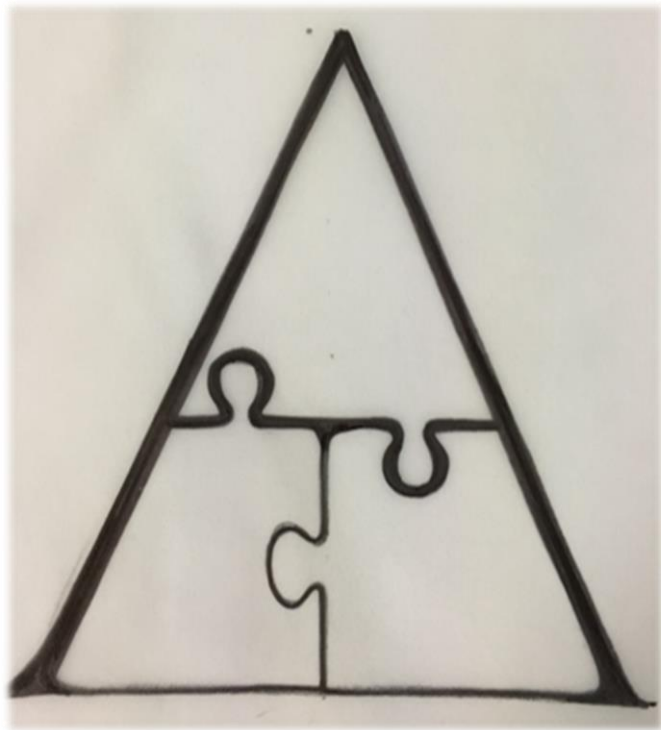


Empowering Carers



Prof. Janet Treasure

KING'S
College
LONDON

University of London

South London and Maudsley



NHS Trust

“Beat Delaying for Years”

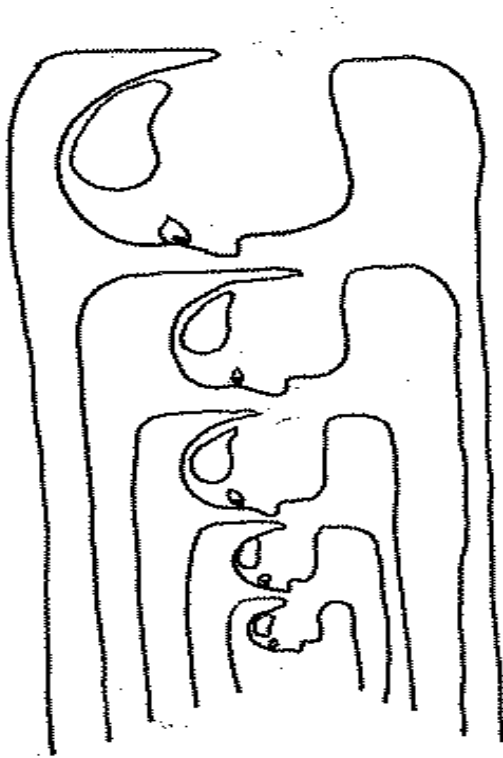


- Carers feel disempowered, alone and distressed when supporting someone with an eating disorder, and their physical and mental health is negatively affected.
- It is therefore important for services to empower and support carers.

Talk map

- We are no longer agnostic about the aetiology of eating disorders.
- How we can moderate some of the secondary interpersonal maintaining factors.
- How we can bridge from the anorexic voice to the recovery identity through social support.

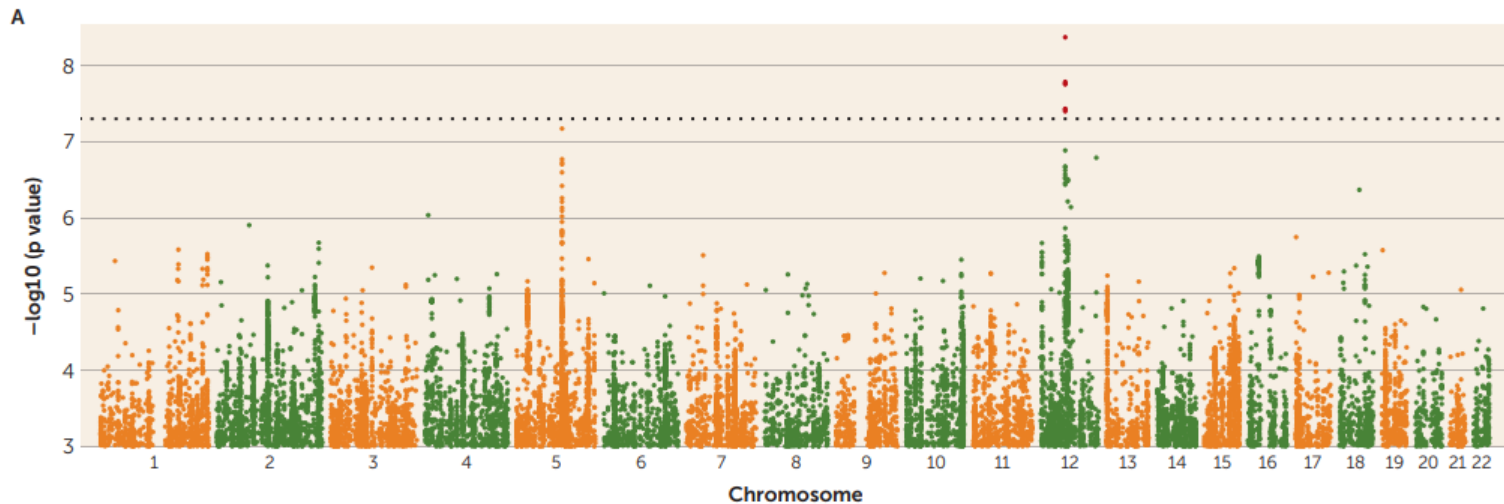
What do we know about heritability of Eating Disorders?



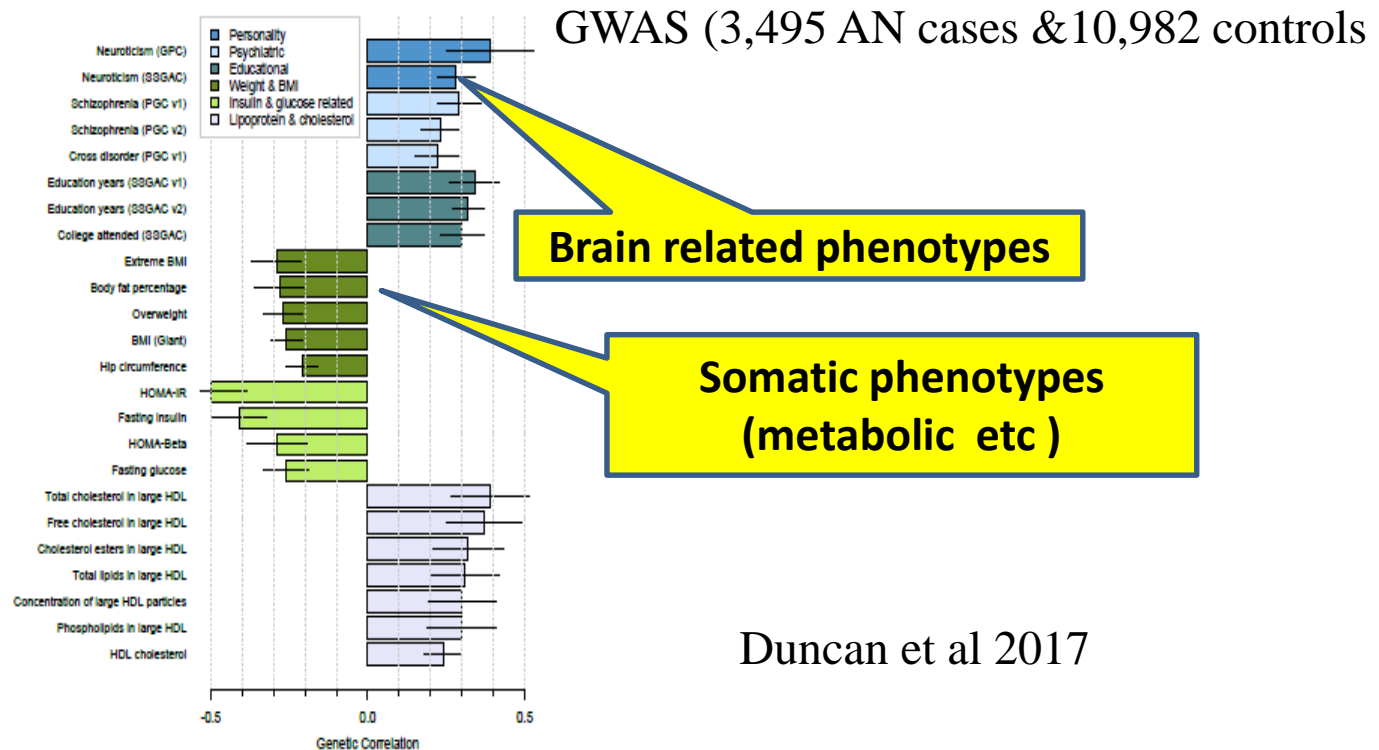
We know about some of the genes involved

- Heritability –58%-88% (Bulik et al., 2000)
- Genome wide significant locus on

FIGURE 1. Manhattan Plot and Regional Plot of the Genome-Wide Significant Locus for Anorexia Nervosa^a



Genetic correlations between AN and diverse phenotypes





- Please write using your non dominant hand
- “ I am writing with my non dominant hand”
- How did you do and how did that feel?

Non Dominant Hand

ANY REFLECTION?

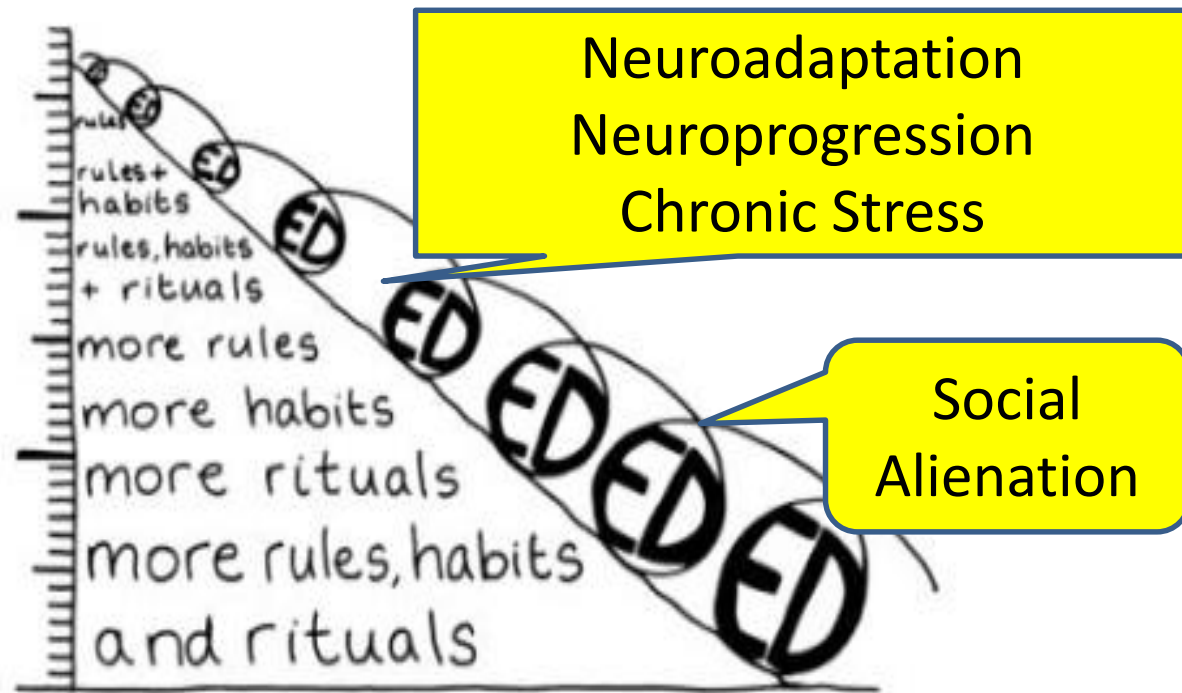


What are the mechanisms underpinning maintenance

Maintaining factors are still in action

Many forms of talking treatment target maintaining factors

What Happens over time in Anorexia Nervosa



Treasure et al 2014, Walsh 2013, Steinglass and Walsh 2016



Chronic Stress: Brain on fire

Neuro adaptation: Emotion learning

**Damage to hippocampus (↓ new
learning/neurogenesis)**

Problems in Social Cognition



Caglar-Nazali et al
*Neuroscience and
Biobehavioral
Reviews* (2013)

Domain	Effect
Negative self evaluation	2.2
Lack facial affect	2.0
Attachment insecurity	1.3
Sensitivity to social ranking	1.1
Alexithymia	0.66
Avoidance emotion	0.44
Low parental care	0.55
Reduced agency	0.39
Parental overprotection	0.29

Problems in Social Cognition

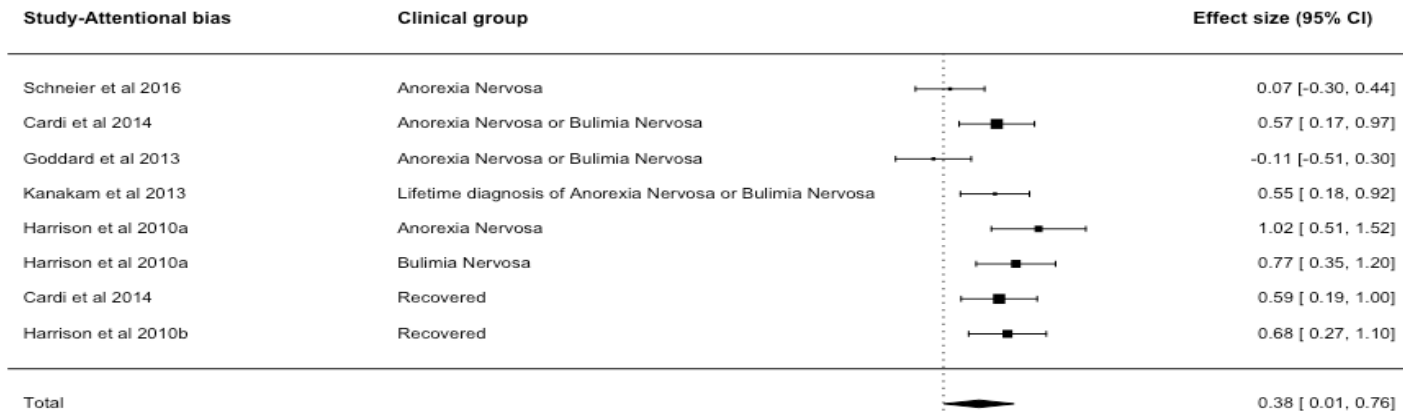


Caglar-Nazali et al
*Neuroscience and
Biobehavioral
Reviews* (2013)

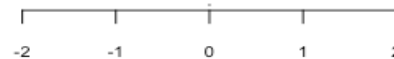
Domain	Effect
Negative self evaluation	2.2
Lack facial affect	2.0
Attachment insecurity	1.3
Sensitivity to social ranking	1.1
Alexithymia	0.66
Avoidance emotion	0.44
Low parental care	0.55
Reduced agency	0.39
Parental overprotection	0.29

A meta analysis of reactivity to interpersonal threat (Monteleone et al 2018)

Dot probe and emotional Stroop task

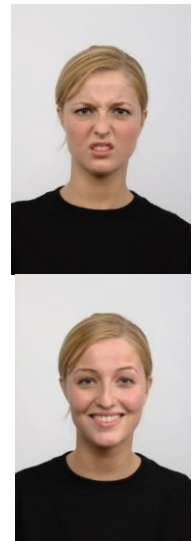


RE Model for All Studies ($Q = 31.04$, $df = 7$, $p = 0.0001$; $I^2 = 76.9\%$)

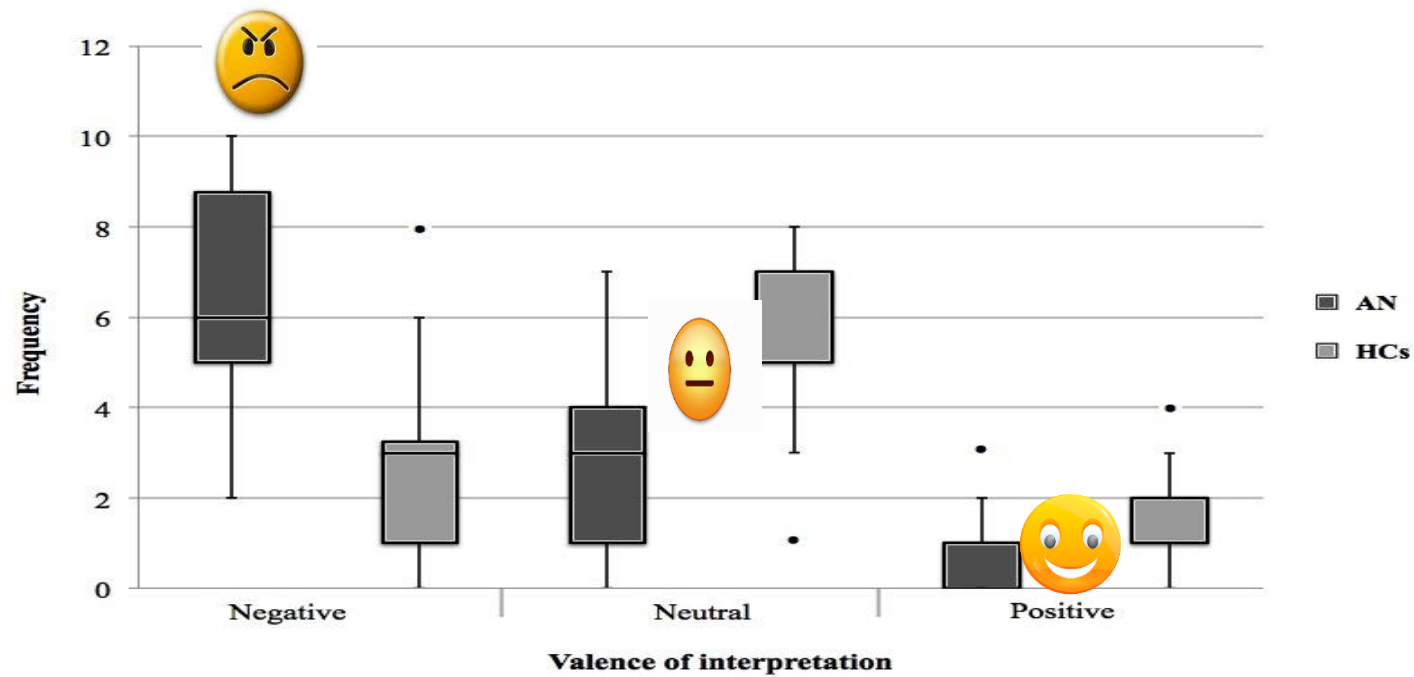


Reduced attention bias in clinical group compared to controls

Increased attention bias in clinical group compared



Interpretation of Ambiguous scenarios





SOCIAL CUES:
ATTENTION FOCUS THREAT
INTERPRETATION FOCUS ON NEGATIVE

ANY REFLECTION?



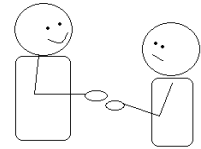
Problems in Social Cognition



Caglar-Nazali et al
*Neuroscience and
Biobehavioral
Reviews* (2013)

Domain	Effect
Negative self evaluation	2.2
Lack facial affect	2.0
Attachment insecurity	1.3
Sensitivity to social ranking	1.1
Alexithymia	0.66
Avoidance emotion	0.44
Low parental care	0.55
Reduced agency	0.39
Parental overprotection	0.29

Reduced facial expressions in acute state



- Acute AN: large +ve/medium-ve ↓ expression. Adult > Adolescent.
- Recovered AN: ↑ positive emotions.

Davies et al., 2016 Neurosci Biobehav Rev

<18 y

>18 y

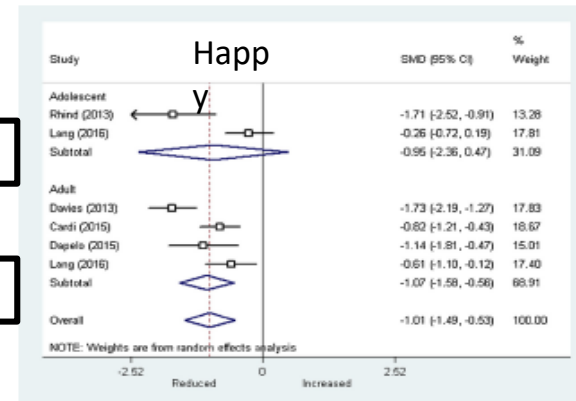


Fig. 2. Forest plot of the meta-analysis for facial emotional expression in response to positive affect in patients with AN.



<18 y

>18 y

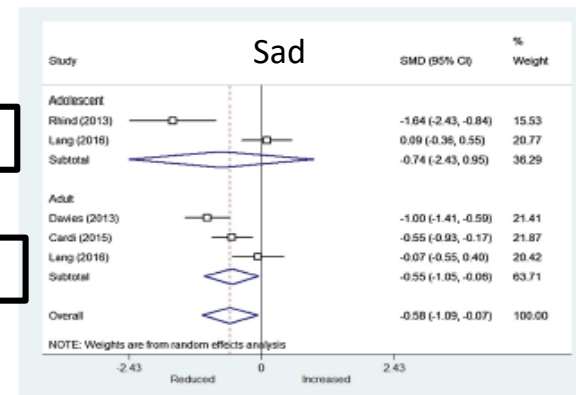
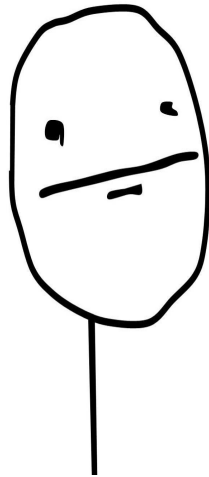


Fig. 3. Forest plot of the meta-analysis for facial emotional expression in response to negative affect in patients with AN.

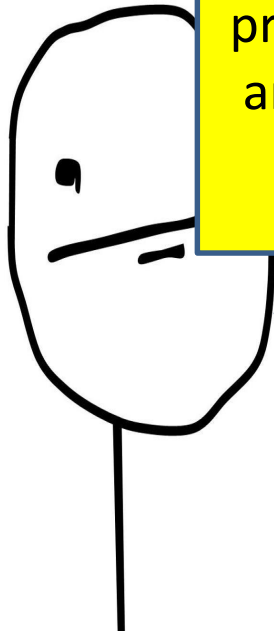


Typical interpersonal relationship with AN

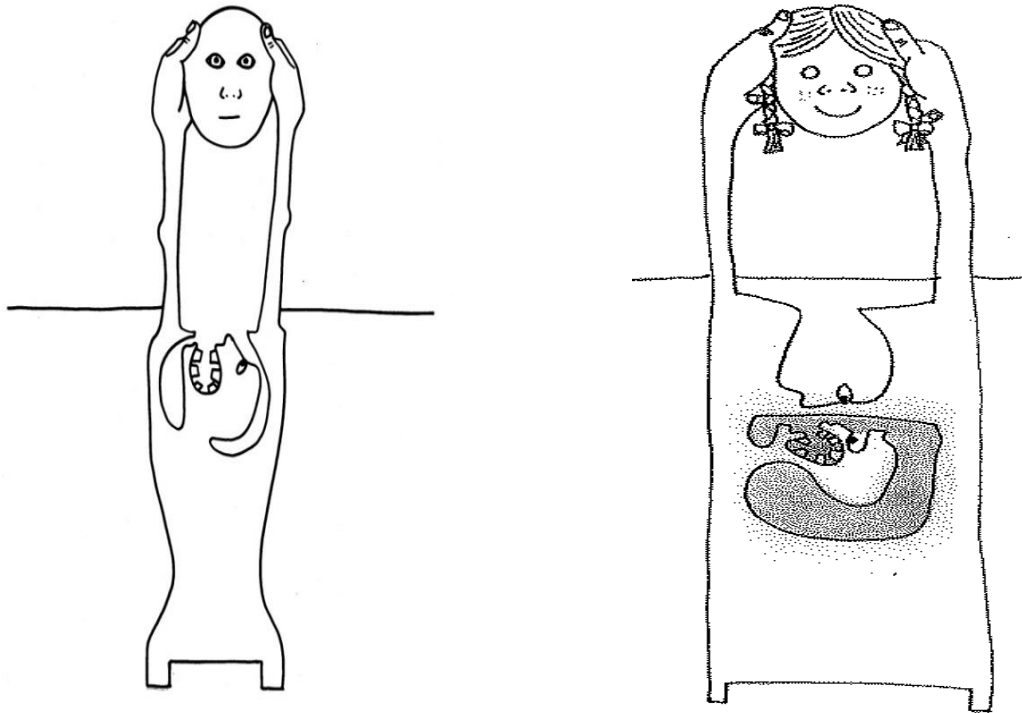


Disruption of interpersonal relationship

Failure of emotional reciprocity is disturbing-
produces a stress reaction –raised blood pressure
and a “not like” response (*Hess et al 2013, Schneider et al
2013, Szczurek et al 2012*)
e.g. Still face paradigm in infants

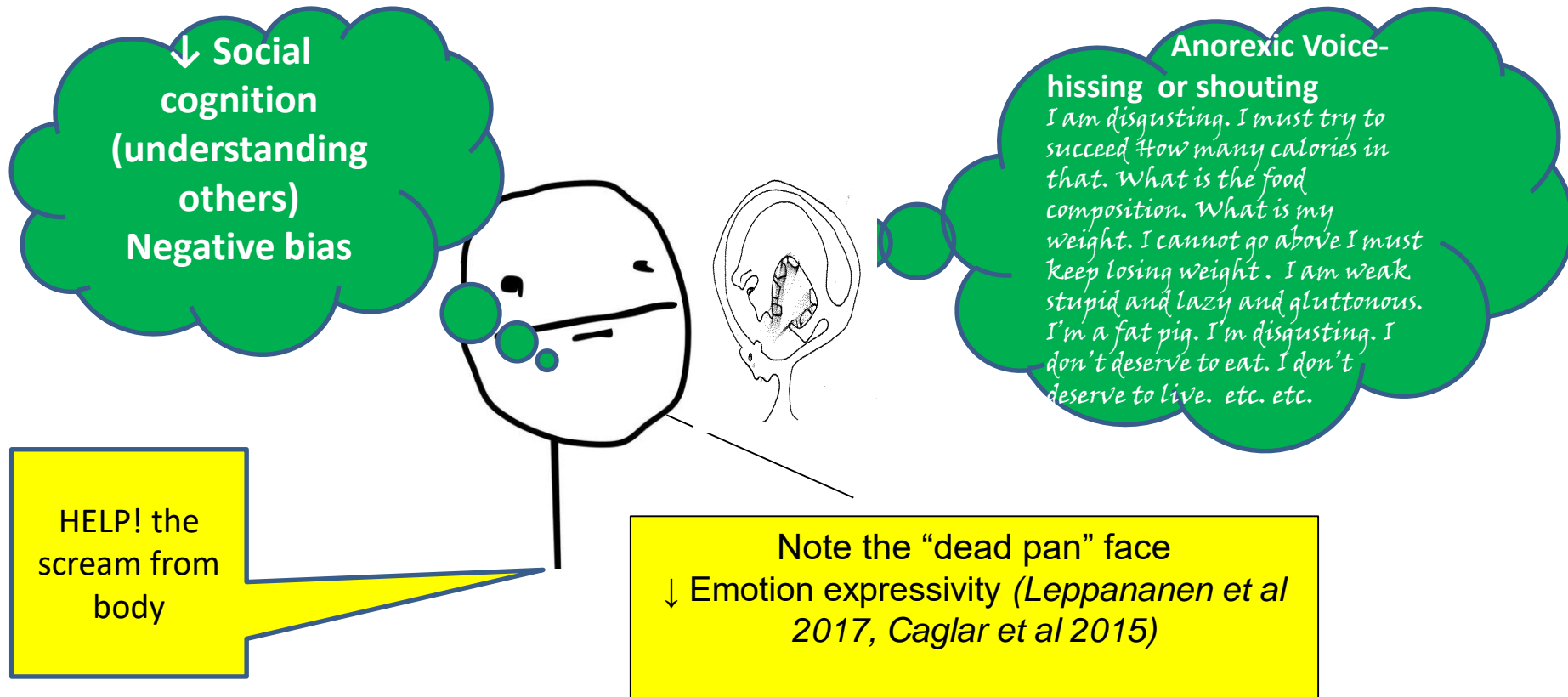


Social communication inhibited: A blank mask or fake pleasing



Davies et al., 2011, 2013; Dapelo et al., 2016; Lang et al., 2016; Leppanen J. et al . (2017)

Confusing Social Signaling



No reciprocity to warmth, a frosty, “aloof” response.

I was known as the “**ice queen**” at Uni



Tutors would get annoyed as **they thought I did not care.**

They did not know what was **going on inside.**

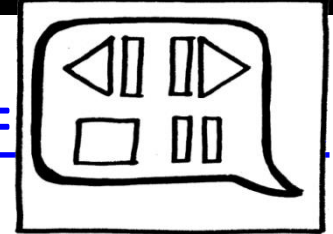
Davies et al 2013, 2014, 2016, Cardi et al 2014, Rhind et al 2014, Ambwani et al 2016

ANY REFLECTION?



The Still face paradigm

- <https://www.youtube.com/watch?v=9w2g>



- In adults dislike and autonomic arousal when interact with still face (Gross et al 2003).
- Also this is recognised in robots as the “uncanny valley effect”.

Problems in Social Perception

- Difficulty detecting intimacy (Costanzo & Archer, 1993)
- Respond coldly to warm feedback (Ambwani et al 2016)
- Less appropriate social problem solving (Sternheim et al., 2012)
- Negative bias attention and interpretation (Cardi et al 2017)





Problematic Interpersonal Relationships

Problems in social cognition in part developmental but become stronger in later stages a feature of neuroprogression
(Caglar et al 2015)

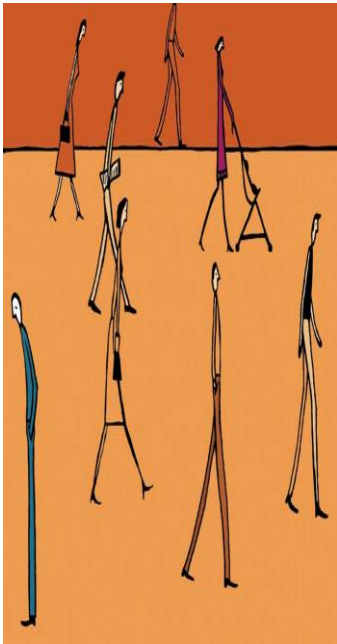
- Problems in social cognition impact on the therapeutic alliance and family & peer relationships.



ANY REFLECTION?



Increasing isolation



- “I was recently asked to sum up my experience of anorexia nervosa in one sentence—actually, I can do it in just one word—isolation.” (McKnight et al 2009)
- “It’s the loneliness that will get you. Not the hunger, or the worrying, or the rituals, or the paranoia. Not even the fear of getting fat. It’s the loneliness that’s the real killer. The longer you’re ill, the worse it is.” Melissa

Social difficulties accumulate over time in families and friends

Honeymoon phase –maybe initial praise .

Families and social networks the start to become organised around the symptoms: accommodate, enable or become angry & frustrated or withdraw because of interpersonal difficulties



Isolation is Maintaining factor. Carer Skill Therapy to improve interpersonal relationships and increase social network



- Magill et al 2016; Hodsall et al 2017

Carers (lay & professional)
have a mixed message

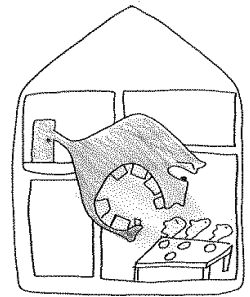


I do not need help- go away.

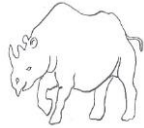
HELP!!!!

Disrupted interpersonal factors

- Living with or caring about someone with AN is exhausting, relationships can rupture.
- Carers swing from being bullied
- *“I really want you to come out to dinner with us, so we’ll make sure we go somewhere that serves plain salad”* (**Accommodating**)
- or exasperated
- *“You’re being ridiculous and ruining everyone else’s meal by being so demanding”*. (**Hostile**)



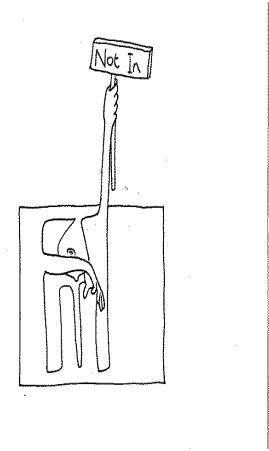
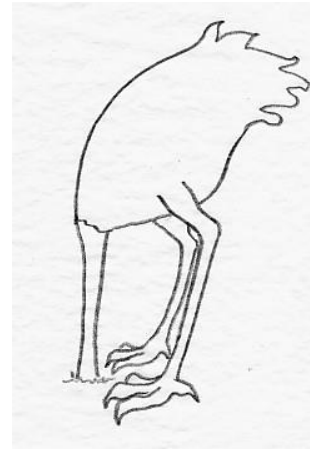
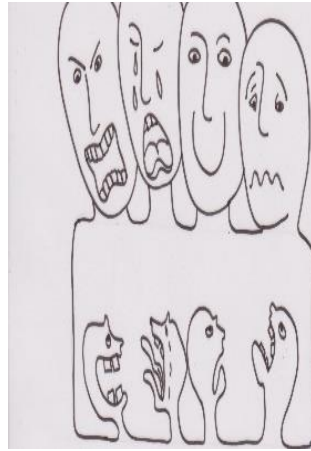
Carers quickly start to reflect on their own responses & behaviours



Jenny Langley's zoo

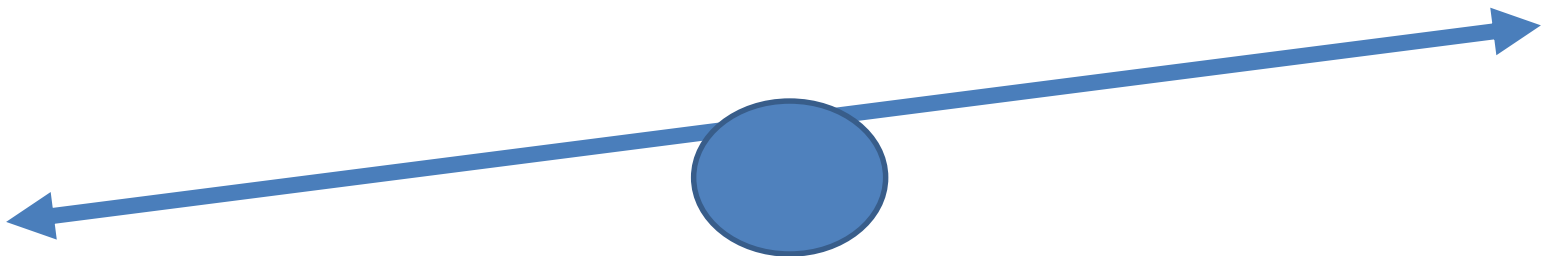


Tension with carer's emotional responses.

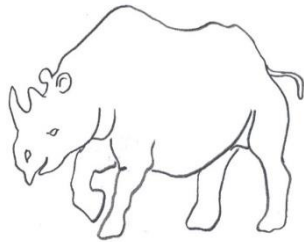


High intensity emotion-jelly fish

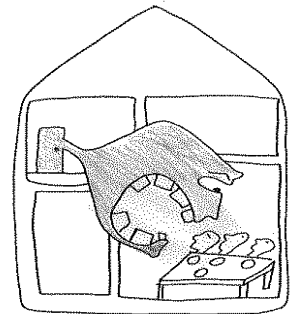
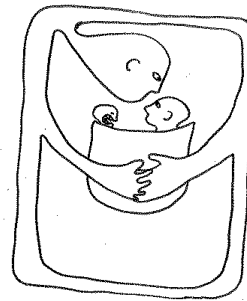
Avoidant Emotional Response



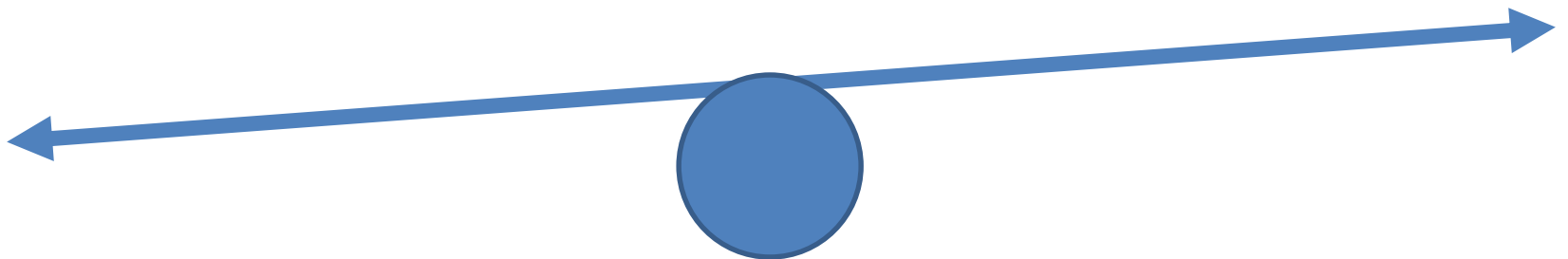
The see saw of emotionally driven behaviours.



Push towards growth
Rhino & terrier



Pull to perfect safety/nurture
-kangaroo, accommodating, reassuring



See Saw produces Splitting



- Within individuals
- Within families
- Within treatment teams
- Within friends
- Between families and treatment team

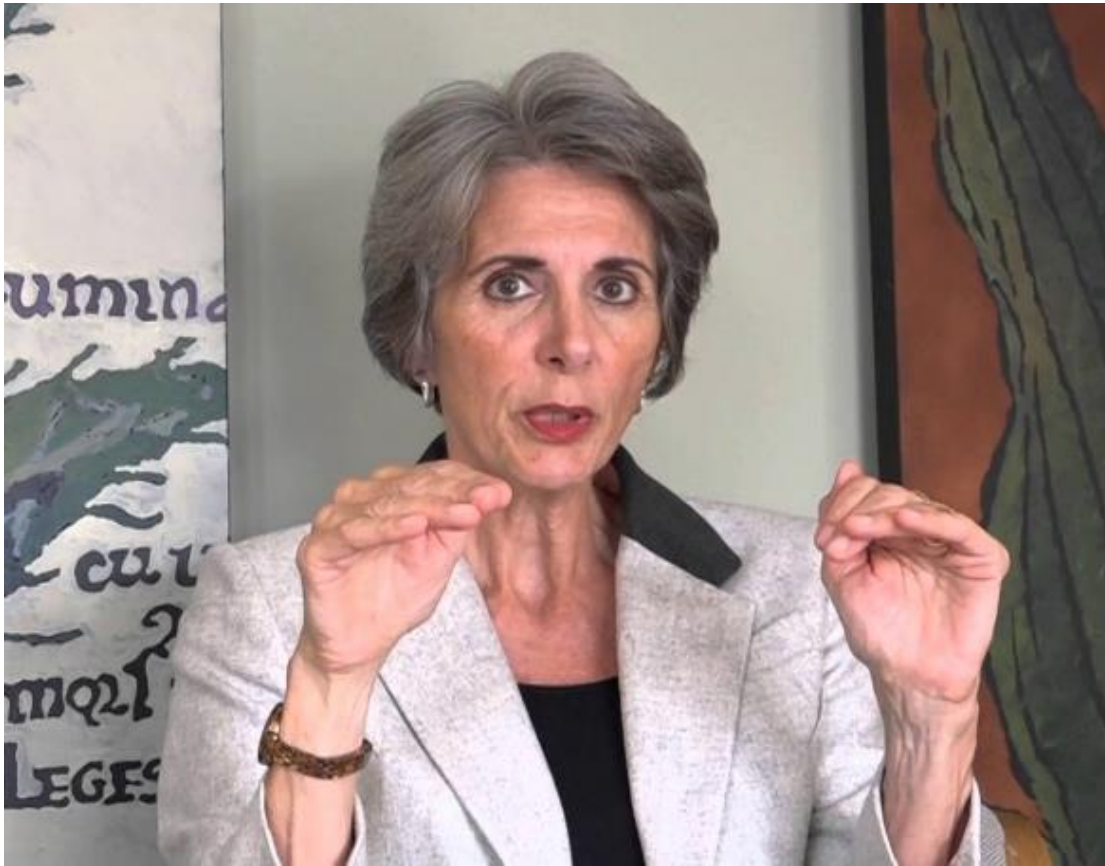
Collaborative approach within Families & Between Families & Treatment team





Fathers play an important role in treatment



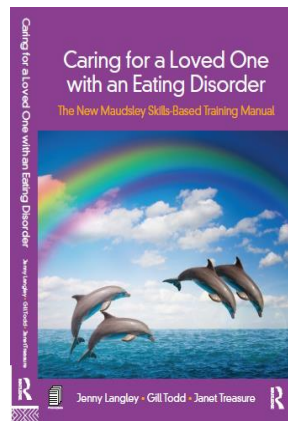
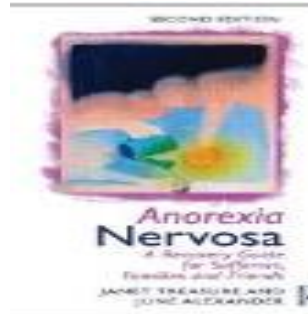
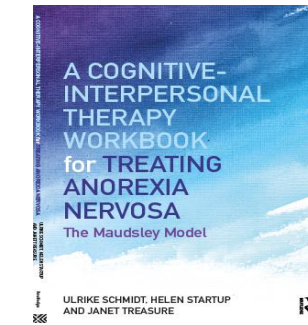
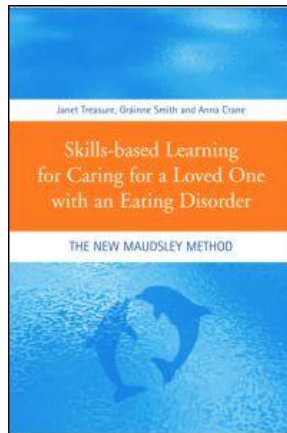


- Please write using your non dominant hand
- “ I am writing with my non dominant hand”
- Your partner needs to have no empathy for your disability and has no patience and should get you to hurry. Also they may be critical of your efforts.

Non Dominant Hand

ANY REFLECTION?

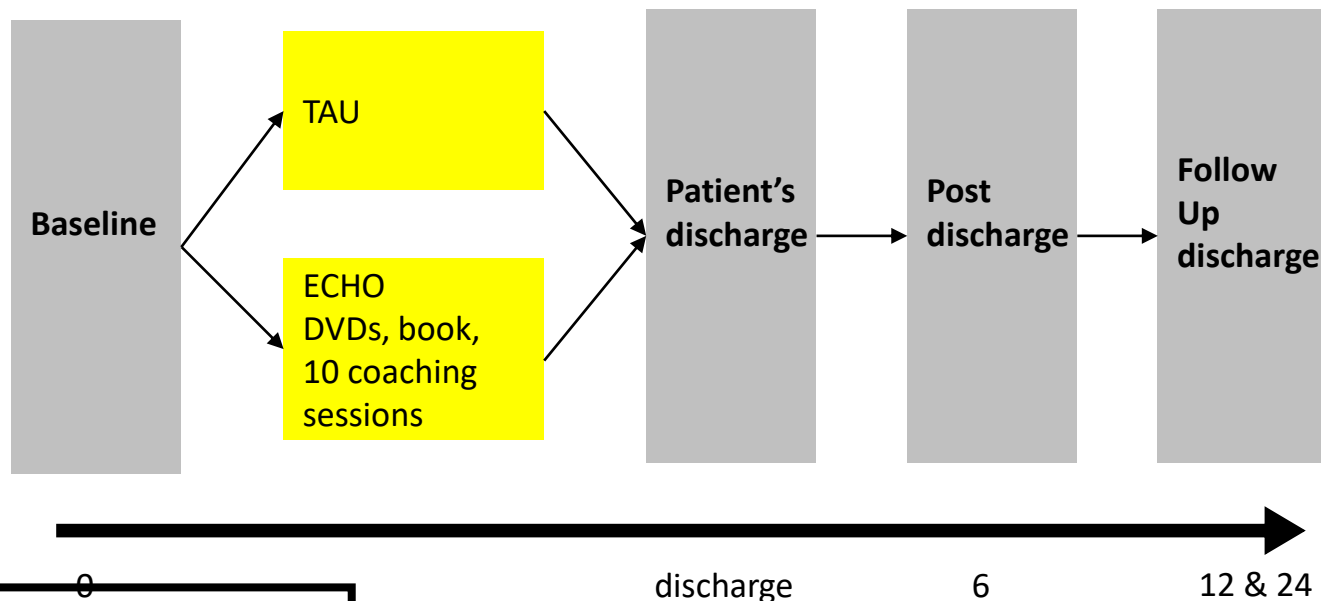




Materials used for guided task sharing with carers (lay and professional). Skills to reduce interpersonal maintaining factors

Does ECHO improve outcome from inpatient care for patients with severe enduring anorexia nervosa?

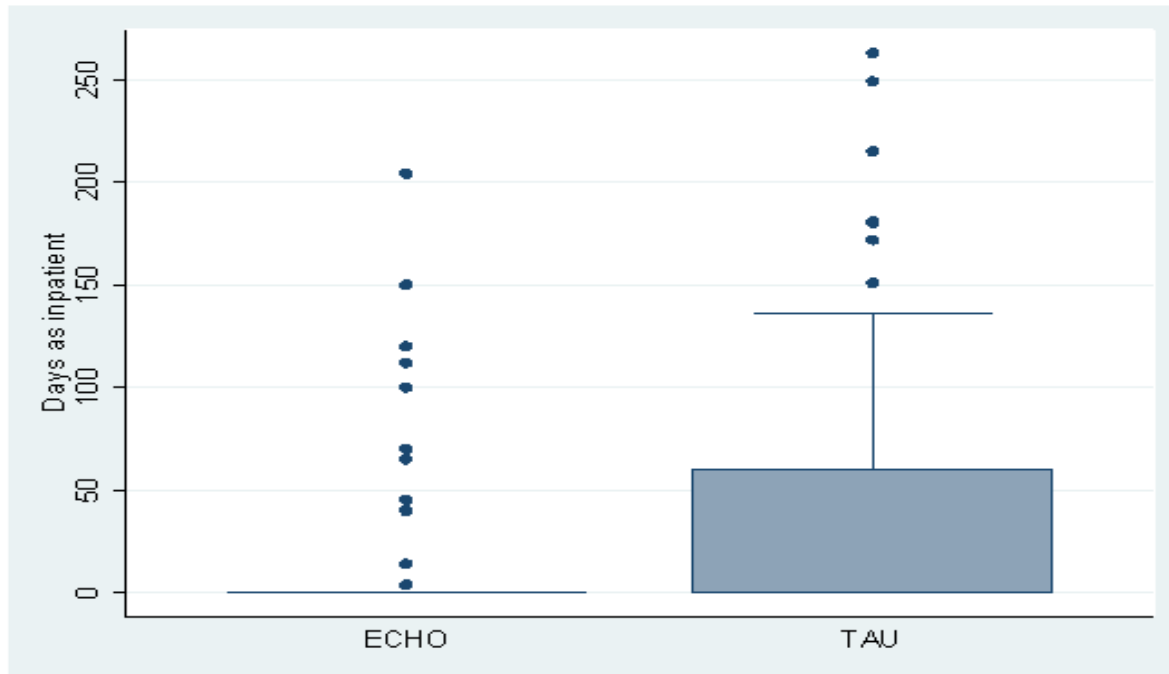
Assessment carer (n= 267) and patient (n=178)



Hibbs et al 2016, Magill et al 2017

BMI =14 (2.1) ; Age 27 (9.3) : 69% > 3y, 47%> 6y

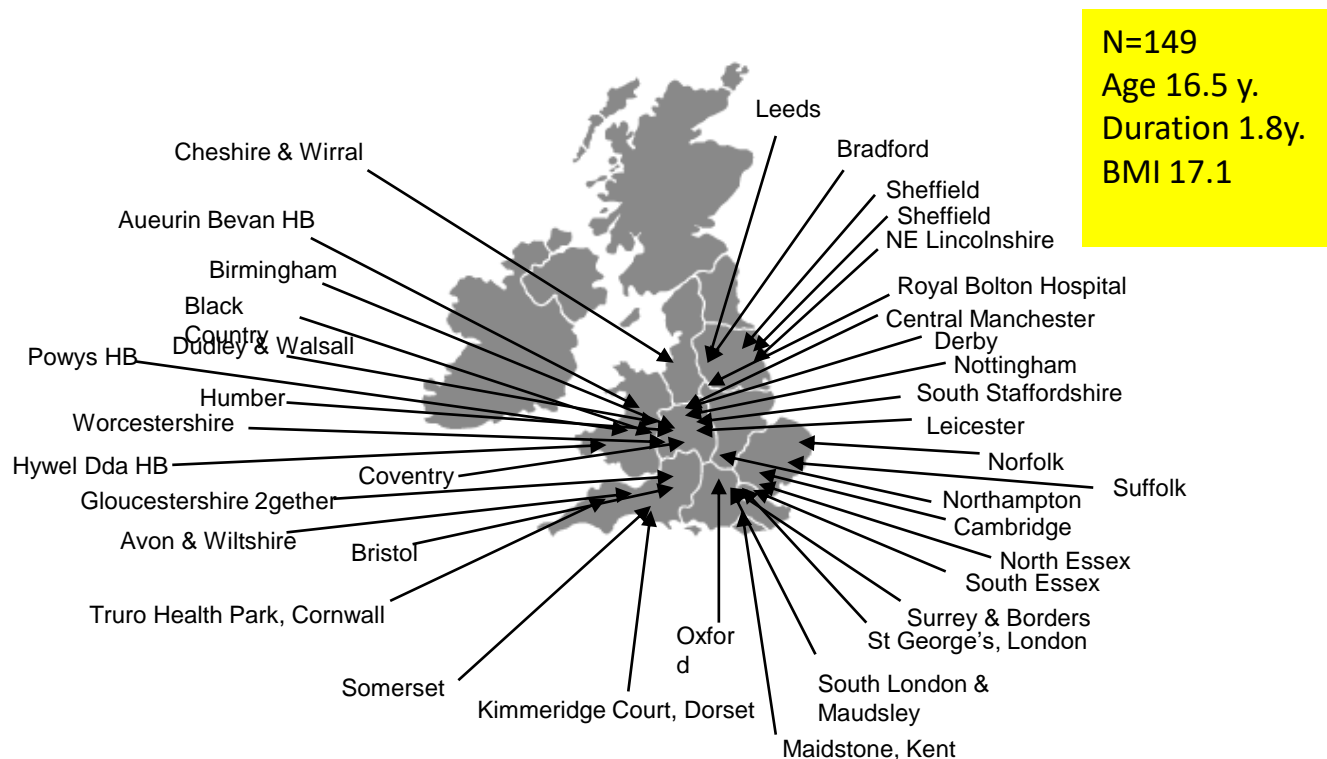
Adult : Bed Usage in first 6 months after admission



Hibbs et al BJPsych Open 2015;1(1):56-66.

Multi centre RCT for outpatients under 21years (Hodsall et al 2017)

38 NHS ED services (17 CAMHS, 13 adult, 8 both)



Number of Hospital Admissions: Adolescents (Hodsall et al 2017)

Patient/carer Group	6 months	12 months
ECHO	12%	9%
TAU	16%	8%

THE IMPACT ON CARERS

- Skills ↑
- Expressed emotion ↓
- Accommodate ↓
- Time caring ↓



The good news

- We can moderate interpersonal environment.
- Skills training for carers reduces the need for admissions and improves carer well being.



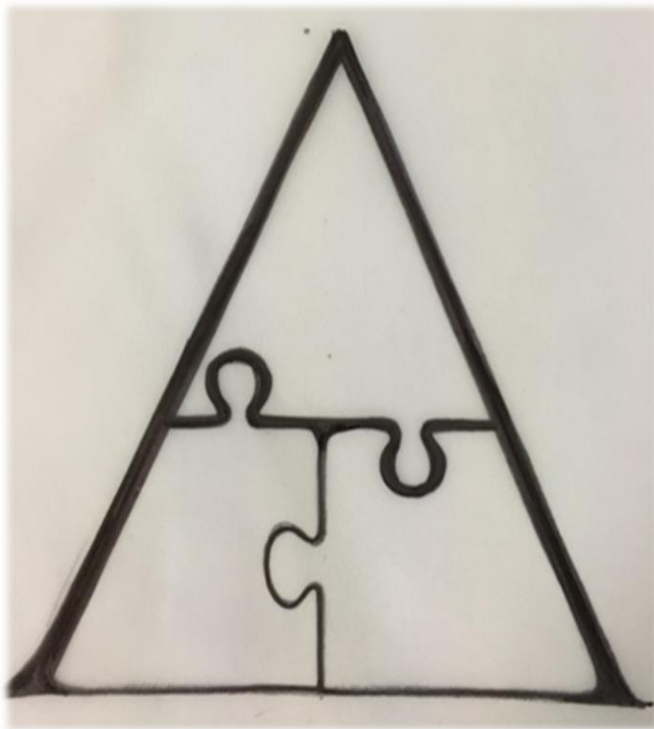
Goddard et al 2011, Hibbs et al 2015, Magill et al 2015, Hodsoll et al 2016

All providers of eating disorder services should:

1. Have a policy that ensures family empowerment
2. Train all staff accordingly
3. Provide useful and comprehensive information
4. Offer all carers and siblings an assessment of their own needs.
5. Offer all carers peer-to-peer support.
6. Offer training to provide optimum support for their loved ones.
7. Support carers when a loved one faces a transition between services.
8. Seek and act upon carers' input and feedback

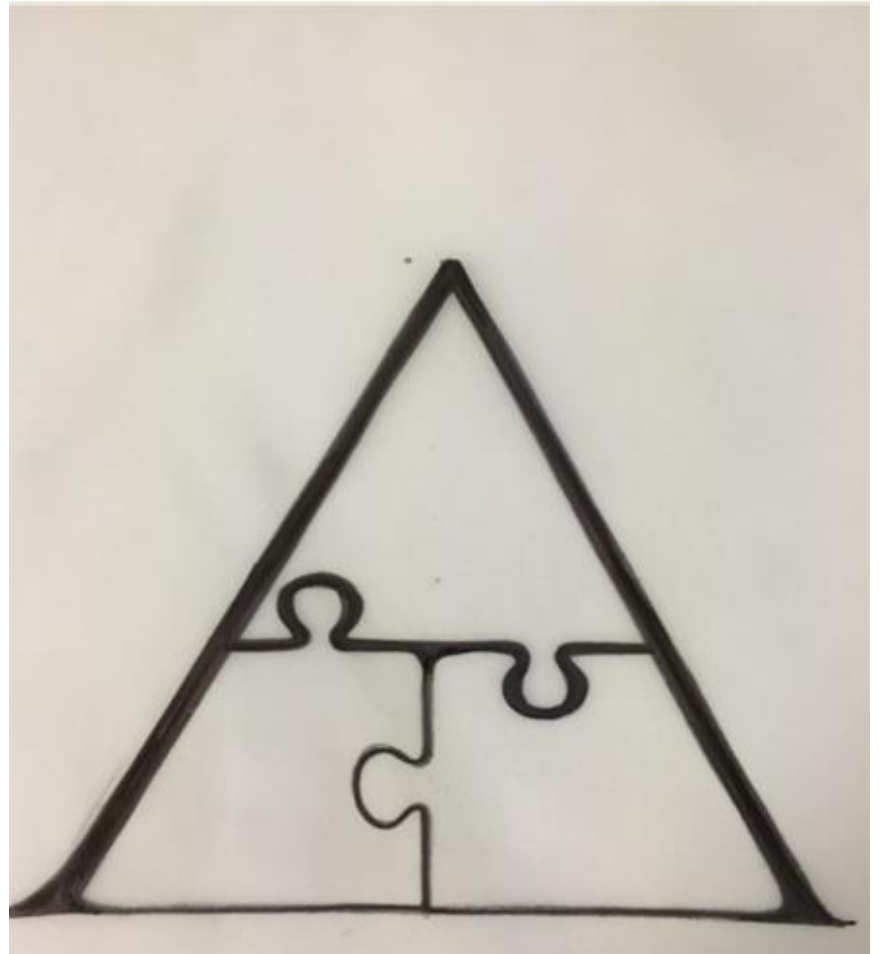
TRIANGLE

Transition care in AN: Through guidance online
from peer and carer experts



Conclusions

- Historically families were excluded but they are now embraced as part of the team.
- Social isolation is a key maintaining factor that results from problems in all relationships (friend, family and therapist) and can be moderated.
- Carers can develop skills to target patient needs and improve carer and patient Interpersonal relationships.
- This can improve wider relationships.



Many thanks

- MHRN, CSOs and experienced carers who made all this possible.
- Rhind, C., Hibbs, R., Goddard, E., Macdonald, P., Gowers, S., Schmidt, U., Tchanturia, K., Micali, N., Yolanta Quiles. Maria Quiles, Maria Troiani, Maria Stephanis, G Pepin, R King, Maria Quiles, Yolanda Quiles, Ana Sepulveda, Laura Salerno, Le Coco, K Rowlands, V Aye, V Cardi , F Fernandez



Please Help by
supporting
TRIANGLE