

Carer Support

Book 3



You are not alone

This is a summary of the support, advice and guidance from lived experiences offered at the weekly online Carers Support Group.

April 2021 to September 2021

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Introduction

Introduction

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

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

Facilitators:

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

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

Format

The format 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, meeting times

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

2nd Tuesday of month: 6.30 - 8.00 pm presentation

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

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

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

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

20 April 2021 – First Birthday, Key principles and themes

First Birthday

Thank you to everyone for celebrating our first birthday with, I have to say, some style! Many efforts should be mentioned in dispatches - I am rather jealous of Dxxxx's hat - but for organising a banner, wearing a tiara and enjoying a cup of tea I am awarding top honours to Rxxxxx. No prize, just the glory! And thank you to Sarah and Gxxxx for revealing (some of) their secrets; at least Dxxxxx now knows Gxxxxx's favourite food?!

Key principles and themes

We did, eventually, get down to some serious business. Here are some of the principles / themes that I think came through our discussion:

- As parent/carers we can support our loved ones by **discussing the pros and cons of their eating disorder and by making connections between their eating disorder and its consequences**. For example, we can calmly and factually present the positives of putting on weight - the things it allows them to do - to help our loved ones cope with change.
- **Weight restoration is not necessarily steady and linear.**
Its pace can vary, it may reverse or it may overshoot the target. Again, our role is to help our loved one manage any anxiety, e.g. helping them learn calming strategies to use during the stressful situation, such as breathing techniques, and validating and empathising so that they know they are not making it up and that you recognise how difficult it is. Information about the famous Minnesota study that Sarah referred to can be found here: <https://www.apa.org/monitor/2013/10/hunger>.
- **Medical monitoring.**
A new system is being rolled out across Cambridgeshire and Peterborough, which will mean much greater consistency. Up until now practice has varied from one GP surgery to another. High risk patients will be monitored at an eating disorder clinic (and occasionally at home) while mild to moderate risk patients will be monitored at GP surgeries. Emma explained that the monitoring is very personalised, e.g. if our loved one does not want to see or know their weight they will have the option of stepping backwards onto the scales.
- **Blips:** not a medical term but you know what I mean.
Things can be going well and then, often out of nowhere, our loved one's progress takes a dip on the roller coaster. That's a good metaphor because I bet many of us have had that sinking feeling in our stomachs that we didn't realise could come back so quickly. It's so hard. We've discussed this before and we concluded that it is vital to remember the '**3 Cs**' - **stay calm, be compassionate, show you care**. And then ask yourself, 'What would a good dolphin do?' If there has been a blip before what helped our loved one get back up again? This scenario also emphasises the

20 April 2021 – First Birthday, Key principles and themes

importance of keeping your first aid kit to hand because you may well need support - the friend you can ring, BEAT's helpline or NHS 111 Option 2 in an emergency and the contact details for this support group, which you can come back to anytime. Sarah reminded us that our empathy is a massive strength but that it also means we can suffer; it's not our job to eliminate our loved one's suffering but to be a good dolphin.

Next week is a '18.30 Support Group Discussion'. I will get the invite out at the weekend. See you then.

Keith

27 April 2021 – Weight restoration is rarely steady, Transition and Assertiveness

We covered some really important topics in this week's discussion, with plenty of helpful ideas from the group's experience. I've summarised the key points below.

Weight restoration is rarely steady and linear

Last week we talked about weight restoration being rarely steady and linear. We concluded that our role is to help our loved one manage any anxiety and to provide validation and empathy so that they know they are not making it up and that you recognise how difficult it is. Showing your loved one that 'someone gets it' is really important and helpful. We considered a 'what if'... we are not supposed to talk about food to our loved one at their and/or the hospital's request. There are still things we can do, e.g. giving the staff any information that you think might be helpful to them, such as what has helped in the past. Nor should we underestimate the importance of simply listening, and of the motivational impact of talking about non-eating disorder topics, such as our loved one's general interests and, hopefully, ambitions.

Transition from a specialist inpatient unit to home

We talked briefly about the transition from a specialist inpatient unit to home. 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. It is important to remember that our loved one's are responsible for their own health, not us. It can take a while for everyone to get used to each other again. Routines, likes and dislikes may have changed. Gary summed it up: 'Give yourself a bit of time to get used to the new normal'.

Assertiveness

Our major discussion took us back to Georgina's 'Assertiveness' presentation. How can we change our behaviour to be more assertive and less passive so that we don't accommodate the illness, e.g. by going from supermarket to supermarket to buy the 'proper' food, or by baking an extra cake when we know it's not going to help in the long run? Sarah asked three deceptively simple questions that made the penny drop for at least one of us (me):

- What are you frightened of? The answers came thick and fast and were almost all things that show how much we care, i.e. good intentions - we are frightened of our loved ones not eating at all, of becoming distressed, of upsetting others in the family.
- Which of Georgina's four characters - Aggressive Alf, Manipulative Mike, Passive Pete or Assertive Ned - would we most like as a friend? We all agreed we would prefer Assertive Ned.

27 April 2021 – Weight restoration is rarely steady, Transition and Assertiveness

- So, which character would our loved ones prefer? The answer is easy once you think about it... Assertive Ned, of course.

Sarah then reminded us that we have the choice of being assertive. It takes practice; we need to have in our tool box 'how to manage those strong emotions / distress' because, and especially in the short term, our loved ones may push back; and sometimes the quiet life is OK, or life can become intolerable. I think we should share examples of successes (and failures) as we learn to be 'more NED' and 'less Pete, Mike and Alf'.

Next week (Tuesday, 4th May) is a '16.30 Support Group Discussion' with a bit of a difference. We are going to show a video of a former patient talking about 'What bulimia taught me'. There are some great messages to all eating disorders and recovery, and we are confident it will stimulate a really good discussion.

And finally, Renata sent in the attached. She thinks it could be renamed 'The Wholehearted Dolphin Manifesto'. I agree.

Keith

Resources

The Wholehearted Parenting (Dolphin) Manifesto



The Wholehearted Parenting Manifesto

Above all else, I want you to know that you are *loved and lovable*. You will learn this from my words and actions - the lessons on love are in how I treat you and how I treat myself.

I want you to engage with the world from a place of worthiness. You will learn that *you are worthy of love, belonging, and joy* every time you see me practice self-compassion and embrace my own imperfections.

We will practice *courage* in our family by showing up, letting ourselves be seen, and honoring vulnerability. We will share our stories of struggle and strength.

There will always be room in our home for both.

We will teach you compassion by practicing *compassion* with ourselves first; then with each other. We will set and respect *boundaries*; we will honor hard work, hope, and perseverance. *Rest and play* will be family values, as well as family practices.

You will learn *accountability and respect* by watching me make mistakes and make amends, and by watching how I ask for what I need and talk about how I feel.

I want you to know *joy*, so together we will practice *gratitude*.

I want you to feel joy, so together *we will learn how to be vulnerable*.

When uncertainty and scarcity visit, you will be able to draw from the *spirit* that is a part of our everyday life.

Together we will cry and face fear and grief. I will want to take away your pain, but instead I will sit with you and *teach you how to feel it*.

We will *laugh and sing and dance and create*. We will always have permission to be ourselves with each other. No matter what, *you will always belong here*.

As you begin your Wholehearted journey, the greatest gift that I can give to you is to *live and love with my whole heart* and to dare greatly.

I will not teach or love or show you anything perfectly, but I will let you see me, and I will always hold sacred the gift of seeing you. *Truly deeply seeing you*.



4 May 2021 – Bulimia

4 May 2021 – Bulimia

We organised the session a little differently this week, beginning with a video about Susannah Laing's recovery from bulimia. Susannah was born in Troon, Scotland. In the video she talked about what living with bulimia has taught her about fear, trauma, and being in a loving relationship with her body. It is a powerful, hard hitting presentation, which you can view here: https://www.youtube.com/watch?v=3Q76l_4lDsA.

We then discussed our observations, thoughts and reactions to the issues raised:

- Susannah was very young (eleven or twelve) when her illness first manifested itself - emphasising the importance of parent/carers knowing the signs and symptoms <https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/eating-disorders/overview/>.
- Susannah recalled some 'trigger' moments, e.g. when her sports coach told her 'to watch her weight'. Of course, there is no simple cause and effect. Most people who receive such comments do not develop an eating disorder. However, it emphasises the importance of parent/carers being as aware as is possible of changes in behaviour and being curious about why.
- We talk regularly about the importance of empathy and validation. A big part of that is having some understanding of the illness. If there is one thing that this video demonstrated it is that eating disorders are about feelings, not food: 'I was eating over every emotion I could imagine... getting rid of it all. Numbing my whole life.'
- We were struck by the shame Susannah expressed and how the illness made her lie and 'perform an act' to cover up what she was doing. A clear and important reminder that so often it is the illness talking, not our loved ones.
- Susannah reached rock bottom before her recovery began. The group's experience varied but this is not uncommon. We also talked about 'semi recovery' and 'going through the cycle again' - this is not always the case but it is also not uncommon. Recovery very often takes a long time, which is why we need to look after ourselves so that we can continue to support our loved ones.
- Recovery is possible - this was one of Susannah's main messages. Key to Susannah's recovery was learning to be completely honest with herself, having a structure and connecting with her feelings and with other people. These are clear pointers as to what we can support our loved ones with. Susannah described how hard recovery is, e.g. having to learn to eat properly again 'like a baby' - we must recognise and appreciate the achievements our loved ones make as they recover, however small the steps might appear.
- Recovery is 'always a work in progress'. Susannah said that in times of stress the old voices come back but that she now has the resilience to deal with them.

4 May 2021 – Bulimia

- Susannah said that she did not regret the years bulimia had taken away from her, rather she was grateful because she knew how precious the years of life she has ahead of her now that she has recovered - years that others may take for granted.

Perhaps you have watched a video that you think would be a good stimulus for discussion? Let me know. The format worked well (I have since learnt that it is not possible to share audio from a Mac to a PC, although a future upgrade may allow this.....) and it is something we could build into the programme if you would like to.

We still had time for introductions and updates. It was good to hear some positive news and, as ever, the group had ideas for those who are struggling.

Next week is a '18.30 Presentation Session'. Dr Pia Thiemann will be talking to us about the relationship between autism and eating disorders, which is increasingly being seen as significant to the diagnosis and treatment of eating disorders. I look forward to seeing you then.

And finally, let me know if you would like me to email you Axxx's wonderful and fully searchable compilation of the second six months of these summaries.

All best wishes

Keith

Resources

Websites

Video: https://www.youtube.com/watch?v=3Q76l_4lDsA

NHS: <https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/eating-disorders/overview/>

11 May 2021 – Presentation - Autism and Eating Disorders – Dr Pia Thiemann

This week's session was a presentation by Dr Pia Thiemann about autism and eating disorders. Pia was beset by technical problems, (which she tells me continued the next day), so she was not able to share her PowerPoint, or the video. Pia gave a brilliant demonstration of how to stay calm... and carry on! Pia's presentation is attached and I have referred to its page numbers in this summary.

Pia began by defining autism (p 3) and describing its main characteristics (pp 4 & 5). People with autism may struggle with decoding non-verbal communication, can have difficulties maintaining friends, may be over dependent on routines and can find change very difficult. Also, people with autism may have differences in sensory processing: this video link gives an idea of what this can be like <https://www.youtube.com/watch?v=plPNhooUUuc&t=1s> .

Pia emphasised three key facts:

- These characteristics form a continuum and everyone is different
- There are many associated symptoms (p 7).
- 35% of people with an Eating Disorder have Autism or high Autistic traits (p 8).

There are many ways in which autism can lead to an eating disorder (p 9). Often the eating disorder is an attempt to cope with problems that are related to the autistic traits e.g. to cope with anxiety or to connect with others... 'If I was the right weight I would be able to fit in with the other girls'. In addition autistic traits fuel the eating disorder, e.g. sensory issues affect the consumption of food. In therapy it is important to get an understanding of the link between our loved one's autism and their eating disorder because it may not be obvious; for example, the 'classic' reason for not eating a sausage is that it contains too many calories but for our loved one on the autistic spectrum it may be a sensory issue, e.g. disliking the texture or an autistic rule was formed in the past.

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

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

- If we think autism might be an issue we should push for a test and diagnosis (p 11). Even if our loved one's score is slightly below the threshold treatment should be adapted to the individual. Without stepping in and taking over, we can be their champion to make sure this happens. Pia recommended the PEACE pathway website <https://peacepathway.org> .

11 May 2021 – Presentation - Autism and Eating Disorders – Dr Pia Thiemann

- We can provide invaluable information to our loved one's therapist because we will be most aware of how they are accommodating their autistic traits. For example, we will know how they try to manage social interactions.
- We need to be aware of - and can take reassurance from, i.e. it's not us - the knowledge that some people with autism can be very spiky (yes, we have a new animal, the hedgehog, to add to our menagerie!). This makes it all the more important to have a range of 'keeping calm' strategies, which is also good modelling for them. Getting into a confrontation will not work, our loved one will simply shut down.
- It is also important for us to know that for most people with autism their treatment takes longer because of a range of factors, e.g. they may need more time to process information and/or to build trust and/or to learn how to control anxiety. This makes recovery an ultra-marathon, not just a marathon, so it is even more vital that we look after ourselves.

Thank you, Pia, for such an informative presentation. We are very lucky to have a champion for autism as part of CPFT's service, not all teams do. With more being learnt all the time I can confidently predict that we will be inviting you back!

Next week's session (Tuesday, 18th May) is a 16.30 Support Group Discussion. I look forward to seeing you there.

Keith

Resources**Video**

<https://www.youtube.com/watch?v=plPNhooUUuc&t=1s>

Websites

<https://peacepathway.org>

Presentation

Eating Disorders and Autism

Carers Group 11th May 2021; Dr Pia Thiemann (Clinical Psychologist)

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Overview

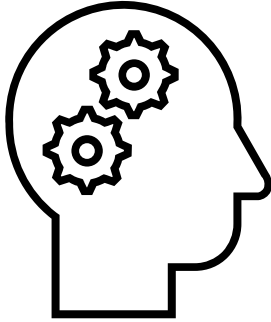
What is Autism?

Autism and Eating Disorders

Support and challenges

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What is Autism?



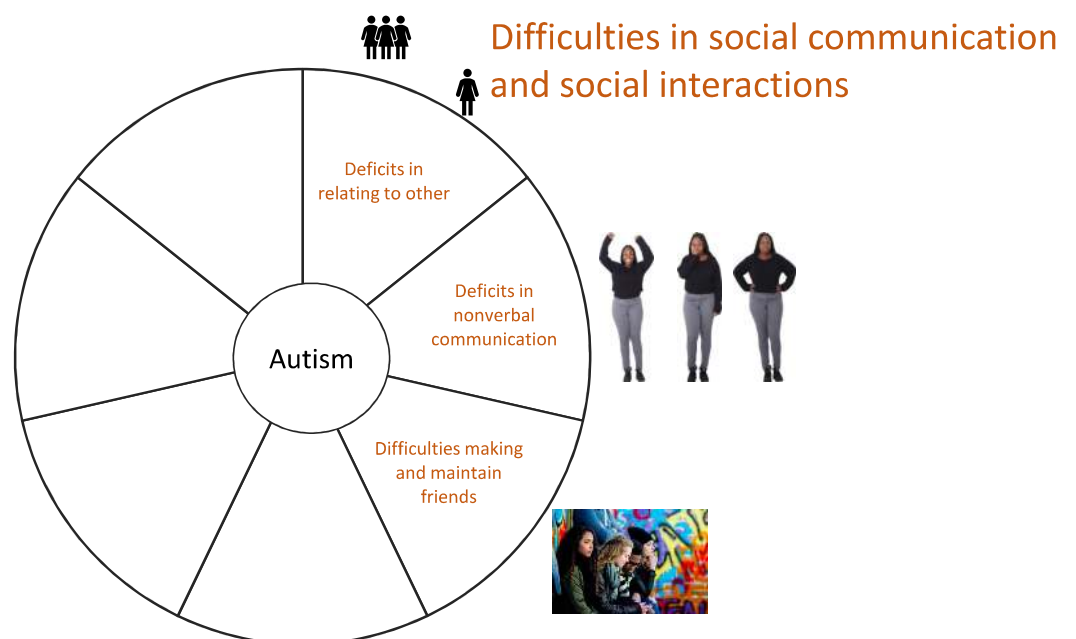
The brain of an autistic person works differently.

The way they think about and experience the world is different.

This can create difficulties and strengths.

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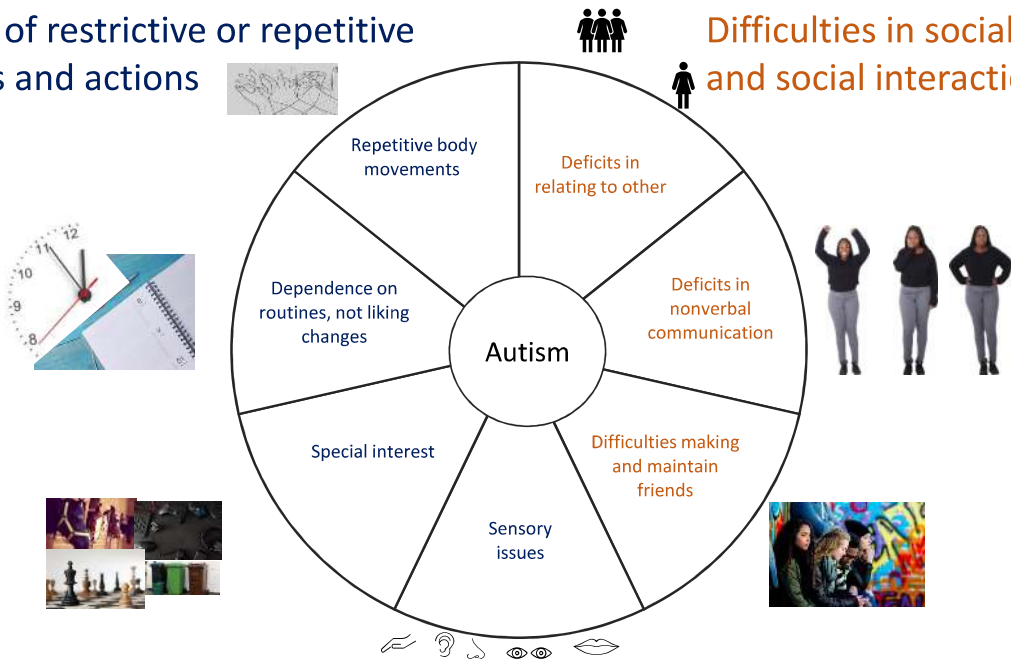
What is Autism characteristics – diagnostic criteria



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What is Autism characteristics – diagnostic criteria

Presence of restrictive or repetitive behaviors and actions



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Differences in sensory processing

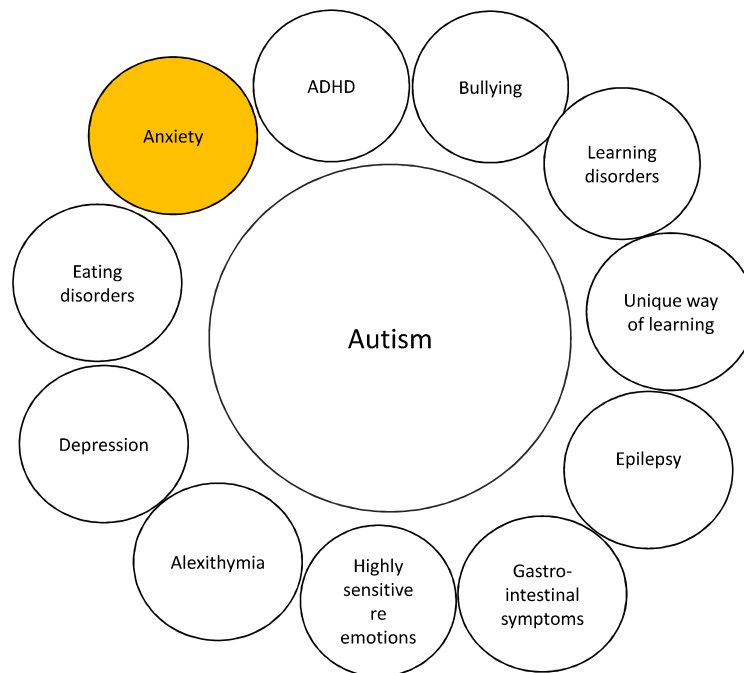
Video includes loud sound and bright light



<https://www.youtube.com/watch?v=plPNhooUUuc&t=1s>

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What is Autism associated symptoms



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Autism and Eating Disorders - prevalence

35% of people with an Eating Disorder have Autism or high Autistic traits

18-23% of patients with Anorexia Nervosa have Autism



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Autistic pathway into an Eating Disorder

Eating Disorder as a coping strategy

- Negative self perception
- Connecting with others
- Way of coping with anxiety
- Attempted to prevent change
- Special interest
- Autistic rules
- Sensory issues

Autistic traits fuel the Eating Disorder

- Sensory issues
- Rigid thinking style
- Emotional processing
- Gastrointestinal problems

Low weight and a starved brain put autistic traits in “overdrive”

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Support

What works well?

What is challenging?

Screening questionnaires

AQ (Autism-Spectrum Quotient Test)

Scores in the 0-25 range indicate few or no Autistic traits

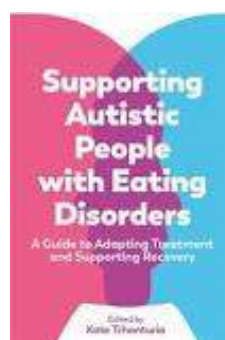
<https://psychology-tools.com/test/autism-spectrum-quotient>

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Resources



<https://peacepathway.org/carers>



<https://www.autism.org.uk/advice-and-guidance/topics/mental-health/anxiety>

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Additional slides

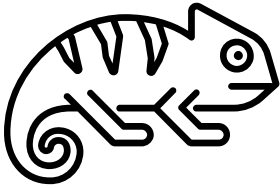
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Avoidant/Restrictive Food Intake Disorder (ARFID)

- Persistent food restriction where nutritional needs are not met
- Loss of interest in food
- Concern about the consequences of eating (e.g. vomiting)
- Avoidance and anxiety due to the **sensory** characteristics of food

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Autism in girls and women



- Less common
- Identifying more with boys
- Trying to fit in ⚡ go against conventions
- Camouflaging

18 May 2021 – Stepping back, Hard to share,

18 May 2021 – Stepping back, Hard to share,

It was good to join you for a very useful discussion. We picked up quite a lot of issues as we went along. Here are a few that stood out:

Stepping back

Stepping back - not stepping in with advice / comment / judgement. It's so hard when we are so anxious that our loved ones make and/or maintain progress. We know that 'stepping in' doesn't work, what is more helpful to do? It's a question we've discussed before and I'm sure we'll return to it again; each time we add more experience to our 'toolkit'.

- From our previous discussions: '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'.
- From today's discussion, Rxxxx said that their experience was 'Don't try to understand it, go with the flow. The less we say it seems to help them. Our loved ones' thinking is different'. This was very much supported by others in the group.
- Also, remember that if our loved one does not want to change their behaviour we will not be able to argue them out of it, we will just back them into a corner. What we can do in this situation is give feedback - factual statements - about their health, e.g. 'I have noticed that you are able to do very little the day after a long bike ride' or 'I noticed that you were limping after your run, have you picked up an injury?'. Our loved ones are the experts, they know about the importance of nutrition, this conversation shows that we notice and care, and allows them to draw conclusions as and when they are ready to do so.

Our loved ones have stepped in to help us

Looking back through my notes I was struck by a number of the group who mentioned that our loved ones had stepped in to help us when we had some difficulties. Perhaps we need to ask ourselves, '**Are we doing too much? Could we step back a bit more?**'. Our loved one should gain confidence and a sense of purpose from helping out.

Hard to share

We concluded by discussing how hard it is to share what we are going through with family and friends. This is an important question because **we need a 'ring of support'**, we cannot do this alone. One barrier can be that there is still a stigma around mental illness, including eating disorders. However, a good friend and a supportive family will not be influenced by that and many of the group had positive experiences of sharing, despite some nervousness to begin with. As we know only too well, eating disorders are hard to understand - one place to start is sharing BEAT's Friends and Families leaflet

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

18 May 2021 – Stepping back, Hard to share,

A difficult issue is if our loved one does not want us to tell anyone. It is important to respect their confidentiality and have consent to share. However, it is equally important for our loved ones to understand that we need support, for ourselves, and so that we can continue to support them. We need to rehearse an 'assertive conversation', e.g. 'I understand that you are having a tough time at the moment, to be honest I am too. I would find it really helpful to talk to _____, I know I can trust them'. By being honest about the need for support we are also being a good role model. At the end of the day, we are responsible for our own health and may have to seek help. We need to balance confidentiality with the need for support and this can be done, e.g. saying to a friend or employer, 'I'm having a tough time... I can't go into details... but it would be really helpful if...'

A number of links to information and recent news were suggested, see Resources:

I look forward to seeing you all next week for an '18.30 Support Group Discussion'. I'll send the invites out on Sunday or Monday morning.

All best wishes

Keith

Resources

From Axxxxxxx -

FEAST's 'First 30 days'

<https://www.feast-ed.org/register-now-for-our-30-day-educational-service/>

And from Axxxxxxx -

Newspaper articles

<https://www.theguardian.com/society/2021/apr/22/eating-disorders-families-tube-feeding-patients-at-home-amid-nhs-bed-shortage>

<https://www.google.co.uk/amp/s/amp.theguardian.com/society/2021/apr/22/eating-disorders-families-tube-feeding-patients-at-home-amid-nhs-bed-shortage>

Television coverage

<https://www.itv.com/news/london/2021-05-13/sharp-rise-in-children-waiting-for-treatment-in-london-for-eating-disorders>

<https://news.sky.com/story/eating-disorder-services-under-constant-pressure-after-covid-lockdown-12309708>

18 May 2021 – Stepping back, Hard to share,

And for those of you with Twitter

https://twitter.com/5_News/status/1392899074739867653

https://mobile.twitter.com/5_News/status/1392899074739867653

25 May 2021 – Ups and Downs, Key points to remember, 3 Carer wishes

Ups and downs

We began this week's meeting by welcoming two new members to the group, xxxx and xxxx. You are very welcome and we are so pleased that you have been able to join us. We introduced ourselves and gave our weekly update. As ever, some ups and downs but, reading through my notes, I am struck by how level headed and practical everyone is being - whether it's an 'up' or a 'down'. We talked about how our loved one's mood can dip even when things are going well. It is another example of how complex this illness is. The group's experience is 'hang in there' because it will improve; offer to talk; and remain calm. It is really hard and you as the carer need support to manage what is understandably a very worrying time, e.g. from a friend, or a group like this.

Key points to remember

xxxx and xxxx introduced themselves. They are both in a similar situation in that their loved ones have been referred but are waiting for treatment to commence. This is a situation that almost all of the group are familiar with and it can be a particularly difficult time. The group offered thoughts and advice based on our experience. There is a danger of 'advice overload' but here are some of the key points - useful reminders for all of us:

- It is not your fault - there is no evidence that parents/carers are responsible for eating disorders, they are a complex mental illness.
- Your loved one is not the eating disorder - keep your connection with who they really are, e.g. by having topics of conversation that are nothing to do with food.
- Look after yourself - you need to be well for your own sake, and so that you can provide the best possible care.
- Don't argue with an eating disorder - perversely your loved one is getting a benefit from the eating disorder because it is their way of trying to control thoughts, feelings and emotions that they find overwhelming.
- Stay calm, caring and compassionate.
- You're not alone - you have found us and there is plenty more support available.
- It takes time to learn how to be a carer for a loved one with an eating disorder - you will make mistakes (and learn from them). Try not to get downhearted, there will be a way forward.
- Above all, always remember that recovery is not only possible, it is the most likely outcome, although it can take a long time.

25 May 2021 – Ups and Downs, Key points to remember, 3 Carer wishes

Three Carer wishes

I concluded by giving you a magic wand and asking for your three 'carer' wishes. In summary these were:

- First, for your loved one's recovery;
- Second, for your own support needs to be met, especially access to groups like this; and
- Third, for the knowledge, understanding and skills to help your loved one's recovery.

I hope I have faithfully represented your views in a video clip for Carers Week (7th - 13th June) that the Trust is compiling and will endeavour to show it to you at some point!

Resources**New Maudsley Autism and Eating Disorders**

Attached is the handout about autism and eating disorders I mentioned, a topic that we will definitely be returning to.

New Maudsley Skills Workshops for Carers Additional Capsule – Autism and Eating Disorders

In recent years there has been much written about possible links between autism and eating disorders. Many eating disorder clinics now routinely screen new patients for autism and will then adapt treatment according to the patient's individual needs. There is no one recommended approach, although there is a large study currently being undertaken at the Maudsley hospital in London which is considering how treatment can most effectively be adapted for patients with a dual diagnosis of autism and anorexia.

Of course, people with autism spectrum conditions (ASC) can present with a wide array of eating difficulties, not just restrictive eating. The main eating disorder categories can exist within the ASC population including anorexia, bulimia, and binge eating disorder. Individuals might overeat certain foods because of the comfort it gives them or they might never experience feelings of fullness. At the other end of the scales certain tastes, textures and colours might be avoided as they trigger sensory overload for example. Avoidant restrictive food intake disorder (ARFID) is thought to be more common within the ASC population, in which we see apparent loss of interest in food but which might be related to the fact that thoughts around food have become all consuming and the child is experiencing overwhelming levels of anxiety, concerns about the consequences of eating (eg vomiting) and/or avoidance due to sensory characteristics of food. Many eating disorder services now include assistance for ARFID although this is not always the case, especially when there are no weight or shape concerns.

Top Tip: If you are concerned that your loved one with autism is developing an eating disorder write a list of any changes in behaviour that you are observing and in particular around food, weight, exercise and mood. Early intervention results in better outcomes and the more specific you can be about your observations, the more helpful this will be to the GP or other medical professional assessing whether or not to make a referral to a specialist team. You know your loved one best and so are in a good place to spot the signs that an eating disorder might be emerging.

What do we know about co-occurring anorexia and autism?

- 70% of children with autism have co occurring psychiatric illnesses eg anxiety & depression & OCD. This is not because they have autism per se, and may be driven by the environment, perhaps difficulties at school such as exclusion or bullying, lack of understanding, and the stress of trying to fit in
- Young people with eating disorders are very likely to struggle with co occurring psychiatric illnesses, which may be driven in part by the effect of starvation and/or chaotic eating on the brain, and pre existing personality types such as perfectionism and low self esteem
- Up to 35% of women with anorexia have autism, or high autistic features, which is often undiagnosed until after the anorexia diagnosis (compared to 1% of women with autism in general population)

Common features of anorexia and autism

- Anorexia: desire to lose weight, low self esteem, body image issues
- Anorexia & Autism: need for control, rigid thought patterns, lack of flexibility, sensory difficulties, social confusion & struggling to relate to others, organisational problems, exercise issues
- Starvation can present like autism. If traits such as rigidity resolve once re-nourished then it would suggest that autism is not a feature

“Same behaviours, different reasons: what do patients with co-occurring anorexia and autism want from treatment?”

A study carried out in 2019 found that:

- Treatment needs to be person centred and preferably in an autism friendly environment (no loud noises, small rooms, avoid chaotic settings etc)
- CBT should be adapted, and incorporating activities such as art, music, lego therapy can be powerful
- Aim to distinguish between ED behaviours and autism behaviours (parents can provide a great deal of information about personality traits before the eating disorder appeared. Friendship issues, self criticism, always was a worrier, perfectionism and lack of empathy might all indicate autistic traits)
- Treatment may take longer
- Recovery will be different and should aim for quality of life accepting that the autism related behaviours can co exist with sufficient nourishment

Special diets for autism - do they work?

Much has been written about the role of “special diets” and vitamins as a therapeutic approach to autism, although the UK Government’s NICE guidelines advise against this approach because of lack of a clear evidence base.

Of course some children might respond well to changes in their diet The important thing to remember is that every time you try one of these approaches it is an experiment which may or may not be successful. Ideally you would have a dietitian or nutritionist monitoring progress. Having said that always be aware that any sort of restrictive diet can increase the risk of developing an eating disorder.

Restoring regular nutrition - intervention and strategies

It is recommended that dietary advice is part of the treatment package for young people with eating disorders, although how this is given varies widely between treatment teams. Some families are offered the services of a dietitian who specialises in eating disorders, others are tasked with following their instinct with parents being told “you know how to feed your child”.

When managing both autism and eating disorders it is important to take into account the special nutritional features that can occur with autism such as the individual’s sensory needs, and the special and differing relationship with food that may have existed prior to the eating disorder. Sensory information is not just limited to the traditional five senses. For example interoception is a sense that provides information about the internal condition of our body—how our body is feeling on the inside. Interoception allows us to experience many body sensations such as a growling stomach, dry mouth, tense muscles or racing heart. Hunger and thirst are two such body sensations and have direct relevance to the amount of food consumed. For most of us we automatically recognise when we are hungry and thirsty, and when we are full and hydrated. With ASC this is often not the case and it is a very individual thing. One young person with ASC may never feel hunger and so is not motivated to eat. Another young person might experience hunger but never experience feelings of fullness and so will not be able to tell if they are overeating. This overeating might then lead to weight gain or involuntary purging. Another might experience hunger but will feel full after eating the tiniest amount. Occupational therapy (with an OT with specialist sensory training) can be really useful where these features are being observed. Parental input around the child’s eating habits before the eating disorder emerged is invaluable so that the therapist is able to adapt the therapeutic intervention. Regular routines around mealtimes and food can be really helpful so the young person learns when and how much they need to eat, including parental guidance if necessary, on when to stop eating.

A young person with autism might be able to restore regular and sufficient nutrition to be healthy, whilst also sticking with many of their pre existing rules around food and mealtimes.

Some methods that have proved successful include:

- Behavioural experiments - testing hypotheses regarding the young person’s beliefs around food
- Food chaining - linking foods that are already being eaten with new foods that are similar in taste or texture
- Social stories and comic strip conversations - the young person might enjoy being the artist
- Mindfulness - to consider the senses with regard to the taste, smell, colour and texture of food, as well as feelings of hunger and fullness.
- Desensitization and “taste trials”. Being gradually exposed to rejected food with a view to eventually tasting it.
- Art or photography of food groups. This can help with desensitization.

Helping with Communication

Young people with autism and young people with eating disorders often struggle with social interaction and communication. It can be helpful to explore different ways of communication when face to face interactions are proving difficult. It is interesting that with the growth in the use of online tools such as Zoom since COVID, many young people have expressed a preference for this type of social interaction. Communication can be in many forms so be as flexible as possible and help your loved one to explore different avenues. Many families have found the following useful:

- Family notebook - in which family members write messages to each other
- Post it notes
- Hand written letters
- Email
- Text
- Phone
- Whatsapp
- Facetime
- Skype
- Zoom

Communication can also be through mediums such as art, drama, music poetry, clay or other creative tools. My son found art therapy particularly useful when he was very poorly.

Some young people find it useful to create a “crisis” card or an “about me” card that can be laminated and carried everywhere. For example;

“When I am feeling really anxious I will.....” Having a range of options is helpful including someone to talk to or a helpline.

“When I am feeling anxious I might.....” This card might list the ways a young person behaves that might seem unacceptable or naughty, but are triggered by anxiety.

“I have autism and this means I have difficulties communicating.....” This card might also contain a list of things that this person struggles with:

- I may say things that sound rude but I don’t mean them
- I might be loud when I need to be quiet

And things that are helpful:

- If I’m inappropriate please don’t tell me off. Instead just quietly and discretely ask me to stop
- I might not understand what is being said to me. I will try to ask for clarification
- I might need things explained to me in different ways
- If I am feeling overwhelmed I might need some space, or I might need to leave the room. When I come back please don’t make a fuss, just let me settle back in

The key to successful communication and building confidence around social interactions is to be flexible and work with the young person to find the optimum solution.

Recovery

It is important to acknowledge that mental health conditions such as eating disorders, anxiety and depressions are treatable and recoverable from, this is not the same for ASC. ASC are an inherent part of who the young person is.

“I learnt it’s ok to be who I am and it’s ok if that is different..... that I can still be happy, in myself and in my life and that I’ll be ok.”

(Niamh)

King’s College Research

Kate Tchanturia and her team at the Maudsley have several research studies ongoing including the PEACE pathway study which aims to develop a tailored approach to improve the experience for patients, families and clinicians where there is autism and eating disorder co morbidity [PEACE Pathway - Home](#)

Kate’s book is being released in March 2021

Recommended Books

Supporting Autistic People with Eating Disorders: A Guide to Adapting Treatment and Supporting Recovery by Kate Tchanturia

Autism and Eating Disorders in Teens - A guide for Parents and Professionals

By Fiona Fisher Bullivant & Sharleen Woods

What to say to kids when nothing seems to work

By Adele Lafrance and Ashley Miller

Skills Based Caring for a Loved One with an Eating Disorder: The New Maudsley Method

By Janet Treasure et al

Caring for a Loved One with an Eating Disorder: The New Maudsley Skills-Based Training Manual

By Jenny Langley et al

Can I tell you about Eating Disorders?: A guide for friends, family and professionals (suitable to read with children age 7+)

by Lucy Watson and Fiona Field

Videos

Pooky Knightsmith (short version) on her personal journey with autism and anorexia

[Autism & Anorexia | 5 Things you need to know about the interplay - YouTube](#)

Pooky Knightsmith (long version) on her personal journey with autism and anorexia

[Anorexia and Autism – lessons learned on the road to recovery - YouTube](#)

Pooky Knightsmith on being diagnosed with autism in her thirties whilst being treated as an inpatient for anorexia

[Adult Autism: what's it like to get a late diagnosis? My story.. - Bing video](#)

Conclusion

Over recent years we have learnt a great deal about the links/overlaps between autism and eating disorders. Many girls who have presented to eating disorder services have then been diagnosed with autism, and we have learnt that it is important to distinguish between behaviours that have come about because of the eating disorders, and behaviours that are more readily explained by the autism diagnosis. Trying to “cure” a young person of their autism related behaviours can lead to a great deal of upset for everyone involved. In addition, many patients who have struggled with eating disorders for years, who have then received a diagnosis of autism have felt a great sense of relief. Treatment can then be adapted to take into account their autism related behaviours and this can be simple things like reducing background noise in treatment rooms, or maybe more complex adaptations. There is still much to be learnt but at the very least our eating disorder services are learning to adapt to the differences that come with an autism diagnosis.



Jenny Langley 2020

1 June 2021 – Support, Mental Health First Aid

Support

We began the session with our updates and three or four of the group had had really difficult weeks. I'm glad we were able to provide some support and we are thinking of all of you, and of the importance of 'looking after yourself'. We touched on some new topics and the group's experience rose to the challenge. One question was about our loved one securing professional support pre or post treatment, outside of the NHS; e.g., from a charity, or from a private provider. A number of suggestions were made:

- Cambridgeshire Clinical Psychology Services
<https://cambridgeclinicalpsychologyservices.co.uk>
- Cogwheel Counselling <https://www.cogwheel.org.uk>
- ORRI <https://www.orri-uk.com>
- PEDS <https://www.pedsupport.co.uk>

Members of the group have had, or heard, positive experiences of these providers.

Mental Health First Aid

Dxxxxx talked very positively about a mental health first aid course that she had attended, which had helped her confidence in advance of her daughter coming home on Friday. (We will be thinking of you!). Dxxxxx had completed her training with Transpire Training <https://www.transpiretraining.com/mental-health-first-aid-chelmsford>.

Googling 'mental health first aid cambridgeshire' comes up with a number of other providers, including St John Ambulance and CPSL Mind. It seems such a good idea that I have to put it into my 'why on earth didn't you think of that before?' category. A big thank you to Dxxxxx for the suggestion.

Setbacks

We touched on a very common and understandable concern about our loved ones experiencing a set back in their recovery. One issue is that as our loved one's weight restores they can no longer fit into their clothes and this can be very difficult for them to deal with emotionally. Rxxxxx advised acknowledging that it is really painful for them and, at the same time, reminding them of the positive consequences of their health improving, e.g. being well enough to return to university, or to go on holiday with friends. Sarah described that this is tackled as part of therapy, with our loved ones bundling up their 'ill clothes' to take to a charity shop. In a previous meeting one idea was them cutting up their old clothes and using the fabric creatively, e.g. for a piece of patchwork art.

1 June 2021 – Support, Mental Health First Aid

Change Cycle

I then showed a short video about the Change Cycle Eating Disorders: The Stages of Change, which was very relevant to our discussion. Key messages were:

- it is quite normal for the recovery journey to involve going backwards as well as forwards;
- it is important not to panic if our loved one has a bad day, or 'goes backwards'. Understanding that this is possible and knowing from experience that our loved one's progress will almost certainly 'go up' again allows us to step back and remain calm, which is the most helpful emotional response; and
- there are things we can do to support each stage of the change cycle, such as talking about the 'pros' and 'cons' of their illness if they are in the contemplation stage, or helping them come up with ideas if they are in the planning stage.

Resources**Video 'It's not about the nail'**

The video 'It's not about the nail' was recommended:

[It's Not About The Nail..](#)

I have just watched it and I can see why!

Next week is our monthly presentation starting at 18.30 when Derri Davies will be talking to us about the new Support and Stability Treatment Pathway. I look forward to seeing you all then, I'll get the invite out at the weekend.

8 June 2021 – Presentation - Support and Stability programme, Derri Davies, Clinical Nurse Specialist

8 June 2021 – Presentation - Support and Stability programme, Derri Davies, Clinical Nurse Specialist

We began this week's meeting by welcoming new members to the group. We are really pleased that you are able to join us. We then welcomed Derri Davies, Clinical Nurse Specialist with Adult Eating Disorders, who gave a presentation about the new, locally developed, Support and Stability (S&S) Pathway. Derri's slides are attached. Key points are:

- The pathway is for people who have been ill for five or more years, have attempted at least two evidence-based treatments (inpatient or outpatient) and who want to focus on quality of life.
- It is a personalised programme that begins with collaborative goal setting.
- There is no fixed structure but typically there are monthly appointments, regular medical monitoring and a mix of other support.
- Liaison with carers is a key principle, together with carer and family support. This is also personalised, e.g. attending appointments, or family therapy.
- It aims to improve quality of life and to help build 'a life worth getting well for'.

Although not an evidence-based eating disorders treatment, like MANTRA, (Maudsley Model of Anorexia Nervosa Treatment for Adults), by addressing our loved one's well-being the S&S pathway has the potential to make a big difference to how our loved one feels, which can only be of benefit to future recovery. Initial feedback has been very positive, from patients and carers.

Thank you, Derri, for a really interesting and informative presentation, and for answering our questions.

Steps in the right direction

We then introduced ourselves and gave an update on how things are for us. It was good to hear that quite a few of our loved ones have made steps (how small doesn't matter) in the right direction, and for those whose loved ones are struggling there was plenty of support.

We picked up on a number of issues, here are a couple of particular relevance to our new members:

- **How can we best encourage our loved ones when they are starting to make progress?** Rxxx had found tackling a list of 'fear foods' in a systematic way had been helpful, i.e. always choosing one or two a week to work on. Ruth also mentioned putting fear foods onto post-its in a jar and pulling them out at random as a different way of presenting the challenge. Pxxx and Rxxxx have found making the positive


8 June 2021 – Presentation - Support and Stability programme, Derri Davies, Clinical Nurse Specialist

connection between a healthier weight and what it allows our loved ones to do, e.g. playing a sport, going on holiday with friends to be motivating.

- **How can we best support our loved ones when we are providing care at a distance**, e.g. if they are away at university? The principles are the same as for all support: stay calm, be compassionate and show you care. The method will be different - calls, emails, texts. A number of us have found texts useful because it gives you time to think before you reply. It is better to be a 'dolphin' nudging and encouraging your loved one, than a 'rhino' charging in with the solution. Don't argue with an eating disorder - perversely your loved one is getting a benefit from the eating disorder because it is their way of trying to control thoughts, feelings and emotions that they find overwhelming. Nor is being a 'kangaroo' helpful - although it is natural to want to protect your loved one if you put them in your pouch to keep them safe they will never have to face up to their illness.
- And **remember to look after yourself** because unless you are physically and mentally well you will not be able to support your loved one. There is no shame in seeking help for yourself.

I will drop our new members an email with some hopefully useful links, over the weekend, as well as getting the invite out for next Tuesday's 16.30 Support Group Discussion.



Resources**Presentation**


Cambridgeshire and Peterborough
NHS Foundation Trust

Support and Stability Pathway.

Adult eating disorders community team.

8th June 2021



Pride in our adults and specialist mental health services

This session will provide you with an understanding of;

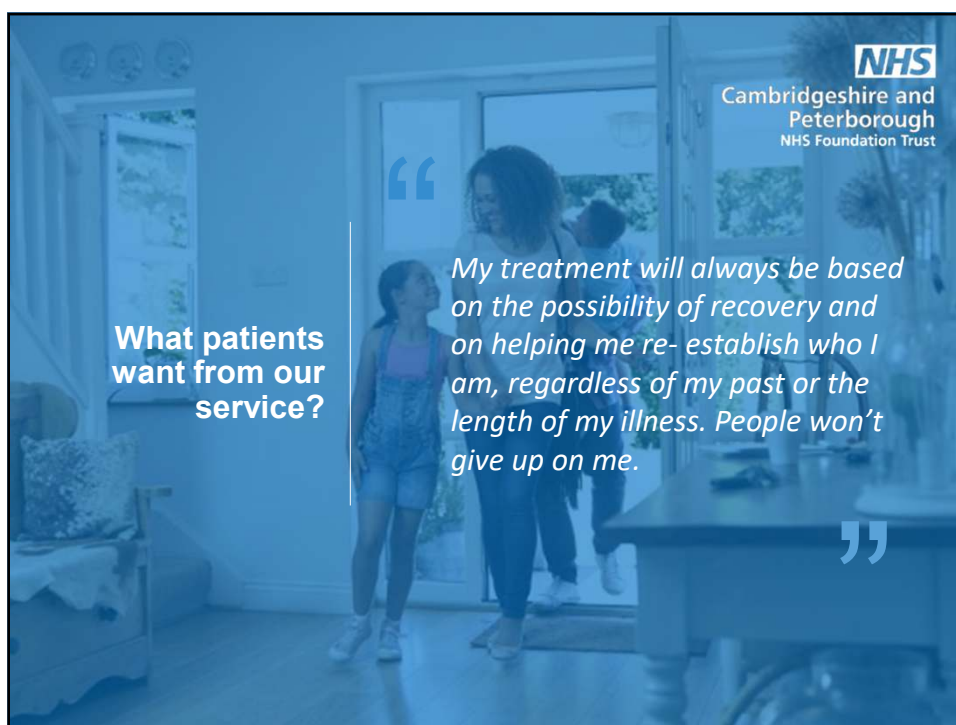
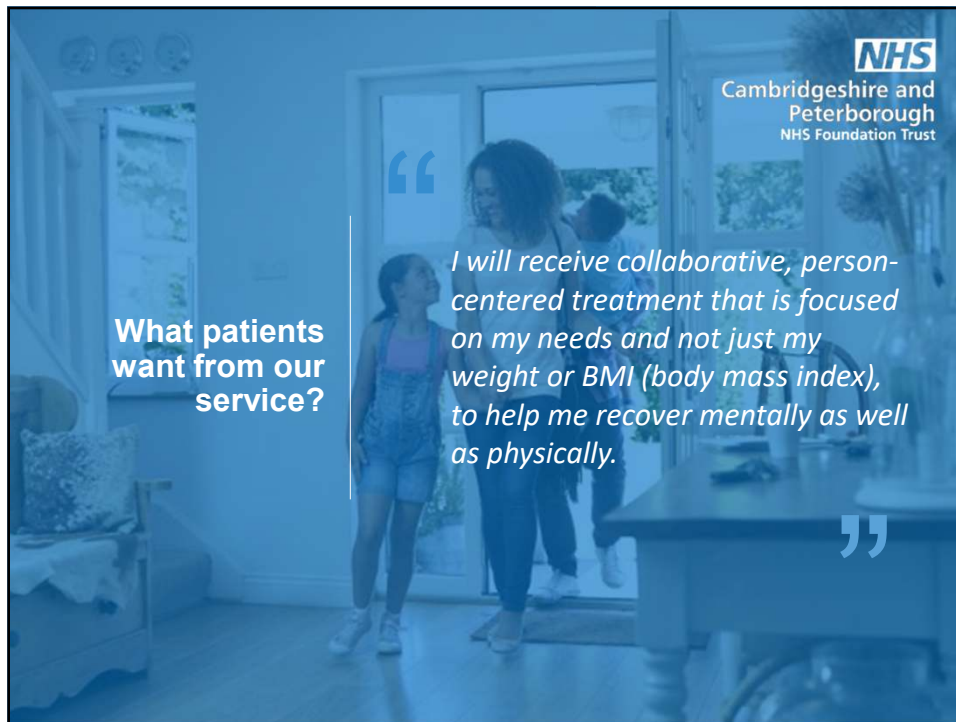
- 01 The aims of the Support and Stability (S&S) Pathway.
- 02 Who would come onto the S&S pathway.
- 03 Who works on the S&S pathway.

And offer you the opportunity to...

- 04 Ask any Questions




Cambridgeshire and Peterborough
NHS Foundation Trust



What are the aims of the Support and Stability Pathway?



Improve quality of life

To improve the quality of life of your loved one.



Provision Personalized care

To provide coordinated and person-centered care within a Multi disciplinary team approach



Support Individualized goals

To support individualized goals that are not covered with therapy on the treatment pathway.



Enable engagement back into life

To enable engagement back into their home and community life



What care could my loved one receive?



Medical Monitoring



Care Programme approach
(if applicable)



Ongoing relapse prevention and crisis planning



Ongoing liaison with other's involved in their care



Collaborative goal setting



Ongoing carer and family support



Continuation of formulation and goal focused work identified from the therapy

Who would come onto the S&S Pathway?

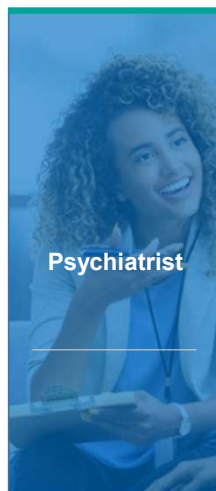
Referral Criteria;

- More than 20 years old
- Diagnosed with a severe ED for more than 5 years
- Has attempted at least 2 evidence-based treatments
- Wants to focus on Quality of Life
- Has further goals following treatment which would require a short intervention.
- Experiencing a transition in their life e.g. going to university following treatment.

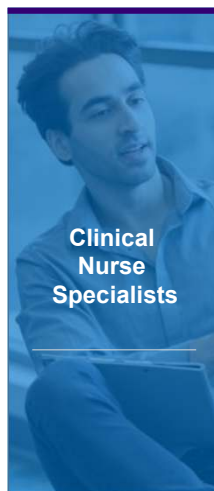


Decision made with the patient, family/carers and MDT individually

Who works on the pathway?



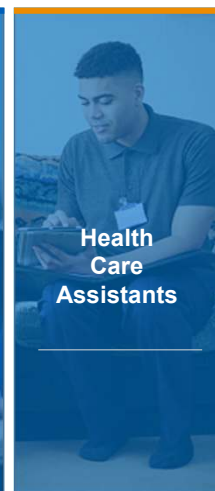
Psychiatrist




Clinical Nurse Specialists



Mental Health Practitioner



Health Care Assistants





Example...

33 year old female, diagnosed with Anorexia Nervosa age 16.



Throughout has had 8 separate inpatient admissions, some detained under the mental health act.

Whilst an inpatient, they tried group therapy including MANTRA.

In the community they have received individual therapy – on two separate occasions with two different practitioners and have also received Family Therapy.



Any Questions?



Pride in our adults and specialist mental health services

15 June 2021 – Bereavement and Life events, What ifs...

Another really good discussion - we welcomed Mxxxx to the group and it was great that Cxxxx's mother, Axxxx, could join us. We picked up issues as we went along and here is my summary of some of the key ones:

Bereavement and Life events

The death of a family member or friend is upsetting for anyone. A bereavement will inevitably add to the strong - often overwhelming - emotions that our loved ones are experiencing. They may react by 'using' their eating disorder to cope with these emotions and/or in their response to us, e.g. being short-tempered and 'prickly'. And we are affected as well, so not at our best for coping with this situation. The group made a number of suggestions based on their own experiences:

- Step back - it may be necessary to walk away, take a breather and come back when you are feeling calmer.
- Show warmth and validate their feelings - it is quite understandable that they are upset.
- Take care of your own emotional health - they need to know how you feel, and especially how you feel about their behaviour; to quote Sarah 'you are not a punch bag'.

Life events such as relationship breakdowns, being made redundant. As carers we are understandably concerned that events such as these could disrupt our loved one's recovery or trigger a relapse. They are pretty much inevitable, so how do we support our loved ones and manage our own anxieties when they happen? 'Back to basics' was the consensus: stay calm; acknowledge the situation; be there to offer practical support if it is wanted; be reassured by the resilience they have learnt from the challenges they have already been through; and look after yourself, for your own sake and so that you can give them the best possible support.

What if...

What if... our loved one is set on a course of action that we really disagree with that we think is definitely not in their best interest? There are many possible examples: a determination to get pregnant with a boyfriend they have not met; going to university against medical advice; hitch hiking across Europe by themselves. Any of our children could present us with this sort of situation but when our loved one's health is vulnerable it is understandable that we are anxious. The group felt there were some important 'do's and 'don'ts':

- **Don't ignore or dismiss** - do listen and do try to discuss in low stress moments.
- **Don't over-react**, stay calm and try to understand their motivation.

15 June 2021 – Bereavement and Life events, What ifs...

- **Arguing won't work.** It's important not to push too hard against a negative thought. Our loved one will simply come up with more reasons for why they are right.
- **Ask questions that will make them think about the consequences** of their plan: 'How will having a baby make things better for you?', 'Where are you going to live?', 'How are you going to support yourselves?' Don't push for answers, leave the questions hanging for them to think about.
- **Remember that it is not our job to sort out our loved one's lives**, nor can we, although there is still a lot we can do to enable them to make healthier life choices.

Top tips for newcomers to the group

Mxxx introduced herself and explained that her daughter was coming home at the end of her university course having relatively recently been diagnosed with an eating disorder. I asked the group for their top tips. I suggested three but we're not good at counting:

- **Don't make food and eating the focus of your lives**, find something that your daughter likes engaging with so that your relationship is not dominated by the eating disorder.
- **Give a bit of time to get used to each other again** and don't panic if your relationship is not like it used to be. Spend some time settling in.
- **It is not your fault.** There is no evidence that parents or carers cause eating disorders. They are a complex mental illness that most people recover from, although it can take a long time.
- **And don't forget to look after yourself.**

22 June 2021 – Key Issues

I've summarised this week's discussion as a series of key issues, which I hope is a useful reminder of the ground we covered. I found it an extremely supportive and helpful conversation.

It's not our job to fix our loved one's problems

It is not our job to fix our loved one's problems. It is helpful to empathise and validate to show that we understand and that we recognise how hard it is for them, e.g. 'I can see how difficult this is for you. I can see why you feel like that. I can see how hard you are trying'.

Sometimes it is necessary to 'step in'

Sometimes it is necessary to 'step in' to save our loved ones from harm when they are unable to take a decision for themselves. **This should be an exception**, not the rule, because it is important not to encourage dependency. It should be a 'stepping stone' to helping our loved one secure professional support and/or to take some action to address the situation. The group's experience was that there were times when our loved ones were relieved that a decision they knew they should take, but couldn't, had been taken for them. Ultimately, though, they have to take their own decisions: 'Only they can do it, but they can't do it alone'.

A meal plan can be very challenging

A meal plan, especially in the early days of recovery, can be very challenging for our loved ones. The group had a lot to say about this. Some key points were:

- Acknowledge how hard it is and encourage your loved one to express their feelings.
- Listen carefully. If they are in two minds, offer 'pros' and 'cons', e.g. 'On the one hand you'd like to have the energy to go swimming with your friends and on the other you are really struggling to follow your meal plan'. Let the comments hang so that they can reach their own conclusions.
- If your 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.
- Don't risk losing trust by undermining the meal plan, e.g. by trying to slip in extra butter to the potatoes.
- If your loved one is making a change, e.g. introducing a food that they would like to eat but find difficult, provide '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.

22 June 2021 – Key Issues

- Blame the dietitian! It is quite legitimate to appeal to a 'higher authority', e.g. 'It is important that I try to help you with the meal plan that your dietitian has said you need to get healthy'.

Covid vaccinations

No-one has heard that people with eating disorders should not have the covid vaccination. Emma has spoken to Dr Melanie Bruneau who says there is no problem whatsoever with severely underweight or anorexic patients having their Covid jabs. It is, of course, important to follow any specific medical advice.

Encouraging our loved ones to take more responsibility

Encouraging our loved ones to take more responsibility. The goal has to be for our loved ones to take responsibility for their own health and wellbeing. In the early stages of their recovery we may find ourselves having to provide quite a lot of support, e.g. with meal preparation. There is a danger that they become dependent on this support and that by continuing to provide it we not only make things harder for ourselves but also deny them the opportunity to learn what 'normal' looks like. The group suggested:

- Have 'taking responsibility' as part of the recovery plan.
- Discuss small steps that can be taken towards achieving this goal.
- Encourage and enable, but step back so that they can learn for themselves.

Rising to a challenge

It was interesting how a number of our loved ones have risen to the challenge of a crisis, e.g. not being there to cook, so they've had to do it; maybe a tactical 'crisis' or two needs to be part of the plan?!

Aims can be motivating

An aim can be powerfully motivating, e.g. wanting to return to university. Our role is to encourage and to stay calm, caring and compassionate if it proves too hard; there will be a next time.

Arguing with an eating disorder doesn't work

Arguing with an eating disorder doesn't work, it just backs our loved one into a corner because you are arguing with something that is important to them. At the same time, it is very important to remember that it is the illness talking; our 'real' loved one is still there and as they recover they will come back to us.

Recovery is the most likely outcome

Recovery is the most likely outcome but it can take a long time. Small steps should be praised because to our loved ones they probably appear massive steps, e.g. even some progress at the end of a period of treatment is an achievement.

Some extras

Here is a link to a CPFT survey for carers who are currently being treated by the service <https://bit.ly/3flehp3> . You may have to paste the link into your browser but if you are the carer of a current service user it would be really helpful if you would complete it. It is very short, I had a look!

Would you be interested in contributing your thoughts on autism and eating disorders to a representative of a Royal College of Psychiatrists working group? They are putting together some guidance and (rightly!) want to include the carer view. Please email me if you are.

Resources

Link

This is the link Axxx mentioned about recovering from smell loss, e.g. from Covid <https://abscent.org/> .

Next week's session is a '18.30 Support Group Discussion' (the fifth Tuesday of the month). I am away (weather permitting in a boat off the Dorset coast). You will be more than ably looked after by Axxx and Suzanne. I will be sending the invite out as usual. I will text in if I see any dolphins.

29 June 2021 – Current situations, What the group offers to us

29 June 2021 – Current situations, What the group offers to us

A very big thank you to Ann and Suzanne for facilitating the group last Tuesday when I was away for a short break. Ann's summary is below and it is easy to tell that it was an interesting and, as ever, supportive meeting. I am extremely grateful to all of you. I was on a boat, sailing along the East Devon coastline. I'm sorry to say that I did not see any dolphins, but your dolphin skills are clearly in evidence in the summary below!

I will be sending the invite out for next week's meeting shortly.

All best wishes

Keith

Current situations

We shared updates and support on our current situations:

- Having an autism diagnosis improving the sense of control by giving an understanding of the need for a schedule.
- That a loved one had admitted that anxiety made the ED more difficult, which we felt was positive as sharing was progress.
- A wobble that was well managed.
- A wide discussion about going on holiday and how to manage; with suggestions for using the same supermarket so the meals were known, looking at menus before going out so safe choices could be made at a calm time, planning in advance so we can enjoy our holiday.

Dxxxx shared a wonderful analogy she had been given for the wobbles we all experience as carers:

Consider a crash test dummy. When a crash test takes place there are two impacts, the car hits the wall and then the dummy hits the screen.

As the parent/carer of a loved one with an ED and we have to deal with a situation of conflict – the crash. Imagine we are the crash test dummy, we know there is going to be an impact and we have a choice; if we blame ourselves for the situation we hit the wall and the windscreen; if we put the seatbelt on, there will still be an impact but we don't blame ourselves and only have to deal with the situation.

29 June 2021 – Current situations, What the group offers to us

What this group offers to us

We then moved on to what we get from attending the group:

- Realising that we are not alone in this journey.
- Being able to communicate with others who know what it is like and who understand what we are going through.
- The only place where I can talk about it as I can't with anyone else.
- To share knowledge and experiences and learn from each other.

We asked if there are similar groups elsewhere in the country; in the small group present it was understood that few have met during the pandemic and pre-pandemic most were run by volunteers and did not have the input from professional ED teams. The online meetings were considered to be extremely valuable and all felt they should continue as they enabled carers to get support from a distance, which may not be possible in their local services.

We would like to see our group used as best practice; with the professionals using their networking opportunities to advocate for similar schemes around the country; we can only ask!

Take care all. Ann.

6 July 2021 – Long distance caring, Every mistake is a treasure, Small steps

It was good to be back and I really enjoyed our discussion. As ever, we covered a range of issues and I've pulled out a few of them that have some general relevance. It was great that some of the group had positive news to report. We were reminded of how quickly sometimes our loved ones' health and wellbeing can improve. It can be hard to explain why. I was reminded of Amy and Ana's presentation about their recovery journey. Neither could identify a 'magic moment' that led to recovery but both talked about a number of things that, combined, helped. Hitting 'rock bottom', improved self-awareness and a goal or ambition are mentioned regularly by patients. As carers it is important to remember that recovery is always possible.

Long distance caring

Dxxxx and Rxxxx described their daughter's further progress with the 'Hello Fresh' meal boxes where you choose meals online and the ingredients are delivered to your door, with cooking instructions. She has now taken first steps in buying her own ingredients for the recipe cards of her favourite meals and cooking them herself. Their 'Hello Fresh' journey illustrates some really good points:

- Initially, their daughter reacted against them ordering these for her - a good example of trying to do something helpful but being too direct.
- They brought the issue to the support group and our experience was 'step back, don't make an issue of it and let her decide'.
- This worked - their daughter eventually accepted them on her own terms and came to find them useful, enjoying cooking and eating her selected meals.
- They have continued to support the supply of boxes - good long distance caring.
- Their daughter has now started using the recipe cards under her own steam, without prompting, and delivery of boxes is reduced.
- This gives plenty of opportunities for appropriate praise and encouragement.

We stayed with the theme of long distance caring. What if our loved one wants (or needs) to go abroad for study, work or travel? Again, it comes back to the principles of good caring:

- It's their decision - it could go really well because it is something that they are motivated by. As carers we can help their motivation by presenting the pros and cons, e.g. 'On the one hand you want your year abroad and on the other your physical health is going to make it difficult'. This will help them reach their own conclusions.
- Support their planning, e.g. with accommodation. It may even be possible for them to arrange for medical support, e.g. at an overseas university.
- Make sure you have support because it is bound to be an anxious time!

'Every mistake is a treasure'

We had some good examples of 'tomorrow is another day' and 'every mistake is a treasure', i.e. we can put bad experiences behind us and learn from them. Holidays can be particularly challenging, even if you have planned in advance, because situations can change, e.g. a restaurant changing its menu..... If our loved one can't do something, or eat something, at least they have tried and there will be another opportunity. As carers we need to dig deep and stay calm. But if we don't (and I will never forget a meltdown I had in a supermarket in a well-known seaside town) it's really important not to beat ourselves up for it - we are only human - and to remember that, as I've said, tomorrow is another day, and you will have learnt something.

Small steps

There were also good examples of small steps lead to success: buying some new clothes, being more comfortable eating out with the family, agreeing to be weighed at home, finding a therapy / therapist they can relate to, going away for an overnight stay. Over time these small steps add up to a successful journey.

Next week we have a presentation on Motivational Communication by Dr Ophelia Beer. I cannot recommend this approach enough, we found it really helpful and more importantly so did our son. It's from 18.30 - 20.00 so I hope you will be able to join us.

And finally...

Here is the link to PEDS, a Peterborough based charity that provides a range of support for patients and carers: <https://www.pedsupport.co.uk>

David said that he has a number of introductory offer vouchers for anyone who wishes to try Hello Fresh for their loved ones. Please contact David if you would like to take up this offer.

And thank you to Suzanne for looking after us all!

13 July 2021 – Presentation - The Change Cycle, Keith Ann and Renata

As you know, Dr Ophelia Beer was unable to give her presentation on Motivational Communication this week, so myself, Ann and Renata stepped in to reprise our presentation on the Change Cycle, which has been part of the 'Saturday Workshop' from the outset until the pandemic brought a halt to face to face sessions. Naomi couldn't join us this week - our fourth member of the band - so Sarah stepped in, and then Emma took over without missing a beat. A big thank you to all of you!

The presentation is attached and here are some of the key points we made and/or discussed:

The Change Cycle

The Change Cycle is not a straightforward, regular progression - perhaps the arrows should go in both directions. However, one way or another most people find their way through these stages to 'maintenance'. Recovery is not only possible, it is the most likely outcome, but sometimes it takes a long time.

Pre-contemplation

Even when our loved one cannot contemplate change there are things that we can do as carers to help move their thinking. Feedback about their health - factual and non-judgemental - is really important because it shows that you have noticed how they are and will sow seeds / encourage thoughts they might already be having. 'I've noticed...' is a really good sentence starter, e.g. 'I've noticed that you are really cold', as a statement that you leave hanging without any further comment, allows our loved ones - potentially - to reach their own conclusions, whereas 'You look as if you're freezing, I'm not surprised, you haven't eaten anything all day' will antagonise our loved ones and be counter-productive. Those with bulimia are usually, not always, more motivated towards change than those with anorexia. However, the same principle applies - say what you see, without judgement; it will help.

Contemplation

When discussing 'pros' and 'cons' it is helpful to think about our loved one's health, behaviour and the activities they can and can't do. Again, leave the sentences hanging. For example, 'On the one hand you want to return to university and on the other you don't have the energy to concentrate properly'. It is important to manage your own anxiety. Stay calm, or the temptation is to start saying what your loved one should do, not what they could do. Be curious about the 'pros' of the eating disorder, why they are hanging onto it.

13 July 2021 – Presentation - The Change Cycle, Keith Ann and Renata

Preparation

This stage requires all of the 'dolphin' skills: stay alongside, nudge, encourage, step back, step in again if they are struggling and want help. We discussed 'aims'. The group's conclusion was that whilst an aim can be powerfully motivating, many of our loved ones struggle looking too far into the future, so it is important to think in terms of 'small steps'. Those whose loved ones are autistic commented that 'what would success look like?' was too vague and more structure / detail is needed. We also discussed 'Try not to enable them to be ill'. Of course we want our loved ones to get better - we must guard against our own reaction to them changing, which might, for example, affect a routine we've got used to and 'is a bit of a nuisance to change'... no it isn't!

Action

'How can I help?' is a really important question when our loved one is in the 'action stage'. You may not get an answer straight away, that's not a problem. Empathy, validation and praise are really important: 'I can see how hard you are trying and it's going so well'. Whilst praise must not be indiscriminate or it loses its currency, it is important to praise what might seem like small achievements to us but are huge successes to them.

Maintenance

A key point here is not to worry about minor blips, which are almost inevitable. Keep up the dolphin skills, nudging towards independence and checking how you can help. Instead of 'pros' and 'cons' make connections, e.g. 'It is great that you've been able to return to university, you wouldn't have been able to do that six months ago'.


Relapse

Think of this stage as 'lapse' not 'relapse'. It is very common and it is really important as a carer to stay calm, despite the lurch your stomach takes. Your loved one's resilience comes from understanding how they got through difficult patches in the past, so ask them about this, e.g. 'what did you find helpful when you felt like this before?' It is really important to look after yourself to avoid going into a tail spin.

In summary


The Change Cycle is really helpful to us as carers because we can adapt the support we give to our loved one's stage in their recovery journey. It allows us to answer two key questions: 'Where is our loved one at?' and 'How can I tailor my support?' We can always 'roll down' to a previous stage when things do not progress smoothly.

Resources**Presentation**





The Change Cycle and Eating Disorders

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




South London and Maudsley NHS Foundation Trust




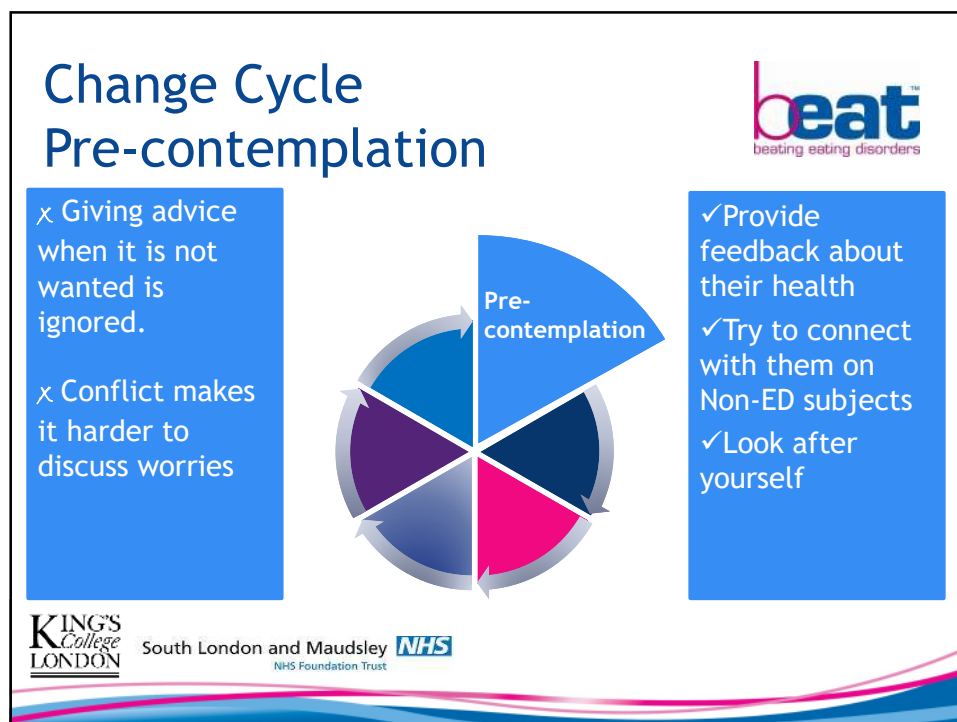
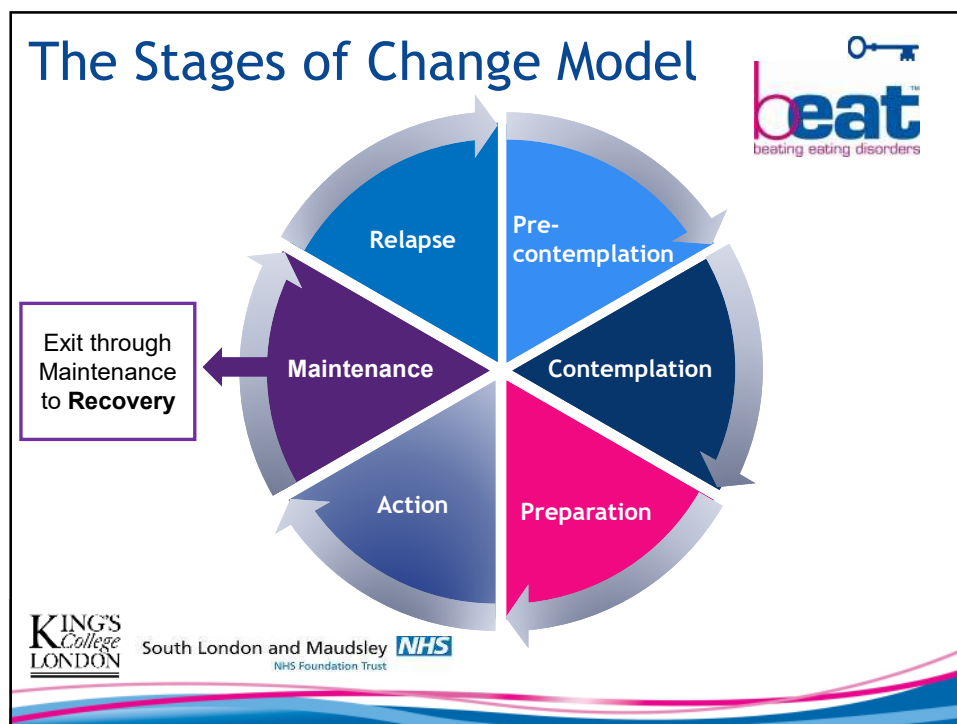
Aims and objectives

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



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Change Cycle Contemplation

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

Contemplation

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

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Change Cycle Preparation

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

✗ Try not to *enable* them to be ill.

Preparation

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

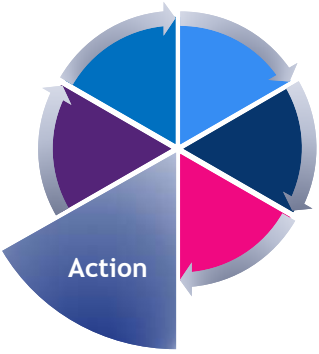
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Change Cycle Action

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

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



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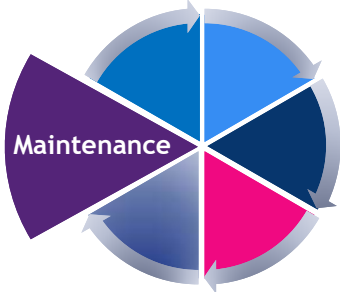
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Change Cycle Maintenance

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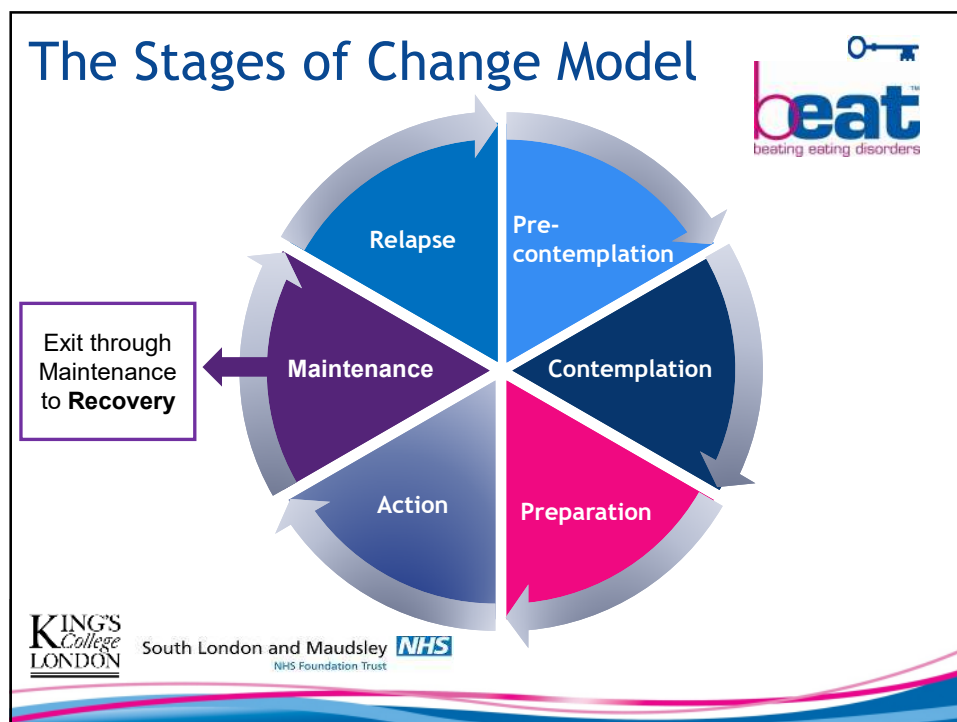
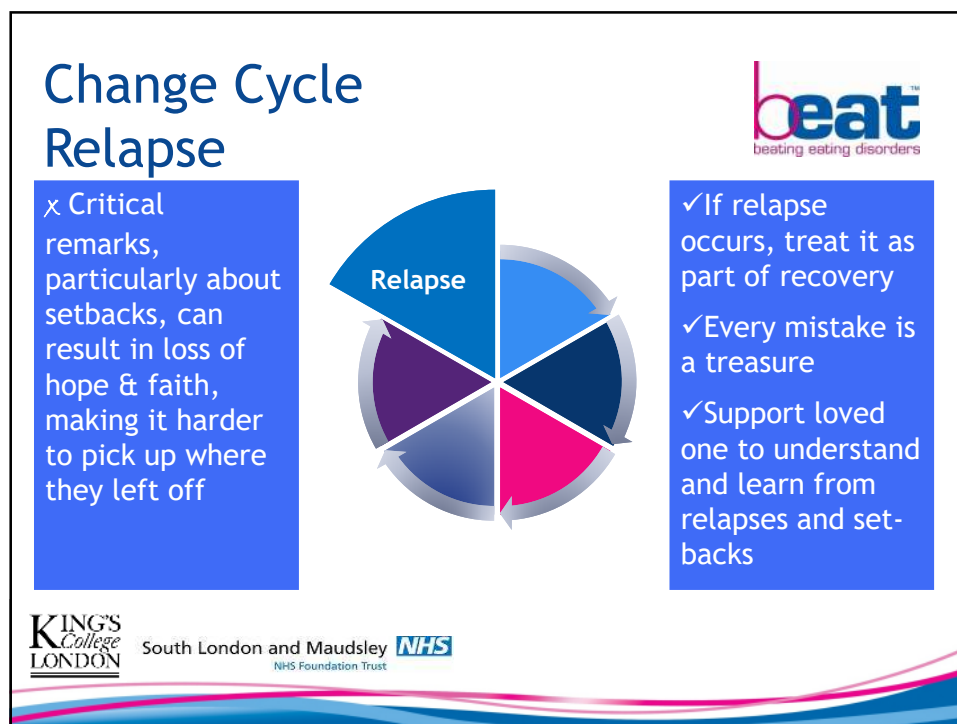
× Criticism & hostility with a shortfall on goals reduces confidence in change attempts

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



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Model of Change

When in doubt...

Roll Down

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

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Key points

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


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beat
beating eating disorders



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



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20 July 2021 - Coping with change, Boundaries and Listening

We began by welcoming Chloe Flack to the group. Chloe has recently joined the Adult Eating Disorders Service as a Mental Health Practitioner. Thank you for joining us, you are welcome any time! We discussed a number of topics that we've talked about before but I thought that it was really interesting that we were able to bring new ideas to them. I have summarised some of the key points below.

Coping with change

Most of our loved ones find **coping with change** difficult:

- Some changes can be opportunities as well as challenges, e.g. moving house. This can provide an element of a fresh start because the new home isn't associated with bad experiences. The same applies if it is a move to a new area.
- Our loved ones can be simultaneously in different parts of the 'change cycle'. For example, they could be in the 'action stage' with regards to increasing calorie intake and in the 'contemplation stage' for increasing saturated fat intake. This means that the support we give also needs to vary: assisting them with new learning strategies and praising their achievements in the 'action stage' and discussing the pros and cons in the 'contemplation stage', e.g. 'On the one hand you want to get back to university and on the other your meal plan is not giving you the energy you need'.
- Thinking back to what has worked before can be really helpful for our loved ones if they 'lapse', e.g. looking back to a previously successful meal plan.

Boundaries

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

This is the link to Dr Georgina Hurford's presentation about assertiveness for those new to the group (see 20th October 2020):

https://www.keep-your-head.com/assets/2/aeds_online_carers_support_group_summaries_book2_.pdf.

It's hard to do but it is really important to try. It is also good modelling for our loved ones.

20 July 2021 - Coping with change, Boundaries and Listening

Listening

Listening is really important. I am pretty confident that all experienced carers will say how important listening is and also how they couldn't quite believe this when their loved one was first unwell because 'it feels like you aren't doing anything'. The reality is that active listening is hard work - you need to stay calm, to help your loved one articulate their thoughts and feelings and you need the discipline to 'let comments hang' and wait for your loved one to draw their own conclusions. We heard some really good examples this week: letting a loved one 'offload' after a distressing assessment without stepping in with solutions; making a statement and letting it hang, rather than making a judgement, 'I can see that you are drinking a lot of alcohol'. This keeps the line of communication open and lets our loved one come to us when they are ready.

There were some brilliant examples of 'staying calm' this week, even when we want to shout for joy! When our loved one says they are hungry, or wants some more, or has eaten a decent meal for the first time since you can remember - who hasn't wanted to punch the air and shout 'At last!?' This would place too much pressure on our loved ones. 'Yes, sure, of course' - these acknowledge the achievement in an appropriate way - they know how well they have done and the fact that they've asked you shows how much they value your support.

Resources**Training Programme for carers**

Dxxxx recommended, and told us about, Caring Together's 'Hope' training programme for carers. This is an online course that you can take at your own pace. Here is the link <https://www.caringtogether.org/news/hope-programme-for-carers> .

Next week is a 18.30 Peer Support Group discussion and I will send the invite out over the weekend. I hope to see you then.

27 July 2021 – Guilt, Long Distance Caring, Listening, New resources website

At the end of this week's meeting, Emma commented how good it had been to hear so many encouraging stories, even though things are really difficult for some of our loved ones, and us. I agree 100%. There were numerous great examples of good caring skills:

- How a goal or ambition can be really motivating, e.g. applying for a new job.
- Acknowledging small steps towards recovery - beginning to talk about fears and worries, accepting a biscuit without having to think about it.
- Planning in advance - not just 'plan B' but 'plan C' as well!
- Recognising a growing resilience and encouraging this by helping our loved ones to think about how they have got through difficult issues in the past.
- 'Stepping back' and letting our loved one's anxiety pass whilst remaining calm, caring and compassionate.
- Using opportunities to discuss 'pros' and 'cons' as our loved one contemplates new challenges, e.g. wanting to run a half marathon... 'on the one hand you really want to join your friends in the half marathon and on the other you don't have enough energy to complete the training sessions'.

We discussed some issues in greater depth:

Guilt

Our loved ones expressing guilt about the impact their illness is having on us. The first thing to say is that, as Sarah reminded us, it is really good that they feel confident enough to tell us. The group's experience is that the guilt expressed is a complicated emotion - how bad they feel will vary. Regardless, our role is to listen and accept what they are telling us, and to acknowledge how hard they are trying.

Long Distance Caring

We discussed a topic we have visited before, 'long distance caring'. This is timely because a number of our loved ones are planning their return to university. Below are the notes from our discussion from April 2020:

- 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

27 July 2021 – Guilt, Long Distance Caring, Listening, New resources website

Much depends on our loved one and their preferred style of communication. It has to work for us, too. Some have found text messages to be useful because they are less intrusive than a phone call and give time to think before responding.

Family Therapy

We also talked about our experiences of family therapy, which were very positive. Should other family members, especially siblings, be involved? The group's experience was 'yes' if it is possible and they want to, but that it is counter-productive to force the issue. Siblings may not want to be involved in a family therapy session but they can still be incredibly helpful and supportive. If you think it would be helpful to talk to the therapist without your loved one present, this is something you should ask about. It may be possible and appropriate.

New Resources website

Ann and I presented the website that we (me, Ann, Naomi and Karen) have had the pleasure of working on with the SUN Network. Here is the notice that has gone out to professionals across the East of England, and nationally:

New online materials to support people with an eating disorder, and their carers.

The SUN Network, commissioned by Cambs and P'boro CCG, has co-produced with service users and carers new online support materials

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

Parent / Carer Support is an East of England Eating Disorders Network priority and the carer support materials

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

have a unique selling point, a set of Frequently Asked Questions, the top 21 questions asked at the Cambridgeshire and Peterborough Foundation Trust's Adult Eating Disorders Carers Online Support Group over the last year. The answers draw on the lived experience of the support group and have all been moderated by specialist eating disorder staff. Although there is specific signposting to Cambridgeshire and Peterborough services, the general advice is applicable anywhere, so please share widely.

We are very proud of it - the whole group should be, too, it would not exist without you.



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

3 August 2021 – Sharing, “LESS” is more, Services under pressure

Once again, thank you to everyone for your willingness to share and discuss your concerns and to offer words of support and encouragement. We covered a range of experiences and I have selected some of the general principles for this summary.

Sharing

It was encouraging how many of the group commented that their loved ones were **sharing their thoughts, feelings and information**, e.g. saying that they feel low, sharing a medical report, talking about what they want to do. This may not seem like much but it is a real achievement for our loved ones because any acknowledgement of their illness is a step towards a recovery that they might be ambivalent about - giving up something that is helping you to control otherwise unmanageable emotions is not an easy choice. The group's response was spot on: staying calm, listening patiently and remaining non-judgemental. Their concerns may be the ideal opportunity for a helpful comment or statement that might nudge them in the right direction, e.g. 'On the one hand you are upset that you no longer fit into your coat and on the other you want to gain weight'. We may find that what they tell us is upsetting and worrying - especially if they save up all their concerns for us - so it is very important that we have someone to talk to and/or have our 'carer coping strategies' to hand.

Some **golden nuggets** from this week's conversation:

- It is a good sign if our loved one takes a break from exercise if they have an injury because it shows that they are able to make a healthy choice and not be controlled by their illness.
- It is good if they can exercise with others as part of a group activity, rather than exercising alone because it helps their social as well as their physical recovery.
- If you get it wrong... you can always go back and say, 'What I wish I'd said was...'
- Planning is vital... and if it doesn't work you will have learnt something.
- Problem solving is not just for Christmas - please see the attached Sarah's 'Coping with Christmas' presentation, but it is definitely for all seasons!

'LESS is more'

'LESS is more'. I was reminded of this acronym by a friend recently. It summarises ideas we have discussed many times. It can be particularly useful when you find yourself thinking, 'What should I do or say?' It works well for 'long distance caring', too. I have edited a description of 'Less is more' by Jenny Langley <https://newmaudsleycarers-kent.co.uk>.

Listen - Listening conveys respect for another person's views and emotions. If you are a 'long distance carer', giving the message 'there are other people who can listen if you want to talk to someone else' can be helpful. There are lots of organisations who offer great listening services and/or online support (BEAT, Samaritans etc).

3 August 2021 – Sharing, “LESS” is more, Services under pressure

- Empathy** - Empathy means trying to step in to the other person's shoes and see things from their perspective. Think how can you communicate empathy in a compassionate, non-confrontational, non-judgemental way. 'We don't know exactly how you are feeling, we do know you are experiencing a very challenging time, we are here for you'. Also, remember you cannot force your loved one to make changes, it has to be in their own time and at their own pace.
- Support** - When your loved one hurls an avalanche of abuse and/or hides behind a wall of silence carers can feel battered, bruised and unappreciated. Remember it is the eating disorder, and the best way to keep connections open with your loved one is to keep calm and seek to create a warm and caring atmosphere.
- Share** - In non-eating disorder conversations and activities. Remember your loved one is living with the ED bully. Communicate that you know they are more than the ED. Make connections through any medium you can that isn't about the ED, e.g. work, their hobbies, friends.

Issues arising from services under pressure

There may be times when we think our loved one is not getting the service they deserve or need. Eating disorder services are under tremendous pressure at the moment but it is still important to raise concerns, ideally supporting your loved one to do so. For example, if they have been discharged from an inpatient unit they should be a 'priority', they should not have to go back to the end of the queue if they are experiencing difficulties. Talking to the team that is looking after our loved one is probably best in the first instance. If that isn't possible, or is unsatisfactory, all Trusts have a Patient Advice and Liaison Service (PALS) who provide confidential advice, information and support to help sort out any concerns. The NICE Guidelines will tell you the standard of treatment you should expect:

<https://www.nice.org.uk/guidance/ng69>

A very small number of the group have used the private sector - contact me if you would like to know their recommendations. It's not just eating disorder services under pressure, either, because we heard about student finance / support decisions being delayed; if they say they are going to get back in a certain number of days and don't, we can give them a bit of slack, but not too much.

Next week, Tuesday 11th August, is our monthly '18.30 Presentation Session'. Dr Rebecca Ellard, who is the Service GP lead will be talking to us about the GP's perspective on eating disorders, and medical monitoring, and answering our questions. I look forward to seeing you there.

10 August 2021 – Presentation - Enabling and Accommodating – Dr Sarah Beglin

A big thank you to Dr Sarah Beglin for stepping in at short notice to give a presentation entitled 'Stepping out of Eating Disorder traps: accommodating and enabling caring behaviours'. Dr Rebecca Ellard apologised for not being able to attend; she would very much like to talk to us about the 'GP Perspective' and we will find another date.

Sarah's presentation is attached. Here are some of the key points, and a few additional points from our discussion:

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

It was a really interesting, relevant and stimulating presentation - thank you again.

Seeking Research participants


Here is the opportunity from FEAST that Ann spoke about: Seeking research participants for an autism and eating disorders study

<https://www.feast-ed.org/seeking-uk-research-participants-age-18/>

Goodbye



And finally, a very big thank you to Suzanne for her support for the group over the last year. We have really appreciated your calm, practical and honest advice, and your encouragement. We wish you all the best in your new role!

Next week is a '16.30 Support Group Discussion'. I'll get the invite out over the weekend.


Cambridgeshire and
Peterborough
NHS Foundation Trust

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

Dr Sarah Beglin
Consultant Clinical Psychologist
Carers group – 10.8.21


A member of Cambridge University Health Partners



Before and after....

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

Examples of accommodation/enabling behaviours

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

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

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

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

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

Eating Disorder Traps

Long-term: maintains

ED Symptoms

Person with ED's distress is alleviated in the short-term

Carers worried and concerned

Carers attempt to alleviate loved ones distress
-Accommodating and enabling caring behaviours

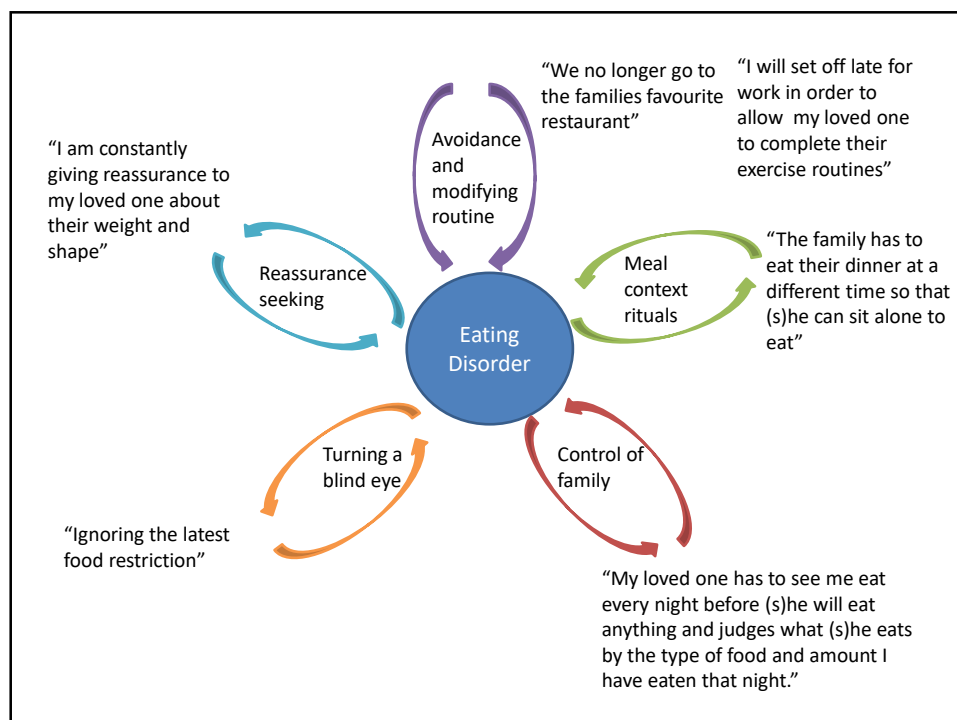
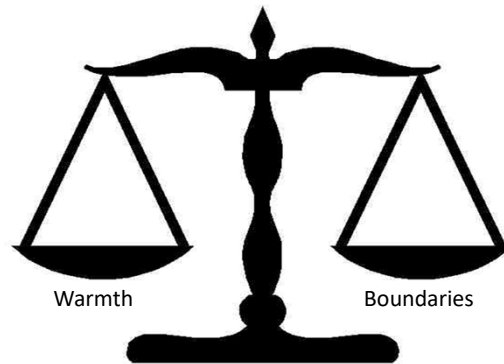
Ways in which the family responds to eating disorder


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

What can we do to help?



Before we start... Getting the balance right





**PLEASE
DO NOT
FEED
THE
FEARS**

Barriers to change?

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

Steps to change

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

Tips for stepping out of ED traps

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

17 August 2021 – The value of the support group

17 August 2021 – The value of the support group

For me, this week's discussion double underlined the value of a carers support group. Not only does it provide practical advice based on our own experiences but it also enables the group to see what we as individuals often can't see because we are too emotionally involved - **the amazing support that you are giving to your loved ones**. I think the whole group, including staff, deserve the 'dolphin of the week award'!

Some key messages came out of our discussion:

- If our loved one is beginning to take responsibility, e.g. for their own shopping and cooking, it doesn't matter if they don't get it quite right at first. Our role is to notice and praise their efforts, and to encourage further independence.
- Sometimes it's necessary to step back and look after our own health and wellbeing, or we are not going to be able to support our loved one in the longer term.
- New situations - going on holiday, a new job, a residential training course - can cause our loved ones (and us) anxiety but, at the right time, they can provide the motivation our loved one needs to move forward. Sarah reminded us that it's not necessarily a bad thing if a situation is really hard and stressful because our loved ones, at some point, have to try to engage with 'normal' - eating disorders are not compatible with having a good life and only by experiencing the downside may they be motivated to improve.
- Small steps are really important and lead to success. The first step can be hard - Sarah suggested, 'I'm not happy with how things are...' as a good, assertive start point for a negotiation. It can also be a 'half step' if the 'full step' is too big a distance, e.g. we may feel that we are accommodating and enabling the eating disorder by agreeing to make them exactly what they want to eat or drink when they could do it themselves, but we do not feel that we can take the 'full step' of not doing it... An alternative is to take a 'half step', e.g. 'Okay, I'll make it, but you will have to ask me'. This transfers at least some of the responsibility and is a foundation to build on.
- Staying calm and 'hanging in there' is tough, especially when our loved one is on a 'big dipper'. As well as looking after ourselves, it is important to remember that they've got back up after being down before, so they can do it again. When they are down, help your loved one 'name' the jumble of stressful feelings they are experiencing, it will help them sort things out. Be curious about how you might be able to support. When they are back up again and things are calmer, help them reflect so that they can better understand the resilience they are developing, which is so important for a sustainable recovery.

17 August 2021 – The value of the support group

- It is often easier to respond in writing, e.g. by text, than instantly on the phone. If you feel you need time to think before responding, take it. You can thank them for really being open with you and/or asking really important questions and you can be honest and assertive and say, for example, 'I can see that you are really trying and that is a really important question. Tell me a bit more about it and I will have a really hard think - I need to get my own ideas sorted out if I am going to do your hard work justice'.

As you can see, we covered a lot of ground.

Here is the link to the BEAT conference for carers I mentioned. It looks good, although it's two days - I can't do the first, I may be able to do the second.

This conference is designed for family members and for those working with patients on a daily basis. It aims to give those caring for people with eating disorders a place to come together, hear from experts by profession and experience, and learn new skills to help them both support those suffering and take care of their own wellbeing. Tickets are now available to buy. If you would like more information regarding this conference, I have attached our flier and the URL to our website explaining more about Frontline:

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

Next week is a '18.30 Support Group Discussion'. We will definitely 'go round the room' and we'll see where that takes us. I will also include some ideas on 'affirmations'. It's a phrase we use a lot and my former mentor, Jenny Langley, has sent me some really good examples of 'affirmations to build confidence' for different situations, e.g. 'expressing emotions rather than avoiding them', and 'flexibility rather than rigidity'. I look forward to seeing you there.

24 August 2021 - Important issues for new carers and Affirmations

Important issues for new carers

We began this week by welcoming Axxxxx to her first meeting, we are really pleased that you are able to join us. Our discussion covered some really important issues, which I have summarised below:

- **Medical Monitoring:** blood results for patients monitored by the Service are always checked by a medical specialist. If there is any cause for concern, e.g. an aspect of blood chemistry that is significantly abnormal, the patient will be contacted. If our loved one is worried about a result we should encourage them to ask their care coordinator/ key worker, or anyone involved with their treatment, to follow it up and we should check that they get a response.
- **Communication:** keep the line of communication open. Avoid judgements and opinions, unless asked. Focus on feelings, not food, i.e. be curious about how your loved one is feeling and avoid detailed discussions about food / calories etc. (This is supportive because our loved one is probably experiencing a jumble of powerful emotions and 'naming the feeling' can help them sort things out.)
- **Writing is a really good communication strategy** - text / email / letter. It gives us time to think calmly, gather our thoughts and explain things clearly. It gives our loved one time to reflect outside the heat of the moment.
- **Manage our own anxiety:** our loved ones' behaviours can be extremely upsetting, e.g. self-harm. It's important to stay calm. Step back if necessary, make sure you have someone to talk to (partner, friend, colleague, support group) and learn how you can best look after yourself.
- **Recovery is not only possible, it is the most likely outcome** - although it can take longer than you expected with quite a few ups and downs. When Amy and Ana spoke to us about their recovery journeys neither could identify a 'magic moment' that led to recovery but both talked about a number of things that, combined, helped.
- **Excessive exercise.** 'Excessive' is less about 'how much' and more about 'the reason', e.g. exercise being used to compensate for what has been eaten, or to control feelings. See 'What should we do if our loved one is over-exercising?' for ideas

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

24 August 2021 - Important issues for new carers and Affirmations

Affirmations

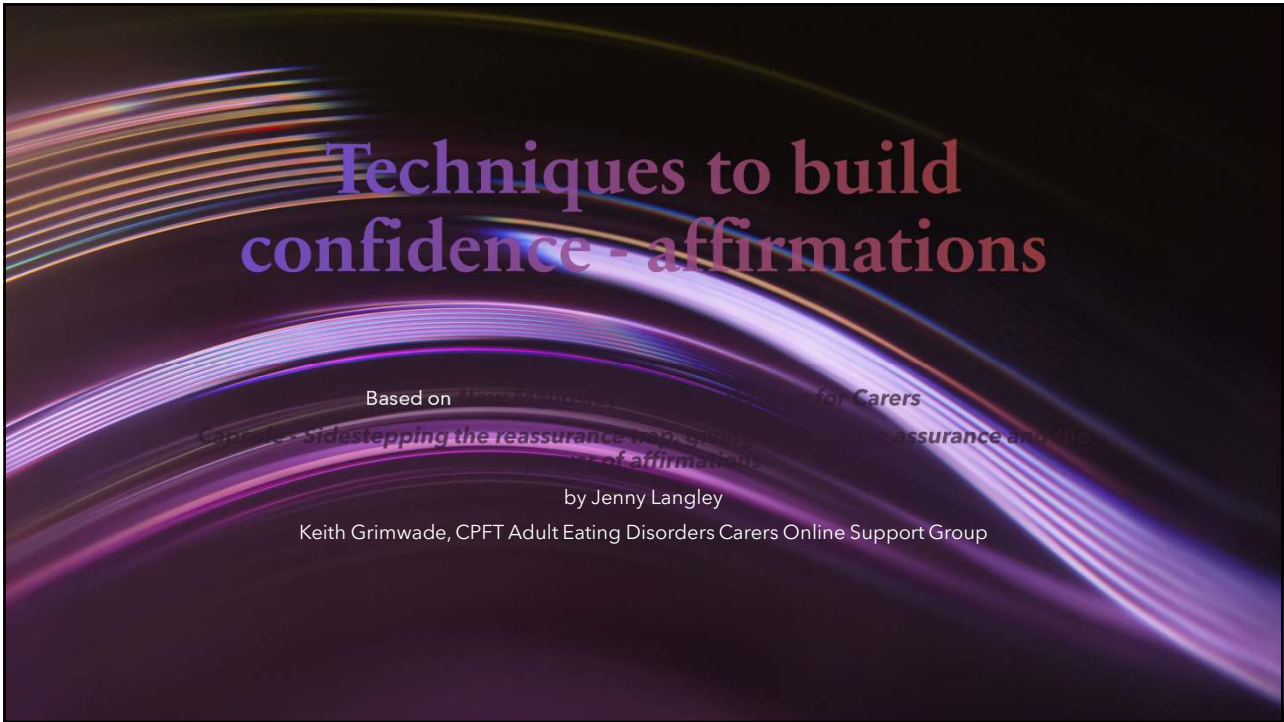
I then gave a short presentation about 'affirmations', attached. An affirmation is a little bit different to praise - both are important.

An affirmation is a positive statement that helps overcome a negative thought, whereas praise is an expression of approval.

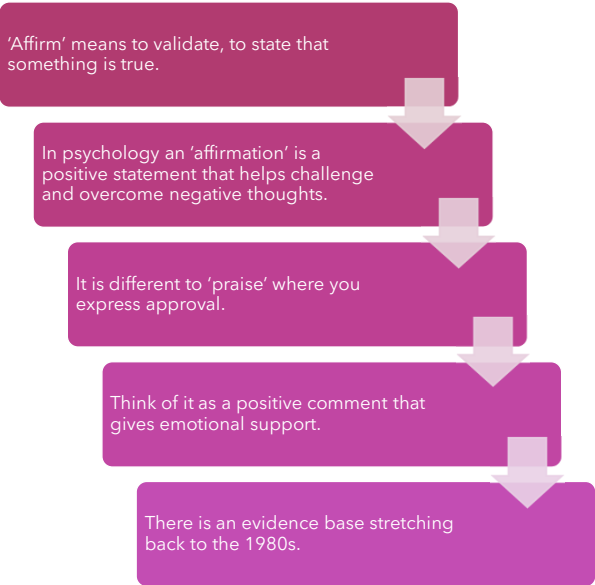
In practice the distinction is not always clear cut, so don't worry about it! There is plenty of evidence that affirmations are helpful to recovery, so we should use them in our conversations with our loved ones. The presentation gives a number of examples, and the occasions when they might be appropriate. We can come back to these in our future discussions.

And finally for this week, an opportunity: A Regional Steering Group (aiming to meet quarterly each year) is being set up with the purpose of developing a pathway for students suffering from an eating disorder who attend university. If you would be interested in being part of this group as a carer representative, let me know and I will pass your name on to the organiser.

Next week is a '18.30 Support Group Discussion' - IT'S THE FIFTH TUESDAY OF THE MONTH! I will get the invite out over the weekend.



Introduction



Praise or Affirmation?

Well done on coping with your sister's party.

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

Positive character strengths

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

How to write an affirmation

- Personal.
- Positive.
- Process or outcome.
- Present, not the future.

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

Connecting to others & the world rather than isolating themselves

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

Expressing rather than avoiding emotions

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

Flexibility rather than rigidity

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

Going for bigger picture rather than focusing on the detail

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

31 August 2021 – Discharge, Recovery takes bravery, Exercise, Carers are not punchbags

We had a lot to discuss this week, so much that we overran. It was the group at its best, coming together to provide support and encouragement based on our experience, with invaluable professional support from Sarah. I have summarised some of the key points below.

Discharge

There are many different types of discharge from treatment. It can be unplanned, when our loved one discharges themselves. It can be from inpatients to the community team, which is more of a transition than a discharge. It can be a planned discharge from the community team, which can also be for different reasons, e.g. our loved one has recovered to the extent that specialist support is no longer needed, or our loved one is unable to benefit from, and/or engage with, the available treatment. Regardless, there should always be a discharge letter, summarising progress, which may include a relapse prevention plan and guidance on how to get back into the service if needed. For us, as carers, discharge brings a range of potential emotions: excitement and relief that our loved one is well enough to stand on their own two feet again; concern if they are ready for such a step; and anxiety as to whether they will manage. It is a time to revisit the basic principles of being a good carer: stay calm and manage your own anxiety; ask what you can do to help; encourage and support without stepping in and taking over; and be there to talk about their relapse recovery plan if they stumble. Your loved one should understand why they have been discharged - be curious if this is not the case and encourage them to ask and/or to let you help them ask.

Recovery takes bravery - so does being a carer

We have talked on many occasions about small steps leading to recovery. Even small steps can seem like giant leaps to our loved ones. We need to be brave when our loved one starts to take back control, e.g. preparing their own meals. They might not get it right but they will never learn unless we give them the chance. We need to be the 'dolphin', encouraging and nudging them in the right direction, and not the 'kangaroo', keeping them safe in our pouch for ever. And we also need to stay calm like the 'St Bernard' and not show our anxiety like the transparent 'jelly fish'. For those new to the group, here is a video that explains the last two sentences!

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

Excessive / compulsive exercise

This is a characteristic shared by quite a few of our loved ones. It can be deeply upsetting for our loved ones and for us, and can dominate our relationship. Dr Pia Thiemann made a number of key points when she talked to us about excessive exercise:

Treatment has to be tailored to the individual. There are three stages: Preparation (e.g. creating an awareness of the problem), Change ('cold turkey' or 'stepped') and Recovery (e.g. 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, e.g. are they very tired, or in pain. You can try to share observations in a calm moment, e.g. 'I've noticed that you are very tired'.

Contemplation (beginning to think about change). Create ambivalence, e.g. '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, e.g. '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.

Pia also said that it is important to remember that our loved one's behaviours should not dictate our behaviours, e.g. the benefits of normal exercise can be a very important part of carer coping. This link takes you to our previous discussions about this topic and signposts some further information:

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

31 August 2021 – Discharge, Recovery takes bravery, Exercise, Carers are not punchbags

Carers are not a punch bag

I can confidently say that we will all have been on the receiving end of unpleasant, unnecessary and possibly bullying behaviour. It is important to remember that this is the illness talking, not our loved one. It is equally important that we explain how we feel and that we calmly, but assertively, maintain important boundaries. Sarah gave us a framework for this: acknowledge and name their suffering; say that if you could take this away from you would in an instant; keep giving this validation - generally, if our loved knows you have heard them they will not feel the need to repeat themselves. It can be helpful to write this down in a letter, as we discussed last week. If our loved one 'lashes out' walk away if necessary - you are not a punch bag. Tell them how you feel calmly and put some distance between you.

Some other issues we touched on were:

- Long distance caring - see 'How can we help our loved one if they live away from us?' at <https://www.keep-your-head.com/adults/MH/eating-disorders/caring-for-someone-with-an-eating-disorder> .

- PEDS is a Peterborough based charity that supports people with an eating disorder and their carers;

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

Recently, it has been closed to referrals because of unprecedented demand but it re-opened from the beginning of September.

- A diagnosis for ADHD: some patients find the validation of a diagnosis reassuring, 'I'm not making it up', and ADHD can be treated by medication.
- Should we inform social services that our loved one is engaging in unsafe behaviour? This had been suggested by a GP. The feeling of the group was 'why?' really needed to be clear, and that if it was so important then the GP should probably be doing it, especially as it could jeopardise trust in your relationship. The general feeling was that this is not something that we should do unless advised to do so by the person responsible for treating our loved one.

And finally, here is the link to the Autism study that Pxxxxx referred to:

https://spectrum10k.org/?utm_source=google&utm_medium=paidsearch&utm_campaign=spectrum10klaunch&utm_content=general_ad2

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

7 September 2021 – Presentation – Self Compassion - Daniela Melamed Trainee Clinical Psychologist

7 September 2021 – Presentation – Self Compassion - Daniela Melamed Trainee Clinical Psychologist**Self Compassion**

This week we enjoyed an excellent presentation on self-compassion by Daniela Melamed, a Trainee Clinical Psychologist with the Adult Eating Disorders Service. Daniela's presentation is attached, and here are a few key points from our discussion.

- Compassion can be defined as being moved by the suffering of oneself and others, and being motivated to reduce that suffering.
- Self-compassion is important, but it is often not easy to do! We live in a culture that gives us conflicting messages, such as experiencing fear or sadness is a weakness; 'pull yourself together', 'tough it out' are all too common responses. These messages can get us stuck in a cycle of blaming and shaming ourselves for having normal human emotions. As Daniela's fifth slide says very clearly, 'This is NOT helpful!'
- This is unhelpful because it can affect our health, our wellbeing and our ability to support our loved one. Most - if not all - of our loved ones struggle with self-compassion, so it is important that we model this healthy emotional response. Remember the metaphor- "put your own oxygen mask on before helping those around you".
- Emotions such as pain, fear, sadness, anger, loss and grief are normal human experiences and avoiding, denying or refusing to acknowledge and work through these can produce more suffering.
- But it's easier said than done - Slide 11 is the list we came up with of why it's hard to be self-compassionate, and it is a long one!
- Fortunately, there are things we can do to develop this important skill but like any skill it takes effort and practice. If we can face these difficult emotions and learn to tolerate and deal with them, we can learn to feel better in ourselves and feel better able to support our loved ones.
- Daniela skilfully took us through some 'starter' activities to help us develop this skill. Slide 16 'Values or Qualities of Compassion' is really interesting because so many of these characteristics are things that we talk about at these support groups, e.g. listening, being non-judgemental, caring. In other words we are not starting from scratch!
- Some key principles are take breaks, pause; pay attention to thoughts and feelings, don't ignore them; find your strategy for creating some 'headspace', e.g. mindful breathing, visualising your 'safe/favourite' place; and practise, practise, practise!

7 September 2021 – Presentation – Self Compassion - Daniela Melamed Trainee Clinical Psychologist

For many of us this will feel counter-intuitive because as the group shared 'carers put their loved ones first' but Daniela demonstrated beyond doubt the importance of looking after ourselves, to the benefit of ourselves and our loved ones.

Thank you, Daniela, for taking us through this difficult topic in such a clear and supportive way. We wish you all the best for your future career.

Sibling Support Group

I am genuinely excited to tell you that an initiative that came out of our support group presentation / discussion about siblings is coming to fruition. Centre 33, which is commissioned by Cambridgeshire County Council and Peterborough City Council to provide support for young carers, is piloting a support group for siblings whose brother or sister has an eating disorder, in the second half of the autumn term. They would like to fine tune their support so that it really meets the needs of this important group of people who can be so significantly affected. Here is some further information and a link to an online questionnaire for siblings to complete. If you have a son or daughter who might benefit from this support group, or know someone who does, please would you pass the details and link on to them.

Do you live with a brother or sister with an eating disorder? Can you help us?

Centre 33 is a young people's charity that has been providing support to young people across Cambridgeshire and Peterborough for the last 40 years. Centre 33 vision is that every young person is listened to and respected for who they are; and that they receive the support to enable them to be who they want to be. To do this, our mission is to support young people with their practical and emotional needs. You can find out more about Centre 33 and the work we do on our website www.centre33.org.uk Centre 33 Young Carers Project at present provides support for a young person that looks after someone in their family with a disability, mental or physical illness, or is dependent on alcohol or drugs.

Young people are often feeling proud to support their family member, but we also know from what young people tell us there can be challenges too. We would also like to understand more about the experiences of young people who are living with a family member with an eating disorder. We would like to hear from you about what support you think would be helpful and how we can put this in place to make sure we are offering the best support we can to young people.

We would like to invite you to complete a short questionnaire to share your views on what support you believe would benefit you. As a thank you for your time, you will be entered into a prize draw for a £10 amazon voucher. The closing date is 24th September.

Please click on the link below or use the QR code attached if you would like to take part in our short questionnaire.

<https://www.surveymonkey.co.uk/r/9Q9SFLR>

7 September 2021 – Presentation – Self Compassion - Daniela Melamed Trainee Clinical Psychologist

Next week is a '18.30 Presentation Session'. Dr Ophelia Beer will be talking to us about Motivational Communication - how best to communicate with our loved ones to help their recovery. Ann will be Master of Ceremonies as I am taking a week off - I am sorry to be missing it but look forward to seeing the slide set! I will get the invite out on Friday, and the invite for the following week will go out on Monday, 20th September, when I'm back from holiday.

Resources

And finally, Ann sent me these links

<https://www.feast-ed.org/quicksand-of-perceived-failure/> , is a short piece by Judy Krasna from FEAST. It is such a powerful and supportive statement that we had to share it.

Self-care September <https://www.actionforhappiness.org/self-care-september> - which chimes very much with today's presentation!

Presentation



Cambridgeshire and
Peterborough
NHS Foundation Trust

Introduction to self-compassion

Daniela Melamed
Trainee Clinical Psychologist



A member of Cambridge University Health Partners

What is
Compassion?

- What comes to mind when you think of compassion?
- What does compassion mean to you?



What is compassion?

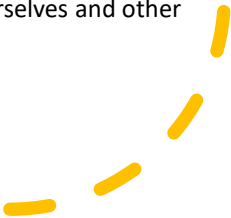
- Empathy
- Kindness
- Understanding
- A deep sense of care
- Consideration
- Wanting the best for someone, yourself, or someone else
- Hopefulness
- Being gentle
- Giving time
- Staying with someone who's suffering

What is Compassion?

- Compassion can be defined as being moved by the suffering of oneself and others, and being motivated to reduce that suffering
- It involves two components:
 - Openness and sensitive to suffering: **we accept** the suffering and pain of ourselves and others
 - Motivation to reduce it: **we want to help** when we see ourselves or others suffering and in pain




Compassion

- Compassion is a very different way of dealing with emotional pain and suffering than we may be used to and what society might tell us
 - In our culture we can receive messages that are opposite to this
 - *"If we are hurting that means something is wrong with us"*
 - *"If we experience emotions like fear or sadness it means we are weak or undeserving of sympathy"*
 - *"When life gets difficult we should 'tough it out' without difficulty"*
 - Instead of helping with our emotions, these messages can get us stuck in a cycle of blaming and shaming ourselves and other people for having normal human emotions.
 - It is NOT helpful!
- 



Compassion

- What are the types of messages that you have heard from others, society, that you notice in yourself that may contradict compassion?
- 

Types of Unhelpful Messages

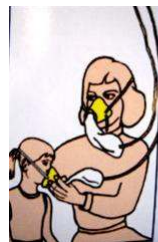
- Battle through it
- Pull yourself together
- Don't wallow in your feelings
- Toughen up
- Stay positive, it's not that bad
- It will pass
- Worse things happen to other people
- We've heard it all before
- These messages can make us feel inadequate, guilty, angry, frustrated, worthless, selfish, alone, self-indulgent
- It leads us to stop talking, hiding, pretend it's all ok, switch off, isolate yourself,

Compassionate Approach

- A compassionate approach looks much different to this
 - Life is filled with challenges and we all feel difficult emotions, such as pain, fear, sadness, anger, loss, grief, in our lives
 - These are not signs of weakness, but are **normal human experiences**
 - Avoiding, denying, or refusing to acknowledge and work through these difficulties can produce suffering
 - We can develop this compassion if we have the courage and skills to acknowledge these difficulties and work with them directly
 - A compassionate approach involves learning to develop compassionate strategies to relate to ourselves and others

Compassionate Approach


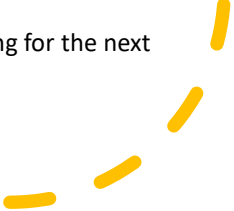
- It is difficult to care for others and loved ones when we do not have compassion developed for ourselves
- We need to prioritize our needs to be able to effectively care for someone else



Put on your own
oxygen mask
before helping
those around you.

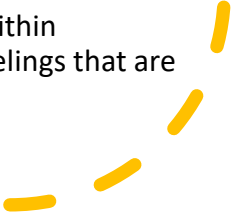
When do you notice lacking compassion for yourselves?

- Hard on self, not satisfied with how you have done something, done something wrong
- When things are more difficult
- When life is busy and time is being pulled in multiple directions (less space for compassion)
- When making small mistakes
- Harder if I feel like I am already failing- can be an excuse to beat myself up
- When we remember past mistakes
- When I feel I haven't done a good job and I'm not managing
- Critical voices (people in family)
- When caring for someone else, feel like the bottom of the line (don't prioritize yourself)
- When you're really tired and had a long day

- 
- 
- Why is it hard to be self-compassionate?
 - Taught from when we are young to get on with it
 - We don't acknowledge our own needs and treat ourselves as equal to others
 - Feels like I've run out of compassion
 - Feel responsible for other people and not necessarily yourself
 - Hard to take the step back from putting your child first
 - Self-compassion is seen as selfishness
 - If you look into it it can feel too overwhelming, not be able to cope
 - Caring for a loved one it seems bigger than putting yourself first
 - Feels like there is only so much to give
 - Too tired to be kind to yourself
 - Get critical when I'm tired
 - Under stress, can't let go and relax, waiting for the next argument or crisis
 - Don't know what is coming next




Developing the compassionate self

- 
- When we think about compassion we can think of our emotions
 - We have angry parts- we think, feel, and want to make change
 - We have anxious parts- we think, feel, and react to make us safe
 - We have sad parts- we think, feel, and process loss
 - All of which involve ways of thinking, feeling, and drives us to act in certain ways
 - Developing compassionate patterns within ourselves can help us deal with our feelings that are unpleasant or difficult




Developing the compassionate self

- Compassion can soothe anger, anxiety, and sadness, help us have the courage to face these difficult emotions, to tolerate them and to deal with them
 - Just like developing any quality, it takes effort and practice
- 




Discussion

- What helps you tune into your own self-compassion
 - When is it easier or harder to have self-compassion? What do you notice?
 - How has this group help develop those self-compassion skills?
- 

- Seeing other people have self-compassion
- Easier when not feeling moody
- If someone reminds or helps you
- Someone noticing how you are feeling and is able to say that in a caring way
- When we are alone its harder to be compassionate




Developing Self- Compassion

- Lets consider what values or qualities are related to compassion?
 - Patience
 - Listening
 - Having time to listen
 - Non-judgemental
 - Caring – compassionate people care
 - Kind and understanding
 - Risk feeling a little bit of what someone else feels (the difficult emotions)
 - reflective
- 




Developing Self- compassion

Compassionate Imagery exercise

- What do I pay attention to?
 - What do I think about?
 - What sorts of things am I imagining?
 - What am I motivated to do?
 - What sorts of things do I do?
 - What emotions do I feel?
- 



Developing Self- compassion

- Allowing yourself to take breaks and moments of pause
 - Paying attention to thoughts and feelings that may come up in a non-judgmental way
 - Mindful breathing (e.g. headspace)
 - Practice journaling those thoughts and feelings
- 

Building Self-Compassion


SELF-SOOTHING ACTIVITIES:	
Make a nice meal or snack for yourself Go out for a nice meal or snack Enjoy a favourite drink (non-alcohol) Go to a favourite cafe Have a picnic Meet with a friend for coffee, lunch, a walk, etc. Phone a friend to chat Take a walk in lovely surroundings Look at beautiful art or scenery Go to a beautiful place Enjoy time in the sunshine Go to the beach Light a candle Watch the stars Put on soothing or enjoyable music Enjoy the sounds of nature Sing Use a favourite perfume or lotion Enjoy the smells of nature or flowers Have a bubble bath Have a long shower	Have a massage Pamper yourself Soak your feet Gently brush your hair Do your nails Read a good book or magazine Watch a good movie or TV show Pat your dog or cat Hug yourself Hug someone else Imagine a relaxing scene or safe place Do some relaxation or meditation Do some slow breathing Smile to yourself Laugh out loud Take a break (enjoy staying in bed for 20mins) Others:

Developing
Self-
compassion

- Compassionate kit big
 - A Compassionate Kit Bag is that place to put reminders for your compassionate self, so you can use your resources to nourish you along life's journey.
 - Collect together items that are meaningful, or those you know will be helpful. You might find these items inspiring, empowering, calming, soothing, motivating, bringing confidence, strength, calm composure and wisdom.
 - Choose items that make you feel good about yourself - perhaps they bring up a positive memory, or represent something that is important, inspiring, motivating or gives you a boost in some way



Developing Self- compassion

- What is one thing you can start doing to help develop your self-compassion skills?
- 



Compassion video

- <https://www.youtube.com/watch?v=11U0h0DPu7k>
- 

14 September 2021 – Presentation – Motivational Communication (E-OARS) - Dr Ophelia Beer

14 September 2021 – Presentation – Motivational Communication (E-OARS) - Dr Ophelia Beer

This week we enjoyed an excellent presentation on E-OARS by Dr Ophelia Beer, copy attached. This included:

- The importance of really listening to our loved ones, not just hearing what they are saying
- Animal analogies; and in addition to our regular hedgehog (or porcupine) an introduction to the Donkey (Strong, Persistent, Sturdy, with very Big Ears for listening)
- An outline of the change cycle
- E-OARS
 - Empathy
 - Open
 - Affirmation
 - Reflective and
 - Summary
- Suggestions on how to communicate at each stage of the cycle

Key points to remember are not to offer advice; to model normal behaviour, including acknowledging when we get it wrong; and to look after ourselves.

There was only a little time for questions including how to effectively communicate with our loved ones with autism and young men over exercising. A very big thank you to Ophelia for the clear presentation.

We briefly welcomed new members -thanks for the tech support during the presentation!

Ann

MOTIVATIONAL COMMUNICATION

DR OPHELIA BEER

WARD CLINICAL PSYCHOLOGIST



OVERVIEW OF TODAY

- What are eating disorders about?
- The importance of LISTENING with all our senses
- Stages of change / animal metaphors recap
- What is motivational communication?
- E-OARS
- Which strategies to focus on when and depending on your animal type!
- Questions

WHAT ARE EATING DISORDERS?

They are incredibly complex psychological illnesses that are created and maintained in a complex way

1. Families, carers, loved ones, are NOT the cause
2. Eating disorders often destroy the healthiest of communication between people
3. Carer support and interventions are one of the biggest factors once ED has started.
4. Playing a big part in the process of change and recovery is not the same as blame
5. It takes a skilled village...



WHAT ARE EATING DISORDERS?

Food has become a metaphor for distress. Conscious and unconscious awareness. Try not to make assumptions! Contradictory.

1. Struggle with unpredictability of life ("At least I can control my eating...")
2. Struggle with managing emotions ("If I starve / binge / vomit, think about calories I temporarily feel better / worse...")
3. Not feeling good enough ("If I'm thin people will like me / I'll be more successful...")
4. Struggle with allowing all nourishment in ("I don't deserve it...")
5. Struggle with feeling lonely or separating ("If I am unwell I don't have to leave home" "People will stop caring if I am better...")

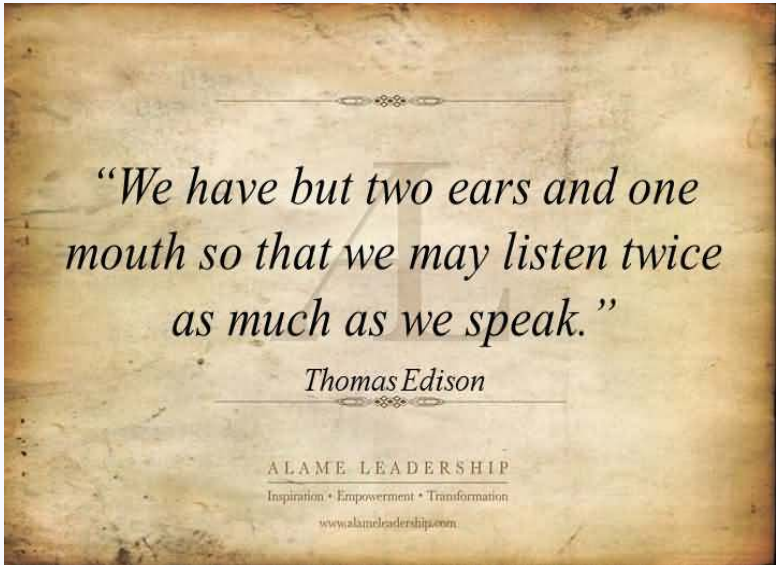
The most basic of all human needs is
the need to understand and be
understood. The best way to
understand people is to listen to them.

— Ralph Nichols



**MOST PEOPLE
DO NOT LISTEN
WITH THE INTENT
TO UNDERSTAND;
THEY LISTEN
WITH THE INTENT
TO REPLY.**

KUSHANDWIZDOM



“We have but two ears and one mouth so that we may listen twice as much as we speak.”

Thomas Edison

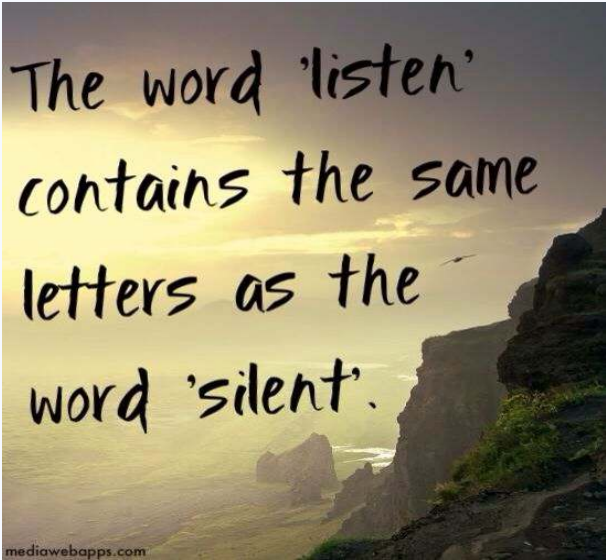
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When you talk, you are only repeating what you already know. But if you listen, you may learn something new.

- Dalai Lama

sun-gazing.com



The word 'listen'
contains the same
letters as the
word 'silent'.

mediawebapps.com

*Spoken words only account for **30-35%** of the meaning. The rest is transmitted through nonverbal communication that only can be detected through visual and auditory listening*

(Birdwhistell, 1970).



"Listening looks easy,
but it's not simple.
Every head is a world."

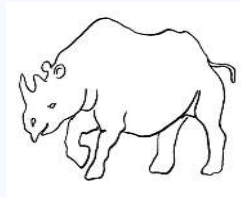
-- Cuban Proverb



HOW DO WE MAKE OTHER PEOPLE CHANGE?

- **We can't....**
- The more we push, the more effort is put into resistance, argument, and defense of the ED, rather than thinking about what choices there really are.
- ... **But**, there are things we can say and do which will influence the path they decide to take

ANIMAL TYPES



STAGES OF CHANGE

- Model describes the process a person has to go through to make change
- Fluid, constant movement
- MOTIVATIONAL COMMUNICATION can help to support a person to move forwards rather than backwards
- In particular, motivational communication can help people weigh up pros and cons of behaviour
- Ideally, communication needs to match the stage people are in...



WHAT IS MOTIVATIONAL COMMUNICATION?

- A style of communicating that can enhance motivation to change
- Providing warmth, love, and understanding, is much more effective than adding to perceived pressure, which can make someone cling tighter to their ED.
- By listening, we allow someone to voice their mixed feelings and contemplate change.
- Increases confidence that change is possible



MI AND “E-OARS”

- Warmth, strength, persistence, and good listening ears..!
- Not there to fix, solve, offer advice or solutions, just listen...
- **E**MPATHY
- **O**PEN QUESTIONNING
- **A**FFIRMATIONS
- **R**EFLECTIONS
- **S**UMMARIES



HOW CAN WE SHOW EMPATHY?



PUT YOURSELF IN THEIR SHOES



MAKE EMOTIONS PART OF YOUR LANGUAGE



BE PRESENT, ACCEPTING, NO AGENDA

WHAT IS EMPATHY NOT?



IT'S NOT YOU IN DIFFERENT SHOES



TOO MUCH EMOTION!



FIXING, SOLVING, OFFERING SOLUTIONS

Empathy is not Sympathy

Sympathy involves 'feeling sorry' for the other person or imaging how we would feel if we were experiencing what is happening to them. Empathy differs in that we try to imagine what it is like being that person and experiencing things as they do, not as we would.

Theresa Wiseman, A concept analysis of empathy (1996)

NAMING THE
EMOTION
AT THE
DINNER
TABLE...



INSIDE OUT

Eating disorders are complex and contradictory.

Often, what we think is loving and supportive when it comes to emotions, is not...

<https://www.youtube.com/watch?v=QT6FdhKriB8>

OPEN QUESTIONS

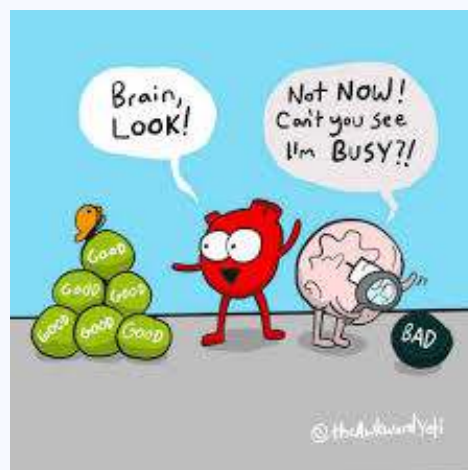
1. The choice of answer is not already defined (yes / no). Normal in everyday / small talk but... **"Did you have a good day"** ok (ish) if someone loves their job, not so much if they don't.
2. Gives the person room to elaborate, and gives you room to LISTEN
3. "Why / when" questions in theory open, but can be confrontational (eg **"Why haven't you been to the doctor yet?"**, **"When are you going to see this is causing problems?"**) Closed masquerading as open.
4. BE GENUINELY CURIOUS TO LISTEN. We see what we look for, we hear what we look for.

AFFIRMATIONS

- Please see Keith's slides!!
- Validation and encouragement of efforts, rather than approval and praise for outcome (which can be experienced as condescending or addictive to a perfectionist / someone with low self esteem)

"I can see how determined you were to stick to your plan" v "well done on finishing your meal".

- Be genuine and authentic
- Be specific and detailed
- Model it yourself!



REFLECTIVE LISTENING

- It sounds like...
- So you're saying...
- From your point of view...
- On the one hand you want... on the other...
- You're feeling...
- Let me check I've understood...
- **Be genuinely curious**



SUMMARIES

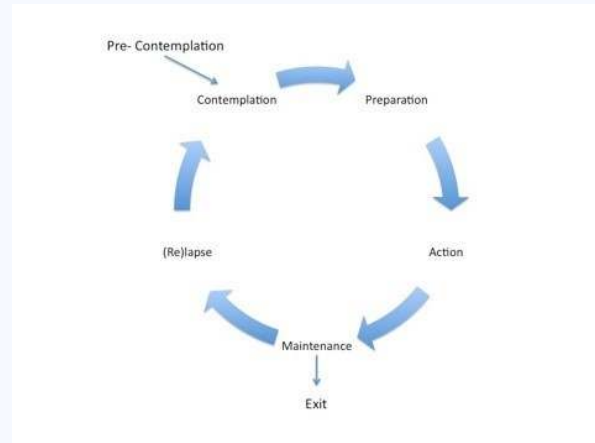
- Providing a short summary of what someone has said, to show you have listened, and you are trying to understand.
- Pay attention to the **FEELINGS**, and **THEMES** not the list of facts...
- Pay attention to **DISCREPANCIES**... An opportunity to reflect back discomfort
- Use this opportunity for **AFFIRMATIONS**
- Hard to get it wrong if you're really being curious, in providing a summary the other person can contradict or correct you
- Mistakes can be helpful - "No that's not what I meant..."
- Allows them to process and explore what they believe

PASCAL (FRENCH PHILOSOPHER):

“People are generally better persuaded by the reasons which they have themselves discovered than by those which have come into the mind of others”

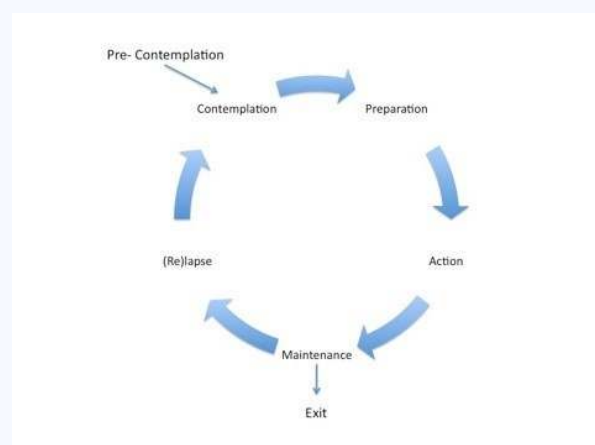
PRECONTEMPLATION

- NO ADVICE!
- **EMPATHY** AROUND FEELINGS (BE AWARE OF ENABLING!)
- **EMPATHY** WITH YOURSELF, SELF CARE
- **OPEN QUESTIONS**, UNDERSTAND



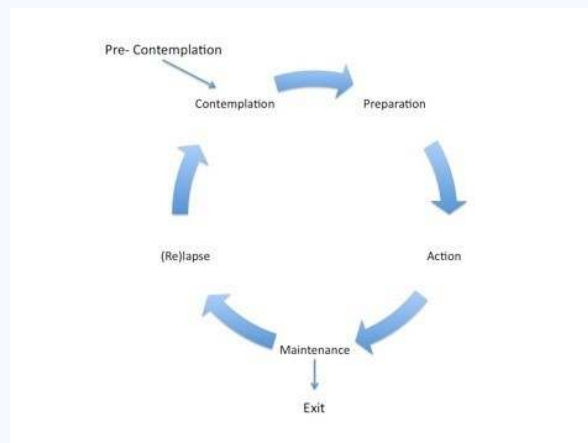
CONTEMPLATION

- NO ADVICE!
- **EMPATHY** AROUND FEELINGS
- **OPEN QUESTIONS**, UNDERSTAND THE CONFLICT
- **REFLECTIONS AND SUMMARIES** to emphasise the pros and cons and make connections.
- **BEWARE OF THE WORD "BUT"... "AND" IS YOUR FRIEND**
- "I know you're upset but..."



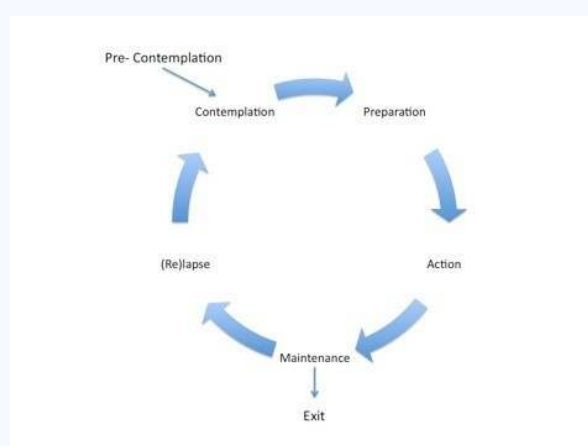
PREPARATION

- NO ADVICE!
- **EMPATHY** AROUND FEELINGS. LISTEN OUT FOR CHANGE TALK!
- **OPEN QUESTIONS**, HOW CAN I HELP?
- **AFFIRMATIONS** BECOME EVEN MORE IMPORTANT. BELIEVE IN THEM



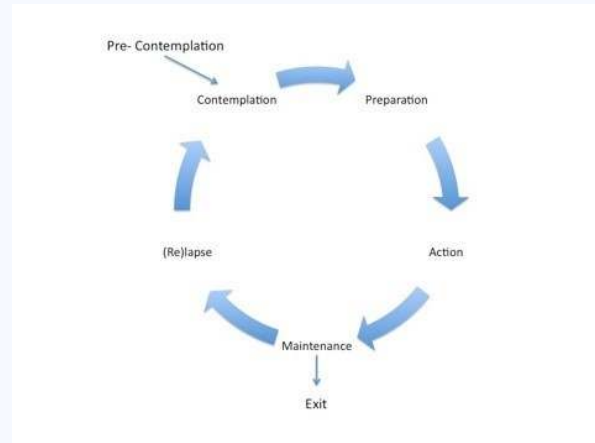
ACTION / MAINTENANCE

- NO ADVICE!
- **EMPATHY** AROUND FEELINGS, ESPECIALLY FEARS OF BEING WELL
- **OPEN QUESTIONS**, HOW CAN I HELP WITH YOUR NEW STRATEGIES?
- **AFFIRMATIONS** FOR ANY IMPROVEMENTS
- **REFLECTIONS AND SUMMARIES**: HELP THEM LINK THEIR CHANGE TO LIFE GOALS
- **WHEN IN DOUBT STEP BACK A LEVEL**



RELAPSE

- NO ADVICE!
- **EMPATHY** AROUND FEELINGS, OF SHAME. NORMALISE AND VALIDATE (REMEMBERING YOU ARE NEVER BACK TO SQUARE ONE)
- **AFFIRMATIONS** FOR HANDLING OF MISTAKES AND SETBACKS



INHABIT THE SPACE IN BETWEEN...



ANOREXIA / CRITICAL
SELF

CONSCIOUS AWARENESS

HEALTHY WISE SELF



Questions?

References: "How to talk so kids will listen and listen so kids will talk" – Adele Faber

"Skills Based Learning for Caring for a Loved One with an Eating Disorder" – Janet Treasure

28th September 2021 – Support for some challenging issues and Green Shoots

Challenging Issues

We enjoyed another full and productive discussion, offering our lived experience to support a number of challenging issues. Thank you to everyone for being so willing to share - here is my summary of some of the key points:

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

Many of us have faced this situation. In Cambridgeshire and Peterborough blood results for patients monitored by the Service are always checked by a medical specialist. If there is any cause for concern, e.g. an aspect of blood chemistry that is significantly abnormal, the patient will be contacted - this is important reassurance for us as carers. Practice varies around the country, so this is something you should ask your loved one about, and encourage them to ask if they do not know. Confidentiality means that even if you were to ask for their medical monitoring information it would not be provided, and trying to find out behind your loved one's back would unnecessarily risk your relationship. At the same time it is really important not to ignore the issue - this will send the wrong message to your loved one, i.e. ‘They’ve not said anything, so I must be alright’. The group's experience is that you need to find a calm moment to be brave and gently offer an observation, e.g. ‘You’re probably not going to like me saying this but I’ve noticed that..... Perhaps there is something I can do to help?’ Some interesting, and very individual strategies, emerged from our discussion, e.g. entering information onto a shared spreadsheet, a weekly ‘Zoom’ weigh-in.

‘Our loved one has moved away from home (e.g. to university) and has chosen not to engage with the eating disorder service in their new locality’.

The group's experience is that if our loved one's health is in a reasonably good place this might not be an unreasonable decision, e.g. they may have found motivation from the opportunity to establish new friendships not defined by their eating disorder. If their health is not in such a good place, we cannot make them engage; we have to fall back on our ‘dolphin’ skills - keep the line of communication open, practise gentle curiosity, encourage and know who to contact if you think things have deteriorated to the point at which intervention for their safety is needed. It is important to remember that their decision not to engage with their new local service is not irreversible.

‘Our loved one's treatment has yet to start and they are still in the ‘pre-contemplation’ stage - what can I do’.

The group agreed that this is a really difficult, and very worrying time for carers. There are things you can still do if your loved one is in the pre-contemplation stage, especially providing feedback about their health and keeping the lines of communication open with discussion about non-eating disorder subjects. It is also really important that look after

28th September 2021 – Support for some challenging issues and Green Shoots

yourself so that you are fit and well for your caring role, and you can also begin to find about the skills we as carers need to provide the best possible support - most of us would agree that the place to start is the 'animal metaphors', how to become a good dolphin - Janet Treasure's book is a good place to start (Skills-based Caring for a Loved One with an Eating Disorder by Janet Treasure, Grainne Smith and Anna Crane. Routledge. ISBN 978-1-138-82663-2. 2nd Edition).

'Our loved one has moved away from home and is caring for themselves - how do they get variety into their diet when buying single portions of ingredients is not possible, or economic?'

This proved to be another common issue, often associated with going to university. Suggestions included finding someone to cook and share with, buying a small fridge to keep in their room to keep food fresh, booking a home delivery with flat mates.

Green Shoots

We heard some great examples of progress this week, too; real green shoots of recovery. Some examples: voluntarily sending a video to show that they are having their morning snack; joining in with Freshers' Week activities; and challenging themselves to try 'difficult' foods. We also heard how a fresh start in a new place can be very motivating.

Sibling Support Group - More Feedback Needed

I mentioned this a few weeks ago. Centre 33, which is commissioned by Cambridgeshire County Council and Peterborough City Council to provide support for young carers, is piloting a support group for siblings whose brother or sister has an eating disorder, in the second half of the autumn term. They would like to fine tune their support so that it really meets the needs of this important group of people who can be so significantly affected. Here is some further information and a link to an online questionnaire for siblings to complete. If you have a son or daughter who might benefit from this support group, or know someone who does, please would you pass the details and link on to them, they've had a few responses but need more to get the service right. The original deadline has been extended but they need responses as soon as possible.

Do you live with a brother or sister with an eating disorder? Can you help us?

Centre 33 is a young people's charity that has been providing support to young people across Cambridgeshire and Peterborough for the last 40 years. Centre 33 vision is that every young person is listened to and respected for who they are; and that they receive the support to enable them to be who they want to be. To do this, our mission is to support young people with their practical and emotional needs. You can find out more about Centre 33 and the work we do on our website www.centre33.org.uk Centre 33 Young Carers Project at present provides support for a young person that looks after someone in their family with a disability, mental or physical illness, or is dependent on alcohol or drugs.

28th September 2021 – Support for some challenging issues and Green Shoots

Young people are often feeling proud to support their family member, but we also know from what young people tell us there can be challenges too. We would also like to understand more about the experiences of young people who are living with a family member with an eating disorder. We would like to hear from you about what support you think would be helpful and how we can put this in place to make sure we are offering the best support we can to young people.

We would like to invite you to complete a short questionnaire to share your views on what support you believe would benefit you. As a thank you for your time, you will be entered into a prize draw for a £10 amazon voucher.

Please click on the link below or use the QR code attached if you would like to take part in our short questionnaire.

<https://www.surveymonkey.co.uk/r/9Q9SFLR>