My Interest in Understanding Eating Disorders:

• My son had anorexia age 12
• Raising Awareness that Boys get Eating Disorders
  www.boyanorexia.com
• Support for families in the South East
• Maudsley Eating Disorder research team
• Education in schools and the local community
My son Joe

- Suddenly developed anorexia age 12
- Came out of the blue
- He was a happy sporty boy
- He became a very different person
- We worked closely with his school and medical team
- He has made a full recovery!
My son Joe

- Desire to be a better sportsman

— “Mummy I thought if I lost some weight I would be able to play football better, and I wanted to win the school cross country run.”
Joe’s description

“Mummy I have become obsessed about losing weight and I don’t know how to stop. I thought if I lost some weight I would be able to play football better, and I wanted to win the school cross-country run. Now I can’t even play football or run.”
Joe’s Weight Loss

- Joe
- Average
- 9th centile
Frequently Asked Questions

• Why did your son have anorexia?
• What were the signs?
• What did you do?
• Could you have nipped it in the bud?
• How did he recover?
Possible Answers

• Why did your son have anorexia?
  – Genetics
  – Biology
  – Personality type
  – Peer pressure - sport
  – Academic pressure
  – Culture

• Look Forward Not Back..........................
Possible Answers

• What were the signs?
  – Exercise
  – Mood
  – Weight
  – Food

• Write everything down that you observe
• This can help get an early diagnosis
Possible Answers

• What did you do?
  • 1. Panic
  • 2. Tried to persuade Joe to stop exercising and to eat more. He didn’t!!
  • 3. Learn
  • 4. Panic again
  • 5. Learn some more
  • 6. Worked with medical team and school
How we felt to start with
Our Natural Reactions

• On the one hand we crept around our son trying not to upset him further......like treading on eggshells. It was like the eating disorder was controlling us too.
• On the other hand we were like rabbits in the headlights.....”frozen with fear”, which handicapped our ability to think straight.
• Neither reaction helped!
The Eating Disorder Sucks Everyone In

• The eating disorder behaviours can easily become all consuming to everyone involved.
• The sufferer feels their whole identity depends on them keeping the eating disorder
• Everyone can inadvertently help to maintain the eating disorder
• BUT a little understanding and knowledge can really help to break this vicious cycle.
Understanding Anorexic Behaviour/ Feeding the brain is key.....

• What does your brain need to function properly?
Feeding the brain

• Your brain weighs around 3 lbs
• It needs 500 calories a day
• Plus a teaspoon of “good” oil
• A teenage brain is still developing fast
• If damaged it can repair itself
Starvation and the brain
Minnesota Starvation Study

Minnesota Starvation Study

- Social isolation, anxiety, neglecting personal hygiene, apathy
- Irritable, impatient, angry
- Depression and fluctuating mood
- Obsession over food and rituals around food
- Loss of sex drive
- Emotional anger at people with enough food
- Strong discipline (driving them to keep with programme)
Recent Research - Reduced Function of Self-Regulation System

- Decreases
  - Social cognition
  - Emotional regulation
  - Decision Making
  - Flexibility
  - Planning

- Increases
  - Compulsive behaviours
  - Avoidance
  - Threat reactivity
  - Punishment sensitivity

Area responsible for rational thought & self-regulation most sensitive to starvation and stress
Re-feeding and beyond

• Rehabilitation took much longer than expected
• The men had insatiable appetites and appeared to be overeating – *metabolic effect*
• On average the men regained their original weight plus 10%
• With unlimited food and unrestricted eating, their weights plateaued and finally after about 9 months they had naturally returned to their initial weights
Recovery is really tough

- The starved brain leads to numb emotions
- When you re-feed the brain those emotions reappear
- Re-feeding requires so much food
- It is often very traumatic and hard to face up to
- Emotional support is essential
- A student in recovery can be incredibly challenging
Crap Day Exercise – How would you feel?
My son’s world contracted

“Before anorexia came to visit I loved football, cricket, sailing, skiing and messing about with my mates...... The anorexia tries to steal all that from you and makes you feel so sad and depressed and lonely. You think you are in control, but the anorexia ends up controlling you more.”
The Eating Disorder is a Coping Mechanism

"I used eating as a way of keeping control, I didn't have much confidence but felt that if I could control what I ate I could cope with everything."
Recovery requires re-feeding plus understanding and emotional support

- Many of the strange and difficult behaviours are caused by the physical effect of starvation
- Re-feeding is crucial, but also needs to be accompanied by emotional support to establish more healthy coping strategies
- Beat recovery booklet can be a useful tool for sufferers, peers and staff.
• Road to Recovery Video

Created by Beat Young
Ambassadors
How can I help my child?

Some Successful Strategies

Be realistic about how much you can help:
Who is the one person in this room you can change?

Learn when to take a step back

Give more attention to the behaviours you like and less attention to behaviours you don’t like
“I’m worried you might have an eating disorder”

Is likely to be met with denial and/or emotional outbursts
Mind Your Language – open questions

• Are you ok, you seem awfully quiet right now?
• If you ever need to talk I am always in my room on xxxx
• Your friends are worried about you, do you know why that might be?
• I can see that something is up. How can I support you?
Mind Your Language - Listen and Praise

Listen 3x more than you speak. Reflect back what you have heard

Acknowledge how hard it is and praise even the tiniest steps forward
My son’s message

“Never give up hope.
Remember all those things you used to enjoy before anorexia came to visit. For me it was .............

You have to eat to have the strength to fight back. It was hard for me

too, at times I felt like giving up and that nobody understood me, but

with the support of my family and friends I did beat it.....completely.........and it hasn’t dared to come back. I am doing really well now and enjoying my sport and my life”
Social Factors in Joe’s Recovery

- Joe’s determination and passion for football
- Education within close family
- Close family working together
- Supportive family and friends
- Supportive school
- Speed of decline and subsequent recovery
Family Factors in Joe’s Recovery

• Singing from the same songsheet
• We all had to change a little bit
• We had to learn when to back off
• We had to let Joe take responsibility for his nutrition
• We had fun!
Treatment Factors in Joe’s Recovery

- Rigid re-feeding and bed rest
- Input from dietician
- Relations between medical team and family
- Very pro-active community medical team
- Family therapy
- Follow up support from GP and school nurse
Joe’s Story

• Every case is unique
• Recovery is possible
• The earlier the treatment the better the outcome
• The school environment is a very important part of the collaborative care
• School staff (teachers, pastoral care, school nurses etc) can play a significant role in the recovery process
What can Parents Do?

• Keep an eye on your teenagers’s
  – Food intake
  – Exercise levels
  – Mood
  – Weight
• Write everything down
• Seek help from your GP as soon as you are concerned
• Become an “expert”
• Collaborate with the school and medical professionals
Resources/ Toolkit

• Beat downloadable leaflets and website
  • (www.b-eat.co.uk)

• IoP downloadable leaflets and website
  (http://www.kcl.ac.uk/iop/depts/pm/research/eatingdisorders/index.aspx)

• NICE guidelines and DSM (www.nice.org.uk/cg009)

• Eating Disorders Advice
  (www.eatingdisordersadvice.co.uk)
Further Resources

- **Tonbridge Carers Support**
  - [www.eda-westkent.org.uk](http://www.eda-westkent.org.uk)
  - jenny@eda-westkent.org.uk

- **Boys Get Anorexia Too**
  - [www.boyanorexia.com](http://www.boyanorexia.com)
  - jenny@boyanorexia.com