CPFT Adult Eating Disorder Service

Carer Support

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.

October 2020 to April 2021

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

Contents

Introduction

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

Facilitators:

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

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

Format

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

Each meeting was run in three sections:

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

Attendance

Was by invitation only.

The first six months of summaries has been published as a standalone summary.

This is a summary of all the discussions from the online Carers Support Group meetings held between October 2020 and April 2021, compiled by Keith Grimwade, including open and specialist led meetings.

Presentation slides have been copied into the relevant section.

Resources are highlighted.

Additional resource files are included in the appendix.

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

6 October 2020 –#SelfCareChallenge, Intervention, Manipulation, Extreme Distress

#SelfCareChallenge

I will start this week with Axxxx's presentation, attached, about World Mental Health Day, this coming Saturday 10th October. Slide 3 is the critical one, the **#SelfCareChallenge**:

'This week I'm taking care of myself by _____'.

Fill in the missing word and be prepared to share; I'll go first!

To what extent should we intervene / take over

We discussed three substantial topics, which I have summarised below. The first was 'To what extent should we intervene / take over?' The specific example was **'not knowing what to do about an appointment at the home Service whilst away at university'**. I got this wrong by immediately thinking that there was an administrative solution and I went straight to Sarah… to be gently reminded that dolphins are more effective than rhinos! Much better to:

- Support our loved one to come up with a solution by discussing 'what could we do' - phone, email, write.
- In doing so, consider if they have dealt successfully with a similar situation before.
- Present 'facts', e.g. the letter about the appointment does need to be responded to.
- Help with the chosen way forward, e.g. supporting our loved one to prepare a phone call.
- Show faith in their ability to sort it out themselves.

What to do when we feel manipulated

The second was what to do when we feel manipulated by our loved one, e.g. them constantly asking for money for food (if we don't give it they will not eat…) or making excessive amounts of food for us to eat that they don't (we feel forced to because if we don't eat it we are giving the wrong message). Some key points from our discussion were:

- At the very least make sure that they retain some responsibility, e.g. 'OK and it's your choice to do xxxxx'.
- Explain why you feel concerned and say that you really want to help them.
- Show empathy, e.g. 'I know how hard it is for you to manage on your student budget' and maintain the line you know you cannot/ should not cross.

Sarah said that this was a really common theme and encouraged us **to catch the emotion underlying the manipulation**. If, for example, our loved one is behaving in this way to control their anxiety we can support them manage this in healthier ways. 'Anxiety Management' is a big topic and we will organise a presentation about it. The most important thing is to understand that giving in to anxiety does not work in the long run, as demonstrated by **the Reassurance Trap** - please see the attached slides.

We considered a related issue - **clothes no longer fitting**. Should we buy new ones? Should we throw the old clothes away? As ever, it's applying the principles:

- Support them to find a way forward, don't step in with a solution (telling them what to do) or shield them from the problem (throwing old clothes away without talking about it).
- Do empathise: with clothes, in particular, it is a big issue.
- Praise to build confidence when they take steps in the right direction, even if they are only small ones.

A lovely idea was encouraging our loved one to use the fabric creatively, e.g. to make new clothes, a piece of patchwork art.

What we can do as carers to support our loved one when they are showing extreme distress

Our third issue was what we can do as carers to support our loved one when they are showing extreme distress, e.g. heart palpitations, screaming, hitting themselves at meal times. The group had found a small number of strategies helpful:

- **Calming strategies to use in advance** of the stressful situation, e.g. meditation, taking the dog for a walk.
- **Calming strategies to use during** the stressful situation, e.g. breathing techniques.
- **Distraction** - watching the television, reading a book during the meal.
- **Empathy** to acknowledge that you know how hard it is for them.

Such extreme distress will be addressed by your loved one's therapy, so hearing from your loved one and/or their therapist will also be helpful.

Next week's session will include a short presentation by Christine Burton, manager of 'Making Space' who have been awarded the contract to provide general support for carers of loved ones with a mental health illness by the Cambridgeshire and Peterborough local authorities. We will have a chance to ask questions as well as time for our usual peer group discussion. (Making Space is a national charity so it will be of relevance to those of you who do not live locally.)

Stay safe and don't forget your #SelfCareChallenge!

Resources

This week, I'm taking care of myself by _____.

#SelfCareChallenge

…

Completing …
my tax return form
(it's been bugging me!)

Finding …
my SAD light as its getting dark
and I need the brightness

Going …
for a walk in the rain
With the forecast it wont be too difficult
☺

Take it further …

31 days

31 day self care challenge

Write a gratitude list	Reach out to an old friend
Practice an old hobby	Clean for 20 minutes
Make a playlist	Workout
Make and eat your favourite meal	Write (and send) a letter
Take a walk outside	Watch an old movie
Hour without technology	Have an early night
List of future plans	Make and eat your favourite dessert/cake
Binge watch a TV show	Clean the "man" drawer
Try a new recipe	Look at old pictures
Dress up	Stop procrastinating
Day without social media	Plan a holiday
Listen to a podcast	Try yoga
Brain dump	Read a childhood book
Learn a new skill	Take a break
Practice kindness	Laugh out loud
Choose your favourite challenges and do them again	

World Mental Health Day 10 October

Do one thing for better mental health

mind for better mental health

https://www.mind.org.uk/

13th October 2020 – Making Space, Self-Discharge, Social Interaction

Making Space – National Charity Support for Carers

We began this week's meeting with a presentation by Christine Burton, Care Support Worker with Making Space, which has been commissioned by Cambridgeshire and Peterborough local authorities to provide support to carers of a loved one with mental ill health.

Christine explained that even if you do not live locally, if your loved one is receiving treatment here you are eligible for support, although 'out of county' support is by phone. You can self-refer and Christine and her team can provide 1:1 support ranging from signposting opportunities, to help with benefits, to supporting carers at tribunals; and for as long as is required. Making Space also organise support group meetings and events, although their programme is currently affected by Covid restrictions. I have attached a copy of the self-referral form and Christine says, 'It's a generic form, so any carers referring themselves only need to complete the sections they know. We'll do the rest. It can either be emailed to C&P Referrals or to me'. Christine also says, 'if any of your carers would like more information or just want a chat' to contact her. I have pasted Christine's contact details, and Making Space's web address at the bottom of this email. Thank you, Christine, for joining us.

What to do if our loved one is an inpatient and wants to discharge themselves

We had some time to follow up some of the issues raised in our introductions and updates. One issue that we discussed earlier in the year came up again, i.e. what to do if our loved one is an inpatient and wants to discharge themselves. The conclusions we came to last time (11th August) were:

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

- Do be a dolphin/St Bernard but don't be a rhino/ostrich, i.e. don't avoid 'tough discussions' but do be supportive and calm.

Ann shared the 'readiness ruler' (Flow) she and her husband developed to help their discussions with their daughter when they had this experience. Ann said that her daughter is good at visual images and they found this an effective way to get the message across. It was something they could leave with her to help her make her own decision. Ann has kindly shared this, attached.

Support our loved ones with social interaction

We then discussed how we can support our loved ones with social interaction. Eating disorders are a very isolating illness and compound problems for those who find making new friends difficult. There are times when this is a particular issue, e.g. starting at university, leaving hospital after a lengthy admission. We came up with the following ideas:

- Praise any ideas they have and encourage them to be the problem-solver.
- Validate and share their anxiety without feeling the need to solve it: at this present moment in time, in particular, it's really difficult to make new friends and join in with new activities because of the Covid restrictions and it's OK to feel that it's rubbish.
- With their permission (i.e. not charging in with 'You could do this, you could do that') suggesting opportunities such as voluntary work, joining clubs and societies, online games, contacting Nightline https://www.nightline.ac.uk .

It was good to hear that some of our loved ones - at least eventually - have been able to reduce their isolation, through, for example, taking the leap and signing up for some activities and/or planning carefully so that they are not always stuck in their room… unless required to self-isolate...

Next week Dr Georgina Hurford will lead our discussion with a presentation on 'Assertiveness', which is a really important topic. I will get the invites out before the weekend - see you then.

Resources

Contact Details

making space

Christine Burton
Carer Support Worker
01480 211 006 / 07595 271 553
Suite 4 The Stables, St Neots, Cambridgeshire, PE19 2BU
Church Street
www.wearemakingspace.co.uk

Making Space Self-Referral form

Making Space

Cambridgeshire and Peterborough Carers Support Service

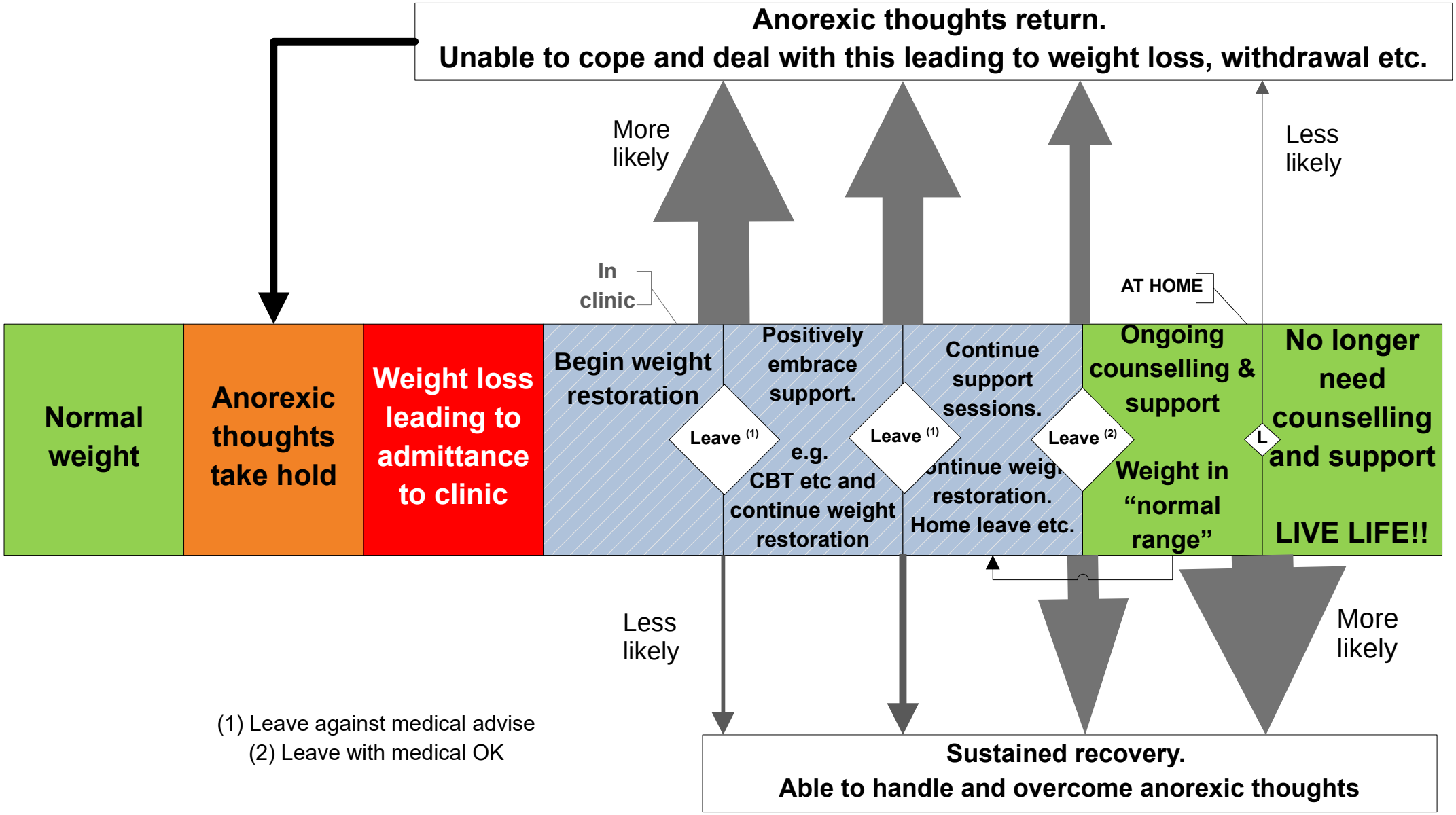
Referral Details

Carers Name	
Address	
D.O.B	
Ethnicity	
Main contact number	
Mobile	
Email (optional)	
Relationship to cared for person	
G.P.	
Cared for persons name	
Address	
D.O.B	

Other relevant information e.g. diagnosis/carers assessment needed **Any known risk**	
Other services involved	
Referred By/ contact details	
Date of referral	

Please phone 01480 211006 for more information on the service

Referrals should be sent to: C&PReferrals@makingspace.co.uk or post to Making Space 4 The Stables, Church St. St Neots, Cambs.



13th October 2020 – Regret and Guilt

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

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

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

Our loved ones feeling guilty / bad about falling short

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

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

20 October 2020 – Presentation - Assertiveness Dr Georgina Hurford

We began this week's session by welcoming new members to the group and sharing our recent experiences. '**Transitions'** was very much a theme and it was good to hear that most - not all - of our loved ones are coping at university, which has been a concern for many of us in recent weeks. We heard some great examples of 'not jumping in to solve the problem' and 'praising green shoots'. We can come back to where things have not been going so well in our peer group discussion next week.

Assertiveness

We then welcomed Dr Georgina Hurford who led us through a presentation on 'Assertiveness', attached. Georgina began by demonstrating four different communication styles on Rob, our willing volunteer! I will not repeat Georgina's slides but some key points were:

- **Assertiveness is being clear and open** about what you think and feel without being blamey or critical of other people.
- We should aim to be '**Assertive Ned**'.
- Try the ELF strategy: **Express, Listen, Field**.
- **Use 'and'**, not 'but'.
- The **'I feel'** statement is key.

We then discussed how this approach could be applied to some of our real-life issues. It's really hard. For example, an 'I feel' statement can easily be followed by an aggressive statement (I feel very worried, you should eat your dinner) when it is better followed by a positive, enabling statement (I feel very worried and I would like to talk about how best I can help you, I know how hard it is).

One issue was when our loved one avoids talking about food/eating, which we know is so important. Being direct is likely to provoke a defensive response. The experience of the group is that it is better to open up conversations in other areas, which shows that you are not trying to take control; ask open questions to help them explore their feelings; and give every opportunity for them to take responsibility for themselves. Let them take the lead in how much they want you involved. Ultimately, this approach is more likely to be successful.

Another issue is when our loved one dominates the conversation, often with a single topic - so much so that it isn't really a conversation. It is absolutely right that we should say something, it's a question of when and how. Ideally, it would be best to discuss this at another time, in a calm moment, but this can be difficult if the conversation is on the phone. One 'after the event' option would be to email or text. 'How' is to be assertive - unemotional, with empathy, 'It was really good to catch up with you. I feel that there are some things we don't have time to talk about as much as I would like and it would be great if next time we could spend a few minutes catching up on xxxxx'.

Assertiveness is such a big and important topic. This was the second session Georgina has led for us and there is still more to cover so she has promised to come back for 'Part 3'... and there could well be a Part 4. Thank you again!

Some notices:

Feedback from the Eastern Region 'New Care Model' Consultation Event

Some of you attended this - thank you - and the feedback slides are attached.

Consultation Events

Consultation Events for the Cambridgeshire and Peterborough Community Eating Disorders Service Project. Some of you have attended previous consultation events about this project. Some more events are planned and you are warmly invited. They will cover: Evaluation of the new service, we really want to understand what is a measurable outcome for you and create a satisfaction survey so we can make sure the services are delivering what you need them to; and the development of materials, leaflets and information, so people accessing services understand what is available to them and what they can access whilst waiting for treatment to commence. There are a series of meetings dates and times to enable people to attend, there is no expectation to attend all of these.

Wed 4th November
9.00- 10.00 - Individual with lived Experience-Adult
11.00-12.00- Carer
16.00-17.00 Individual with Lived Experience-CYP
19.00-20.00-Individual with lived Experience-Adult
Thurs 5th November
13.00-14.00- Individual with lived Experience-Adult
Tuesday 10th November
13.00-14.00-Carer
19.00-20.00-Carer
Thursday 12th November
16.00-17.00- Individual with Lived Experience-CYP
19.00-20.00-Individual with Lived Experience-CYP
Contact lois.sidney@sunnetwork.org.uk or phone/text/whatsapp 07712 358172 to get involved and receive the meeting link.

Support Group Summaries - the first six months.

Axxxx has kindly and skilfully compiled (and anonymised) the summaries and supplementary information into a single document. If you would like a copy email me and I will pop one over to you. (N.B. it is a large file, 5.5 MB.)

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Introduction to Assertiveness

Dr Georgina Hurford
Clinical Psychologist

A member of Cambridge University Health Partners

What is assertiveness?

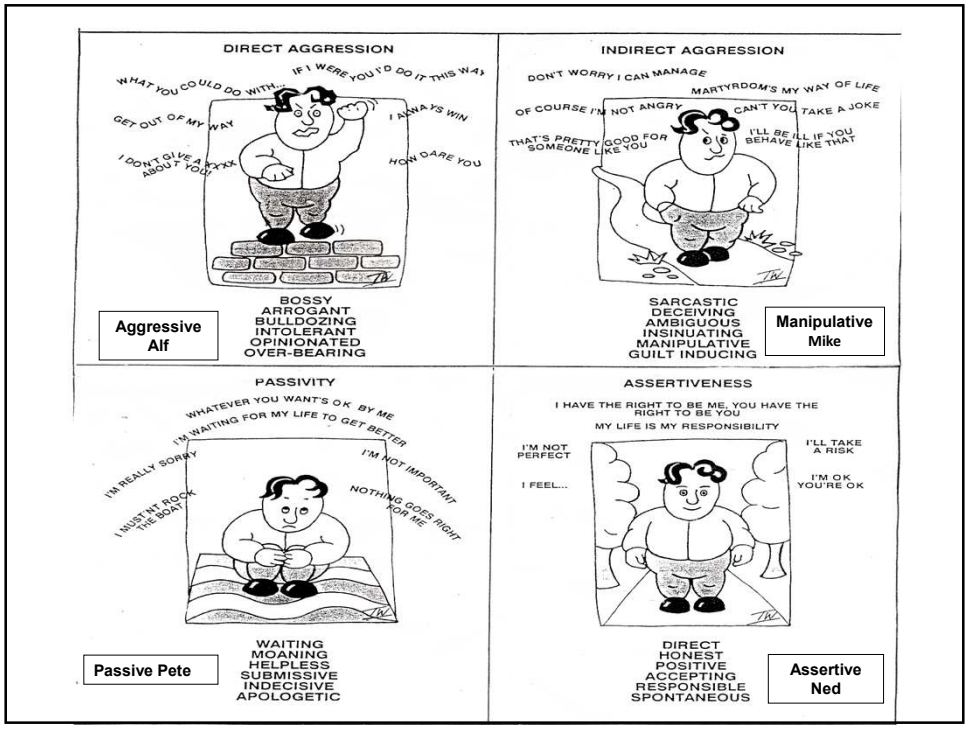
- Communication style
- Openly communicating your feelings, preferences and opinions with an "I'm OK, you're OK" attitude.
- That is, **being clear and open about what you think and feel without being blamey or critical of other people**.

The three communication styles

Passive: Violates own rights. Others needs given priority

Assertive: Respects own needs and needs of others

Aggressive: Violates rights of others. Own needs have priority



How to do it

Use assertiveness as a general life strategy. And when you are stressed instead of:

- Aggressive Alf

Directly taking it out on others – "you're doing it wrong!"

- Manipulative Mike

Indirectly taking it out on others – "I'll be ill if you behave like that"

- Passive Pete

Being passive – "it's not important, I won't bother others"

How to do it

Assertive Ned

- "I feel upset. I would have preferred it if you had told me".
- "I can see your point of view. I disagree. I see it like this…"
- "I like the second option. That makes me happy".

- Try to be like Ned in your communication with others:
- direct, honest, accepting, responsible (and avoid being critical or blamey).

Try the **ELF** strategy:

- Express
- Listen
- Field (show you have understood and 'caught' the other persons views)

Try to avoid 'but…'

Strategies for saying no

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

Making requests

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

Providing corrective feedback

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

Assertiveness skills to overcome ED triggers

Calm

Compassionate

Caring and concerned

Coaching

Not colluding

Calm coaching comments

"It's not helpful to focus on what sort/what calories/what amount"

"I know there is more to you than food and weight. Let's keep going and get there"

Examples

Your daughter/son/partner becomes upset when you or other family members try to use the kitchen while she/he are preparing their meal.

What would be an assertive way to broach this situation with them?

Examples

Your daughter/son/partner is very anxious at the table, saying that they will become fat if they eat.

What would be an assertive way to respond to this?

27 October 2020 – Eating Out, Not engaging / too poorly, Inpatient support and consent

We have welcomed some new members to the group in the last two weeks. This made me think about the many issues we have discussed in the last six months. If there were just three things to pass on, what would they be? Here's my list - yours might be different:

- 'They alone can do it, but they can't do it alone' - we can't make our loved ones better, but there is much we can do to help.
- 'Be a dolphin' - get alongside your loved one and compassionately nudge them in the right direction. Stepping in with the solution, or shielding them from the problem, will not work in the long run.
- 'Look after yourself' - unless you are physically and mentally well you will not be able to support your loved one through what is often a marathon and sometimes an ultra marathon. There is no shame in seeking help for yourself.

What have I missed out?! Let me know and I'll compile our 'top ten'.

Eating Out / Social Occasions

We began by discussing **the challenge of eating out with family and friends / joining in with social occasions**. Gary nailed it for me when he said that it can be quite an operation. The principle is to plan well in advance, in a calm moment, listening to our loved one's concerns and helping them to come up with strategies. If you can, check out menus online before the event. Talk through some 'what ifs'… 'what if they've run out?', 'what if I can't manage the dessert?' For some of our loved ones a particular issue at the moment is attending drinks receptions / buffets at the start of college term. Given that we are providing support 'at a distance' it is more difficult to help but the group's experience is 'be there to listen > ask lots of open questions > don't give an opinion unless asked > help them find their own way forward'.

Not engaging / Too poorly to think

We then considered one of the most challenging times of all, i.e. **when our loved one will not engage with professional support, but is too poorly to think straight**. This can become a whirlpool that is hard to get out of. The group made a number of comments:

- If there are things your loved one would like to do but can't, e.g. joining friends on holiday, going swimming, applying to university you can help by making connections between their eating disorder and its consequences, e.g. 'On the one hand you would like to start your university course, but on the other you don't have the energy to revise for your exams'. Let them, and give them time, to reach their own conclusions, don't tell them the answer. In this way, you are helping to give them a vision of the future.

- If our loved ones find it impossible to think about changing their behaviour - and it is important to remember that in the beginning the eating disorder is helping them to control unbearably strong emotions, so why would they give it up? - giving facts about their health (not judgements) can be motivating, e.g. reflecting that they have difficulty walking or doing an activity for any length of time. Sometimes, as we heard, the penny drops.
- If the professionals have asked you to support a particular routine, e.g. 'three meals / three snacks a day' be *assertive* - calmly, compassionately hold the line, appealing to the 'higher authority'. Stay calm if it is too much for them, getting into an argument will not help.
- Look after yourself - this is a stage in their recovery where you need to be as fit and well as you can be because it will be an emotional roller coaster.

Inpatient support and consent / confidentiality

We finished by discussing **the complex landscapes of inpatient support and consent / confidentiality**. For example, a number of us have had experience of a loved one in an acute hospital, with the involvement of a Community ED Service plus Liaison Psychiatry, and our loved one has given only some of these teams consent to share information. How do we manage this complexity? The group's experience was that this is possible - and definitely beneficial:

- One issue is 'should we contact the professionals whether or not we have our loved one's permission?' We discussed this back in June, and here is what we said:
- *If you have information that is important to your loved one's recovery you can always pass it on - you might not get a response, but it will be taken into consideration; the team supporting your loved one's recovery would rather know than not.*
- *The principles of planning in advance, in low stress moments and of asking permission can be very helpful: 'What would you want me to do if....?'*
- *If safety is an issue, do not hesitate.*
- *There is a difference between 'acting for and on behalf of' your loved one and 'contacting with important information to help their recovery'; the former does have to be agreed and recorded in your loved one's file.*
- *Confidentiality is, of course, an important issue. What your loved is willing to share with you, and what they are not, will be discussed and recorded at the start of their treatment and regularly reviewed.*

  Confidentiality should be breached if your loved one's life, or someone else's life, is at risk.

- Families and carers are seen as a vital part of the treatment for eating disorders, so the aim will always be to involve you.

- Another is what happens when they are discharged? First, there will be a Care Discharge Plan and hopefully you will be involved - if necessary, ask.
- If the person for whom you have a caring responsibility does not want you involved, there are still important things you can do, the main one being keeping the lines of communication open. Try to have something that isn't the eating disorder to talk about - our loved ones are more likely to answer the phone if they are confident that the call is not going to finish with an argument about their health.
- Remember that you can't control things you have no control over - put your energies into things you can control.
- If you think your loved one's life is at imminent risk, press the alarm button. That is not being a rhino, that is being a dolphin that is aware of its role!

Resources

For those of you new to the group:

- The key text is 'Skills-based Caring for a Loved One with an Eating Disorder' by Janet Treasure, Grainne Smith and Anna Crane. It really is essential reading.
- Check out these videos, made by Dr Beglin and the Carers Group a couple of years ago:

A Carer's Perspective:

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

A Professional's Perspective:

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

Other websites

- Jenny Langley's website is well worth a visit https://newmaudsleycarers-kent.co.uk/about-us/ .
- So too is Eva Musby's, although as I said at the meeting, Eva is often talking about younger children where the role of the parent/carer is a little different https://anorexiafamily.com/about-me-parent-eating-disorder/?v=79cba1185463 .
- And don't forget the BEAT website, which has lots of useful information and links to support groups https://www.beateatingdisorders.org.uk .

And don't forget, if you would like Axxxx's compilation of the first six months of summaries, drop me a line and I will email it to you.

3 November 2020 – Activity in recovery, Managing our own feelings, Process of discharge, Lockdown 2

I always enjoy our discussions but this week I thought we got into a really good gear. It's great to see how the group brings its experience to bear on the issues we raise: **supportive, practical, realistic**. Thank you!

The importance of activity in recovery

Cxxxx mentioned that her daughter was enjoying, and benefiting from, an interest in creative writing and we began by discussing **the importance of activity in recovery**. Our loved ones have found a range of interests - from crochet to crosswords - to get involved with. It was interesting that these were often 'new' not 'old' interests; if they have dropped an activity that they used to be really good at and enjoyed, at an appropriate moment in their recovery you could be curious and explore why - hearing your praise might give them the confidence to give it another go. These activities not only give pleasure but also an opportunity for expression, which can be very therapeutic. They are also **a really good 'non-eating disorder' topic of conversation**, which is so important. We can 'gently nudge' our loved ones towards activities, but we can't force them. The important thing is not to give up because the experience of the group is that, in time, they will find an activity that they enjoy.

How we manage our own feelings

We then talked about **how we manage our own feelings when we so much want our loved ones to make more rapid progress**. Understanding that most people take a long time to recover from an eating disorder but that they do recover is important. Seeing the positives rather than the negatives, and not taking the negatives personally, is also important. Our own perceptions might not be shared by our loved ones - they could be doing better than we think - so it is important to look out for 'green shoots', however small, and encourage them with appropriate praise. And we say this every week, simply because it is so important - **we have to be kind to ourselves and look after ourselves** to be fit for what could well be a marathon.

The process of discharge

I then asked Sarah if she could explain to us a little bit about **the process of discharge**. Sarah explained that there is a difference between discharge from a specialist eating disorder unit and discharge from an acute hospital. Discharge from a specialist unit is planned over a number of weeks and includes a range of activities as appropriate, e.g. meal preparation, eating out. Carers will be involved in this process. The aim is for our loved one to be able to manage their health successfully when they leave the unit. It is hard to say how long preparation for discharge will take because it varies according to the individual. The aim of acute hospitals is usually to stabilise our loved one medically, not to treat their eating disorder from 'start to finish'. The acute hospital may discharge our loved one to the

Community Eating Disorder Service, or sometimes to an inpatient service, to continue their recovery. Regardless, there will be a discharge planning process that - unless your loved one requests otherwise - you will be involved with, and it is certainly something that you can ask about.

Lockdown 2

With us entering 'Lockdown 2' I have attached the presentation Sarah gave at our very first online meeting in April. It contains some very useful advice and is well worth re-reading; do ask if you have any questions about it.

I have also attached 'The 5 Cs of Wellbeing' created by a teacher at Linton Infants after Cxxxx passed on Axxxx's message about World Mental Health Day. I think it is wonderful!

I look forward to seeing you all next week. With all best wishes

Resources

Coping with lockdown

The 5 Cs of Wellbeing

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

Carer Coping in COVID-19 Times

Dr Sarah Beglin
Consultant Clinical Psychologist
21st April 2020

Pride in our adults and specialist mental health services

Focus of today…

Part one:
Carers coping with COVID-19

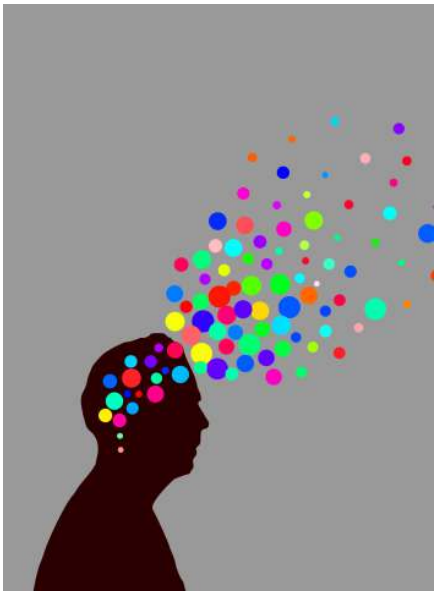
Part two:
Carers living with loved ones coping with COVID-19

We are all at sea…..

But not necessarily in the same boat….

Unprecedented times: Emotions are normal

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



We are in threat mode

Our chimp is out of its box

Concentrate on what you can do..

Things I can't control

- The virus
- The government's decisions
- Other people's behaviour
- The duration of lockdown
- Social media

Things I can control

- My actions
- How I deal with stress
- Following government guidelines
- My response to others

Managing your stress levels..

- Observe thoughts and feelings – accept them
- Focus on body – breathing, posture, grounding
- Engage fully in what you are doing – use your senses
- Take committed action

A note on over-monitoring

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

Take action

- Importance of routines
- Importance of balance
- Activity scheduling - Pleasure /mastery list
- Include self care, soothing, calming activies

Activity Scheduling

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

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

Activity Schedule

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

Part Two – lockdown with someone with an eating disorder

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

What can we do to help?

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

Over to you…

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

References and links:

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

3 November 2020 – Activity in recovery, Managing our own feelings, Process of discharge, Lockdown 2

The 5 Cs of Wellbeing'

10 November 2020 – Discharge, Consent and Confidentiality; Coroner's Statement

Welcome to this week's summary. We spent quite a bit of time on the introductions, exploring some of the issues raised and celebrating some successes. Here are a few of the key points:

- **We don't always say the right thing** - do not beat yourself up about this! Remember that 'every mistake is a treasure' and we are in it for the long haul. It may even by possible to flip a mistake into a positive learning point, i.e. in a calm moment it may be possible to return to the issue and discuss your concerns with your loved one.
- **Eating disorders are not logical**. Our loved ones' behaviour may seem bizarre to us, but to them it is generally a way of controlling feelings that they find unmanageable. Showing that we understand that is important - a simple empathetic sentence, 'I can see how difficult this is for you...' can be very supportive.
- **A conversation doesn't need a conclusion or action plan to be a success**. Ruth described her daughter being disappointed about the outcome of a meeting with her therapist, but it allowed them to have a good conversation. Ruth was able to help her daughter clarify her thoughts and feelings and was able to leave it at that. Later, her daughter reached her own conclusion about a positive way forward.
- **Our loved one may have recovered, but they can still have dips**; so don't get rid of the dolphin suit too quickly!

Discharge, consent and confidentiality

We then returned to the discussion we had a couple of weeks ago about discharge, consent and confidentiality. Sarah Beglin emphasised that the Eating Disorder Service will always try to assess and engage a patient who is being treated in an acute hospital, and they will always try to involve us, the carers, if at all possible. If you have information that is important to your loved one's recovery you can - should - pass it on - you might not get a response, but it will be taken into consideration; the team supporting your loved one's recovery would rather know than not.

Coroner's statement

We spent the bulk of our subsequent discussion on the coroner's statement at the end of the inquests into the tragic deaths of five patients with an eating disorder since 2012

https://www.bbc.co.uk/news/uk-england-cambridgeshire-53920996 .

A number of the group shared experiences of poor transition between children's and adults services, and between home and university. Locally work is well underway to improve this aspect of provision, but it is a national issue and as carers we must continue to make our views known, e.g. to our MPs

https://www.bbc.co.uk/news/uk-england-cambridgeshire-54886954

I gave a personal summary of what I think we should take from these inquests:

- They remind us that this is a serious illness that can have the worst possible outcome.
- However, it's really important to remember that most people recover.
- There is much that needs improving.
- The knowledge and understanding of non-specialists, e.g. GPs, acute hospital doctors is variable and needs improving; as carers, we may have to be assertive.
- We can have confidence in the specialist staff caring for our loved ones.

I read part of Simon Brown's interview with the BBC. Simon's daughter Emma died having been ill with anorexia and bulimia nervosa for 15 years. 'Simon Brown, Emma Brown's father, bears no grudge and has nothing but admiration for the clinicians involved in his daughter's care, even inviting some to her funeral.

> *"I don't know where they (the professionals) find the drive, the skill, to keep going back. You're not that well supported, you're under-staffed, under-budgeted, the patients hate you, the parents blame you, there's not enough money and actually we don't yet really know how to treat these people anyway. Why would anybody do that? Who am I to find blame in the people that have devoted their professional lives to trying to help people like Emma?"'*

Next week's session is a presentation about 'Motivational Interviewing', which will be led by Lynn Eldred, AEDS's Team Manager, not a peer group discussion as I said. I think I've got 'Lockdown plot loss'! I'll send the invite out via Teams.

Resources

And finally, here is the information about 'Shift your mindset' that Axxxx came across. It fits very much with our discussions about trying not to stress about the things we can't control; I'm trying!

Shift your mindset – let your worries go

There are times we will face unexpected and tragic challenges to overcome - the year 2020 and its hardships have taught us this. LeNaya Smith Crawford, LMFT, an adolescent, marriage, and family therapist with a specialization in trauma therapy, urges people to shift their mindset. Instead of focusing on the need to go back to a sense of normalcy, Crawford states the importance of coming to terms with the fact that "normal" isn't attainable anymore - what we once considered normal is an unrealistic expectation to have.

"The greatest level of anxiety resides in the areas we have the least amount of control of," Crawford said, adding that, with many of her clients, she does a writing exercise to help them release what they ruminate over in a productive way. It's all about compartmentalizing and is really quite simple:

- Jot down everything that is causing you anxiety, worry, and fear. Anything at all.
- This can be a regular bulleted list of what's making you feel overwhelmed.
- Then, divide that list up into the things you can control and the things you cannot control.
- Look over the things you can't control, and recognize and honour that you have no control over those situations. Choose to let them go.
- Turn your attention to the things you actually have control over.

Crawford said that "nine times out of 10," what we can't control causes the most anxiety, and actively tending to what you can control promises to reduce that anxiety. She noted that you can do the writing exercise with or without a mental health professional and it can be done whenever you feel yourself fall into a spiral of worrying. The writing tool may pinpoint exactly where those worries are coming from and will help you sort through the noise to find what you should be focusing your energy on.

Though letting worries go is definitely easier said than done, this exercise might provide you with the perspective you need. Give yourself grace and try it out.

17 November 2020 – Presentation - Motivational Communication – Lynn Eldred

We heard in the introductions this week that two of the group have had the most difficult of situations to deal with. We are all thinking of you and we are 100% confident that you are giving the best possible support to your loved ones. We heard good news, too - the best reminder that although it can take a long time, recovery is not only possible, it is the most likely outcome.

Motivational Communication

We welcomed Lynn Eldred, the Adult Eating Disorders Service's Team Manager who gave us a really useful presentation on 'motivational communication'. Lynn's slides are attached and here are a few summary points:

- Motivation to recover is a particular challenge when supporting people with an eating disorder because, particularly in the early days, they very often cannot even contemplate changing their behaviour as it is helping them to control feelings that they find otherwise unmanageable. Motivational communication aims to move our loved ones to a place in the change cycle where they can begin to think about change, to think about some of the advantages as well as the disadvantages. It is also important to remember that how our loved ones feel about change will vary even when recovery is under way - motivational communication will help move them through these stages, too.
- Lynn outlined five key principles:
    - Express empathy: accept how hard recovery is.
    - Validate: acknowledge that they are doing the best they can… small steps lead to success.
    - Develop discrepancy: help our loved ones to see a gap between what they would like to do and what they can do, e.g. 'On the one hand you are pleased to fit into the clothes you like and on the other you don't have the energy to play tennis, which you really miss'.
    - Roll with resistance: getting into an argument will only back our loved ones into a corner.
    - Support self-efficacy: believe that they can change and encourage any green shoots of recovery.

Lynn then took is through the **animal types**. **We must aim to be a dolphin**:

- swim alongside with encouragement;
- swim ahead sometimes,
- leading the way; swim at a distance if appropriate; and
- quietly swim behind when they are managing.

As a former (?) rhino I know how hard it is to become a dolphin but I eventually worked out that **being a rhino (or any of the other less desirable animal types) doesn't work!**

EOARS

EOARS brings it all together: five ingredients for good communication. They don't have to be in this order as long as they are there. This is a very good structure for 'long distance' caring, on the phone in particular, because it makes you listen really hard.

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

The group discussed some great examples of how they have adjusted their communication style - with the important reminder that you sometimes get it wrong - in the grand scheme of things it doesn't matter and is something to learn from.

A BIG THANK YOU to Lynn for leading such an important discussion.

Next week we'll have a chance to pick up some of the issues raised in our introductions and to continue discussing communication styles and strategies. I'll get the invite out before the weekend.

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Introduction to Motivational Interview Approaches

Lynn Eldred

November 2020

Pride in our adults and specialist mental health services

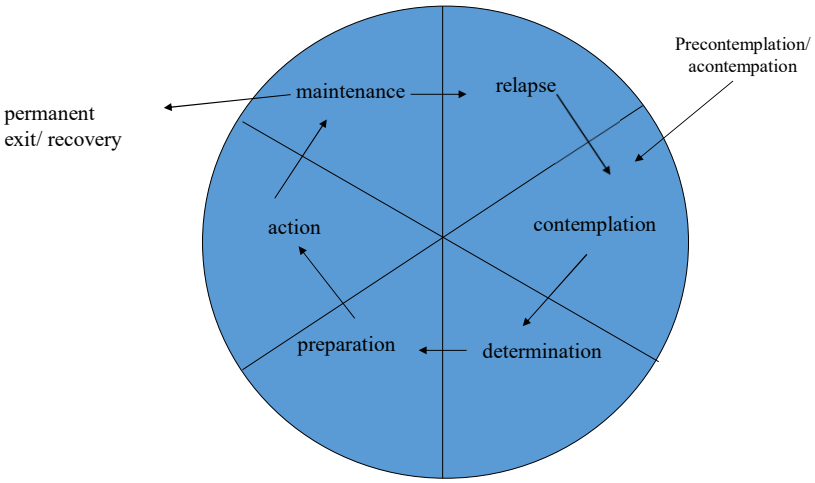
Nature of anorexia nervosa

- People with anorexia nervosa are often not motivated to give up their symptoms
- Motivational approaches are about encouraging people to enter the stage of contemplation – this is where ambivalence resides.

Ambivalence

- ".. A reasonable place to visit but you wouldn't want to live there"…(Bill Miller)
- Being ambivalent (in two minds) is a normal aspect of human nature (e.g. giving up smoking, changing job, moving house, taking medication etc.)
- Understanding and hearing about the ambivalence is a helpful part of the change process

Cycle of change
Prochaska and DiClemente '94



General principals of Motivational Enhancement Therapy

- **Express empathy**: Acceptance, skilful reflective listening, ambivalence is normal.
- **Validate :** discuss problems as very understandable given client's past and current experiences. They are doing the best they can.
- **Develop discrepancy**: Patient argues for change by experiencing a discrepancy between current behaviour and personal goals and values
- **Roll with resistance**: Avoiding argument, inviting new perspectives, emphasis on client to find solutions
- **Support self-efficacy**: Belief in possibility of change, patient chooses and carries out change, therapist believes in client's abilities to change

Discrepancy

- The gap between where you are and where you want to be
- Where there is ambivalence there is a discrepancy
- This is psychologically uncomfortable
- There is often an emotional response
- People can feel motivated to bring this unpleasant state to an end

Example of a decisional balance in anorexia nervosa.

Costs

- Cold all the time
- Tired
- Dizzy
- Socially isolated
- Poor concentration (college/work suffering)
- People nagging me

Benefits

- I'm in control
- Helps me cope with feelings
- People notice me and show care
- I'm achieving something - special
- I look better
- Gives me a reason for not succeeding – way out of pressure

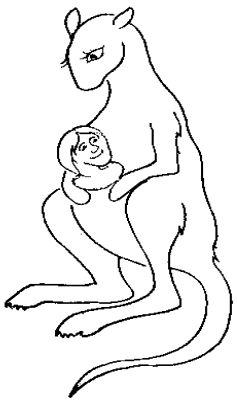
MET: Communication styles

- Common and understandable communication styles that family, carers and services can all slip into:
  - Maudsley Method: Animal Types
  - E-OARs as alternatives

The Animal Types
Treasure et al (2007)

- Short-hand for common responses to a loved one with a chronic health problem
- New Maudsley Method

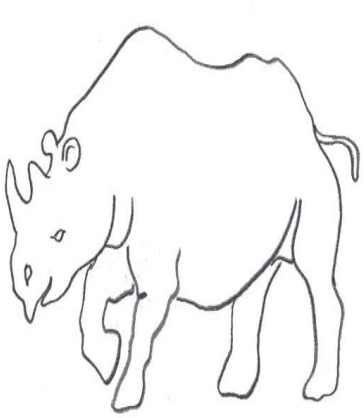
  -Expressing support
  -Expressing emotion



Kangaroo

Puts sufferer in pouch, protect
warm/ safe / protecting / loving

But...
Infantilising
Suffocates growth
Prevents independence & mastery of challenges for self-confidence
Gives message world is dangerous

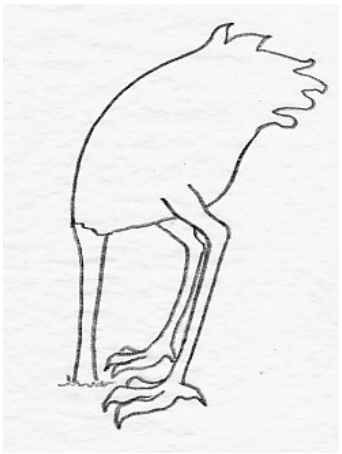


Rhinoceros

Shout, try to control and 'win' ED arguments
Strong / Loving / Wants to make them 'see sense'

But…
Sufferer feels upset
Cant turn to carer for support
Arguing gives chance to argue for ED

Counter argument – 'I won't give in!'



Ostrich

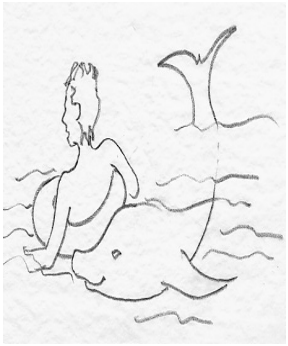
Avoiding seeing, thinking & dealing with problem
Head in the sand
Avoids getting over-involved/emotional
ED talk doesn't dominate, avoids arguments

But…
Sufferer feels problems un-noticed → un-loved
Cant turn to carer for support
Role-modelling emotional avoidance

Jellyfish

Emotional Response transparent
- Overtly distressed, depressed, anxious,
Weepy, tearful
Shows compassion, love

But...
Sufferer upset at hurting loved ones
Avoids telling truth for fear of hurting others
Reduces self-esteem
Creates a feeling of hopelessness



Dolphin

Swimming alongside with encouragement

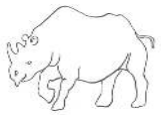
Swimming ahead, leading the way

Swim at a distance if needed

Quietly swimming behind

Review: noticing the pulls and finding the balance

Too much control & direction



Too much sympathy and micromanagement

Just enough
Gentle support when invited
'Good Enough' Caring

Too much expressed emotion

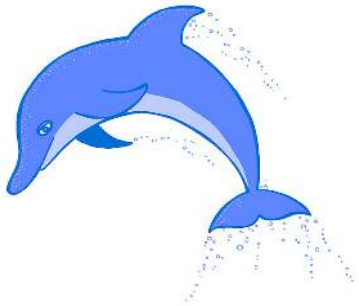
Emotion? Problem?

The animal types

Do you recognise yourself in any animal type?
- Personally?
- Professionally?

What did it feel like?
What was the outcome?

Enhancing communication - OARS



- E - Empathy
- O – Open questions
- A – Affirmations
- R – Reflections:
  - Repeating
  - Rephrasing
  - Name the feeling
  - Double sided (on the one hand…)
  - Over/undershooting
- S - Summaries

Try not to…

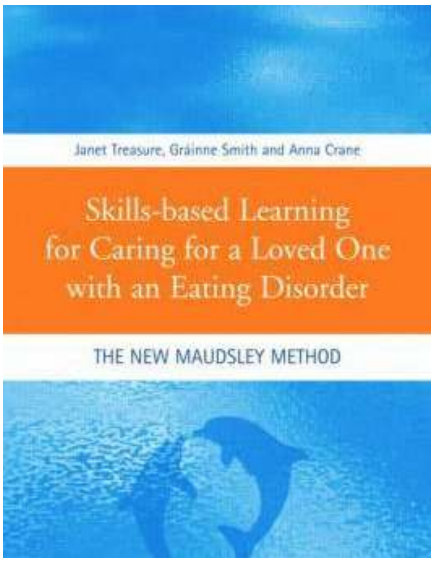
- Argue, lecture or persuade with logic. Pushing against resistance entrenches it
- Assume an authoritarian or expert role (practice one downman ship)
- Do most of the talking
- Ask more than 3 questions in a row
- Get into debates and stuggles
- Remember that "resistance" is just the other side of the ambivalence

Final reflections

- Changing patterns of communication is hard
- You will need to be patient with yourself
- The more you practise the easier it will get
- Don't give up!

Recommended Reading

- The techniques described in these workshops are also explained in this book



24 November 2020 – Interruptions, Our Feelings – 'Snakes and Ladders', Triggers, Men and ED

Another great turn out this week and a really good discussion. We began by welcoming new members and we were really pleased to hear that things had been better for two of the group who, last week, had been dealing with the most difficult of situations.

Interruptions - stepping out and stepping back in again

We discussed three issues in detail, the first of which was 'Interruptions - stepping out and stepping back in again'. Many of our loved ones have had their time at school or university interrupted. Jobs and other life ambitions can similarly be affected. The group's experience was:

- Taking time out and then repeating a year, or picking up from where our loved ones left off, is often possible and deciding to do that can be a very positive decision, demonstrating an awareness of the impact of the illness and a willingness to recover.
- Changing courses / jobs is possible and can be very successful - some of the group reported that their loved ones found a 'break from the past' helpful.
- Alternative qualifications, e.g. a modern apprenticeship might be more appropriate because they better suit our loved ones' recovery.
- A change of institution is also possible, e.g. a fresh start at a new university, or studying part-time at a College of Higher Education.

Our role, as ever, is to support our loved ones through these difficult decisions, helping them to make up their own minds.

Our Feelings – 'Snakes and Ladders'

We then spent some time talking about when it feels as if our loved one's health has declined to the point when it feels like they have gone **back to the beginning**; when they've gone up a ladder and then all the way back down a snake. We know that it's not right back to the beginning because they, and we, have more understanding, but it feels like back to the beginning. A number of us described this as the hardest time of all, and a time when it is really important to look after yourself. We can help by staying as calm as possible and thinking about (and applying) what worked before to motivate our loved ones towards recovery. Suzanne reflected the phrase 'recovery is what we can live with' - this takes finding and is an important topic to return to. (On 12th January we will be hearing from a former patient about their recovery journey.)

Triggers

We also discussed **triggers for a decline in physical and mental health**, which for many include the nights drawing in and the weather worsening.

Some of the group have found light boxes to be helpful with SAD (Seasonal Affective Disorder).

Other tips were the routine of a daily walk in the daylight, supplementing your diet with vitamins and creative activities (some impressive knitting is underway).

Emma Mitchell's 'Making Winter' was recommended.

A general principle is that activity is really important for mood.

Men and ED

We briefly touched on men and eating disorders. The interview with Freddie Flintoff in which he talks candidly about his eating disorder is still available on iPlayer. There is an increasing amount of support material available.

Some Notices

Carers Rights Day

I concluded by mentioning that it is Carers Rights Day on 26th November - an important day to do something to look after yourself - and

Consultation Event

Flagging up the opportunity to join a consultation event about Cambridgeshire and Peterborough's Healthy Eating initiative, see below.

Thank you again for such an informative and supportive discussion.

Resources

Book

https://www.waterstones.com/book/making-winter/emma-mitchell/9781910552650 (other book stores are available!).

For Men

https://www.beateatingdisorders.org.uk/do-men-get-eating-disorders is a good place to start.

https://www.malevoiced.com/

24 November 2020 – Interruptions, Our Feelings – 'Snakes and Ladders', Triggers, Men and ED

BE INVOLVED, BE HEARD AND HAVE YOUR SAY!

BMI Can Do It—Healthy Eating

Help shape Cambridgeshire's BMI Can Do It campaign

In collaboration with the SUN Network, The BMI can do it campaign team are wanting to develop healthy eating as part of the campaign and are looking for individuals to help, who experience mental health challenges with food, have an eating disorder or negative body image.

Would you like to take part in a small group discussion with members of the BMI Can do It team, the SUN Network and others with lived experience of challenges with food, to discuss how best to communicate about food and healthy eating to ensure it is inclusive to everyone?

How to be involved

When: Thursday 3rd December 2020

Time: 14.00—15.30

Where: Online (you will need to have access to online facilities)

If you would like to be involved then please book your place by clicking on the link

https://www.surveymonkey.co.uk/r/involveU

then ticking the box BMI Can Do It - Healthy Eating

or you can

CALL / TEXT or WhatsApp: 07921 879318

Once your place is confirmed, a link for the online meeting will be sent to you.

Closing date for booking your place is on Monday 30th November 2020 at 16.00

We look forward to hearing from you.

The sun network

1 December 2020 – Burden, EOARS, Where do we go from here?

Well, here we are, it's December and, as I write, only 21 shopping days to Christmas, although I'm not quite sure what 'shopping days' are anymore. What I do know is that we had another really good discussion and that Dr Sarah Beglin will be giving us a presentation next week (8th December) on 'Coping with Christmas', which I can guarantee will be invaluable whether you are 'new' or 'experienced'.

Burden

We began by discussing **'burden'** - when our loved one feels a burden to medical staff and as a consequence does not want to engage with support and/or when our loved one feels a burden to us and wants us, for example, to go on a visit, trip or holiday without them. The group's experience is that this is a complex issue because a number of emotions could be involved including low self-worth, fear about the activity itself and guilt.

- **Gentle questioning** - with permission to understand these emotions can be helpful,

  e.g. 'I can see how this might be hard for you and it would be great if you could tell me a bit about it so that we can discuss if there is anything I could do to help'.

- **Start small** - maybe the fear is because the activity is too big.

  A walk with the dog is clearly defined, whereas going out for a day means eating out as well.

- **Plan and prepare**, even for small activities, in calm moments.

- **Flip it** - if your loved one tells you they are a burden, tell them what you like about them. You could ask them what they think a friend would say about them.

- **List positives** / things they are good at on post-its and leave them on a desk or mirror, without fanfare or comment.

- **Make sure that in your concern to help them you don't stifle** their opportunities to help you / the family.

  'Don't worry, I'll sort it' may deny them the opportunity to do something that would make them feel useful and contribute to their self-worth.

- You may be able to provide valuable information to the professionals to help them build their relationship with your loved one,

  e.g. that they take a while to get to know someone and that they enjoy talking about (list) these non-eating disorder topics.

There is plenty here to try and what works will vary from person to person.

EOARS

Nxxxx then explained why she has found motivational communication - EOARS - so helpful. This was introduced to us by Lynn Eldred and is one we will come back to again. Naomi commented that:

E - empathy - this is noticing the fear / anxiety / how difficult things are.

O - open questions - can be really basic, not too deep, at least at first. They can get the conversation going.

A - affirmation - praising the green shoots, e.g. 'That was a really brave decision'.

R - reflection - saying back what you think you've heard to check that you've got it right.

S - summary - pulling the conversation together.

It can be a bit clunky at first - stick with it - all five components (in any order) add up to a good conversation. I have attached the slides we use on our Saturday Workshop (well, used pre-Covid) and we will return to this in the New Year.

Where do we go from here?

The 'Where do we go from here?' question comes up when our loved ones appear to go backwards / disengage from (an aspect of) treatment / get stuck. I think we could all give examples. The general principles were:

- **Stay calm**
- **Look after yourself**
- Search for and **nurture any green shoots** / positives, e.g. your loved one returns home, disengages from monitoring but registers with a GP - that they have registered is a real positive, if they wanted to disengage completely they wouldn't do this.
- **Think about how open to change they are** and encourage as appropriate.

We have feelings too

Let's be honest, **our loved one's behaviour can be very upsetting**. When they are very poorly there is not much they can do about this and it is important that if you find yourself getting uncontrollably upset - a real jellyfish - **you should consider getting help yourself**. Remember, **it is their illness that is upsetting you, not them**. When you are feeling a bit stronger and they are a bit better it is important to let them know how their behaviour (not them) makes you feel because that is part of a 'normal' relationship**. Communicate unemotionally and in a way that they are most receptive to**, e.g. text messages allow time for thinking before replying.

Finally, let's model how to take a compliment!

Suzanne said how brilliant you must be and how good it is that you can share so openly. She said that it sounds as if it's really difficult for you but you are still here. Thank you, Suzanne, that is really appreciated.

See you next week for 'Coping with Christmas'.

MI Communication: OARS

- **O**pen questions: Skillful questioning style
- **A**ffirmations: Praise to build confidence and motivation
- **R**eflective listening: Skillful listening style
- **S**ummarizing: Demonstrating you have understood

- **OARS** helps you row the conversation in the direction you want it to go, rather than drifting along the usual current.

Types of Question

Closed questions
The choice of answers is already defined by the question. Are you going to eat what's on your plate? (yes/no)

Open questions
Give the person room to elaborate and answer how they choose: What can I do that might make this easier for you? (many options)

Open questions are more productive & increase understanding. Aim to use open questions wherever possible.

Beware of:
Leading Questions – not really a question at all but a statement and request for the other person to conform: "Don't you think that..."
'Why' Questions – can feel accusational.

Affirmation

Praise to build confidence and motivation:

- Do praise 'green shoots'
- Do praise the process as well as the outcome, e.g. if their behaviour has been flexible rather than rigid
- Do praise in the way that your loved one best receives praise
- Do praise discriminately

Reflective Listening

Understanding what they are saying, listening for the emotion underneath.
Repeating back to the speaker in your own words, checking for accuracy.

"It sounds to me like…"

"So you're saying…"

"From your point of view…"

"Let me check I've understood.

You're feeling…"

Roadblocks to Listening

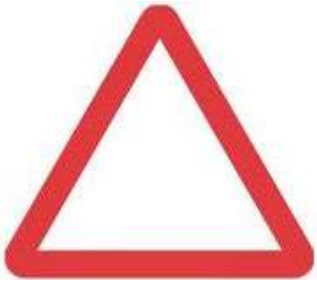
Dis/agreeing

Being distracted

Suggesting

Too much empathising

Rehearsing



Dis/approving

Arguing

Reassuring

Judging

Feeling upset

Summarising

Providing a short summary of what Edi has said, to show you have heard and understood.

A summary reflection pulls together what Edi has said, with attention to important elements of the discussion (particularly helpful if Edi is struggling with concentration).

Opportunity to pick out the green shoots – small positives that might otherwise go unnoticed.

Paraphrase where necessary - "So let me check I've got this right...."

Giving Advice in MI

- Giving advice increases resistance
- Implies we don't believe they have the power to find their own answer
- Less likely to act on advice than their own decision

Tools for Lowering Resistance (for when advice is necessary)

Ask Permission – e.g. 'May I make a suggestion?' / 'Would you mind if I tell you one concern I have about that plan?'

Offer Choices – When informing, offer a series of choices simultaneously. 'Pick a card, any card'

What other's do – Talk about what you have heard someone else has done in a similar situation.

Consult higher authority – e.g. 'The hospital has told me that it is not helpful if I give you mindless reassurance'

8 December 2020 – Coping with Christmas

A very big thank you to Sarah for her presentation on Coping with Christmas and for taking us through a problem solving framework that could be applied more generally. Sarah's presentation is attached and here are a few notes summarising the wealth of ideas the group came up with.

First, the problems

- What shall we give our loved one for Christmas lunch?
- How to support our loved one with the burden of all the challenges of Christmas.
- How to cope with 'judgemental / critical' grandparents… or aunts/uncles… or…
- How to make Christmas good for siblings / all.
- How do we cope with Christmas without our loved one being at home?
- How do we balance our needs and our loved one's needs at Christmas?

Second, the problem solving framework

Second, we tried out the problem solving framework on 'How to make Christmas good for siblings / all' at the heart of which is the issue of the eating disorder not dominating Christmas for everyone. Here is the list of suggested ideas - without comment:

1. Ask everyone 'What is the one thing you'd like to do this Christmas?'
2. Organise a few non-food activities you can do together as a family - board games, films, charades, Desert Island Discs.
3. Similarly, play some party games not to do with food.
4. Christmas 'disaster bingo' - think about all the things that could go wrong / be said… and then tick them off as the day progresses. (Editor's note: this seemed to be alarmingly popular!)
5. Plan the day carefully, with timings.
6. Have a couple of days off.
7. Discuss / negotiate with your loved one how they are going to manage the meal itself, e.g. having the chair nearest the door so that they can leave if it gets too much without causing a physical disruption.
8. Prepare grandparents, aunts/uncles, friends/family in advance. (See BEAT's guidance for friends and family: https://www.beateatingdisorders.org.uk/uploads/documents/2017/10/carers-booklet.pdf).
9. Ask siblings what they are worried about / what you can do to help, do not make assumptions.
10. Have contingency plans (plural).
11. Include a walk as part of the plan.
12. Play some music together!

13. Involve siblings in the preparations / activities.
14. Everyone suggests the food they want to eat.

Third, Pros and Cons

The third phase of the problem solving model is to list the pros and cons of each of the ideas. We did not have time to discuss them all, so Sarah demonstrated the technique with the first suggestion "Ask everyone 'What is the one thing you'd like to do this Christmas?'" For example, advantage: everyone will feel that they've had a chance to have their say and therefore have a stake in the occasion; disadvantage: some of the ideas might not be feasible, or might be incompatible, leading to disappointment.

Having worked through all of the ideas it will then be possible to give them a score out of ten so that you can rank them and draw up a list of the top three or four things to do.

Some good ideas

Some good ideas came up in the general discussion, too good to be lost:

- With siblings it is really important to listen to their concerns / worries and to validate these - it is rotten for them and that is a perfectly normal reaction, they should not feel guilty about it. Unless you know what they are thinking and feeling you are flying blind and they won't feel that their views are being taken into account.
- If your loved one is in an inpatient unit over Christmas and will therefore not be with you, it is not going to feel the same as usual and this has to be acknowledged. On the other hand, it is an opportunity to look after yourselves, to relax the best you can, and not feel guilty.
- If it gets too much, have a bit of time out and then come back. To misquote Shakespeare, although I'm sure it's what he intended to say, 'Exit, pursued by a dolphin', i.e. calmly swim out of view for a few moments before swimming back!

Next week's meeting is a discussion session, I will get the invite out before the end of the week. There will be meetings on 22nd and 29th December and 5th January to cover us over the Christmas period. 12th January will be a discussion session and our next presentation is on 19th January when we will be hearing a recovery story.

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

Coping with Christmas

Dr Sarah Beglin
Consultant Clinical Psychologist
8th December 2020

Pride in our adults and specialist mental health services

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

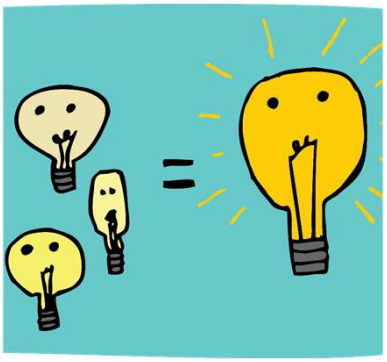
- COVID-19 restrictions
- Christmas for someone with an eating disorder- its challenging
- Being with someone with an eating disorder at Christmas - challenging

Why is Christmas so hard for those with eating problems?

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

Christmas Problem solving

- Today we are going to talk about a method to help you to think about and plan for the inevitable difficulties that might occur over the festive period
- You can do this on your own or with your loved one



Step one

Define the problem – be specific and clear

Step two

- Generate as many ideas to solve this problems as you can
- Blue sky thinking
- Indulge your creativity
- Don't get into discussing the merits of the ideas – just get them down
- Allow yourselves to be silly – humour goes a long way!

Step three

- Go through each idea listing the pros and cons

Step four

- Now give each idea a rating out of 10
- Rank the ideas in order

Step five

- Pick the best idea and plan it
- Maybe have a back up idea (or two) for plan B/C..

Remember to review – how did it go? What did you learn?

Step six

Over to you…

- What are your Christmas worries/problems?

15 December 2020 – Difficult situations

I am constantly impressed by the willingness of the group not to flinch from the really hard questions. The group ethic means that we feel safe sharing difficult situations and using our experiences to help and support. This week was a perfect example - a number of the group are having to cope with a great deal at the moment and there are understandable anxieties about the approaching Christmas holiday. (Good to hear that 'disaster bingo' is coming together well, I am looking forward to playing it, although disasters are not compulsory!)

Experience of Admission to Acute / General hospitals

Our first major topic was our experience of loved ones being admitted to acute / general hospitals - in summary, mixed. Many of us had experienced nurses and doctors with little knowledge and understanding of eating disorders, which is perhaps not surprising because unless you specialise in eating disorders you get very little training. There is guidance for hospitals (google MARSIPAN) but very few hospitals have been able to implement this in full for a variety of reasons, not least of which is the funding to do so. Anne is campaigning for a roving team of Eating Disorder nurses who can support patients whichever ward they end up on, including at weekends, a really interesting idea.

Addressing this issue is a national priority but I am sure that it will be some time before provision is consistently good. However, the group's experience is that there are things we as carers can do to help our loved ones:

- Supporting our loved ones with explaining to the staff how they (the nurses and doctors) can best communicate and help;
- Giving information to the staff that they might find helpful. If our loved ones have not given staff consent to talk to us about their treatment, they may not be able to respond but they will always be interested in any information that could lead to a better outcome; and
- Aim to be the 'St Bernard' - calm and compassionate… which is a tough ask, so it is especially important to look after yourself - visiting big, noisy hospitals is exhausting at any time and especially at the moment.

'Conditional Treatment'

We then discussed 'conditional treatment', i.e. our loved ones being required to do certain things in order to be accepted onto, or to continue with, a treatment pathway; for example, keeping a food diary or weekly weigh-ins. There are a number of different reasons why an Eating Disorder Service might make stipulations like these; for example, it could be to see evidence of a willingness to change, without which the treatment would be unsuccessful. In practice, patients are not 'abandoned' but it is understandable that there have to be boundaries and limits - we know that you cannot force someone to recover from an eating disorder so there is little point placing someone on a treatment pathway that they are simply not going to benefit from. If our loved ones' struggle to meet 'conditions' but are

willing to engage to some extent then their thoughts and feelings are often used as part of an appropriate therapy.

Again, the group's experience is that there are things we can do to support our loved ones:

- Problem-solving, using last week's framework, to come up with some practical ways forward - examples included not leaving the scales out to prevent constant weighing, or arranging a specific place to go to be weighed once a week;
- With permission, advocating on our loved one's behalf, e.g. helping the transition to university by writing to the GP Practice Manager and securing their support with a weekly weigh in; and
- Developing those dolphin skills - empathy and encouragement to nudge them gently in the right direction.

I concluded with a reminder that the sessions will run over Christmas on 22nd and 29th December and the 5th January, although I will be having a break from preparing summaries.

23 December 2020 – Christmas Update

No summary this week, I'm taking a break to wrap up some presents, but it was a really good discussion. Thank you. I will be sending out an invite for 29th December and 5th January as per usual.

Attached are a couple of Christmas goodies. The Carers Help Booklet was sent to me by PEDS (Personalised Eating Disorders Service). PEDS is based in Peterborough and works alongside CPFT on a number of initiatives. The booklet is grounded in the New Maudsley Method ('dolphin' for short!) principles. A former service user, who has recovered from their eating disorder, helped compile it, which adds to its relevance and interest.

The flyer is an invitation to join a consultation event that Healthwatch is organising as part of a project to improve young people's mental health care. There is a particular focus on transition from CAMHS to Adult Services, which I know some of you have strong views about. Emma Amez, the organiser, is happy for you to contact her direct - her email address is on the poster.

Resources

Carers Help booklet

Mental Health workshop (Note- Not included in summary as for February 2021)

Videos

Here are the links to the two videos I mentioned, for those who are relatively new to the group. (You may have to paste these links into your browser.)

Films to support carers. The NHS East of England Eating Disorders Clinical Network has made two films aimed at supporting carers and parents of children and young people through the recovery process of an eating disorder. You can stream or download the films (30 mins each) by copying and pasting these links:

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

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

Stay safe and well, and see you soon.

Personalised Eating Disorder Support

Carers Booklet

Index

What is an eating disorder?

Eating disorders are serious conditions related to persistent eating behaviours that negatively impacts the individual's health, emotions and ability to function in important areas of life.

Most eating disorders involve the individual focusing too much on weight, body shape and food, leading to dangerous eating behaviours. These behaviours can significantly impact their body's ability to get appropriate nutrition. Eating disorders can harm the heart, digestive system, bones, and teeth and mouth, and lead to other diseases.

Eating disorders often develop in the teen and young adult years, although they can develop at other ages. With treatment, they can return to healthier eating habits and sometimes reverse serious complications caused by the eating disorder. (1)

The main types of eating disorders and their symptoms

Anorexia Nervosa – is an eating disorder characterised by an abnormally low body weight, or a dramatic decrease in body weight, intense fear of gaining weight and a distorted perception of weight or shape. People with anorexia use extreme efforts to control their weight and shape, which often significantly interferes with their health and life activities. When you have anorexia, you excessively limit calories or use other methods to lose weight. (1)

Bulimia Nervosa – individuals with this eating disorder binge and purge. They may secretly binge – eating large amounts of food with a loss of control over the eating – and then purge, trying to get rid of the extra calories in an unhealthy way. To get rid of calories and prevent weight gain, people with bulimia may use different methods such as: regular self-induced vomiting or may misuse laxatives, weight-loss supplements, diuretics or enemas after bingeing. They may also use other ways of getting rid of calories and preventing weight gain by fasting, strict dieting or excessive exercise. (1)

Binge eating disorder – is an eating disorder in which an individual frequently consumes unusually large amounts of food and feel unable to stop eating. Almost everyone overeats on occasion but for some people, excessive overeating that feels out of control can become a regular occurrence and this is known as binge eating disorder. When an individual has binge eating disorder, they may be embarrassed about overeating and vow to stop, but due to have such a compulsion to binge and strong urges, they find it extremely difficult to stop. (1)

Other types of eating disorders

PICA – an eating disorder where the individual eats things that are not considered food.

Rumination Disorder – where an individual will voluntarily regurgitate their food after previously chewing and swallowing it, re-chews it and then either swallows it again or spits it out.

Avoidant/restrictive food intake disorder – people with this disorder experience disturbed eating either due to lack of interest in eating or distaste for certain smells, tastes, colours, textures or temperatures.

Purging Disorder – individuals purge but do not binge.

Night eating syndrome – people with this syndrome frequently eat excessively at night time, often after awakening from sleep

Orthorexia – individuals with this disorder have an obsessive focus on healthy eating, to an extent that disrupts their daily lives.

Other specified feeding or eating disorder (OFSED) – this includes eating disorders that greatly affect an individual's life but do not fit into any of the categories above. (2)

Behavioural and physical signs of Eating disorders

Behavioural signs of an eating disorder

- Intense fear of gaining weight
- Negative or distorted self-image
- Frequent checking in the mirror for perceived flaws
- Self-worth and self-esteem dependent on body shape and weight
- Fear of eating in public or with others
- Preoccupation with food
- Eating tiny portions or refusing to eat
- Avoiding eating with others
- Hoarding and hiding food
- Eating in secret
- Disappearing after eating—often to the bathroom
- Unusual food rituals (cutting food into small pieces, chewing each bite an unusually large number of times, eating very slowly)
- Any new practice with food or fad diets, including cutting out entire food groups (no sugar, no carbs, no dairy, vegetarianism/veganism)
- Little concern over extreme weight loss
- Obsessive interest in cooking shows on television and collecting recipes
- Consumption of only “safe” or “healthy” foods
- Social withdrawal
- Making excuses for not eating
- Cooking elaborate meals for others, but refusing to eat them themselves
- Eating strange combinations of foods
- Elaborate food rituals
- Withdrawing from normal social activities
- Hiding weight loss by wearing bulky clothes
- Flat mood or lack of emotion
- Irritability
- Mood swings
- Hyperactivity and restlessness (unable to sit down, etc.)
- Rigidity in behaviours and routines, and experience of extreme anxiety if these are interrupted
- Excessive exercising
- Exercising even when ill or injured, or for the sole purpose of burning calories (3)

Physical symptoms of an eating disorder

- Noticeable fluctuations in weight, both up and down
- Stomach cramps, other non-specific gastrointestinal complaints (constipation, acid reflux, etc.)
- Menstrual irregularities—missing periods or only having a period while on hormonal contraceptives (this is not considered a “true” period)
- Difficulties concentrating
- Abnormal laboratory findings (anaemia, low thyroid and hormone levels, low potassium, low blood cell counts, slow heart rate)
- Dizziness
- Fainting/syncope
- Feeling cold all the time
- Sleep problems
- Cuts and calluses across the top of finger joints (a result of inducing vomiting)
- Dental problems, such as enamel erosion, cavities, and tooth sensitivity
- Dry skin
- Dry and brittle nails
- Swelling around area of salivary glands
- Fine hair on body
- Thinning of hair on head, dry and brittle hair (lanugo)
- Cavities, or discoloration of teeth, from vomiting
- Muscle weakness
- Yellow skin (in context of eating large amounts of carrots)
- Cold, mottled hands and feet or swelling of feet
- Poor wound healing
- Impaired immune functioning (3)

Signs of Anorexia nervosa

- Dramatic weight loss
- Dresses in layers to hide weight, food, calories, fat grams and dieting
- Refuses to eat certain foods, progressing to restrictions against whole categories of food (e.g. no carbs)
- Makes frequent comments about feeling 'fat' or overweight despite weight loss
- Complains of constipation, abdominal pain, cold intolerance, lethargy and excess energy
- Denies feeling hungry
- Develops food rituals (e.g. eating foods in certain orders, excessive chewing, rearranging food on a plate)
- Cooks meals for others without eating
- Consistently makes excuses to avoid mealtimes or situations involving food
- Maintains an excessive, rigid exercise regimen – despite weather, fatigue, illness, or injury, the need to 'burn off' calories taken in
- Withdraws from usual friend and activities and becomes more isolated, withdrawn and secretive
- Seems concerned about eating in public
- Has limited social spontaneity
- Resists maintaining body weight appropriate for the age, height and build
- Has intense fear of weight gain or being 'fat' even though underweight
- Has disturbed experience of body weight or being 'fat', even though they're typically underweight
- Has disturbed experience of body weight or shape, undue influence of weight or shape on self-evaluation, or denial of the seriousness of low body weight
- Post puberty female loses menstrual period
- Has a strong need for control
- Shows inflexible thinking
- Has overly restrained initiative and emotional expression (3)

Signs of Bulimia nervosa

- In general, behaviours and attitudes indicate that weight loss, dieting and control of food are becoming primary concerns (3)
- Evidence of binge eating, including disappearance of large amounts of food in short periods of time or lots of empty wrappers and containers indicating consumption of large amounts of food
- Evidence of purging behaviours, including frequent trips to the bathroom after meals, signs and/or smells of vomiting, presence of wrappers or packages of laxatives or diuretics
- Appears uncomfortable eating around others
- Develops food rituals (e.g. eats only a particular food or food group, such as condiments)
- Skips meals or takes small portions of food at regular meals
- Steals or hoards food in strange places
- Drinks excessive amounts of water
- Uses excessive amounts of mouthwash, mints and chewing gum
- Hides body with baggy clothes
- Maintains excessive, rigid exercise regimen to 'burn off calories'
- Shows unusual swelling of cheeks and jaw area
- Has calluses on knuckles and back of hands from self-induced vomiting
- Teeth are coloured and stained
- Creates lifestyle schedules or rituals to make time for binge-and-purge sessions
- Withdraws from usual friends and activities
- Looks bloated from fluid retention
- Frequently diets
- Shows extreme concern with bodyweight and shape
- Has secret recurring episodes of binge eating
- Purges after a binge (e.g. self-induced vomiting, abuse of laxatives, diet pills and/or diuretics, excessive exercising and fasting)
- Body weight is typically within the normal weight range and may be overweight

Signs of Binge eating disorder

- Evidence of binge eating, including disappearance of large amounts of food in short periods of time or lots of empty wrappers and containers indicating consumption of large amounts of food
- Develops food rituals, such as only eating one particular food or food group
- Steals or hoards food in strange places
- Hides body with baggy clothes
- Creates lifestyle schedules or rituals to make for binge sessions
- Skips meals or takes small portions of food at regular intervals
- Has periods of uncontrolled, impulsive or continuous eating beyond the point of feeling comfortably full
- Does not purge
- Engages in sporadic fasting or repetitive dieting
- Body weight varies from normal to mild, moderate or severe obesity (3)

Why does my child have an eating disorder?

There is no single cause for an eating disorder, this may shock some people, as we always look for causes in childhood experiences or traumas.
What is known is that there are several risk factors which make it more likely that a person will develop an eating disorder. And there are known risk factors for specific types of eating disorders.
Someone with any kind of eating disorder is more likely to be sensitive, prone to anxiety, has high standards yet poor self-confidence. The reasons why these factors have come together in one individual will be personal. Sometimes it's just genetics, other times it's environmental, but mostly it is a mix of both. (4)

Risk factors

Psychological risk factors

- Perfectionism
- Anxiety
- Depression
- Difficulty regulating emotions
- Obsessive compulsive behaviours
- Rigid thinking style (thinking there's only one correct way to do things, etc.)

Sociocultural risk factors

- Cultural promotion of the thin ideal
- Size and weight prejudice
- Emphasis on dieting
- 'ideal bodies' include only a narrow range of shapes and sizes

Biological risk factors

- Having a close family member with an eating disorder
- Family or personal history of depression, anxiety and/or addiction
- Presence of food allergies that contribute to picky or restrictive eating (coeliac disease)
- Presence of Type 1 Diabetes (4)

FAQ

How common are eating disorders?

- The eating disorders anorexia nervosa and bulimia nervosa affect 0.5-3% of people over their lifetime. The most common age of onset is between 12-25. Although they appear to be more common in females, 10% of cases are also detected in males. Binge eating disorder and OFSTED are more common and affect up to 6% of the population

Are certain personality traits more common in individuals with eating disorders?

- Individuals who develop eating disorder often are perfectionistic, eager to please, sensitive to criticism and self-doubting. They may have difficulty adapting to change and be routine bound. A smaller group of patients with eating disorder have a more extroverted temperament anf are novelty-seeking and impulsive with difficulty mainting stable relationships. There is no one personality associated with eating disorders, however. (5)

Can you tell by looking at someone if they have an eating disorder?

- No, you cannot determine if an individual has an eating disorder simply by looking at them. Behaviours and attitudes should be used to determine if someone may be struggling, rather than weight and body size.

Is it my fault that my child suffers from an eating disorder?

- No, your child's eating disorder is not your fault. There are many factors that contribute to the development of an eating disorder. You can, however, encourage recovery with love and support. Seek professional help to find out how you can best be supportive in your child's unique journey towards recovery.

Can eating disorders be fatal?

- Yes, eating disorders have the second highest fatality rates among all mental illnesses. The first you should do, if you are concerned for yourself or a loved one, is find a doctor who understands eating disorders and ask for a check-up. Be as honest as you can because they can help you when they know the truth.

Is recovery possible?

- Yes, recovery is possible! It takes a lot of work, but it is worth it. (6)

How to get help for your loved one and the treatment options available

Eating disorders are treatable
It's usually very difficult for people with eating disorders to get better on their own, so it's important that your loved one or you know where to find professional help and support as soon as possible. The sooner someone is treated for an eating disorder, the better their chance of making a full recovery.

Where to get help
Gaining access to treatment isn't always as straightforward as we would like it to be and you might find that you're faced with a wait before getting NHS treatment. In these instances, there are online helplines you can contact such as PEDS.

The first port of call when you're looking for help is your GP. Your GP is an important step to take as they will be able to refer your loved one to local eating disorder services and can monitor their weight, bloods, etc. The NICE guidelines for eating disorders, which are based on available evidence and which your doctor should take into account while making decisions about your treatment, makes it very clear that immediate referral is the best course of action. If the GP does not refer your loved one straight away, please don't let them see this as a sign that they do not deserve treatment – instead see a different GP if your first visit does not go as well as you hope. It's also important to have family and friends around you who are supportive and are able to listen in hard times.

Once your loved one has been referred to eating disorder services, you will usually receive a letter or phone call letting you know the date of the appointment. At the appointment they will do a full assessment of you loved one and will decide what treatment is the best way forward. (7)

Either inpatient or outpatient treatment options will be given. Outpatient is usually the first option they will use and if that does not help or the patient is too unwell, they will then go inpatient.

The types of therapies they use for the treatment of eating disorders are:

Cognitive based therapy (CBT)
Group therapy and individual therapy
Family therapy
Interpersonal Psychotherapy
Modified Dialectal Behavioural Therapy (DBT)
Mindfulness
Body image/ acceptance and understanding emotions group
Relapse prevention groups (7)

Stages of Recovery

Recovery from an eating disorder can be a long process that requires not only a qualified team of professionals, but also the love and support of family and friends.

There are five Stages of change that occur in the recovery process: pre-contemplation, contemplation, preparation, action and maintenance.

Precontemplation stage
The precontemplation stage is evident when a person does not believe they have a problem. Close family and friends are bound to pick up on symptoms before the individual admits to it. They may refuse to discuss the topic and deny they need help. At this stage, it is necessary to gently educate the individual about the devastating effects the disorder will have on their health and life, and the positive aspects of change.

- Do not be in denial of your loved ones eating disorder
- Be aware of the signs and symptoms
- Avoid rationalising their eating disorder behaviours
- Openly share your thoughts and concerns with your loved one

Contemplation stage
The contemplation stage occurs when an individual is willing to admit that they have a problem and are now open to receiving help. The fear of change may be very strong, and it is during this phase that a psychotherapist should assist the individual in discovering the function of their eating disorder so they can understand why it is their life and how it no longer serves them. This, in turn, helps the individual move closer toward the next stage of change.

- If your loved one is under the age of 18, insist that they receive professional help from a qualified eating disorder specialist
- Educate yourself about the disorder
- Be a good listener
- Do not try to 'fix' the problem yourself
- Seek your own encouragement from a local eating disorder support group for family and friends

Preparation Stage
The person transitions into the Preparation Stage when they are ready to change but are uncertain about how to do it. Time is spent establishing specific coping skills such as appropriate boundary setting and assertiveness, effective ways of dealing with negative eating disorder thoughts and emotions, and ways to tend to their personal needs. Potential barriers to change are identified. This is usually when a plan of action is developed by the treatment team, (i.e. psychotherapist, nutritionist, and physician) as well as the individual and designated family members. This generally includes a list of people to call during times of crisis.

- If supporting a loved one in their recovery, identify what your role is in the recovery process.
- Explore your own thoughts and beliefs about food, weight, shape, and appearance.
- Ask your child/loved one and the treatment team how you can be best involved in the recovery process and what you can do to be supportive.

Action Stage
The Action Stage begins when the person is ready to implement their strategy and confront the eating disorder behavior head on. At this point, they are open to trying new ideas and behaviors, and are willing to face fears in order for change to occur. Trusting the treatment team and their support network is essential to making the Action Stage successful.

- Follow the treatment team's recommendations.
- Remove triggers from your environment: no diet foods, no scales, and no stress.
- Be warm and caring, yet appropriate and determined with boundaries, rules, and guidelines.
- Reinforce positive changes without focusing on weight, shape, or appearance

Maintenance/Relapse

The Maintenance Stage evolves when the person has sustained the Action Stage for approximately six months or longer. During this period, they actively practice new behaviors and new ways of thinking as well as consistently use both healthy self-care and coping skills. Part of this stage also includes revisiting potential triggers in order to prevent relapse, establishing new areas of interests, and beginning to live their life in a meaningful way.

- Applaud your loved one's efforts and successes.
- Continue to adjust to new developments.
- Redefine the boundaries at home as necessary.
- Maintain positive communications.
- Be aware of possible recovery backsliding

A possible sixth stage

The Termination Stage & Relapse Prevention. Relapse is sometimes grouped with the maintenance stage since recovery in nonlinear and it is not uncommon to return to old behaviors during the overall recovery process.

So, how do you know when it is time to discontinue treatment? With the understanding that this decision is best made in consultation with your treatment team, ask yourself the following questions:

- Have I mastered the Stages of Change in the major areas of my eating disorder?
- Do I have the coping skills necessary to maintain these changes?
- Do I have a relapse prevention plan in place?
- Am I willing to resume treatment in the future if necessary?
-

To prevent relapsing do not forget to ask for help, communicate your thoughts and feelings, address and resolve problems as they arise, live a healthful and balanced life, and remember that you would not have made it this far if it were not for your strong determination and dedication toward recovery.[8]

Tips to help a loved one suffering

- Recognise that you are not to blame.
- Acknowledge to your loved one that they are not to blame.
- Recognise how distressing the illness is for your loved one.
- Educate yourself about eating disorders where you can.
- Ask your loved one how they are feeling and what they are thinking, rather than making assumptions.
- Avoid discussing weight, shape, food, and diets in front of your loved one, and model a balanced relationship with your own food and exercise.
- Remind yourself that things can change and reassure your loved one that recovery is possible.
- Ask your loved one what you can do to help – for example, helping them to stick to regular eating, putting in boundaries following mealtimes, having a space to talk about how they are feeling. Your loved one may respond that you can just "leave them alone" or that you can't do anything to help, so here it can be helpful to remind them you can hear their distress and how difficult things are, and you are there if they need you.
- Recognise any 'accommodating or enabling behaviours' – behaviours that you do to help reduce your loved one's distress from the eating disorder, for example, cleaning up vomit or cooking different meals for them, but that collude with the disorder and cover up the negative consequences of the behaviours [9]

Activities to help distract them from the eating disorder

- Go for a short walk in the fresh air (if they are physically well enough to and if they don't see it as a way to 'burn calories') Walking is both regulating and calming. It soothes your nervous system and helps to calm your mind and body.
- Meditate / mindfulness
- Do a pamper day/evening
- Get them to pet your cat or dog or rabbit or bird! Pets have been proven to calm down your mind and body.
- Go to the movies if the food there is not a trigger
- Lay down and watch a heart-warming or funny movie on Netflix. Get them to do something with their hands like beading or knitting while you're watching to engage all your senses
- Draw, paint or colour.
- Go for a nice scenic drive
- Journaling /scrapbooking
- Make a vision board filled with future goals and recovery quotes
- Do their hair play some board games
- Write some notes with positive messages and post them around your home or get out of the house and put them up in dressing rooms, public restroom mirrors, restaurants

Activities to help them rationalise/ control the thoughts

- Get them to draw on a very large piece of paper how big they think their body is. Then get them to lay on the piece of paper and draw around their body to show that their actual size and the size they think they are, are completely different. This will show them that their eating disorder lies to them about their size.

- Similarly, you can get a piece of string and get them to tie the string to the size they think a body part is, for example their leg. Once they have done this, put the strong around their leg, mark it and show them what their actual leg size it.

Tips for them:

Externalise and Defuse the Thoughts

Before accepting your thought as a command to follow, externalise it. For example, when you have the thought, "*I can't eat a bagel*," label it as "an eating disorder thought" and rephrase it as "My eating disorder is telling me not to have a bagel."

Once you defuse the thought it becomes easier to choose a more workable course of action which may involve disobeying the eating disorder, such as, "Thank you, eating disorder, but I'm not going to listen to you. I don't want to let my mind bully me."

This is a strategy from acceptance and commitment therapy (ACT).

Challenge the Thought

Ask yourself any combination of the following questions:

- *What is the evidence for that thought?*
  For example: "If I eat a bagel, I will gain 5 pounds." There is no evidence for this thought; a bagel could not possibly constitute enough calories to make me gain 5 pounds.
- *What are alternative beliefs?*
  For example: "I shouldn't eat unless I am truly hungry." An alternative belief is "Since I enjoy eating with family members, I need to sometimes work my mealtimes around the needs of others. This may mean eating when it is time for a meal even if I am not hungry."

What are the consequences of having that thought?
For example: "I've already blown it, so I'm going to go ahead and finish the box of cookies and start my diet tomorrow." The consequence of this thought is that it causes me to binge which makes it worse because I end up eating even more than if I just work on accepting what I've already eaten.

Make a Coping Card

Take an index card and write the automatic or problematic thought on one side and the rational response on the other. This is a great strategy for those problematic thoughts that come up repeatedly. It is a good idea to review the cards daily and to keep them in your wallet. You can also pull them out whenever you find that you are having the automatic thought.
For example, a common problematic thought could be, "I'm bored. Eating will make me feel better." On the other side of this card, write "Eating when I am bored will only make me feel worse."

Run a Behavioural Experiment

Make a prediction, "If I allow myself dessert four nights this week, I will gain five pounds," and run an experiment to test it out. Weigh yourself at the beginning and the end of the week. Have dessert four nights this week. Check to see if your prediction came true.
Over time, you will see that a number of beliefs are not accurate. This is another CBT approach.[10]

Mealtime Tips

Mealtimes can be particularly difficult. You may find the following advice helpful.

- If your child is in treatment, ask their treatment team for advice on how to cope with mealtimes.
- Try to make meal plans with your child that you both agree to.
- Agree with the family that none of you will talk about portion sizes, calories or the fat content of the meal.
- Avoid eating low-calorie or diet foods in front of them or having them in the house.
- Try to keep the atmosphere light-hearted and positive throughout the meal, even if you do not feel that way on the inside.
- If your child attempts to get too involved in cooking the meal as a way of controlling it, gently ask them to set the table or wash up instead.
- Try not to focus too much on them during mealtimes. Enjoy your own meal and try to make conversation.
- A family activity after the meal, such as a game or watching TV, can help distract them from wanting to purge or overexercise.
- Do not despair if a meal goes badly – just move on.

School pressures and recovery

Studies have found a link between the increased academic pressures facing young people and the increasing prevalence of eating disorders.

It is important that although your child still tries to do their best at school, their mental health is more important, and they need to get all the help they can with their eating disorder.

It is a good idea to let your loved one's school know about their eating disorder so they can monitor their eating, behaviours and be there to support them, perhaps even watch them whilst they eat in a separate room from others.

It can also be helpful to ask your love one's school to remove them from PE lessons if they are physically too unwell to take part or if exercising is a trigger to them.

Overall, it is important to take off as many school stresses as possible whilst they are going through recovery.

Holidays and Christmas tips

The holiday season is the time of year most associated with traditions, many of which revolve around food. For those struggling with an eating disorder this can be an especially stressful time, and seemingly simple commitments such as attending a holiday gathering and reuniting with family can become sources of tremendous anxiety and immense emotional strain.

Tips to help you through the holidays

For the one suffering

- Be mindful of the holidays and the fact that they are not for just eating. Take time to reflect on the significance of being present with loved ones and shift the focus away from food.
- Have a “buddy” that you can check in with during difficult meals or help you if you begin to struggle or panic. Ask if you can lean on them when dealing with obsessive or addictive behaviors. Knowing that there is someone who can help through tough times can be extremely powerful.
- Be honest with your family and friends about your worries and concerns. Having an open and honest dialogue can make others aware of the complexity of eating disorders especially around the holidays.
- Decrease stress by making lists, such as deciding what to spend and how much time you will commit to shopping. If you do not find the “perfect” gift, the world will not end.
- Reduce stress surrounding food-related activities. Make peace with the concept of holiday-related food reminding yourself to remain present and not become stuck in common eating disorder related thoughts. Be prepared by consuming a small meal or snack before attending parties. Allow yourself to enjoy a holiday food that you have fond memories of, and if you consume a little more than planned, it’s okay. Tomorrow is a new day. For now, remember to refocus yourself on the reason for the season!

- **Discuss your holiday anticipations** with your treatment team so that they can help you with potential stressors and triggers and enact a plan for coping and overcoming. Preparing for stressful situations and working on strategies beforehand can help you not fall into self-destructive patterns.
- **Stick to your prescribed recovery program.** Structure your day so that you can keep to the recovery disciplines and actions, especially when it comes to scheduled mealtimes.
- **Avoid "overstressing" and "overbooking" yourself.** Cut down on unnecessary events and obligations to give yourself time for relaxation, renewal and self-contemplation. Remember that you do not have to attend every single season-related event.

For those with a loved one suffering from an eating disorder:

- **Avoid the role of "food police"** unless a treatment team has given you a plan to monitor and portion your loved ones' food. This role may backfire and cause increased anxiety.
- **Offer support and words of encouragement.** Ask specifically how you can help them cope with the stressors of the holidays and assist them with their treatment and recovery.
- **Be respectful of the individual's recovery process.** If the person is not yet comfortable eating or celebrating in front of others let them know that you understand and are there to support them. [11]

How to look after your own mental health as a carer

- Take full advantage of carers group and carers helpline
- Take one day at a time. While thinking about the future is normal, try and focus on the challenges of caring just one day at a time.
- Make a list of friends or relatives that can help. A list can clarify how many others you can call on.
- Ask a friend to stay overnight. It may help you get a good night's sleep and provide extra company.
- Discuss flexible work options with your employer. Many employers offer flexible working arrangements. Talk to them about possible options.
- Give yourself regular rewards. Take a break, do something special that lifts your spirits and makes you feel good.
- See a counsellor yourself [12]

Advice to siblings

Siblings often feel forgotten about when an eating disorder occurs at home. Suddenly a lot of attention can be focused on the person suffering and siblings may feel left out or invisible. At the same time siblings have to cope with living in a situation which has suddenly become very stressful. They too experience the arguments, the unbearably tense family meals, and the anxiety over what will happen next.

If your brother or sister has an eating disorder, remember that it is OK for you to find the situation hard as well. It may be difficult for you to find time and space which is not dominated by the eating disorder, so see if you can arrange to spend time with friends or with other family members which is just for you. A regular time with your mum or dad on your own can give you space to chat and to make sure there is time for you.

Siblings often struggle with feeling guilty or with worrying if something they have said or done caused the eating disorder. Remember that an eating disorder is very complicated. You will not have caused it! All siblings argue sometimes, and during those arguments most people say things they later regret. If there are genuine things you wish you had not said then why not write a letter, email or send a card and let your brother or sister know. Don't be afraid to tell them that you love them. If you can find time to spend with them without the eating disorder being at the front of everyone's mind, this will be really helpful – so if there are things you used to do together, try to keep doing them!

Finally, it's not unusual for siblings to struggle with thoughts and feelings about their own eating or weight. With so much focus and discussion about these things you might find yourself thinking about them in a way you wouldn't usually. Make sure you find a channel to talk about these things. It may be that someone from school or somewhere else – an older friend, counsellor or youth worker – can meet up with you from time to time so that you have some space to share your thoughts. Remember that you do still have your own needs – don't feel guilty for these or try to suppress them.

- Communicate with your parents so that they can understand the situation from your perspective and the impact your sibling's eating disorder is having upon you. Don't be afraid to speak up if you feel too much pressure or responsibility. Keeping lines of communication open will ensure everyone is being heard at all times.
- An eating disorder is a psychological illness and therefore affects a person's mind and their character. It can feel as if the person you know and love has gone and in their place is somebody you don't know and can't relate to in the same way. An eating disorder can make a person act differently and your sibling's behaviour might have become quite irrational and they may experience mood swings, which can be quite frightening for you as a brother or sister. Remember that they are still the same person but that they are just struggling and therefore need more support. Do treat them like normal, (however difficult this is for you) and refrain from either directly tackling them on the subject of food and eating or avoiding it altogether. Spend more time together and remind them of the good times you've had in the past – reminiscing can help you to feel closer and is a good way to lead into a deeper conversation.
- As a sibling you're in a really good place as your brother or sister can often feel most comfortable talking to you. You will have a different view of the issues your sibling is struggling with and you may be able to better understand any social or academic pressures they may be facing and help them to identify what could be behind their worries. It is tempting to avoid socialising with them, especially if they have become withdrawn but do include them in social activities and group events. An eating disorder can cause the person to be particularly introspective; helping them to look to future goals can help gain a wider perspective.

- It can feel very lonely at times and it's important to make time for yourself and have a network of supportive people available. You may only want to talk to one person, a good friend, teacher or even a professional, or you might feel able to confide in a few trusted people. It might be a good idea to let a teacher, work colleague/manager, a person in whom you trust, know about the issues you're coping with at home so they can help with any work commitments or academic pressure. Getting involved in group activities, such as team sports, clubs, societies can help you to feel less alone and can help to distract you from your worries about your sibling and the issues at home.
- Your own eating habits and body image. When food has become such an issue and an area of upset and conflict, it's easy to lose the enjoyment of eating and mealtimes. You may feel anxious around the thought of eating as a family and your own appetite might even be affected. It's important that you communicate any anxieties you have around your own eating and/or body image to a person you trust, so you can chat through some of underlying emotions. [13]

Resources

www.pedsupport.co.uk
admin@pedsupport.co.uk
beateatingdisorders.org.uk
mind.org.uk
https://www.eatingdisordertherapyla.com/reading-resources/
https://www.nhs.uk/conditions/eating-disorders/
http://www.eatingdisorderssupport.co.uk/help/links-resources

References

1 - https://www.mayoclinic.org/diseases-conditions/eating-disorders/symptoms-causes/syc-20353603

2 - https://www.healthline.com/nutrition/common-eating-disorders#other

3 - https://www.nationaleatingdisorders.org/toolkit/parent-toolkit/emotional-behavioral-signs

4 - https://eating-disorders.org.uk/information/why-people-get-eating-disorders/

5 - https://www.hopkinsmedicine.org/psychiatry/specialty_areas/eating_disorders/faq.html

6 - https://eatingdisorderfoundation.org/learn-more/faq/

7 - https://www.beateatingdisorders.org.uk/recovery-information/help-treatment

8 - https://www.nationaleatingdisorders.org/stages-recovery

9 - https://www.beateatingdisorders.org.uk/supporting-someone/supporting-somebody

10 - https://www.verywellmind.com/strategies-for-managing-eating-disorder-thoughts-4019116

11 – https://www.eatingdisorderhope.com/information/eating-disorder/eating-disorders-and-developing-healthy-holiday-traditions

12 – https://www.betterhealth.vic.gov.au/health/servicesandsupport/looking-after-yourself-as-a-carer

13 – https://www.anorexiabulimiacare.org.uk/family-and-friends/siblings

29 December 2020 and 5 January 2021

29th December

Our loved one has eaten well at home from university, but will they when they return?

Clearly, there is a limit to what parent/carers can and should do 'at a distance'. The experience of the group is that how we support depends very much on where our loved one is in the change cycle. If they are 'taking action' and willing to joint problem-solve possibilities include 'joining' your loved one on Zoom for some mealtimes. If they are more ambivalent about change and/or less open to your involvement, aim to stay in touch with more general, open questions about how they are doing, and stay calm and reassuring.

Our loved one is drinking alcohol excessively.

Alcohol abuse is a way of managing emotions. The experience of the group was that this can be a particular issue for those with binge/purge anorexia. It is something that will be addressed as part of their treatment. The group's conclusion was 'just be the normal dolphin', i.e. encourage more healthy behaviours. We also discussed that it is possible to let their GP / the Eating Disorders Service know of your concerns even if your loved one has not given consent for the professionals to talk to you about them - they might not be able to answer you, but they will always want to know information that might help them with your loved one's recovery.

Our loved one is denying themselves water / fluids to the point of dehydration and hospitalisation.

Those in the meeting had not experienced this. I sought a response through the British Eating Disorders Workspace and was informed that:

- Fluids are a 'fairly common' issue (support group members had had experience of their loved one water loading to reduce appetite / falsify weight)
- Fluid refusal can be for a number of reasons: self-harm, fear that water contains calories, a way of switching off from feelings because it leaves you 'muzzy minded', patients with OCD as a co-morbidity fearing that water is a contaminant, a way of communicating feelings indirectly ('a cry for help')
- Fluid intake is routinely considered as part of treatment. For us as parent/carers it can be very worrying, but it falls under the 'usual principles' approach - empathy, helping our loved ones to express their feelings and encouraging them towards healthier behaviours.

5th January 2021

We talked about the **increased demand for specialist beds**, for young people in particular, with eating disorders that was covered in the news last week. As a consequence, very ill people are waiting in acute/general hospitals for specialist beds to become available. At least one person in our group is currently affected by this. **'Do all you can', 'never give up hope' and 'look after yourself'** were the key messages, and we talked about what 'do all you can' means in practice. I said that I was aware of this issue being discussed at the highest levels in the NHS, but that short-term solutions were hard to find. There is a desire to do whatever can be done, and I will keep you up to date with what I hear. The group's support goes out to anyone in this position.

I asked about the group's **experience of bulimia**. The general conclusion was that the similarities with other eating disorders are greater than the differences. For example, anorexia and bulimia are both about great distress and as parent/carers it is important to focus on that rather than how it's manifested. As with other eating disorders, our loved ones can be very secretive. Sarah noted that about 50% of people with anorexia nervosa binge eat and that eating disorders can be considered to be transdiagnostic, i.e. they can move around the categories, so this is something we should be aware of. There are, of course, differences, e.g. our loved ones feeling 'good' about anorexia but 'disgusted' about bulimia. The BEAT website provides some very good factual information about the different types of eating disorder.

We finished by discussing '**tools and tips'**, having been inspired by Rxxxxx's problem-solving spider diagram to list anxieties and think about what could be done about them. We shared experiences of supporting our loved one move from a set meal plan to doing their own shopping / cooking. One good idea was our loved one having a virtual 'jar' of all the foods they would like to eat with them choosing one a week to add to their shopping list.

Resources

Link

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

12 January 2021 – Lockdown restrictions and tips for home after inpatient support

Lockdown restrictions and the impact of the ongoing pandemic

Not surprisingly, many of our concerns this week related to the lockdown restrictions and the impact of the ongoing pandemic. I've attached the presentation Dr Sarah Beglin gave at our very first meeting back in April - I didn't think we'd still be needing it but we do! The group offered some 'top tips' from our experience:

- Putting a daily/weekly plan together with your loved one, making sure that there is structure and variety.
- Menu planning could be part of the weekly plan, or a plan in its own right.
- Planning for variety - this, of course, will depend on your loved one's interests but a mix of cultural activities (music, reading, painting), creative activities (painting, knitting), physical activity (a walk or cycle ride) and social events (family challenges, games) is the ideal.
- 'Miranda's Daily Dose of Such Fun!: 365 joy-filled tasks to make life more engaging, fun, caring and jolly' was strongly recommended!

Top tips for when our loved ones return home from inpatient support

We moved on to discussing top tips for when our loved ones return home from inpatient support. A number of the group have had experience of this and made the following points:

- It is inevitably a time of mixed and high emotions - excitement, apprehension, anxiety - for both us and our loved ones: accept and acknowledge that it is going to be challenging.
- 'If I could have my time again I would hand over more of the responsibility to them and ask them how they want to cope with it, and how I could help'.
- Remember where you left the St Bernard and the dolphin - stay calm, encourage and avoid slipping back into unhelpful responses / behaviours.
- Don't forget the rest of the family - they need to be involved and you may need to plan in time just for them so that they are not inadvertently ignored.
- It's definitely a time to look after yourself, or you could burn out quickly.
- You will receive support and advice from the unit, and your loved one will not be abandoned - all discharges will be carefully planned.

Next week we will be hearing from two former patients about their recovery journeys. I have passed on all of your other ideas for presentations - they are all great ideas and will keep us busy until well into 2022! Sarah asked us to let her know (via me) if any of your family would be willing to be involved with a session on 'siblings'.

Resources

Coping with Lockdown (see 3 November 2020 Coping with lockdown)

And finally, a link and a cartoon from Axxxxx with the same very important theme:

https://www.bbc.co.uk/sounds/play/p093089p

For more inspiration see Charlie Mackesy's book

The Boy, The Mole, The Fox and The Horse

or

https://www.charliemackesy.com/

ADVANCE NOTICE - THE TIMING OF THESE SESSIONS IS CHANGING FROM 1st FEBRUARY

I am really pleased that from the beginning of February we will be able to offer some evening sessions so that we can reach a wider group of participants. Until further notice the sequence of meetings will be:

- 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

19 January 2021 – Recovery Journeys

Last week we were privileged to hear from Amy and Ana about their recovery journeys. As Renata said, their presentations were 'complete gold dust'; immensely helpful and hopeful. It has been a pleasure to put together this summary.

Amy and Ana began by describing the onset of their illness; neither could identify a single cause or defining moment. Amy's anorexia began when she agreed with friends to lose weight before they went on holiday together, but things got out of control. Ana's bulimia and then anorexia started when she moved to the USA from Spain and used food as a way of managing her feelings of loneliness. Amy described how she resented everyone, she wanted to be left alone with her illness and she was blind to her impact on others. Ana described similar feelings, saying how annoyed she was that her mother tried to help, although at the same time she wanted help.

There were great similarities in their recovery, too. For both Amy and Ana accepting that there was a problem and seeking, or accepting, help was the beginning. Neither could identify a 'magic moment' that led to recovery but both talked about a number of things that, combined, helped: the impact of therapy, e.g. Amy's letter to her future self made her realise that this was not the life she wanted; hitting 'rock bottom'; improved self-awareness; learning the importance of self-worth and self-compassion, achieved through mindfulness, meditation and yoga.

Both Amy and Ana talked about the important role their families played and how best we as parent/carers can help:

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

We asked about what recovery looks like, and about relapse. Both Amy and Ana **emphasised that recovery is a continuous process**. The thoughts and feelings can still be there but the eating disorder is no longer the goal, they are not defined by their eating disorder and they are in control. They are aware of the triggers that can lead to relapse and have learnt how to manage them.

In Amy and Ana's journeys there is tremendous hope because our wonderful young people can and do recover from this wicked illness to lead meaningful and fulfilling lives. There is also a powerful message that parents and carers are an important part of the recovery process but it is a tough ask. Practical activities like talking about and preparing food can be

unhelpful, whereas 'just being there', which can feel like you are doing very little at all, can be more helpful. Amy's mother said, 'All you can do is hold someone in your arms, listen, be there'. Ana said, 'My mum would have boiled the ocean for me. It mattered that she loved me, even if I didn't appreciate, and resisted, her suggestions'. That tough ask requires emotional and physical stamina, which is why we keep saying 'look after yourselves', it really is important.

Amy and Ana - thank you for talking with us.

Resources

Ana referred to:

Books

1. Daring Greatly: How the Courage to Be Vulnerable Transforms the Way We Live, Love, Parent, and Lead by Brene Brown
2. In the Realm of Hungry Ghosts by Gabor Mate

Ana says, 'Neither of them is ED-specific, but I found Daring Greatly very insightful regarding shame and exploring the role my ED played in my life. In the Realm of Hungry Ghosts helped me understand the brain chemistry that is involved in an ED'.

Yoga

Ana also mentioned Yoga with Adriene, a YouTube channel that really helped her during lockdown, and this was endorsed by some of the group (and my daughter!)

26 January 2021 – Loved one has significantly upset a sibling / Transition to independent living / Getting the best out of family therapy

Our loved one has significantly upset a sibling

Another really good discussion this week. We began by talking about a situation that, at least to some extent, a number of us have experienced, i.e. **our loved one has significantly upset a sibling: what is our role as parent/carer?**

The group's experience very much supported a consistent theme of our discussions, i.e. we are not responsible for sorting this out, but there are things that we can do to make it easier for our loved one to do so; in particular, **Sarah reminded us sibling relationships are different to parental relationships**.

One suggestion was thinking through what you would do if there wasn't an eating disorder involved; this can be helpful, but there could be issues (e.g. the immediate impact on your loved one's health) that require a modified response.

There was **strong support for waiting for emotions to calm down before doing anything**, and for **using text / message** so that you have the opportunity to consider the conversation. Simon explained that behind most actions is a positive intention, e.g. our loved one wants to let their sibling know how they feel but has done it in a way that is not OK. Consequently, we could support our loved one by helping them to name their feelings, e.g. sad / angry.

A number of us can testify that it can take a long time to repair sibling relationships, but they can and do repair. We will be able to explore these ideas further on 9th March when we have a specific presentation on 'Siblings'.

Transition to independent living

We then talked about the transition to independent living. It is not a given that our loved ones will go from home to inpatient treatment to home, for example.

It is possible for them to move to their own accommodation, with support from key workers and/or care staff. There are a lot of 'it depends on' in these scenarios because community support varies across the country but it is possible and it can work.

We developed this discussion to thinking about our role in supporting this transition, e.g. if our loved one can manage independent living but still struggles eating alone, texts 'before' and 'after' meals or Facetime/Zoom during meals could be helpful.

There is a key question here: '**What could I do to help you?**'

Getting the best out of family therapy

In the final minutes I challenged you to come up with three top tips for getting the best out of Family Therapy and you rose to the challenge magnificently!

- **Don't take criticism personally**.
- **Go, even if your loved one won't join you** - you will benefit enormously.
- **Have an open mind** - you may be suspicious of some of the ideas and suggestions but they have worked for others and could work for you! (For example, whoever thought you needed to become a dolphin...)

Resources

Book

Sarah recommended 'Siblings without Rivalry' by Adele Faber, saying this is a really helpful, practical book for reiterating the point, 'Don't come between their relationship, validate both parties, let them find solutions to their problems…'

ADVANCE NOTICE - THE TIMING OF THESE SESSIONS IS CHANGING FROM 1st FEBRUARY

I am really pleased that from the beginning of February we will be able to offer some evening sessions so that we can reach a wider group of participants. Until further notice the sequence of meetings will be:

- 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

2 February 2021 – Ups and downs, Goals, Supporting new members, Co-morbidities

Ups and downs and Goals

Reflecting on the notes I took this week two things stand out. First, **it has been an up and down couple of weeks for many of us**, with lockdown pressures making things extra difficult. Second, **the importance to recovery of our loved ones having a goal**, an ambition, something they enjoy doing; this is so often lost when the illness takes over. Helping our loved ones find this is, of course, a major focus of therapy. Our role in supporting this process is a really important topic and worthy of an in depth discussion - you have been warned! Our brief consideration highlighted **the importance of gentle encouragement, of helping our loved ones to understand their feelings and of giving them permission to enjoy themselves again** through appropriate praise.

Supporting new members

One other thing stood out as well, the most important thing of all, i.e. the ability of the group to support new members, and to support anyone who is having a hard time.

In welcoming Dxxxxx we **took the opportunity to revisit our key messages**:

- **it's not your fault;**
- **you are not alone;**
- **you do not have to pretend things are different;**
- **most people recover from their eating disorder; and**
- **it can take a long time, so you need to look after yourself.**

Co-morbidities

We then discussed co-morbidities, i.e. when our loved one has a significant other diagnosis, **such as Obsessive Compulsive Disorder (OCD), depression or autism**. Does this affect treatment and does it affect our role? The short answer with regards to treatment is it will be taken into account but the main focus will be treating the eating disorder; for example, people with autism may find group therapy unhelpful, or even impossible, so appropriate individual therapy will be needed. As for our role, the group's experience was that it may be necessary for us to be proactive in describing and explaining the history of our loved one's illness so that the professionals can best understand what is so often a set of complex, interrelated problems. However, **our core role remains the same**, perhaps best summarised as the 'three Cs' - **calm, consistent, compassionate**.

I look forward to seeing you on 9th February at 18.30 - 20.00 (our new time for the second Tuesday of the month) when Zuleika Irvanipour will be giving us a presentation on 'Understanding Stress and Finding Ways to Work With It'. I will send the invite out before the weekend.

9 February 2021 – Presentation - 'Understanding Stress and Finding Ways To Work With It'

This week we enjoyed an excellent presentation from Zuleika Irvanipour on 'Understanding Stress and Finding Ways To Work With It'. Zuleika's presentation is attached, with an extra slide giving links to some useful resources. Here is a brief summary of what for me were some of the key points - check the slides for the animal metaphors!

Summary

To understand stress we need to know a little about how our brains and body work.

- Our 'survival' brain (meerkat) works with our 'emotional' brain (elephant), while our 'thinking' brain (monkey) is responsible for socialising, planning, prioritising etc.
- Our emotional brain alerts our survival brain to stressful situations; our survival brain takes over and our logical brain disengages.
- Our emotional brain is not good at telling the difference between a 'real' stress, e.g. a wall is about to fall on you and an 'imaginary' stress, e.g. 'That's too many calories, it will make me fat'.
- Our survival brain triggers our 'fight or flight' response whether it's a real or imaginary stress, it does what our emotional brain tells it to do.

This is important for us as carers because:

- If our loved one is stressed, e.g. at meal times their survival brain will take over and no amount of logical argument from us will help because their thinking brain is switched off; argument will only increase the stress level. However, we can help to reduce the stress level if we communicate calmly and compassionately and by ensuring a calm environment. Some of the group commented that distractions can also help, e.g. having music or the television on, quite literally to distract the emotional brain and change the mood.
- If we are stressed we need to have strategies to avoid 'flipping the lid'. We all know that you can't argue with an eating disorder. Leaving the room, deep breaths, counting to ten… the group mentioned a lot of short-term strategies; in my experience it's remembering to do them that's the problem! I'll come back to longer-term strategies below.

Zuleika also talked about our belief system, what happens in our mind:

- If our loved one has low self-esteem and thinks that they are not good enough they will 'mentally crush' a fact to fit their negative view, e.g. a friend does not reply to a text so it must be because they are no longer liked… when in fact it is because their friend's phone ran out of battery. The significance of this to us, as carers, is that someone's belief system changes slowly, so the best support we can give our loved one is gentle encouragement, the 'dolphin' skills we've discussed before such as labelling feelings, empathy and validation.
- We also need to be aware of the impact of our belief systems on our behaviour because if we have a negative mindset we will not be able to support our loved one as well as we could. That's why it's so important to have support, people to talk to and to look after ourselves.

Zuleika discussed labelling thoughts, thinking traps and self-care in more detail, please see the slides. We also talked about long-term stress and the importance of taking good care of ourselves. A 'light bulb' moment for me was when we considered, 'What is self-care?' and the point was made that self-care is caring for yourself as well as you care for others. How many of us do that? We rounded off by sharing the many strategies we have for taking care of ourselves - we are a talented bunch - but do remember to do them!

From all of us, a very big thank you to Zuleika for a great presentation and we wish you all the best for the future.

Resources

Understanding Stress and Finding Ways To Work With It

AEDS Carers Group Talk (CPFT)
9th Feb 2021

Zuleika – Trainee Clinical Psychologist
Support From Dr. Sarah Beglin and Dr. Pia Thiemann

Things to Cover

- Understanding stress a bit more (What goes on in our body and in our mind)
- What we can do to help ourselves and others

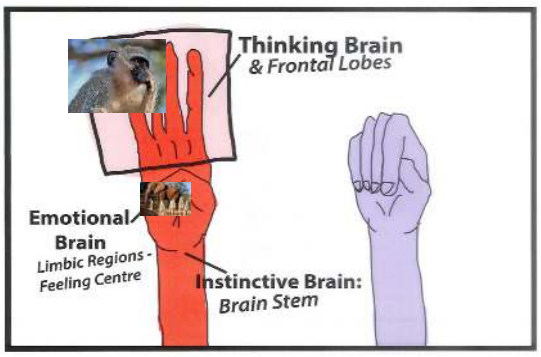
Meerkat, Elephant and Monkey Brain

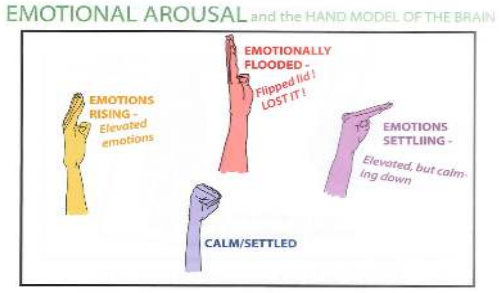
Survival Brain

Emotional Brain

Thinking Brain

Flipping The Lid



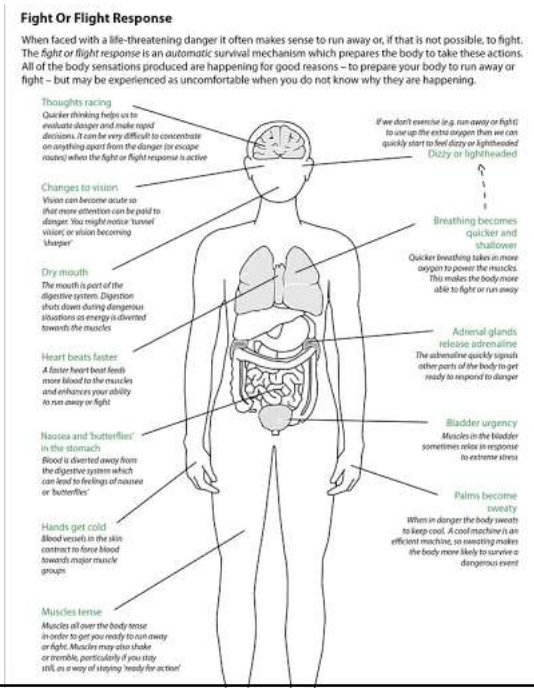


How do we know who's in charge?

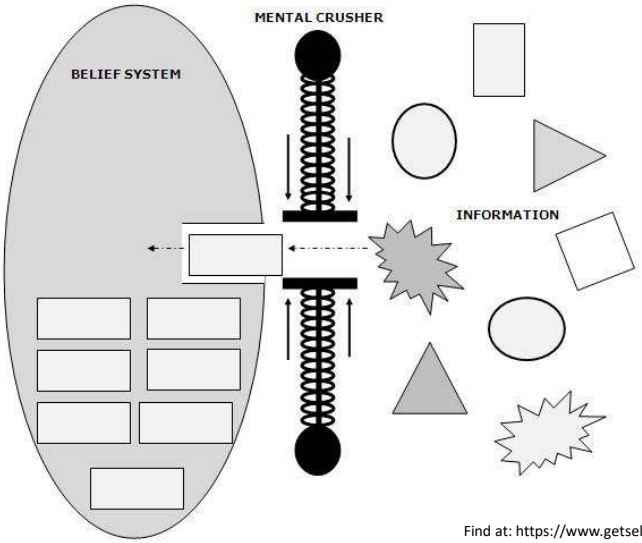
Fight or flight

- Heart Beating Faster
- Butterflies in stomach
- Dry Mouth
- Sweating

Find at: http://www.bayareacognitivetherapy.com/cbtblog/fight-or-flight



Mental Crusher/Mental Filter



Find at: https://www.getselfhelp.co.uk/docs/MentalCrusher.pdf

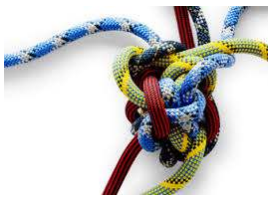
So what does all this mean for us as carers and for the people we care for?

- How does 'flip the lid' show up?
- How could the mental crusher apply?

Things to chat about...

- What do you usually do that works well?
- Is there anything you would like to do differently?
- Short-term and long-term strategies

Labelling Feelings



Labelling Thoughts

Example

What words might we use to describe this picture?

Fact
Evidence-based
- Clown
- Painted face
- Colourful
- Circus performer
- Smiling

Opinion
Varies, personal view
- Funny
- Weird hair
- Scary
- Happy
- Ugly

Unhelpful Thinking Traps

Mental Filter

Compare and Despair

Critical Self

Self Care

- Inside Out – in our mind things

- Outside In – doing things

Near the end..

Taking care of ourselves and others is hard.

Hand on heart, hand on tummy, and breathe.

Kintsugi

Resources to look at if you have time...

- Fact or Opinion Sheet : https://www.getselfhelp.co.uk/docs/FACTorOPINION.pdf
- 'Flipping your Lid' by Dan Siegel : https://www.youtube.com/watch?v=f-m2YcdMdFw
- Fight or Flight Sheet: http://www.bayareacognitivetherapy.com/cbtblog/fight-or-flight
- Mental Crusher: https://www.getselfhelp.co.uk/docs/MentalCrusher.pdf
- Unhelpful Thinking Sheet: https://www.getselfhelp.co.uk/docs/UnhelpfulThinkingHabitsWithAlternatives.pdf
- Kintsugi Explained: https://www.theschooloflife.com/thebookoflife/kintsugi/

16 February 2021 – Every mistake is a treasure…, Caring in a time of lockdown, Supporting recovery after inpatient or community treatment…

The last couple of weeks have seen challenging times for some of the group and everyone is struggling to find their way through the labyrinth of lockdown. However, it was great to hear about ways that the group's support has been of real help. We enjoyed another really good discussion, which I am certain will be equally helpful.

Every mistake is a treasure…

We shared some of our stories of doing the wrong thing with the right intention, e.g. taking a bag of food shopping on a visit, or making a meal without prior discussion 'to be helpful'. The group's experience is this is inevitable, you do learn from it, it gets forgotten about and it can sow a seed of thought. If our loved one reacts strongly try to stay calm, acknowledge your mistake and roll with it until things calm down. Above all, do not beat yourself up about it because… every mistake is a treasure.

Caring in a time of lockdown…

Caring in a time of lockdown… We discussed how challenging visiting has been in lockdown and the negative impact on our loved ones' health. Infection control is an imperative for hospitals, which explains why most inpatient units have stopped visits; for some, 'outdoor visits' may become possible as we emerge from lockdown. For our loved ones who live away from home the government's **'Guidance for those who provide unpaid care to friends or family'** is relevant.

This allows essential travel to deliver this care, and specifically references mental health. It sets out how you can reduce the risk of spreading infection. The guidance requires us to use our own judgement of a situation. Our loved one's opinion is really important, e.g. the guidance may allow a visit but if our loved one is so anxious about it that it is going to make them feel worse, we will need to fall back on telephone, text and Zoom unless we judge that it is a real emergency. The government has clearly been talking to Axxxx because it states, **'It's important you consider what support you might need and how you can access support to maintain your own health and wellbeing'**! Informal carers are in Group 6 for the vaccination roll out but you must be registered with your GP.

Supporting recovery after inpatient or community treatment…

Supporting our loved one's recovery when they leave an inpatient unit or finish a programme of community treatment… It is natural to be concerned that the progress our loved has made will fall away. However, the group's experience is that how we react and behave can help give our loved ones recovery the best possible chance.

First, fall back on one of our key principles - **stay calm, don't panic, keep your own anxiety under control**. You may need to take your panic to a friend, (or support group!), bottling it up will not be helpful.

See where your loved one gets their confidence from, e.g. visible pleasure at being able to go for a long walk, and do what you can to encourage this. Don't worry about minor blips - so what if they miss a meal, everyone does occasionally.

Encourage their non-Eating Disorder personality so that it ceases to define and dominate them; you can do this by showing interest in their non-eating disorder activities and interests.

Ask how you can best support what they are trying to achieve - they may simply want you to stay in the background, or they may have some ideas about how you could help. Link healthy behaviour to perceptible life gains, e.g. 'it's great that you are now able to join your friends on that holiday'.

Support them to try new things that give a reason for living - sow seeds, see what grows and praise the green shoots.

Above all, trust - this can be hard but it's their choice - **small steps lead to success**.

Resources

Links

Unpaid /informal carers

https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care/guidance-for-those-who-provide-unpaid-care-to-friends-or-family

Vaccinations

https://www.carersuk.org/help-and-advice/coronavirus-covid-19/covid-vaccine-faqs

23 February 2021 – Green shoots, Self harm and Suicide

Green shoots

We're good at identifying 'green shoots' and staying pro-recovery and we demonstrated that this week, although some of the group had had some really challenging situations to cope with. The lockdown continues to require resilience… but we do now have some dates to help our planning. The weather has improved and the days are getting longer, so 'outdoors' and 'garden' are going to be easier to add to our 'look after yourself' list.

Self-Harm and Suicide

We discussed two very difficult topics: self-harm and suicide. I have read that the prevalence of self-harm in people with eating disorders is thought to be about 25% and is particularly high among people who engage in the binge-purge cycle of Bulimia Nervosa. Suicidal behaviour is also not uncommon, although it is important to say that the reason for taking an overdose, for example, might not be to take one's own life. It's complicated.

The group brought some very significant experience to bear. One point that came through strongly is that **eating disorders, self-harm and suicidal behaviour can be (unhealthy) strategies to try to manage extreme emotions**. For us as carers this means that all of the principles of good caring - being a good dolphin / St Bernard - should guide our emotional response and behaviour. This is easier said than done because the physical manifestations of self-harm and suicidal behaviour can be very shocking: your 'stay calm' strategies will be tested to the limit and having someone you can talk to is more important than ever because bottling up those strong emotions will not be helpful in the long run.

Some other key points were:

- Be curious about the reason for our loved one's behaviour because it could be serving different functions, e.g. they might be trying to say something that they think they can't express in any other way; this is something we may be able to help them with.
- We described the build-up to a self-harm incident as 'unstoppable' but Sarah suggested that there are strategies that help people to deal with the build-up so that self-harm doesn't become an inevitable outcome. Therapy and in some cases medication may be appropriate to help our loved ones to manage anxiety and to learn to be kinder to themselves. We can help by discussing alternatives behaviours - other things our loved ones could do - outside of the heat of the moment.
- Some of our loved ones find stress relievers to be helpful (I guess they could be helpful for us, too!). A wide variety are available, search 'stress relief toys for adults' on Amazon - don't worry, you will not need to delete your search history. I think I might order the Calma Llama, 'When spit happens give me a squeeze!' Tangle comes highly recommended https://www.tinknstink.co.uk/tangle-creations .

- Sarah mentioned elastic band twanging and ice cubes as less harmful ways of giving the sensation of pain, if that is what our loved feels they need to control their emotions.
- In the same way that there are myths about eating disorders there are myths about suicide. The Zero Suicide Alliance website has a very good, online awareness training course that addresses many of these myths and the site contains a wealth of information. It covers self-harm, and drug and alcohol abuse as well.

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

It all leads back to staying calm, being caring and showing compassion. Recognise the triggers, empathise, help them express their feelings, give feedback about their health, e.g. 'that burn looks like it might need dressing' and put the ball in their court. This support group can definitely do that.

Resources – Sources of Support

Zero Suicide Alliance

https://www.zerosuicidealliance.com

Lifeline

11am - 11pm weekdays, 2pm - 11pm weekends and Bank Holidays, 0808 808 2121

https://www.cpslmind.org.uk/lifeline-plus/ .

Papyrus

Offers support and advice to people under the age of 35

https://www.papyrus-uk.org/get-in-touch/ .

The Samaritans,

116 123 free call, 24/7, is available to carers to ask for support and advice

https://www.samaritans.org .

For Cambridge-based students Nightline

offers confidential advice for students.

https://cambridge.nightline.ac.uk

2 March 2021 – Barriers to accessing treatment, Family Therapy sessions, Motivation

We continue to manage the challenges of lockdown, which adds to our already full plate. Over the next couple of months at least visiting is going to become a bit easier (fingers crossed!). Everyone is anxious about what coming out of lockdown will be like and it is clearly a big issue for our loved ones, as this week's discussion demonstrated. Our conclusion, based on experience, is - of course - to stay calm, caring and compassionate. It is vital, too, that we show ourselves some self-care and self-compassion, and - you know what's coming - look after ourselves!

Barriers to accessing treatment

One of the issues we discussed this week was 'barriers to accessing treatment'. It can be a difficult step for our loved ones to ring up and make an appointment to see their GP. Not all surgeries have online booking. If a surgery is aware of this problem it should make 'reasonable adjustments' to help the patient, e.g. accepting text messages, or allowing someone to book on their behalf. Cxxxxxx told us that most surgeries will have a consent form so that you could be put on record as the named contact, and that most will book six weeks in advance. She also advised that we should get to know our friendly secretary… we need a Cxxxxxx in every surgery! I remember Ana at the 'Patients' Journeys' presentation earlier in the year saying that her mother made an appointment for her, told her about it, but left it up to Ana as to whether she attended or not; and that this was helpful.

Family Therapy Sessions

We also briefly considered Family Therapy Sessions because this is something that some of the group are about to commence. The consensus was that these can be very helpful (a 'life changer' was one comment). It is a safe environment, led by a trained therapist and can be particularly helpful for improving communication, sharing views, better understanding relationships and getting deeper into what our loved ones' feel.

Motivation

Our main topic of discussion was how we can help motivate our loved ones if they are 'stuck' in their stage of recovery. This is a big topic and we only scratched the surface but our experience underlines some key principles:

- **'Active listening'**, i.e. using open questions, listening carefully and reflecting back their conversation to help them clarify their ideas is really important in order to find out what motivates them, rather than us making assumptions or trying 'force' an incentive onto them.
- If our loved one is contemplating change, **discussing different options** (but allowing them to reach their own conclusions) can be really helpful.

- **Accept and acknowledge how hard it is for them**. This will make them feel that they are understood.
- **Encourage the things that give them confidence** - anything that makes them feel good about themselves.
- **Plan variety into the daily plan** so that they/we don't get stuck in a rut.
- **A goal may be motivating** - some examples given were a skiing holiday (author's note - I want to see the pictures!), an exercise bike for their birthday, something that they can't do now but could if…
- **Don't get stuck yourself** - so look after yourself.
- And, finally, Suzanne reminded us to **'just keep going'**! We must never forget that the vast majority of people recover from their eating disorder, although it can take a long time.

Next week is our monthly '18.30 - 20.00 Presentation'. The topic is 'Siblings' and it promises to be a really interesting and useful session. Three siblings will share their experiences and what they found helpful/unhelpful with an eye on what parents can do, and some other siblings will join them for a discussion with us about the issues raised. I'll get the invite out at the end of the week.

9 March 2021 – Siblings

This week we enjoyed an excellent discussion with a very special group of people about their experience of being a sibling of a loved one with an eating disorder. I hope this summary does your contributions justice; it was a pleasure to put it together!

Each sibling's experience was/is unique

But all described **a relationship that went from 'normal'**, e.g. big brother/little sister 'helping her out when she gets into scrapes at school' or very close friends, **to one defined by the illness** - 'they became a completely different person', 'it was like a bereavement'. For some it was a shock, seeing how quickly their sibling's health declined and learning how much they had been struggling. Another common feature was how difficult it can be to talk to friends and colleagues about this illness because it is so difficult to understand and explain. All continue to support their sibling over a long period of time, in different ways and at different intensities.

Powerful and understandable feelings

Some powerful and understandable feelings were described:

- **Thinking that you've done something wrong** that has contributed to the illness.

  You haven't, there is no evidence that parents or siblings cause an eating disorder.

- **Feeling guilty that you are getting on with life** and enjoying yourself.

  You shouldn't, in fact you are helping by showing what 'normal' is and being a good role model.

- **Feeling overwhelmed**.

  This is understandable because it is so easy for the illness to take over family life. It is important to seek help.

Helpful things

Our siblings described **some things that they found helpful to do or remember**:

- **Understand that it's a team effort**, your loved one is the main player. Everyone has a part to play, if they want and are able to. Each player brings different strengths. The team needs to keep communicating.
- **Learn as much as you can about the illness**, your loved one and everyone who is there to help. The more you understand about this complex illness the more you will be able to manage your own feelings and response (e.g. not feeling guilty) and be able to help.
- **Therapy is the key to treatment** - everyone needs to be involved.
- **Don't bottle things up** - talk to friends, partners, support groups if available.

- **Look after yourself**, seek help if it is making you unwell. Sometimes it is difficult to spot the impact on your own health of living in a state of high anxiety for a long period of time.
- **There is only so much you can do**, you can't fix your brother or sister by yourself.
- **Recovery is possible**, you should never give up hope. Even after many years, an event or a realisation can trigger recovery.

How parents can help

We also discussed **how parents can help**. Several of us spoke of an understandable desire to 'shield' brothers and sisters from the illness so that they can have as normal a life as possible. The group's experience is that a more dolphin-like approach is best:

- **Take time to listen and understand siblings' thoughts, feelings and concerns**. They need to be able to say what is worrying them and we need to be able to respond in a calm, caring and compassionate way.
- **Acknowledge how difficult it is** and show them that you - and their sibling - appreciates what they are doing.
- **Keep lines of communication open about 'normal' life**. Don't let the eating disorder dominate every conversation. Enjoy some things that are nothing to do with the eating disorder, even if it is only watching a favourite television programme.
- **Don't push them into helping**, instead support them to contribute as much as they feel able.

Hearing other's experiences is really helpful

Our siblings agreed that hearing other's experiences is really helpful. **We need a siblings support group!** I had invited Kate Rees, a manager at Centre 33, which provides services for Young Carers in Cambridgeshire and Peterborough, who described briefly the support they currently offer.

I will have further discussions with Kate on behalf of Young Carers and Young Adult Carers.

BEAT provide some information and online help, although the siblings' experience had been mixed . There may also be something that we can do.

Conclusion

The conclusion this week is easy - thank you, Sarah, for arranging this session and a massive thank you to the siblings who spoke to us with such bravery and honesty. You are wonderful!

If your sons/daughters joined this session with you, please forward this to them.

Resources

Centre 33

https://centre33.org.uk/help/cambridge-south-cambridgeshire/https://centre33.org.uk/help/peterborough/

BEAT

https://www.beateatingdisorders.org.uk

16 March 2021 – Calorie Counting and Meal plans

We had a lot to update each other on this week. Some good news, some not so good, but always plenty of support and helpful ideas. Our main discussion point was calorie counting / meal plans. The group contributed some interesting and helpful experience. Despite this being a difficult and emotive topic we managed to identify some general principles:

- It is important for us, as carers, to understand the particular eating disorders service's approach because services do vary. We need to work with the service, expressing any concerns we have direct to the service, not to our loved ones. CPFT tries not to get patients into calorie counting because it can become rigid, fixed thinking and is not normal eating. The Team usually will have introduced a meal plan that is appropriate for our loved one's health and recovery.
- Accepting the proviso above, calorie awareness might be useful to guide some patients at a point in their recovery, e.g. as a stepping stone to understanding what a normal portion is. Like painting, doing it without numbers should remain their goal, but they will need to find their own way.
- Our role as parents/carers is to present (or describe) a normal meal, not one that accommodates the eating disorder. This will require discussion and will almost certainly involve negotiation, but the aim will be to encourage normality.
- Some of the group have had success with involving their loved ones - and family - in weekly meal planning. This helps with the weekly shop, it restricts the discussion into one moment in time and it is an opportunity to discuss a rota of cooking and washing up. On the other hand, it can result in our loved ones getting stuck in a rut and, in particular, sticking to their safe foods, although this gives an opportunity to be 'gently curious' about their concerns and to encourage experimentation. If they go off a food it is an opportunity to discuss what would be an equivalent alternative. The cost of food can also be discussed, which can be a valuable lesson in budget planning.
- Others have found that weekly planning has made their loved ones more anxious and that there need to be smaller steps to move away from meal to meal / day to day planning. They might, for example, prefer to be told what they are having and are willing to trust you. The principle here is listening to understand their concerns and to learn how we can best help, mindful of the need for boundaries - it is important that the eating disorder does not take over the whole family's meals because that will help no-one in the long run.
- We heard of success with 'Hello Fresh' meal boxes where you choose meals online and the ingredients are delivered to your door, with cooking instructions. This has worked well as a 'long distance support' tactic - our loved one chooses the meals and is responsible for its preparation, so they are fully involved, but they do not have the potential stress of shopping for a lot of different ingredients.

23 March 2021 – Our moods / their moods, Family members reacting differently

We began this week's discussion by commenting on apparent inconsistent practice with regards to identifying Vaccination Priority Group 6 'Adults aged 16 to 65 years in an at-risk group'. The clinical conditions list is published on the government's website https://www.gov.uk/government/publications/covid-19-vaccination-care-home-and-healthcare-settings-posters/covid-19-vaccination-first-phase-priority-groups and it is easy to see how this is open to interpretation. The group's conclusion was encourage your loved one to contact their GP if they/you think they should be offered the vaccine. Note also that unpaid as well as paid carers are eligible, too.

How can we make our mood less reliant on how our loved one is feeling?

The first topic we discussed was, 'How can we make our mood less reliant on how our loved one is feeling?' One thing we all agreed on is that it is hard. It is also really important for our own well-being, and so that we are as healthy as possible for our caring role. Here are some of the things people in the group have found helpful:

- **An activity that gives a sense of achievement**, even if it finishing that pile of ironing!
- **Physical exercise** - walking, running, swimming - to clear the mind.
- **Gardening** - it's physical and creative and takes you out of yourself.
- **Giving yourself permission to enjoy an activity with your loved one** without worrying about them all the time, whether it is a walk or going to the cinema.

Sarah developed the discussion by saying that it is important to change the definition of success. The fact that we feel low because our loved one is distressed indicates our empathy, which is an indicator of 'good caring'. However, success is that they've opened up to us and we've listened, not that their distress has gone away.

If it really gets on top of us it is important to get help for ourselves.

Family members reacting to our loved one's illness differently

We then discussed the difficult and sensitive topic of partners / family members reacting to our loved one's illness differently, and often unhelpfully. This is very common and very complex. The strain of a loved one with an eating disorder can exacerbate differences and open up small cracks. If one partner has had the lead caring role, the other may feel left out, or begrudge receiving less attention. Many families find it hard to talk about difficult feelings. These are all reasons why family work is such an important part of the treatment for eating disorders. The group described some of the approaches and thinking that have helped:

- **Making sure that you prioritise time for the relationship**, whether it is with your partner / a parent / a special friend. Relationships need nurturing and there is much we can do.

- **Make a real effort to talk as a family**. This may require 'shuttle diplomacy' having 1:1 conversations to begin with.
- If you have been the main carer **be generous and supportive** if your partner, or a friend, wants to be more involved. This can feel a bit threatening - 'Am I not good enough?' - but it could be really helpful, to you and them.
- Remember to remain **'hope full'** because the vast majority of people recover from their eating disorder. It is not for ever.
- **Don't feel guilty**. Relationships sometimes fail even in that 'normal' world outside of the strange world we inhabit.

Apropos the discussion about gendered roles, I received this shortly after our meeting. I suspect the discussion may not suit British time but the presentations will be accessible after the event:

'FEAST is launching a new support network https://www.feast-ed.org/men-of-f-e-a-s-t/ . Starting this Thursday FEAST is introducing a support and skill-building group for men whose lives are impacted by eating disorders (EDs). The goal of the Men of FEAST group is to activate, educate, and motivate men in caring for themselves and becoming more supportive and effective as caregivers, team members, and partners in the ongoing treatment of eating disorders. The Men of FEAST will introduce, teach, and foster an understanding of evidence based treatment and offer other tools to help men develop a variety of skills (e.g., Self-Care, Broken Record, Distress Tolerance, Mindfulness, etc.) in support of refeeding, neural rewiring, and full recovery'.

And finally, a big thank you to Rxxxxxxxx for dropping me a line thus, 'A friend sent me a link to an article about the Floral Rainbow of Hope, which was planted on the Mound in Edinburgh to mark the National Day of Reflection yesterday. It was an initiative by Scottish plant growers to plant a 20m rainbow of primroses to remind us all of the joy that gardening can offer, as well as all its positive effects on health and mental well-being. It is a symbol of hope with the coming of spring, to stay optimistic, especially as we start emerging from lockdown and hopefully into a brighter future. I just thought it was such an appropriate symbol of hope for yesterday's meeting, when some members are going through very tough times'. You can view the article here: https://www.edinburghnews.scotsman.com/health/coronavirus/edinburghs-rainbow-of-hope-brings-some-welcome-colour-after-a-year-of-dark-times-3174214 .

STOP PRESS!! I am delighted to say that I have been able to arrange for Anna Tuke, CPFT'S Associate Director - Involvement and Partnerships, to join us next Tuesday (30th March) to talk to us about Consent and Confidentiality. This is an issue that keeps coming up but we've not really tackled it. CPFT has produced a leaflet called 'Common sense confidentiality' that sets out the Trust's approach, which is very helpful. Anna will join us at 18.30 and we will do updates and our general discussion after her presentation.

31 March 2021 – Confidentiality

Confidentiality

We began this evening's support group meeting by welcoming Anna Tuke, Associate Director for Involvement and Partnerships, to talk to us about CPFT's leaflet 'Common sense confidentiality', which I've attached. The issue of consent and confidentiality is an issue that has come up a number of times in our discussions. It is a complex area and the leaflet interprets what that means in practice for patients, parent/carers and staff in CPFT; other Trusts have very similar policies. Anna drew out some key points for us:

- Confidentiality is very important. Confidential information about a patient should only be shared with their explicit consent. Confidential information about, or provided by, a parent/carer should only be shared with their explicit consent.
- However, confidentiality should and will be breached if your loved one's life, or someone else's life, is at risk.
- It is common for patients to consent to sharing some, but not all, information. This will be discussed and recorded at the start of their treatment and regularly reviewed.
- In the absence of consent staff are encouraged to share non-confidential information with parents/carers because the more we know and understand about our loved one's illness and treatment the better we are able to support.
- If you have information that is important to your loved one's recovery you can always pass it on in confidence - you might not get a response, but it will be taken into consideration; the team supporting your loved one's recovery would rather know than not.
- The principles of planning in advance, in low stress moments and of asking permission can be very helpful: 'What would you want me to do if…?'

There may be times when we feel that we are not being told what we should and that we are not being listened to. This is really difficult and stressful. It is important that we understand the actions being taken by the professionals who are treating our loved one, whether or not we are in agreement. In the first instance we should try to talk to the team that is looking after our loved one. If that isn't possible, or is unsatisfactory, we should contact PALS, the Patient Advice and Liaison Service, who provide confidential advice, information and support to help sort out any concerns we may have about the care CPFT provides.

Thank you, Anna, for navigating us through these complex waters!

Tips for keeping going

It was good to hear that some of our loved ones are making better progress although some are really struggling, which is so difficult for us as carers. A small number of the group are having a really difficult time of it, so I asked everyone for their top tips for keeping going when you are feeling so done for - emotionally and physically - that the finish line of the proverbial marathon seems impossibly far away. The hands shot up:

- Cxxxxx has bought three hens and a coop. The principle here is an activity that is nothing to do with the eating disorder, is satisfying and productive - I envy your neighbours who benefit from those fresh eggs!
- Rxxxx gave a new twist to an idea we have discussed before, i.e. taking time out for a walk. Note how you feel before you go and when you get back; having 'proof' of feeling better reinforces your mood.
- Ixxxx and Dxxxx recommended weighted blankets as a way of dealing with stress and anxiety. (These were new to me but there is a lot of interesting information and research on the web.)
- Dxxxx also recommended the CALM app. (I have had this recommended to me by a father who was totally sceptical and then completely won over.)
- Rxxxx said that she uses a notepad to write everything down and this helps her get it out of her system.
- Axxxx reminded us how helpful a small number of close friends can be, and that it is really important to keep active.
- Axxx described how breathing can help. (This is one I used to be totally sceptical about but I am a convert: breathe in for 7, hold for 4 and breathe out for 11… it really does seem to control (my) anxiety.)
- Gxxxx recommended Matt Haig's 'Notes on a Nervous Planet'. Waterstones says, 'An articulate and thoughtful handbook for coping with a world seemingly designed to get us down and stress us out, Haig's passionate call for sanity and balance chimes with many people's experiences of anxiety. A seminal work on mental health and the perfect companion to Haig's superb memoir, Reasons to Stay Alive'.
- Exxxx reminded us how important it is to, 'Just stop, step back before you step in again'.
- Me? I remember to tell myself that recovery is the most likely outcome, it just takes a long time; I focus on the next day, half day, hour…; and (I didn't confess this last night) I listen to old episodes of 'I'm Sorry I haven't a Clue'.

Thank you to Lxxx for sending us the link to a World Service programme about the history of treating eating disorders. It's only nine minutes, I found it really interesting and it contains some important messages for parents/carers:
https://www.bbc.co.uk/sounds/play/w3ct1x0k .

Next week (Tuesday, 6th April) is a '16.30 Support Group Discussion'. I will get the invite out before the Bank Holiday weekend.

Resources

Links

PALS	https://www.cpft.nhs.uk/patient-advice-and-liaison-service-pals
CALM App	https://www.calm.com
Book	Matt Haig's 'Notes on a Nervous Planet'
Leaflet	Common sense confidentiality

Principles of Best Practice

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

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

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

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

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

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

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

Leaflet published: March 2019
Leaflet review date: March2020

Patient Advice and Liaison Service

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

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

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

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

HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF
T 01223 219400 **F** 01480 398501 **www.cpft.nhs.uk**

A member of Cambridge University Health Partners

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

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

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

A member of Cambridge University Health Partners

Who is a carer

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

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

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

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

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

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

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

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

Consent to Share Information

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

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

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

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Consent to Share Information

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

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

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

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

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

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

6 April 2021 – Purpose and ambition, Know when to act, What we've found helpful

Purpose and ambition

One of the themes we discussed this week was **the importance of purpose and ambition in our loved one's recovery**. Part-time work and/or voluntary work has helped a number of our loved ones because it provides a reason for getting up and out, it occupies time and it provides structure to the day. Having a career aim or life ambition can be very motivating but can also be derailed by our loved one's illness. There are things we can do as carers to support our loved ones in this situation. For example, it is an opportunity to help them clarify their thinking by discussing the pros and cons of change… 'On the one hand you want to go to university, but on the other you would need to eat well enough to have the energy for your studies', or to help them come up with ideas for what they could do, i.e. possible plans of action, leaving the decision with them.

Know when to act

Sometimes dolphins need to move fast! I worry that the animal metaphors could be misunderstood - the 'encouraging' dolphin and the 'calm' St Bernard could sound a bit wishy washy but these animals know when to act. We heard a lovely example from one of the group where they had to leave the support group session because of a food crisis. Now, attending the support group could be considered sacrosanct but the wise dolphin knows when it's needed. Quick action (leaving the meeting), followed by demonstrating normal behaviour (eating the meal that had been prepared) and calm support (for their loved one to make their own alternative meal) not only defused the crisis but left the door open for their loved one to 'try again' on their own terms, which very gratifyingly they did. Every mistake is a treasure but every success should be celebrated, too!

What we've found helpful

We then talked about **what we've found helpful when we've been really stuck and don't know what to do**. First, it's essential to get some help and support, which can come from a number of different places, e.g. the team supporting our loved one, our own GP, helplines and, of course, support groups like ours. Second, our role is to prepare a normal meal, not one that accommodates the eating disorder. This is easier said than done and the group's experience is that it is definitely better to discuss things in advance, at low(er) stress moments, e.g. saying/discussing at the start of the day when and what the plan for meals is going to be. It is really difficult not to go in search of a particular brand because that is all they will eat (my guess is we've all been there), or not to cook something extra or special, but it does not help in the long run even if it avoids an argument in the short run.

Draft of Consent and Confidentiality training with staff

We concluded by discussing this draft scenario that CPFT is planning to use as part of its Consent and Confidentiality training with staff:

Anya is 14 and has a severe eating disorder. She lives with her parents and is being treated intensively at home by the Children and Young People's Community Eating Disorder Service. You are the community mental health nurse and when you are talking privately with Anya she tells you she has been secretly vomiting up food regularly in the past fortnight after meals. Her weight is dangerously low and close to requiring her to be admitted to an inpatient unit. She forbids you to tell her parents. She is an intelligent girl who generally has a good understanding of her illness and what she needs to do to get well. What do you do?

- The group welcomed that an eating disorders example is to be included in the training.
- It was suggested that it is made clear that the community mental health nurse is a specialist in eating disorders.
- The example would be more clear cut if the seriousness of Anya's ill health is emphasised.
- The group's view was that confidentiality should be broken because Anya's life is at serious risk. When someone is very close to requiring inpatient treatment, vomiting can have a catastrophic effect on blood chemistry and organ function. We accepted Anya's general good understanding of her illness and discussed Gillick competence but felt that even in this short paragraph there was clear evidence of the illness preventing Anya from thinking straight.
- However, how confidentiality is broken was considered important: that ideally it would be as part of a family session so that emotions could be managed and/or it should be explained to Anya that it would be better if she told their parents, but if she won't you will have to.

Thank you for these comments, which I will pass on.

Resources

And finally for this week, some really good resource suggestions:

Further to our discussion last week about weighted blankets as a way of dealing with stress and anxiety, Ixxxx sent me this link to a range of weighted soft animals that her daughter has found helpful

http://calmingblankets.co.uk/ .

(Weighted dolphins are available from https://www.sensorydirect.com/ !)

Karen told us about the Tabitha Farrar 'Eating Disorders Recovery' podcast. There are 98 episodes covering a wide range of topics, from the familiar to the not so familiar. They are a refreshing, and hopeful, 'different look' at eating disorders.

6 April 2021 – Purpose and ambition, Know when to act, What we've found helpful

Next week is a '18.30 Presentation Session' when Dr Georgina Hurford will be developing further the ideas she has presented about assertiveness, one of our key themes. I'll get the invite out before the weekend.

13 April 2021 – Presentation – Assertiveness (continued) - Dr Georgina Hurford

This week we were treated to a master class in assertiveness skills led by Dr Georgina Hurford, illustrated with some superb (and at times painfully realistic) role play with Dr Sarah Beglin. Georgina developed the ideas she presented to us last October in her 'Introduction to Assertiveness'. I have attached the complete slide set for ease of reference.

We were given a quick summary of 'What is assertiveness?' (slide 2), 'The three communication styles' (slides 3 and 4) and 'How to do it' (slides 5 and 6). In our discussion the acronym ELF proved particularly helpful because it is a really good framework for assertive communication:

- **Express**… how you feel, e.g. 'I feel upset. I would have preferred it if you had told me'.
- **Listen**… actively and with empathy, e.g. 'I can see your point of view. I disagree. I see it like this…'
- **Field**… show you have understood and 'caught' the other person's views, e.g. 'It sounds like you want to be in the kitchen preparing your meal at the same time we want to be in there and this makes you very anxious'.

Georgina and Sarah then treated us to four versions of the same scenario - our loved one not wanting anyone to be in the kitchen at the same time as they are preparing their meal, which is, of course, disruptive to family life:

- **Passive**: 'OK, don't worry, we won't bother you, I'm sorry we've made you anxious, we'll go away'.
  (Consequence = the issue goes unaddressed, you build up resentment, your loved one carries on with the same behaviour.)
- **Indirect aggression**: 'Still here then? I don't know what you're up to. I don't know, I can't even get into my own kitchen these days'.
  (Consequence = your loved one feels guilty and the situation remains unaddressed.)
- **Aggression**: 'This is stopping. This is my kitchen. From now on you're fitting in with me'.
  (Consequence = your loved one will probably storm out and stop cooking for themselves, to the detriment of their health.)
- **Assertive**: 'I can see how stressed you get. To be honest we're struggling too, we need to get in to cook dinner. There is probably a solution, can we talk about it in one of our 'calm times'?'.
  (Consequence: a discussion in a low stress moment reaches a workable way forward for everyone.)

As Georgina said assertive communication is not easy to do, it takes time and practice. One thing I've found helpful is to think through scenarios I've had, or need to have, and script the four possible conversations. Eventually, with ELF as a framework, my experience is that it becomes easier to be assertive. I'm glad, though, that Georgina stressed how hard it is because I certainly don't always manage it!

We followed this up with a really interesting discussion from our own experience. Some of the key points were:

- How you look, and the tone of your voice, is very important.
- Have an 'emergency phrase' to use when your initial reaction is anger or irritation, e.g. 'That's a really good question', or 'That's interesting, I've not thought about it like that before'.
- Pause - say the second, third or fourth thing that comes into your head, not the first.
- Be a broken record, calmly, warmly and clearly reiterating your thoughts and feelings. Hold the important boundaries, the lines you will not cross.
- Avoid the reassurance trap, e.g. answering a question you've been asked 20 times before might make your loved one feel better for a short while but it will not help them manage their anxiety in the long run. Rather, plan a set of responses, e.g. 'We agreed I wouldn't answer that question again because we've discussed it before'.
- Have the difficult conversations or you will never make progress and resentment will build up. Pick a time, have a plan and take it in stages - small steps lead to recovery.
- Externalising the illness can be useful, e.g. 'I know that is the illness, not you, that is talking'.

Being assertive respects your own needs and the needs of others. It also models good communication to our loved one whose thinking may be very distorted by the illness.

A big thank you, Georgina, for such an interesting, relevant and stimulating session!

First Anniversary!

Next week is the first anniversary of the online support group. Incredible! As discussed, party backgrounds, or hats (or whatever); a glass of apple juice (or whatever); and some cake or nibbles. We will, of course, have a proper support group discussion, although I do feel a short (support group related) quiz coming on. See you on Tuesday at 16.30! I'll get the invite out over the weekend.

Resources

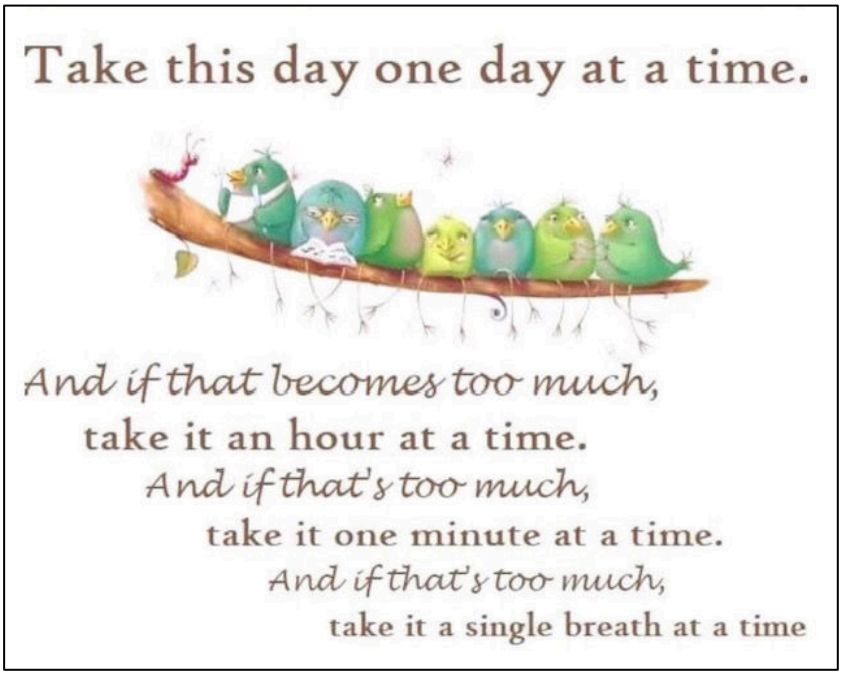
And finally, I have attached two cartoons sent in by Rxxxxx and Axxxxx that fit in very much with what we have been discussing recently.

For more inspiration see Charlie Mackesy's book

The Boy, The Mole, The Fox and The Horse

or

https://www.charliemackesy.com/



Presentation

See 20 October 2020 – Presentation - Assertiveness Dr Georgina Hurford