersonal Distance

We shared **how conversations can be made easier** where eye contact does not need to be held at all times; when in the car, or when completing a shared task. **Talking in the third person** or as if talking about a friend can also be a useful way of depersonalising the conversation, reducing potential feelings of judgement.

- Finally, it was felt that **a lack of communication is a reflection of the illness**, not the person, that **eating disorders thrive on secrecy and control**, so it can be helpful to expect resistance from our loved ones.

A---- has very helpfully spent time combining the numerous summaries from Keith, and highlighted how important notes from past groups will be for furthering the conversation had today. This combined document is to be published soon – thank you! A---- also cited some helpful advice for carers from **Stephanie Yeboah** regarding her recent work **Plus-Size Women Suffer From Eating Disorders Too**.

Finally, and as always, **it's important to remember to look after ourselves, to keep our batteries charged for the marathon that is caring for something with an eating disorder**. We are very much looking forward to Suzanne's talk on this very subject in two weeks' time.

Thank you for this supportive discussion. Have a good day everyone! Best wishes,
Will

Resources

Mindfulness apps

Calm <https://www.calm.com/>

Headspace <https://www.headspace.com/>

Audiobooks or stories from YouTube

Examples were Paddington (Will's 'go to' bedtime stories are the Harry Potter audiobooks read by Stephen Fry).

Autonomous sensory meridian response (ASMR)

A helpful website explaining this concept in more detail and provides some examples videos <https://www.vox.com/2015/7/15/8965393/asmr-video-youtube-autonomous-sensory-meridian-response>

22 September 2020 – Off to Uni, COVID and Motivating

22 September 2020 – Off to Uni, COVID and Motivating

I thoroughly enjoyed my break and it was good to be back! We had a great discussion: one of my reflections on the last six months is that **as we have gained confidence and trust we have begun to talk through some of the 'really hard ones', which can only be helpful**. This week we considered three topics.

Going off to university

We briefly re-visited **going off to university**. Some of our loved ones have gone back and things seem to be going well. Some of our loved ones are still anxious about their imminent return. Those whose loved ones have already gone off to university offered the following based on their recent experience:

- **Listen** to their hopes and concerns; **validate** their worries, **don't try to fix them**; encourage them to think about how they have coped with this and/or other anxiety provoking situations before; **help them to find their own way** forward.
- **Support them to plan**, for example, having a routine. Have a look at Dr Sarah Beglin's slides on Activity Planning in the attached presentation - our very first session, so not all of you will have seen this before. See [21st April 2020 – Presentation - Coping with lockdown - Dr Sarah Beglin](#)
- **More validation** - most people find making friends in a new place an anxious time - hearing from you, for example, that most people feel anxious when they join a club or society but this will pass, and is a good way to get to make new friends, may be very helpful.
- If they are returning to university, **talking about how it is going to be different** in C-19 times may also be helpful.

COVID 19

We then touched briefly on the current situation with regards to **COVID-19** (another reason for re-circulating Sarah's presentation). This is a worrying time for everyone and it is really important that we look after our own health and manage our own anxiety levels.

- Suzanne told us about **CPFT's Recovery College**; we have free access to their online courses.
- A----- told us about '**Better Health - every mind matters**'
- C----- described how **yoga and meditation** had helped her to manage her anxiety levels:

Mindfulness: A practical guide to finding peace in a frantic world by Hachette Audio UK

22 September 2020 – Off to Uni, COVID and Motivating

Motivation

We had a longer discussion about motivation: how can we **help our loved ones to find the motivation to make the next step in their recovery**. Some observations from our experience were:

- **Motivation is very individual.** Generally, it was felt that most people with an eating disorder are not motivated by 'things', for example, 'if you do this, I will give you this reward'. However, some are, with time and context being important too. We heard an example of when the offer of a paid for family holiday had been a good motivator.
- **Listening** is very important because motivation is very individual. Listen for, and pick up on, what your loved one is or might be motivated by and encourage this.
- **Look out for the things that they enjoy**, even if they are only small things - they are 'green shoots' that can be nurtured and help our loved one to see a future.
- **Encourage our loved ones to stay in social networks because eating disorders thrive on isolation.** Friends can be very helpful, although if they lack understanding it can be a problem. BEAT has some good guidance for Family and Friends

'Motivation' is a big topic and I am delighted to say that Lynn Eldred, the Service's Team Manager, has agreed to give a presentation about this on 17th November.

A big thank you to Pia for joining us this week and a reminder that Suzanne White is presenting to us on 'Looking After Yourself' at our next session on 29th September - tomorrow! - remember to have pen and paper to hand to join in with the activities!

Resources**Recovery College**

<https://www.cpft.nhs.uk/about-us/recovery-college-east.htm>

Every Mind Matters

<https://www.nhs.uk/oneyou/every-mind-matters/>

Mindfulness

<https://soundcloud.com/hachetteaudiouk/sets/mindfulness-a-practical-guide-to-finding-peace-in-a-frantic-world>

BEAT guidance for Family and Friends

<https://www.beateatingdisorders.org.uk/uploads/documents/2020/2/beat-carers-booklet-1.pdf>

28 September 2020 – Presentation - Looking after Ourselves Suzanne White, Clinical Support Worker

**28 September 2020 – Presentation - Looking after Ourselves
Suzanne White, Clinical Support Worker**

On everyone's behalf I would like to begin this week's summary with a big thank you to Suzanne White, Clinical Support Worker with the Cambridge AEDS for her presentation 'Looking After Ourselves', which is attached. It was great, and stimulated some really good discussion.

Looking After Ourselves

Suzanne stressed that **good health is made up of many layers**, each of which needs to be cared for:

- **Mental health** - this can be jeopardised by a caring role and there is no shame in seeking professional help if needed.
- **Physical health** - keeping fit is very important to well-being.
- **Social health** - remaining connected to family and friends.
- **Self-identity** - it is important not to sacrifice things that make you who you are, for example, perhaps you always organised a neighbours get together at Christmas - you should try to still do it (COVID compliant, of course!).
- **Sense of purpose** - perhaps you get great satisfaction from helping with a community activity - keep it up if at all possible.

Suzanne challenged us

- **to identify some things that we have not done for a while,**
- **to choose one we think we could do and**
- **to set ourselves a SMART target.**

There was a **wide range of examples** from the group including guitar lessons, time out to listen to music, ballet classes, sorting out the garden shed, tennis lessons, a short break with our loved one's brother or sister, new hobbies, listening to audio books. Wow!

Lynn Eldred, the Service's Team Manager, **reminded us how important it is to take a breath and pause**. If we don't look after ourselves, we cannot carry out our caring role effectively. It's a hard thing to do but it is essential.

The group made a number of contributions that might be **helpful follow-ups**:

- **Making Space** is the organisation commissioned by Cambridgeshire and Peterborough Local Authorities to provide support for carers of loved ones with a mental health illness. We will be asking them to give a presentation to us in the near future;

28 September 2020 – Presentation - Looking after Ourselves Suzanne White, Clinical Support Worker

- **Cambridgeshire County Council Library Service**, which gives access to free e-books, audio books and e-magazines;
- **Balance App**, see resources
- A..... also reminded me of a good way to **prioritise tasks** when you are very busy:

URGENT IMPORTANT DO	URGENT NOT IMPORTANT DELEGATE
NOT URGENT IMPORTANT SCHEDULE	NOT URGENT NOT IMPORTANT FORGET

Mantra Treatment

And finally, we had a brief discussion of the Mantra treatment programme that the Service has just introduced. Here is a link to some information about it

http://thenewmaudsleyapproach.co.uk/wp-content/uploads/2019/05/collaborative_care_slides.pdf

See you next week - in the meantime I hope things go as well as possible for you and your loved one. **And remember - look after yourself!**

Resources

Making Space

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

Cambridgeshire County Council Library Service

<https://www.cambridgeshire.gov.uk/residents/libraries-leisure-culture/libraries/library-online>

28 September 2020 – Presentation - Looking after Ourselves Suzanne White, Clinical Support Worker

Balance App Coach - this week “Support”

'Whenever I'm feeling overwhelmed, I go through a four-step process to support myself.

- *First, I feel my feet against the surface beneath me.*
- *Then I take a few deep breaths, relaxing my body every time I exhale.*
- *And then I listen, allowing myself to be present and relaxed as sounds come and go around me.*
- *Finally, I try to offer myself some kindness. A simple phrase that I like is “I am enough.”*

Of course, you don't have to practice all of these together. You can do any of them by themselves and get some benefit. Give it a try. I hope it's helpful!

CARING FOR OTHERS LOOKING AFTER OURSELVES

BY SUZANNE WHITE

CLINICAL SUPPORT WORKER AEDS CPFT

Looking after ourselves when caring supporting love for others can be a bit of a balancing act.

It easy to put our loves one's needs at the forefront of what we do sometimes not leaving room for our self-care and wellbeing.

CHECK IN: Am I feeling half full or half empty ??



WHAT CAN I DO NEXT???

Thinking about the many ways that you can look after yourself here are some examples

MIND - Mindfulness, self-compassion, talk about what is happening

BODY- Exercise, rest, attend our own medical appointments

CONNECTIONS - Family, friends, sense of community

SELF - IDENTITY - Who am I as an individual ?? what things do I do that are unique to me.

PURPOSE - Volunteering, creative activities, working, nature

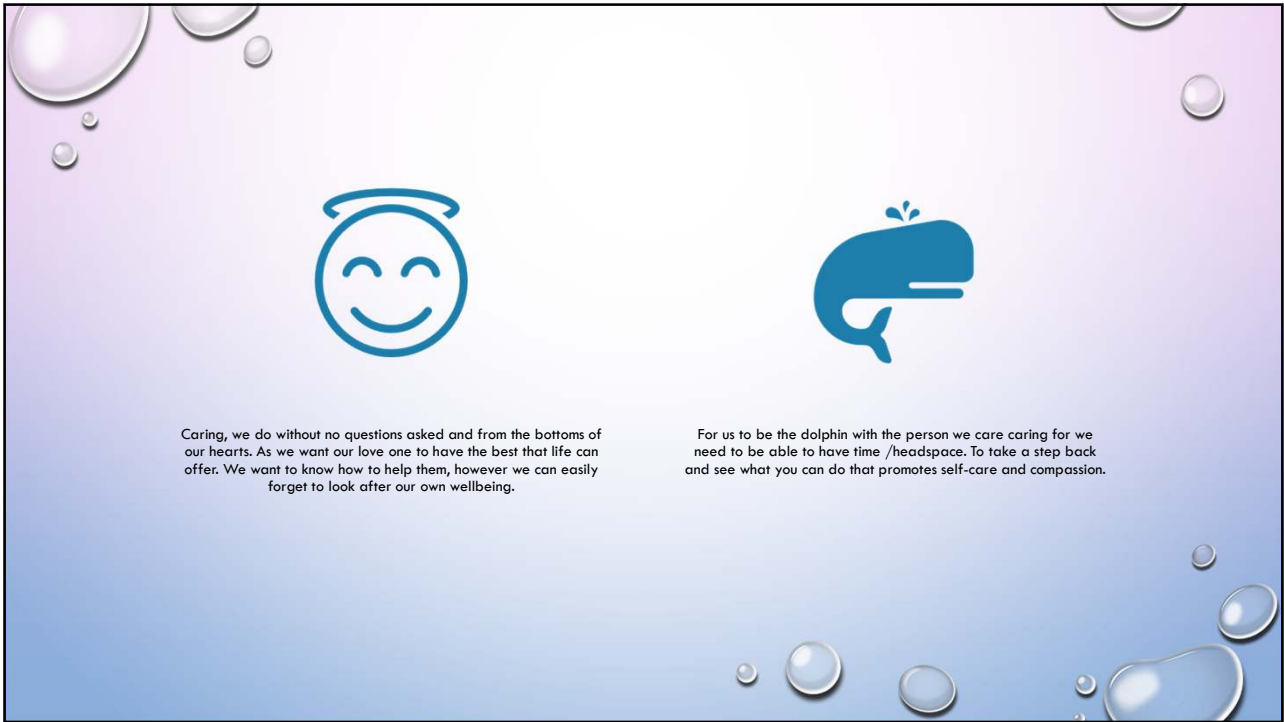
Activity – write down all the things you like doing now and what things you like doing that you have not done for a while.

SET YOUR SELF A GOAL

When setting yourself a goal it useful to remember the following:

- S**pecific (simple, sensible, significant).
- M**easurable (meaningful, motivating).
- A**chievable (agreed, attainable).
- R**elevant (reasonable, realistic and resourced, results-based).
- T**ime bound (time-based, time limited, time/cost limited, timely, time-sensitive).





APPENDIX

APPENDIX

Planning for University

Preparing for University

Collaborative Care New Maudsley Skills Workshops for Carers Additional Workshop Capsule Preparing for University

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 planning to head off for university. This is a major transition and potentially a very exciting step forward, but also can be incredibly daunting for families where an eating disorder is lurking. Eating disorders often emerge and/ or re-emerge at key times of transition, and/ or relapses might be more likely. Transitions might be:

- **Puberty**
- **Moving from adolescent to adult services**
- **Being discharged from services**
- **Leaving school**
- **A bereavement**
- **Going to University**
- **Leaving Home**
- **Relationship changes, marriage/ divorce**
- **Changing jobs/ redundancy**

In this capsule we will focus on the challenges families face when planning for university and also throughout the university course.

Planning for University When Your Loved One has an Eating Disorder.

Contents of Capsule:

- 1. Planning for University – tips for prospective students**
- 2. Using Carer Skills to help your Loved One**
 - OARS**
 - Developing Discrepancy**
 - Readiness Ruler**
- 3. Constructing a Framework for Planning**
 - Contact with Family**
 - Medical Care and Support Networks**
 - Crisis Cards**
 - Warning Signs that your Loved One is Struggling**
- 4. Assessing Medical Risk from a Distance**
- 5. Your Loved One has a Great Support Team but Doesn't Use It Properly**
- 6. The Last Few Weeks Before University can be Tough**
- 7. Appendix - Sources of Support**

1. Planning for University – tips for prospective students

Let us first consider some top tips for prospective students from a young person who has been to university and has had a history of eating disorders.

The top tips below are based on the Beat Booklet “Embracing Change” (see Appendix for link). The young person featured had developed an eating disorder at the age of 13 and became totally obsessed with controlled restrictive eating and obsessive exercise. She says “University became one of my biggest transitions to this day. Coping with further education was difficult due to the extreme pressure I’ve always put on myself. It would have been very beneficial if I had been notified of extra support at student welfare. When I was at university I thought of myself as recovered but thinking back now I still had bad habits, including frequently eating alone, struggling to cope with group meals, cooking with others. However, some things helped me through that time”

Top Tips

1. Be open so that people can help you and try to understand.
2. Don’t be too upset if people say the wrong thing. They might not know anything about eating disorders.
3. Don’t hesitate to seek out help that is available at University or in the community.
4. Take mementos with you & talk to someone who has already moved to that University.
5. Try to set SMART goals around your work schedule and establish a daily structure.
6. Seek out Student Support Services and let your tutor know if you are struggling.
7. Be easy on yourself and plan extra-curricular activities with others.
8. Plan and prepare as much as you can before you go.
9. Accept that nobody is a perfect student.
10. Find out if you are eligible for any financial assistance eg student disability allowance.
11. Find a confidante that you can talk to if you are having a bad day.
12. Plan your social life carefully and at your own pace. Not all students are out drinking every night.
13. Find out if there are any support groups either in the University or locally.
14. Plan your meals so they are comfortable for you.
15. Don’t feel you have to explain your meal choices.
16. If you are going to a restaurant check out the menu online before you go.
17. Decide in advance whether full board, half board or self-catering is going to suit you best. If self-catering work out in advance your food budget and the best places to shop.
18. Keep in touch with your family and friends who have helped support you through your recovery. Plan regular phone calls, texts, skype and visits so you know that you never need to be alone.

As a carer you are most likely to be concerned that your loved one is going to be safe so I would also add to this list

SIGN UP WITH A GP

As a carer you can do much to help your loved one plan for this exciting transition to university. However, the standard health warning still applies and, if anything is even more important as you will no longer be able to monitor your loved one on a daily basis.

If you have doubts about your loved one's ability to look after their own nutritional health you might want to step in.

"If your illness means that you cannot be responsible for your nutritional health then I have a duty of care to safeguard your life. In court I would be considered negligent if I just stood by and did nothing"

Try to balance this with motivational language

"I know you want to go to University and I would like to help you plan for this so that we all feel comfortable that you will be safe when you are there"

2. Using Carer Skills to help your Loved One

One of the problems you might be facing, as a carer, is that your loved one desperately wants to go to university and truly believes that they are absolutely fine. In contrast you are worried about how your loved one will cope, you are not 100% happy that they are medically fit to go, and you are worried that the reason they are excluding you from helping prepare is because the eating disorder is seeing this as an opportunity to take control.

You are in two minds:

- "I need to step back and let my daughter become an independent young adult"

Vs

- "I can see she is incredibly fragile and I will not let this illness take her from me"

HEALTH WARNING

Balance your new carer skills with your assessment of medical risk. Sometimes you will have to step in and take over feeding/ parental control in the short term, but always look for the opportunity to step back and give increasing responsibility to ED

OARS

OARS can be useful to open a conversation about how things are going when your loved one is not inviting you to help out or be involved.

Scenario - Planning for University

George is determined to go to University in September and is adamant that he will be fine. He is currently seeing a counsellor once a week at adult services and has told his parents that the counsellor is completely happy about his plans to go to university and is

pleased that George wants to put his eating disorder behind him and proceed with his life. George is resisting any attempts from his parents to help plan for university. George is struggling to maintain a healthy weight and has recently increased his running and gym workouts. George has never lived away from home and is financially dependent on his parents.

OARS can be used to construct a conversation that might motivate George to let his parents help with the planning process.

Open Question

“George I would like to talk to you about your plans for university. I am concerned about you as I have noticed that you are struggling to maintain your weight and this might be difficult for you to manage at university with everything that will be going on. I know you don’t like me interfering so please can you help me understand what you are doing to ensure you are safe and physically able to join in with college life. Perhaps I am overreacting and you might be able to help me to calm my own worries.”

Affirmations

“We are so proud of everything you have achieved, both in terms of getting the fantastic results to get your place at university, and also in your determination to be independent and move on with your life. It took great courage for you to make that step when you were struggling so much with your eating disorder, and you have made so much progress. You are incredibly talented and I am sure you will do really well at university.”

Reflections

“You feel that you are looking after yourself and I shouldn’t worry so much?
So you would like me to leave you alone. You think I am interfering?”

Summary

“George I am so pleased that we have had this conversation and I can see that you are making a huge effort to be independent and to make a fresh start and establish yourself at university. I love you very much and as your Mum, I admit that I do worry about you and it does help me to understand your perspective so much better when we can have conversations like these. Shall we make a plan that we are both happy with and that will keep you safe?”

Of course the first few attempts at opening a conversation might fall on deaf ears, but you will have sown the seed that you really do care and that you really want to help. Even if George doesn't respond straightaway he will have registered your interest and positive intentions.

Developing Discrepancy and the Readiness Ruler

The aim of **developing discrepancy** is to help the student realise that there is a difference between where they currently are and where they want to be and that their current behaviour might be standing in the way of some of their goals. The goal is to motivate the student to resolve the discrepancy by changing their behavior. So this approach can be useful to sow the seed that maybe your loved one is not as prepared or ready to go to University as she thinks she is. For example:

"I know you really want to go to university in two months time, yet you seem unable to look after your nutritional/ emotional health & wellbeing right now "

"You say you don't want me to be involved in helping you plan for university, yet you keep telling me how helpful your friends' parents are being in helping them to plan"

"You are planning to move to self catering accommodation at university, yet you are currently unable to go to a supermarket on your own"

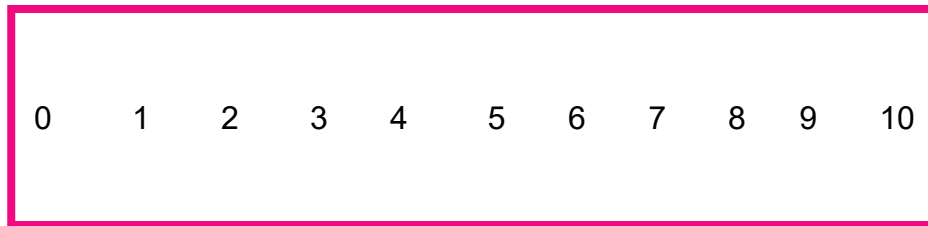
"You are planning to move to catered accommodation, yet at the moment you find eating in public places really difficult/ impossible"

"You don't want to see a therapist whilst at university, yet you tell me how important therapy is for you right now"

Of course you need to be careful how you say these things as your loved one is likely to be supersensitive to any sign of criticism. Calmly making statements that develop discrepancy shows your loved one that you care, that you are observing how things are for her now, and how they might be at University, and may serve to sow a small seed of doubt about the preparations your loved one has made so far. You might then have to take a step back and allow that seed to grow so that your loved one is more prepared to have a conversation with you.

The Readiness Ruler.

This is another really useful tool that carers can use to open up conversations about change



So carers could ask their daughter “On a scale of 0 to 10 how confident are you that you will be able to manage your own nutritional wellbeing when you are at university”

Your daughter might say 8, you might be thinking 2, but rather than arguing with logic you can take this opportunity to explore how she is really feeling by following up with reflections and further questions eg:

“I am impressed at your score. I know you have been struggling with your meal plan lately and I also know you are determined to work this out before you get to university. Help me understand what leads you to give yourself that score?”

This can often elicit some positive statements from your loved one as it helps them to consider any positive thoughts and behaviours that they might have, but have been finding difficult to express or even recognise. Reflections and affirmations can help your loved one to build on their confidence and help to show that you believe they can look after their nutritional wellbeing. Be curious whilst being careful not to criticise or dismiss. Having the conversation is a real step in the right direction even if you don't agree with everything your loved one is telling you.

You could also explore what might move their score, either further up or down.

“What do you think needs to happen for you to increase your score by ½ a point. What help could we give you to help move your score up?”

This recognises that the task is hard and small achievable steps are more likely to be successful than aiming for 10 straight away.

“What might affect this score and maybe push it down a little? Can I help you plan for any possible difficulties that might come up?”

Contingency planning is incredibly useful and this might give you the opportunity to bring in to the conversation things that you can see might be problematic, based on the difficulties you know your loved one has been having at home. This could be anything to do with food such as:

- Type and amount of food available
- Meal times
- Social interaction at meal times

Carers can also use this approach to help **develop discrepancy** whilst at the same time using the ruler, which is another very useful tool to elicit change thoughts and talk.

This can be used to discuss with your loved one how prepared and able they think they are to go off to University, balanced against the evidence that you are currently observing.

“On a scale of 0 to 10 how confident are you that you are fully prepared and ready for university?”

If your loved one claims they can score 8 or 9 on the scale, but the evidence you are seeing is that they are not so fully prepared or ready then you could enquire about this:

“I am interested in your level of confidence. Please could you help me understand why you give yourself an 8 whilst at the moment from what I can see, I can only give you a score somewhere below say a 5. Perhaps I am missing something”

Highlighting that you will always be there for them can be helpful:

“If there is anything I can do to help you with your planning and preparation then please say. I am more than happy to help and support you in any way I can – both practically and emotionally. I trust that when you would like help you will ask me. The offer is always open.”

Scenario

Steven is due to go to university in two months time. You know that he is hiding food and so not consuming sufficient calories to gain weight. Steven says he would score himself at a 6 on the nutritional risk ruler, whereas you would score him lower, say a 3. A conversation around this could be along the lines of

“Would you mind if I use the same ruler to mark where it seems you are from my perspective?”

“I would put you on a 3 because..... I can see you are hiding food and therefore finding it difficult to maintain your weight at the moment.....OR I can see you are very distressed and always seem to be cold.....OR the doctor has recorded that your blood pressure and pulse are very low at the moment etc”

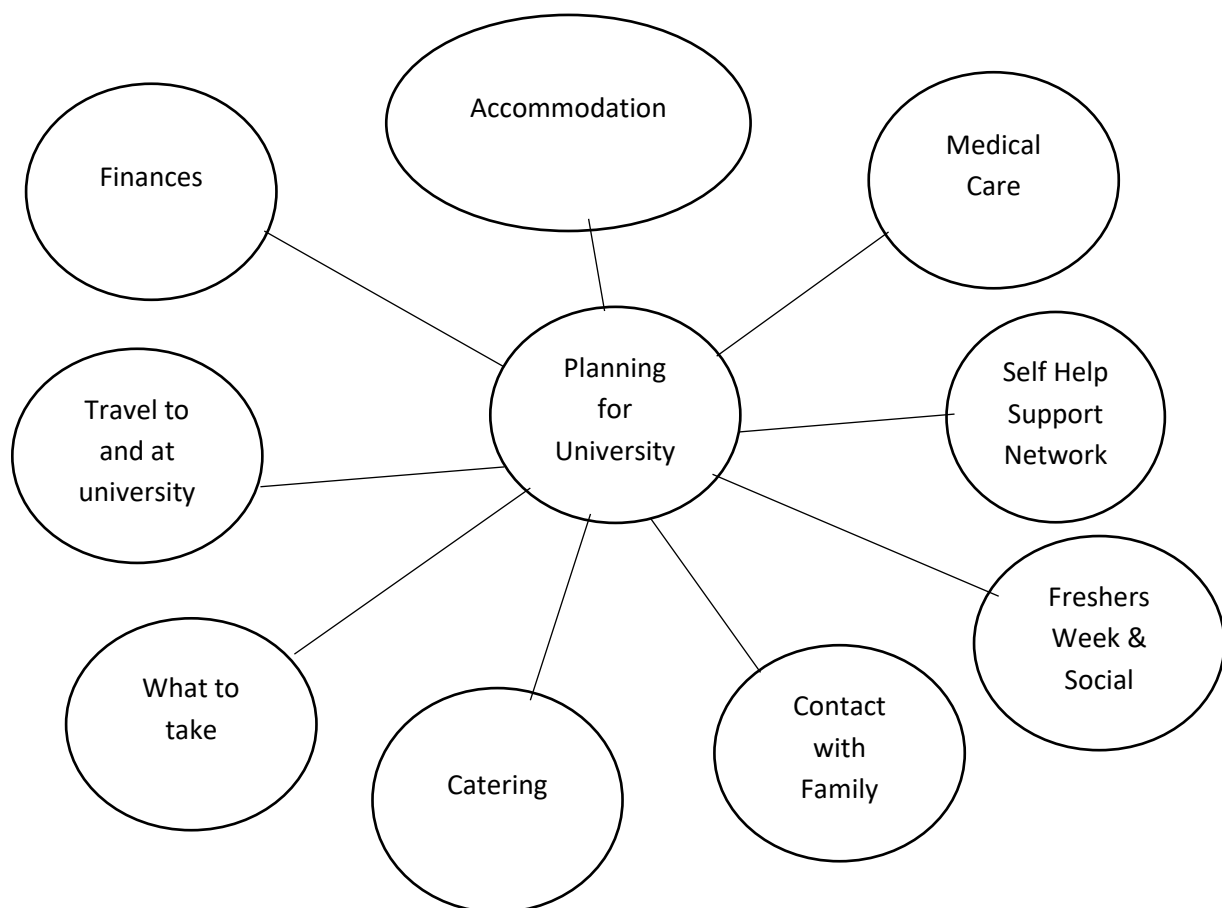
You might **develop discrepancy** by saying

“ On the one hand you want to go to university in two months time, yet on the other hand I can see you are hiding food at every meal which is making you very weak.....” and perhaps adding “ so please could you help me understand how are you going to ensure your nutritional wellbeing to get you through a day at university. I am more than happy to talk this through with you and do anything I can to help you plan for this.”

3. Constructing a Framework for Planning

It is very common for parents to tell me that their loved one wants to be totally independent and that they can manage everything themselves. Because the eating disorder is making everyone feel supersensitive it is easy for carers to be bullied by the eating disorder voice and therefore to take a step back. Try to imagine that your loved one didn't have an eating disorder. It is likely that they would welcome your help in planning for university. Some carers find it useful to compare notes with parents of their loved one's friends to see what sort of involvement they are having. Going to university is a very exciting time and represents a big change for the whole family. The more the family can plan together, the more comfortable and relaxed the whole family is likely to be.

Assuming your loved one is prepared to let you help, then together you could construct a spider diagram showing all the key things that might need careful planning and that you might be able to help out with. A Spider diagram might look something like this:



All of these area are important, but some are trickier to plan, and some are more likely to be affected by the eating disorder voice. Each case is different, but you might prioritise one or two that you and/ or your loved one might be more concerned about.

I have chosen a few for illustration purposes.

Contact with Family

Some students are much better than others with keeping in contact and there are so many different ways of doing this. These are a few ideas that carers have come up with in previous workshops:

Plan a weekend trip around dropping the student off at university. This means that the student doesn't feel pressured in to entertaining Mum & Dad for a whole weekend. You will see where your loved one is living and what the set-up is, and then you can step back and let them settle in. If you are staying somewhere nearby they will be able to call you back quickly if they have a panic about anything.

Develop an interest in the university town or area. Therefore, when you visit it is not just about catching up with your loved one and you have other interesting activities to do. Many students like to meet their parents for lunch or tea, but they might not appreciate you interfering with their Saturday night out. After a heavy night out though they might appreciate Sunday lunch or a trip to stock up with their favourite snacks or other things they might need but can't afford to buy themselves.

Agree in advance what would be reasonable contact. Some families use social media really effectively. A WhatsApp group can keep all the family in contact. Other families prefer phone/ text/ e-mail. Skype is great because you can actually see your loved one. One Mum described how she keeps in contact with her son:

"I text him saying I have got some really exciting news or gossip, or that I want his advice about something that is going on, or to talk about the latest sporting event that I know he is interested in. That usually gets a response"

When you do have contact it is important to try to focus on normal life things first, although you might be really tempted to jump in with welly boots "What have you eaten, how much do you weigh, how much exercise have you been doing?" This is likely to push your loved one away. At least start the conversation with some light-hearted conversation and enquiry into their course or social life first. Remember the expression "Give more attention to the behaviours you like and less to those you don't" If you do have cause for concern then you might need to step in, but don't make it the focus of every interaction that you have.

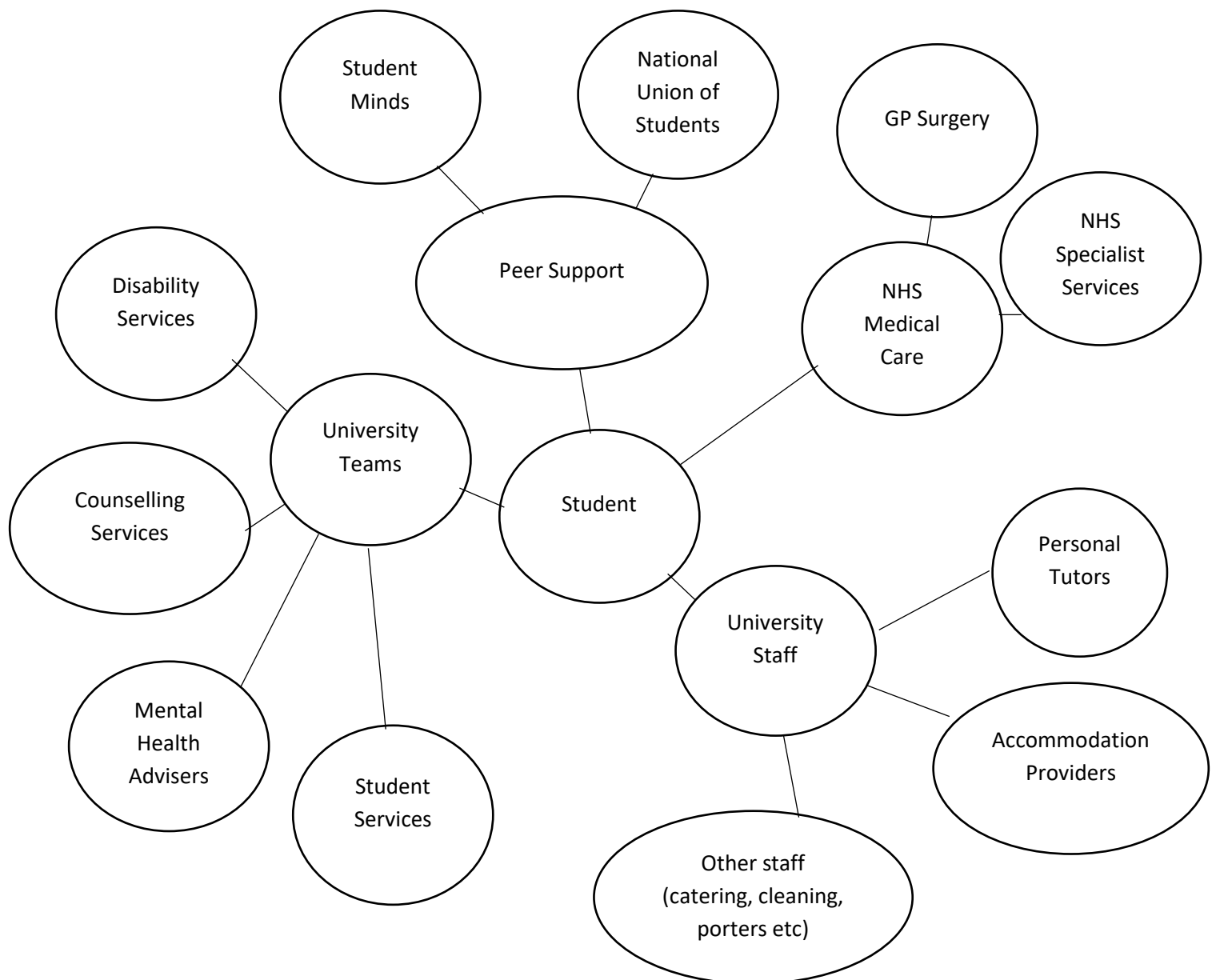
Agree in advance what to do in an emergency. This is sensible planning for any student, but more important when there are ongoing health issues. Is there a friend who can have your number and you can have theirs just in case a problem arises? Many of the families I have worked with have found out their loved one is really struggling because a close friend has noticed a change in behaviour and become worried.

Medical Care and Support Networks

There has been a great deal of research carried out in recent years about mental health issues of university students. Whilst it is generally accepted that around 1 in 10 school children will have a diagnosable mental health issue at any one time, this increases to around 1 in 6 for university

students. Your loved one will therefore not be the only one seeking help. Getting the right help will of course dramatically increase the chances of having a positive experience and fond memories of those university years.

If your loved one has a therapist and/or is under an eating disorder service at home, it is likely that they will benefit from some sort of similar ongoing support at university. Some therapists offer skype/ e-mail/ phone support and this might be an option. Transition within the NHS can be complicated but shouldn't be impossible with enough pre-planning. At the very least your loved one should sign up with a GP at the earliest opportunity. Each university has a different type of support network so finding out in advance what is available can be very helpful. Again a spider diagram can help in this planning process.



Warning Signs that your Loved One is Struggling

Very often carers ask me “How will I know if my loved one is struggling”. There is no one answer to this question, but any changes in levels of contact might be a clue that everything is not so rosy. If the eating disorder has reared its ugly head it will almost certainly be persuading your loved one to hide away from you. Whilst many university students are quite poor at maintaining regular contact with their parents, most will respond if their parents are persistent in their efforts to make contact. Don’t let the eating disorder voice bully you into keeping away. As a parent you still have a great deal of responsibility for the wellbeing of your loved one and you are likely to be the main source of financial and emotional support throughout their university years. In addition, in an emergency situation you are likely to be the first port of call to come and pick up the pieces.

Warning signs that things have deteriorated might include:

- Lack of contact
- Change of contact eg not wanting to Skype or Facetime which are visual
- Resisting contact
- Not wanting you to have contact with friends
- Cancelling planned trips

Follow your instinct, and be persistent if you are at all concerned that your loved one is relapsing in any way.

Crisis Cards

Many students will be carrying some sort of crisis card and this might be something you might consider at the planning stage. In the same way that a student with asthma or diabetes would have no problem carrying a card saying what to do in an emergency, students with any mental health issues are well advised to do the same.

For example a crisis card might say:

I am prone to panic attacks and/or fainting as I have an eating disorder.

If I have a panic attack and/or faint it helps me to sit in a quiet place with my head down and with one person sitting beside me until I feel better.

It really helps me if I can sip water as I get a really dry mouth.

I can be supersensitive to loud noises and bright lights.

If I have a panic attack or faint please call XYZ person who will come and meet me.

My friends details are:

My GP contact details are:

My University Support Services details are:

My family contact details are:

I am on XYZ medication

I am allergic to XYZ.

If I am unable to respond quickly please call 999 and ask for an ambulance

4. Assessing Medical Risk from a Distance

This can be difficult and again it is useful to consider a scenario.

Sally is 19, is at university, and has had anorexia since she was 15. Her weight fluctuates and she has not had a period since her anorexia was diagnosed. She loves running and often goes out running late at night. She says she cannot sleep unless she has an intensive run before bed time

One of her flatmates has contacted her Mum because they are worried that she has become dangerously thin and seems to be running more and more and eating less and less. They have read about the tragic death of Averil Hart ten weeks after starting university

Mum decides to visit and is shocked when she sees Sally face to face.

Sally denies there is a problem and tells Mum she is the one who has the problem and that she needs to back off and allow Sally to get on with her life

Mum decides to try OARS

Open Question

"Sally I am here because I am concerned about you. You have clearly lost a lot of weight since the start of term. I know you don't like me interfering so please can you help me understand what you are doing to ensure you are safe and physically able to join in with college life. Perhaps I am overreacting and you might be able to help me to calm my own worries."

Affirmation

"We are so proud of everything you have achieved, both in terms of getting the fantastic results to get here, and also in settling in and making so many new friends. It took great courage for you to make that step when we know you struggled so hard with friendship issues at school when those girls were picking on you."

Reflections

"So you would like me to leave you alone. You think I am interfering?
You feel that you are looking after yourself and I shouldn't worry so much?"

Summary

"Sally I am so pleased that we have had this conversation and I can see that you are making a huge effort to establish yourself at university. You are working hard and have some really lovely friends. I am worried about you and it does help me to understand your perspective so much better when we can have conversations like these. Let's make a plan that we are both happy with and that will keep you safe?"

After having this conversation Mum is now convinced her daughter needs urgent medical attention. However, she also knows that in the past when she has been concerned she has been a total rhinoceros telling Sally what she needs to do, and on reflection she can see that this has not been helpful. Using the ABC model Mum tries to consider her options.

Antecedent	Behaviour	Consequence
<p>Sally has lost weight and is running late at night</p> <p>Flatmates are clearly worried</p> <p>Mum is anxious and fears for her daughter's safety</p>	<p>Mum tells Sally she needs to get to the doctor as soon as possible to have a proper check up, otherwise she might die</p>	<p>Sally gets really angry and tells Mum to back off and leave her alone</p>

Menu of options

- Mum offers to help Sally set up her own safety plan
- Mum and Sally find a local GP who has experience with eating disorders and Sally signs up
- Sally gets an emergency appointment and the GP does a full medical assessment and makes a follow up appointment for a week later
- Sally and her friends find out about a student support group and they agree to go together. Her friends really want to support her
- Sally and her Mum put together a crisis plan and show it to her friends so that they know what to do if Sally collapses/ gets very confused etc.
- Sally appreciates her Mum's input and says she does feel safer, but now she would like to take control of her own health and promises to call at least once a week.

5. Your Loved One has a Great Support Team but Doesn't Use It Properly

Students are notoriously bad at looking after their physical and emotional wellbeing and it must be frustrating for GPs and specialist teams alike when students simply fail to turn up for their designated appointments. Of course, you cannot force your loved one to go to appointments, especially from a distance, but if you know an appointment is coming up you might want to send a gentle reminder and/or offer to go with them.

Scenario

James is in his third year at university and has a really fantastic therapist who he likes and has been seeing for two years. Recently however James has stopped coming to his appointments. Fortunately, the therapist persuaded James right at the very beginning of therapy that it would be useful to have some contact with the family so that the family could be kept in the loop in terms of James' progress and how best to support him in the holidays. This of course is carefully managed so that it doesn't breach James' rights to confidentiality. The therapist contacts James' Mum to let her know he has missed his last 3 appointments.

Coincidentally, Mum is visiting James that weekend because it is her birthday and a theatre trip has been in the diary for a long time. Mum thinks carefully about how she can broach the subject with James without ruining the weekend. She decides she will broach the subject on the Sunday afternoon while they are walking the dog. She opens the conversation thus:

Open Question

"James, I had a call from Ian, your therapist and he is concerned that you have missed the last three appointments and he hasn't heard from you. Perhaps it has just slipped your mind because I know how busy you are with your dissertation. Having said that it would be courteous if you could give Ian

advance warning if you can't make an appointment as I know he has a long waiting list. It is not acceptable simply not to turn up."

James goes bright red and is clearly very embarrassed.

"Oh my goodness I am so sorry. I think I might have misunderstood because last time I saw Ian he suggested that we might change to meeting monthly rather than weekly and I assumed he meant that we changed immediately. I have it in my diary to see him next Thursday. He must be really mad at me. Also I lost my mobile so he won't have been able to text me a reminder. I will call him tomorrow."

Mum breathes a sigh of relief and gives James a big hug. He appears to be in very good spirits and Mum feels she has nothing to worry about.

Now let us consider an alternative response from James who goes bright red and is really angry.

"Oh my God he is such a pain. I am completely better and I told him I didn't need any more sessions. I am far too busy with my new gym routine to bother with him blabbing on. In fact, he has been really annoying me lately and I have started to hate therapy with a passion. You know Mum you told me that you learned on your course that if something isn't working you should try something different. Well therapy is bloody well not working for me and I have discovered that going to the gym is a much better use of my time."

Mum is now concerned as she has noticed that James has been really agitated all weekend and he has clearly lost quite a considerable amount of weight since she last saw him six weeks previously. She calmly states what she is observing and that she is worried that he might be slipping back which would be such a shame given how far he has come in the past two years, whilst seeing Ian regularly.

She uses **developing discrepancy** to try to sow a seed of doubt in James' mind about his new regime:

"I know you want to start at the law firm next September and you have done so well to get the offer. You also know that it will be a real challenge and competition is really high. If you become unwell again and need to go back to in patient or intensive therapy you might miss out on this amazing opportunity and that would be such a shame. Can we talk about this? Perhaps I could come with you to see Ian and we could make a plan together"

James might get even more angry at this point and Mum might choose to give him some space, thus **rolling with resistance**.

"James I can see that you are really upset and so I think we should change the subject and try to enjoy the rest of our weekend together"

Before she leaves at the end of the weekend though Mum will want to leave a clear message that she can see that James is struggling, she will do whatever she can to help, and that she would like James to reconnect with the therapist Ian. Like Sally's Mum she could use affirmations and reflections to communicate with James in a motivational and caring manner. Before she leaves she might say something like:

“James, thank you so much for spending the weekend with me and I really enjoyed the trip to the theatre and the walk on the beach. I can see that things are a struggle at the moment and that it is hard to manage your time. I imagine many students find year 3 difficult to manage with all the work and other pressures. I have to admit I am worried about you and it does help me to understand your perspective so much better when we can have conversations like these. Let’s make a plan that we are both happy with and that will get you through the next few months. You have come so far in the last few years and I know you can do it”

Once home Mum can make contact with Ian the therapist and relay what she has observed and agreed with James.

The Last Few Weeks Before University can be Tough

Having spent the past year preparing for university the final countdown can be a time fraught with high emotions both for the sufferer and the rest of the family. There are bound to be some unanswered questions and the eating disorder might appear to rear its ugly head at the last minute. Unless you are concerned that medical risk is high, this is a time to try and keep calm and focus as much as you can on the positives and all of your loved one’s strengths.

Scenario

Becky has been struggling with bulimia on and off for the past two years and has identified that stress is a key trigger for her binge/ purge behaviours. All her family know about her condition and they try to help and support Becky when she is feeling vulnerable. In the two weeks before going to university her behaviours have been quite extreme with many tears and much slamming of doors, smashing of plates, aggression particularly directed at her Mum and increased binge/purge behaviours.

Mum, Becky and her younger sister, Clare, have planned a shopping trip but at the last minute Becky decides to stay at home and bake. Baking is something she often turns to as a coping mechanism when feeling stressed.

When Mum and Clare return home it is clear that Becky is very distressed and has binged and purged. She looks very pale, her hair is a mess and she smells strongly of vomit. Mum tries not to react but her body language clearly gives off negative signals, and Clare blurts out “Oh my God what is that smell?” Becky is really upset and runs off crying. She screams “None of you trust me and I’ll be going soon anyway.”

Half an hour later Becky reappears. She has showered and looks much better. She gives her Mum a hug and offers her one of the cakes she has baked whilst they were out shopping. No reference is made to her previous outburst but Mum can’t stop thinking about it.

When this sort of thing happens it is extremely distressing for everyone involved. A good tip is to let everything calm down and then reflect back and try and put yourself in the sufferer’s shoes. What might have been the thought processes that Becky was going through on that afternoon:

- I am worried about going to university and so I am going to bake as this usually helps calm me down.
- I still feel upset even though I have baked.
- I will eat some of the cakes (this triggers a full blown binge and purge)
- I felt better for about five minutes and now I still feel terrible.
- I need a hug.
- I didn't get a hug, in fact Mum gagged and Clare shouted at me.
- Nobody loves me, they will be glad to get rid of me.
- I am a mess I need a shower.
- The shower helped. Now I am in a better place to have a hug.
- My Mum does really love me. I am lucky to have her.
- I am looking forward to university after all.

Now of course we can only guess what was going on in Becky's mind, but this process can help the carer to empathise with the sufferer, and come alongside them.

Having reflected back on this sequence of events Becky's Mum recognises that Becky did something pretty amazing. Even though she was really really upset, she managed to take herself away from a distressing situation and self soothe. She then had the confidence to try again to get the hug she so desperately wanted.

Mum has a positive conversation with Becky the next day:

"I realise that you were upset yesterday and it is not surprising that you might be worried about going to university. It is a big change and several of my friends have told me that their daughters are really nervous. I noticed that you had been sick while we were out shopping and I am so sorry if my reaction made you even more upset. Then you went upstairs and showered and calmed yourself before coming back down for a hug. That shows how far you have come and that you can be compassionate to yourself even when those around you are being insensitive. I know that you will embrace university with a strong heart and courage and that you will be ready for any challenges that might come your way."

In this way Mum sets the scene for a positive farewell rather than one fraught with upset and pessimism about the months ahead.

Appendix - Support for Students Planning for University.

1. Student Minds

Student Minds has a range of useful resources including

<https://www.studentminds.org.uk/supportforafriend-eatingdisorders.html> and
<https://www.studentminds.org.uk/transitionintouniversity.html> and
<https://www.studentminds.org.uk/knowbeforeyougo.html>

2. Checklists of Things for Students to take

There are many useful checklists available. Two such examples are at:

www.studential.com/checklist
www.topuniversities.com/blog/what-take-university
www.mumsnet.com/teenagers/starting-university - has good practical advice for parents

3. Embracing Change – Beat booklet

Beat produced a useful booklet entitled Embracing Change “A collection of tips and experiences to help successfully navigate life transitions” Written by young people for young people, it is also a useful resource for carers, and is full of “Top Tips”

<http://www.nhshighland.scot.nhs.uk/Services/Documents/Beating%20Eating%20Disorders%20Embracing%20Change.pdf>

Beat also has a dedicated student helpline and online support group for students

<https://www.beateatingdisorders.org.uk/support-services/online-groups>

4. Students Against Depression

<http://studentsagainstd Depression.org/>

Students Against Depression offers information and resources validated by health professionals alongside tips and advice from students who have experienced it all themselves, as well as useful self help workbooks.

5. Connecting with People has collaborated with Nightline

<https://www.nightline.ac.uk/want-to-talk/>

There are 39 Nightlines in the UK, all with fully-trained volunteers answering calls, emails, instant messages and texts from fellow students, and all offering a supportive, non-judgmental and anonymous outlet to those who are struggling.

6. Universities UK Guide for Student Mental Wellbeing

Go to www.universitiesuk.ac.uk and search “Guide for Student Mental Wellbeing. This is a good practice guide for UK Universities and so can give Carers/ students an idea of the sorts of things to look out for.

7. Mind Your Head – A Student Guide

Whilst this booklet is aimed at students in Northern Ireland, it is useful for anyone preparing for University and is full of practical tips and information on managing stress and achieving and maintaining positive mental health and emotional wellbeing. It also contains a comprehensive list of helpful local organisations and websites. The booklet targets first year students at university and further and higher education colleges as the transition from school to further education can be a very stressful time. It's distributed at universities and colleges during freshers week and is also available on request from student services or the students union at many campuses.

<http://www.publichealth.hscni.net/publications/mind-your-head-student-guide-mental-health-2>



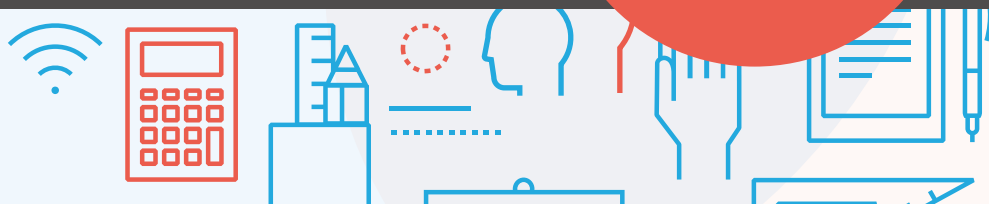
**South London
and Maudsley**
NHS Foundation Trust



Preparing for University

A guide for those recovering from an eating disorder

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About this guide

Starting university is exciting, with lots of opportunities and new experiences. But change brings challenges and there are common difficulties faced by people recovering from an eating disorder.

Whether you are starting university for the first time, or returning after taking some time out, this guide aims to give you tips about how to cope. Then again, being at university is not all about worries and problems, there are so many things to look forward to, so we have focused on all the positives too.

This guide was developed jointly by clinicians and young adults who have gone through university whilst living with or recovering from an eating disorder. They have been where you are now and were keen to pass on their advice.



Throughout this guide, you will see quotes and nuggets of advice from these young people – exactly as they said it.

“

“Looking back, I think I would’ve really benefited from knowing in advance that starting university is not all sunshine and daisies, and that so many of my peers were actually struggling too - something I only found out later, when I plucked up the courage to ask people how they really felt about starting uni”.

Ellie

“

“I would encourage anyone with current or past experience of eating problems to think more than I did about the challenges of university life and not be as ashamed as I felt for many years to seek help.”

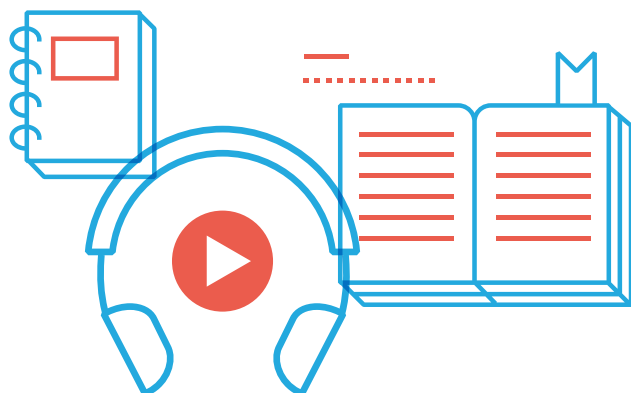
James

“

“You deserve to do what you want and get the most out of life, don’t let your mental health define who you are or hold you back.”

You got this!

Sophia



We would like to thank all our patients who have brought this guide alive with their personal experiences and inspiration.

Am I ready?

It is important to consider whether now is a good time in your recovery for you to start university. Starting at the right time gives you the best chance of enjoying the experience and successfully navigating any challenges that come up.

When deciding if you are ready, you may want to ask yourself:

- Can you take responsibility for feeding yourself? If you see living away from family as an opportunity to increase eating disorder behaviours, it may be hard for you to look after yourself when at university.
 - What you are most excited about? What are you looking forward to? Can you see yourself managing your eating disorder so you are able to do these things?
 - What do the people close to you think? Starting university needs to be your decision. However, you don't have to make that decision on your own. It can be really helpful to have honest conversations with family, friends and health professionals about the pros and cons of university for you at this point in time.
 - Do I meet university 'fit to study' guidelines? You can find these at **www.heops.org.uk**
- Remember that you don't have to be 100% sure of yourself to start – in fact, it is normal to feel a bit unsure!
- At the same time, if you think your health will suffer, taking time out to pursue recovery could help you to have a more enjoyable university experience when you do begin.

“

“I know it's easy to say, but try not to worry about going to university, things always seem much scarier and more difficult before you get to go through it.”

Katrin

Getting ready

Before starting university you need to think about your living situation. Consider your pros and cons for the options below.

Should I choose a university close to home or further afield?

Near home

Molly's Pros

- My family are nearby if I need some support
- I would spend less money on travel

Molly's Cons

- My mum might want to see me all the time!
- It's not my first-choice course

Far away

Molly's Pros

- I love the look of the course
- I'll have to throw myself into meeting new people

Molly's Cons

- I might get homesick
- I'll miss all my school friends



“Register with your GP when you move and also check out which (if any) eating disorder services are available at your university.”

Lydia

F:RE:ED

Should I go for self-catering accommodation or catered halls?

Self-catered

Tom's Pros

- More freedom!
- I want to get better at cooking

Catered

Tom's Pros

- Everyone will eat together
- I don't need to think about what to cook

Tom's Cons

- I'll have to budget for food
- The kitchen could be a mess!

Tom's Cons

- I might not like the meal options

What should I bring to University?

It can be tempting to bring everything you own, but it's likely that your new bedroom won't be very big.

You might like to check out The Student Room's really comprehensive list of what to pack **www.thestudentroom.co.uk**

Also remember:

- Health Documents (such as letters from your treatment team)
- Medications - check that you have a prescription that will cover you until you've had a chance to register with a doctor at university.



Freshers week survival guide

Here are a few tips to help you through week one:

- **Leave your door open when you unpack** – someone is much more likely to pop in and say hello!
- **Know your limits** – your eating disorder may make drinking lots of alcohol risky, especially if you are underweight or struggle with binge eating.

Try to find a balance - you don't need to do it all, but avoid isolating yourself.

“

“When I first started university I loved that everyone was in the same boat - we were all new together!”

Lydia

“

“Although alcohol can be challenging for some, try a few nights out or perhaps just light social drinking - it's a great way to meet people and you might surprise yourself at how much fun you have :)”

Abi

- **Do it your way** - this is your experience of university and no-one else's. It is often a time that people find out lots about who they are and who they want to be. Everyone is different, so try not to feel pressured to 'do' university a certain way, be open to what your path might be.
- **Focus on your own eating** - because of all the partying, people's eating habits might be erratic, such as skipping meals, eating late at night or going for big fry-ups in the middle of the day! Remind yourself what you need to do to stay well – join in when you can, but maintaining some structure to your eating is going to help you keep on track with your recovery.
- **Research your university societies** - It's not all about drinking! What are your passions and interests? Joining a society is a great way to meet people and an opportunity to do more of what you love.



"The best thing about university was having the opportunity to break away from who I thought I was, and start exploring who I could be."

Erin



"I would definitely recommend going to fresher's fair. There are countless different societies - and having these can be a valuable distraction and support network during anxious times. If you don't drink or struggle with alcohol there are lots of different societies without that focus so look into joining one of those!"

Abi



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Telling people about your eating disorder

Telling your university

- There are lots of ways your university can support you.
- You can reach out to your personal tutor, student counselling service or Disability Advisory Service.
- We would really encourage you to let the university know as early as possible. It is best to have these in place as a precaution, rather than waiting until when you really need them.



“If you are struggling in any shape or form, even if you feel like it’s embarrassing or awkward to flag up, reach out to someone sooner rather than late.”

Erin



“They can help you to get extended deadlines, mental health advisors and extra support. Look into getting some kind of ‘Disabled Student Allowance’ (DSA) in place (helps with costs) and don’t be afraid to email or talk to your tutors about the problems you are facing regarding work and your ED. They understand.”

Sophia

Telling your friends

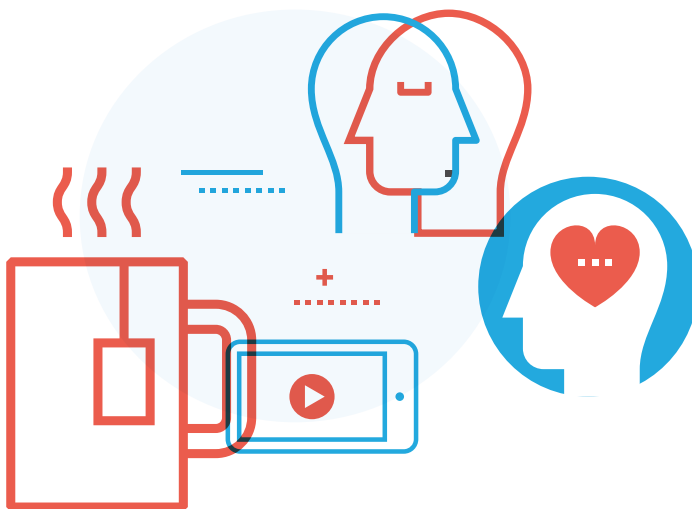
- Telling friends about your eating disorder can be a huge relief, especially if you've been putting a lot of effort into hiding it.
- Talk to someone you can trust, and with whom you can speak openly and comfortably.
- It might take you a little while to figure out who you feel able to trust, no need to rush it.
- It's up to you what information you share with friends. It can be helpful to plan what you want to say beforehand and think about how you'd like them to support you, as friends can feel unsure about what they can do to help.



“If you seem to struggle more than those around you, that is no sign of weakness, and they may well be struggling inside too. If you need to do different things to look after yourself and ask for study and personal support to make things work for you, then do, without feeling ashamed.”

“We don’t chose to face barriers to participating in our learning or lives at university, but you can choose to do everything you can to make it easier.”

James



Eating at university

Make an eating plan for university

Following a plan helps you to meet your nutritional needs and lets you be aware of what you are eating without feeling stressed about it.

It is important that your plan is flexible, so you can adjust it to fit in with activities and to join in with eating with other people.

It might be helpful to check out your plan with someone you trust before you go.

“

“One real difficulty that I experienced was being the sole person responsible for managing my diet, as before I had always shared meals with family and constantly had their input and guidance, but this was the first time I was left to figure out meals and portioning alone.”

Erin

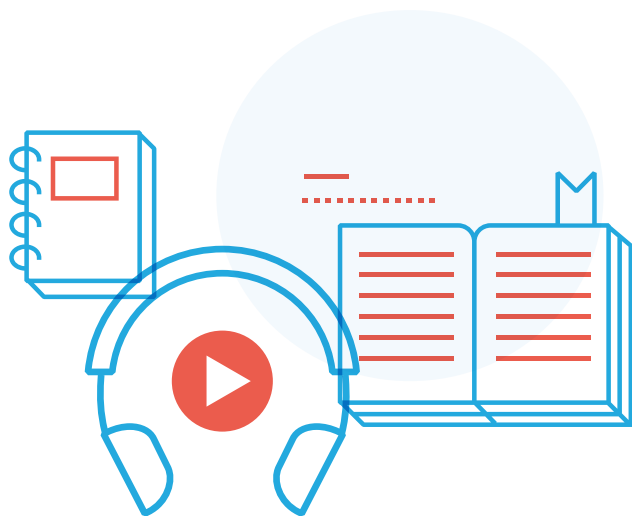
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“Try and prevent yourself from comparing your food intake or body image to the people who surround you; be conscious of doing what is healthiest for you, even if that means not always following the crowd.”

Erin

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- **Get into a good eating routine from day one.** It might be tempting to think that you will sort out other important things first and come back to thinking about your eating later but people often find this difficult to do in practice. It may be helpful to take supplies of food for the early days. If you are in catered accommodation be careful not to avoid the dining room – go from day one!
- **Practice cooking** - Make a list of 6-10 main courses and practice making these for yourself at home before you go. These don't need to be complicated, just balanced meals that you enjoy. Once you have settled in, you can experiment and add to your list of meals so that you have more variety.



“Learn to cook a few meals before you start - it can be very helpful to have some familiarity!”

Abi

If binge eating is a worry for you there are steps that you can take to make this less of a problem:

- Do not to miss any meals or snacks so that you are hungry.
- Be cautious about ‘bulk’ buying food or storing food in your room.
- Drinking alcohol can be a powerful trigger for binge eating, so when you do drink, make sure you have eaten well beforehand and perhaps plan what you will eat the next day.

Living with other people

Living in shared accommodation can be a really fun part of university life, but there are some common pitfalls to communal living, try these tips:

- Whether you tend to be messy or super tidy, other people will have different standards to you when it comes to cleaning. Remember it is not your responsibility to do other people's share.

“

“I loved being in halls and being more independent.”

Lydia

“

“What you value isn't necessarily the same as other people. People might not care if the surfaces aren't clean or the floor isn't swept.”

Issy

- Do you find it difficult to cook or eat with others? The best way to overcome such anxieties, is to face your fears and experiment with eating or cooking with others – what usually happens is that when given lots of practice and time the anxiety reduces.
- It is not uncommon for people to eat others' food, or maybe you are worried you might lose control and take your flatmate's supplies. Perhaps there are some foods your flatmates could buy together using a kitty or have an agreement that any food eaten will be replaced.
- Are you someone who might shy away in your room? Challenge yourself to spend time in communal areas.
- Whether you are living in a party house or with a quieter crowd, you might want to do things differently from your flatmates – that's fine, this is your experience of university. Know your boundaries and learn to say no or yes a bit more!



“

“Overall I would say try to trust yourself and assert yourself, you know you better than anyone else!”

Issy

“

“Ask to move flats/accommodation if you don't like where/ who you've been put with because uni are more than happy to help and there's no point being stuck somewhere you hate for a year!”

Lydia

Managing exercise

University offers many opportunities to be active, whether playing team sports, joining a club, trying new activities or simply from a busy social life. Keeping active is healthy, but it can go too far.



- **Plan ahead** - Be honest with yourself before you go to university, are you someone who is likely to have difficulties with excessive or compulsive exercise? Try to decide some appropriate limits before you go, perhaps discuss these with a professional or loved one.
- **Look out for warning signs** - are you exercising even when injured or sick? Are friends voicing concerns? Do you get anxious if you can't exercise or have to follow a set route when walking? Are you cutting out social events or even lectures to exercise?

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- Find a balance – avoid exercise taking over your life by exploring other interests and making time for them. You could do less intensive exercise (such as pilates or yoga) or try a team based sport rather than exercising by yourself.
- Be mindful of your health - if you are underweight or not eating regularly, hold in mind that you may not have as much energy as your friends – an active day on campus or working followed by a night out clubbing may be too much.
- If you want to play competitive level sport, it is advisable to let your coach know about your eating disorder so that they can support you.



“There is so much on offer more widely to tend to your wellbeing, from exercise classes to mindfulness meditation, with the most important thing being to do what works for you, irrespective of feeling the need to conform to traditions and timetables or any particular student lifestyle.”

James



Body image

Try to focus on who you are as a person, not your appearance.

University offers opportunities to try many new things and meet new people. What are you interested in? What would you like to be involved in?

- Remember that other people, whether or not they have an eating disorder, will have some degree of worry about their appearance, it is normal.
- It can be very common for people to talk about 'feeling fat' or wanting to lose weight. Think about how you can best manage 'body talk' – do you feel able to say that you find it unhelpful? Can you try and change the subject or remove yourself from the conversation?



“University was the opportunity to engage in more of the things I loved...Take every opportunity.

I know people say this all the time and I was told this time and time again and I wish I'd listened.”

Anna

“

“At university there may be a lot of focus on body image – through elements such as social media, or the ritual of getting ready for club nights with friends, or detrimental statements others make about their own self-image – and so it is key to be aware of how your self-perception and self-esteem is being influenced in those moments.”

Erin



- Though hard, try not to compare yourself to others, generally people feel worse, not better after doing this.

- Think carefully about social media – it can be a great way to keep in touch, follow interests and be inspired!

However, remember that many of the images you see will be filtered and not real-life – people only post their best pictures on social media.

Have a look at our social media guide at www.freedfromed.co.uk to find out more.

Budgeting your money

The key thing with budgeting is to know how much money you have to spend, and then how much money you need to allocate to different expenses.

You want these to balance! There are lots of websites and apps designed to help students manage money. You could try 'Goodbudget', 'Money Lover', and 'Money Dashboard', all are free.

When planning your budget, you may want to think about:

- Course materials (check out second hand options and the library too).
- Printing and photocopying costs.
- Transport (locally and for visits home).
- Utility bills, internet and insurance.
- Entertainment / extracurricular activities – factor alcohol in here too.
- Clothes.
- Toiletries / cleaning products.
- Food – at the supermarket and eating out.

Budgeting money for food can be hard when you have an eating disorder – some people find it hard to spend money on food, whereas others can spend a lot of money on food (especially if you have difficulties with binge eating or eating certain types of food).

Planning out your meals and snacks in advance may help. Surveys suggest that most university students spend between £20 and £30 per week on food at the supermarket, plus up to £15 per week on eating out.

If you find you spend much more or much less than this, it may be worth considering how your eating disorder is affecting your spending and nutrition.



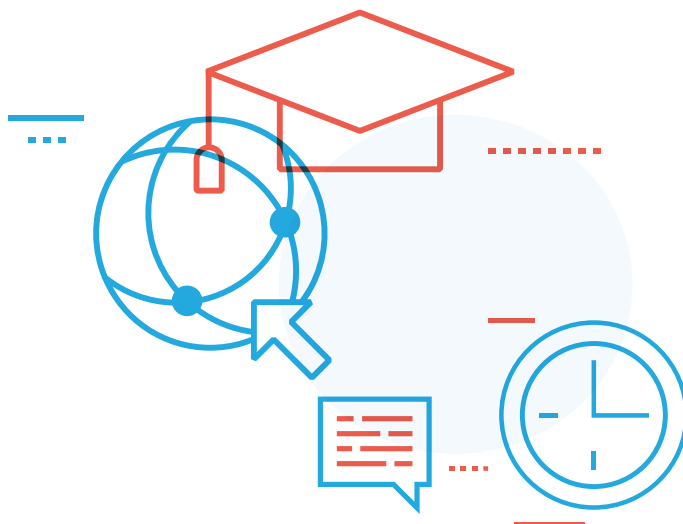
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**“Write a list before food shopping
- the amount of choice can be
daunting and it can help
to budget!”**

Abi

Some students with eating disorders struggle with shoplifting. This can be distressing and often people keep their shoplifting a secret. However, we would urge you to seek support if this is something you experience.

You aren't alone and you can work on this in treatment if you have a treatment team in place.



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Finding time to work, play and recover

Are you a perfectionist?

Perfectionism is exhausting! Look out for warning signs, like setting unrealistic goals, difficulty sharing tasks, taking on too much, fear of failure or worries about being judged.

Try:

- Setting realistic targets which are achievable and motivating – you might need some support for this from your tutor or peers
- Be kind to yourself if you make mistakes, we all do! Beating yourself up won't help.



“Prioritise! If you feel pressured by a heavy workload, do what is most essential and focus on the assignments you find interesting.”

Ellie



“My biggest challenge at university was juggling work, play, and recovery... part of my recovery involved learning to work less and allow myself to relax.”

Ellie

Managing lack of structure

You may have much more 'free time' at university and no longer be in an environment with clear routines around eating and sleeping.

- Try planning your day to create some structure
- Be flexible – don't miss out on a great opportunity, just because you had planned to do something else.
- Allow time for relaxation and fun
- Don't panic if an arrangement with friends falls through. Always have a plan B.

“

“It was a privilege to be surrounded by engaging professors and tutors who wanted to share their knowledge with you... My biggest challenge was to lower my expectations of myself in order to cope and appreciate my studies.”

Erica

“

“Possibly the most important piece of advice I could share, is give yourself permission to have fun! University is a time for intellectual growth, but it's also about finding yourself and enjoying being independent. Don't spend your whole time in the library - try new things, embrace unfamiliar experiences, and seek out what makes you happy. You never know what you might learn about yourself in the process.”

Ellie

“

“I was already quite independent before but living without routine was the biggest challenge.

Routines can be great, to-do lists and agendas are helpful but they can restrict and control your life too much and when there is so much happiness and opportunity around you, you have to let it go a bit.”

Anna

Building social networks

An obvious place to meet new people is in your student halls. But if you don't feel like you get on with the people you live with, there are lots of other places and opportunities to meet people.

- Freshers events and university societies are a great place to meet new people, everyone will be in the same boat!
- People often make friends with people from their course – you know you have a least one thing in common! It can be hard to start conversations in big lecture halls, but this can be a bit easier in smaller groups, such as seminars or lab sessions.
- If you decide to get a part-time job, you might make friends at your work
- Most university halls and courses have Facebook pages or chats, so social media can be another place to link up with new people.

“

“There are hundreds of people going to university each year, if there's even a chance that in the three or four years you'll make one really good friend who you can completely be yourself around and who love you for you, isn't it worth it?”

Karin

Does the idea of starting conversation with someone new make you feel anxious?

Try some of these 'icebreaker' tips:

- Leave your door open
- Offer someone a cup of tea
- Ask how they are finding university so far
- Suggest a trip to town or exploring the campus

Keeping in touch

Making new friends doesn't mean that you have to lose contact with people already in your life. It can be helpful to have regular contact throughout term-time and remember you will probably be home every Christmas, Easter and summer holidays – so lots of opportunities to catch up with your family and old friends.

“

“Meeting new people with similar enjoyments to me has been great. Whether that's through societies, the course or evenings out there's lots of opportunities to get to know people and find people that resonant with me.”

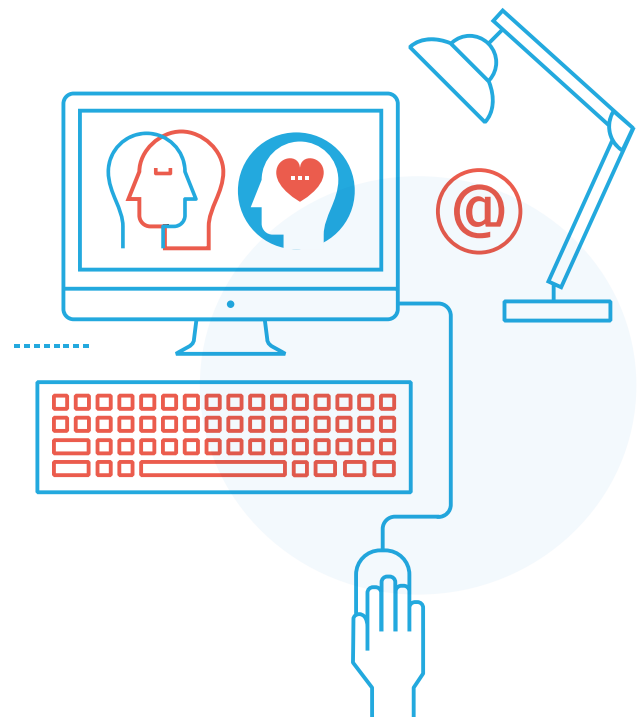
Issy

“

“Remember it's totally ok if you don't click with people straight away!

It took me over a year to find people I'd call “real” friends, and that's completely normal.”

Abi



Keeping yourself safe

Drugs and alcohol

Be mindful of how drinking and taking drugs affects your eating and make sure you balance your recovery with having fun!

Drugs and alcohol can be rife in student life. But it doesn't have to be a big part of your university experience, do what is right for you.

If you are worried about your drug use or concerned about a friend visit

www.talktofrank.com

or **call 0300 123 660**.

Sexual health

You can find your local sexual health service at **www.sxt.org.uk**

Another good website with lots of information is **www.brook.org.uk**

Try not to be embarrassed to ask for help, professionals at these clinics work with these issues all day long and it is best to get symptoms checked out as soon as they arise.

Remember that some sexually transmitted infections may not initially show any symptoms so it is a good idea to get regular sexual health checks.

“

“If you don't drink or struggle with alcohol there are lots of different societies without that focus so look into joining one of those!”

Abi

Support for sexual assault

It is common for victims of sexual assault to blame themselves or minimise what has happened to them. We encourage you to seek help, even if you are unclear about what has happened.

There are places you can go or numbers to call to get support:

- Any sexual assault can be reported to the police – call 999
- Sexual assault referral centres (SARC) offer medical, practical and emotional support. You can find your nearest through the NHS website.
- Victim support is an independent charity that aims to provide support for anyone affected by a traumatic event (**www.victimsupport.org.uk** or call 08 08 16 89 111)



Campus safety

The usual rules to keeping safe at night apply to night-time on campuses – make sure someone knows where you are, keep an eye on your drinks so nothing is added, keep a track of your belongings, stay alert and trust your instincts.

Most universities will have security staff. It can be helpful to know where the security reception is or have the number stored in your phone.



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How to help a friend

Are you worried that one of your friends is having difficulties with eating?

Whether or not you have had difficulties yourself with eating, it can be really hard to know how to help. Here are ways you might be able to support your friend:

- **Talk to them – easier said than done!**

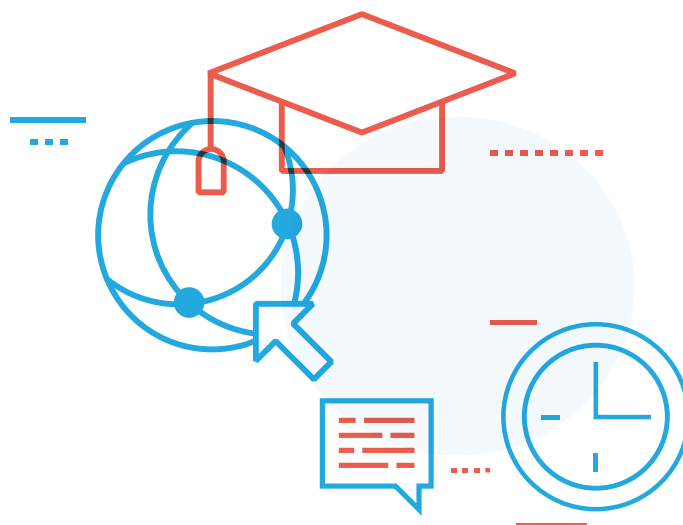
Raising the subject of eating difficulties with someone can be nerve racking (“will I make them worse?”, “what if I have it wrong?”, “will it affect our relationship?”), but in reality, talking to them could be a big step towards getting the help they need. Eating disorders are often secretive, so they may find it hard to be open with you, but you can let them know that you are there for them if they want to talk.

- **Suggest helpful websites** – learning about eating disorders can help people understand what is happening to them and there are some great websites designed to do just that.

We recommend

www.FREEDfromED.co.uk and
www.b-eat.co.uk

- Stop the diet and body talk – talk about losing weight and feeling fat is everywhere, but it can be a very sensitive topic for someone with an eating disorder.
- Encourage your friend to go to their GP – the first step to getting specialist help for an eating disorder is speaking with a GP. This can be a daunting prospect, so suggest your friend asks someone they trust to go with them.
- Look after yourself – supporting someone with an eating disorder can be exhausting, especially if you have had difficulties with eating yourself. Make sure you have someone you can talk to and know your limits - as much as you may want to help your friend, it is important to remind yourself it's not all your responsibility to make them better.





Staying on track: Relapse prevention

Recovery from an eating disorder is rarely a straight path.

It is common to have lapses in your eating. Remember lapses are different from full blown relapses - a slip up does not mean you are back at square one and there is lots you can do to get yourself back on track.

My relapse prevention plan

What are my early signs?

Make a note of the signs that might indicate you are slipping back into your eating disorder:

You might consider factors like skipping meals or snacks, counting calories, increase in body image concerns or socially isolating yourself.

What can I do to help myself?

Make a plan of things that might help you to get your eating back on track:

You might want to consider ideas like doing meal planning, stop body checking, see friends more, focusing on other interests, or setting recovery goals for yourself.

What if I need more support?

Write down the contact details for people who could help should you need extra support. You might want to consider which friends or family you would speak to and who to contact at university. Also note down the contact details for your GP surgery and your local eating disorder service.

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“By keeping yourself on track as much as possible, the experiences you have throughout this handful of years will become so much more rewarding for you, in both the present moment and in your future.”

Erin

“

“Select a trusted individual to hold you accountable, a person who will check in with you regularly to make sure you aren’t slipping into eating disorders habits or thought cycles, and someone who can be your sounding board whenever you are unsure or conflicted.”

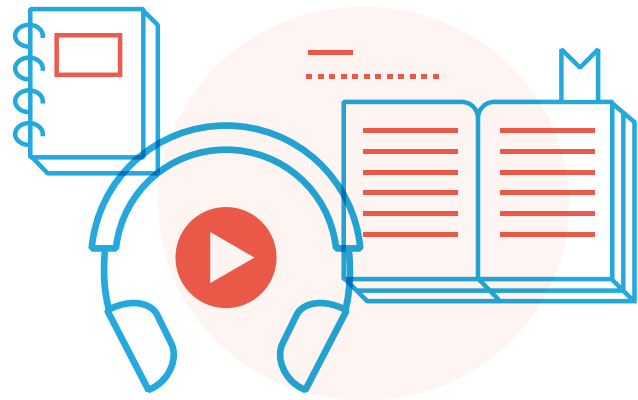
Erin



Seeking further support

The first step to getting treatment in the NHS is seeing your GP, who can make a referral to a specialist service. This might feel like a big step, so here are our tips:

- Don't delay! We know that the earlier someone gets specialist help for their eating disorder the better their chances are of getting well and staying well.
 - Before the appointment, write down the symptoms or behaviours you are concerned about, and any questions you might want to ask your GP.
 - Ask someone you trust to come with you for support.
 - If you don't get the response from your GP you hoped for ask to see another GP.
- If you think you have a problem that needs support, you probably do, so trust yourself.



“

“Recovery wise I would advise reaching out for help as soon as you catch yourself slipping because it can be quite easy to convince yourself that you’re fine and to hide it!”

Lydia

There are other places you can get support for your eating disorder:

- Speaking to your personal tutor, university support or counselling services might be a good first step.
- Beat (‘beating eating disorders’) is the UK’s leading national charity supporting anyone affected by eating disorders. They have a great website with a section on ‘support and services’, including; helplines, message boards, online support groups and peer support groups. Check out their website at **www.b-eat.co.uk**
- Private treatment is also an option for those who can afford to pay.



University: The best bits!

We asked - what was the best thing about university?

Here's what they said:

“

“Being able to choose a course I was really passionate about means that doing work is never really a chore. For me, there's always something interesting to look into that connects me to other captivating things.”

Issy

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“It was through university that I really took the reins and my independence started to grow, and it was during this time that I realised I was much more capable than I had previously believed myself to be.”

Erin

“

“Being able to talk to people from all kinds of different backgrounds and take part in different activities and society helped me to see that there is more to life than my mental health difficulties.”

James

“

“I made some amazing friends in my first year and it was also a chance to study a subject I was truly passionate about.”

Lydia

F:R:E:D

“

“University allowed me to explore my independence more and meet new people who are now my best friends.”

Sophia

“

“I was able to grow beyond the person I had been at home, which was full of associations with the illness, and create the kind of life I’d always wanted to lead.”

Ellie

“

“I’ve always known that staying at university is my number one priority - staying with my amazing friends, joining in with the things I love and working to the best of my ability on my course.”

Anna

“

“While you may be faced with a multitude of challenges everyday, from food and exercise, to socialising, these are ultimately gifts. Navigating your way through these, with support from family, services and friends can be invaluable to your recovery journey.”

Abi

“

“The best thing about going to university was realising I am stronger than I thought I was.”

Katrin

We would love to hear about your experiences of university!

Tweet us @FREEDfromED

Notes

Notes

Notes



This booklet was developed by young people and staff from FREED – First Episode Rapid Early intervention for Eating Disorders. FREED services are based in NHS Trusts across the UK and aim to provide quick and effective early intervention for eating disorders.

For more information see **www.freedfromed.co.uk**

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