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# A Co-ordinated Approach to Eating Disorders

## Shelley Perry

- Multi- award winning nurse social entrepreneur with a vision for providing eating disorder and weight management and mental health interventions that work.
- Following the completion of mental health nurse training at St Martins University, I continued further specialist training and enjoyed a number of roles within different areas of mental health including acute, high dependency, psychiatric intensive care units, eating disorder in patient unit and daycare as a nurse therapist for 14 years before setting up Breathe in 2009.
- Experienced in working for and with the NHS, private sector and third sector. I was
  inspired by her experience and training in these areas, my faith and my own recovery
  from an eating disorder (prior to her nurse training) to set up a service that was
  community based, providing early intervention through to acute care and treatment
  for severe and enduring eating disorders.
- For the last 8 years I have been Clinical Director at Breathe Therapies. As well as being professional member of RCN, NCFED, ABC, Beat, Preston Community Network Health and Wellbeing Commitee.
- And I'm also a mum, a Christian and passionate about most things I do or don't do!



## What is S.E.E.D? – Support & Education for Eating Disorders

Peer Support Groups for eating disorder sufferers

Support for carers and parents

Talks, workshops and training

Information and signposting





- As many as 1 in 20 women will have eating habits which give cause for concern; most will be aged between 14 and 25.
- Children as young as 6 presenting with eating disorders
- Only 9% of children felt they might be able to talk to someone at school
- NHS hospitals treated 58 children under 10 for eating disorders. This included 25 boys in 2006.
- Hospital admissions across the UK for teenagers with eating disorders has nearly double in the last three years.

## Eating Disorders – Know the First Signs?

- LipS: Are they obsessive about food?
- Flips: Is their behaviour changing?
- Hips: Do they have distorted beliefs about their body size?
- Kips: Are they often tired or struggling to concentrate?
- Nips: Do they disappear to the toilet after meals?
- •Skips: Have they started exercising excessively?

## The Importance of Early Intervention:

 "If an eating disorder is suspected, refer immediately to a community –based, age-appropriate eating disorder service for further assessment of treatment.
 NICE Guideline, 23 May 2017

 Applaud the leadership the Department of Health and NHS England have shown in recognising the importance of early intervention and introducing the Access and Waiting Time Standard for Children and Young People

## What is the Access and Waiting Times Standard?

- No more than 4 weeks between referral and start of NICE-approved treatment for 'routine' cases.
- No more than 1 week between referral and start of NICE-approved treatment for 'urgent' cases.
- £30 million per year to CCGs over next 5 years.
- 95% by 2020/21
- First results announced 11<sup>th</sup> May.

## What do the urgent results show (2016-17)?

#### For urgent cases:

- 65% of patients who were assessed as 'urgent' access treatment within 1 week (660 patients out of the 1016 referred).
- 101 patients (10%) who were assessed as 'urgent' had to wait longer than 4 weeks to start treatment.
- At least 13 of these patients had to wait over 12 weeks to start treatment.

## What do the results show (2016 - 17)

#### For 'routine' cases:

- 73% of patients who were assessed as 'routine' accessed treatment within 4 weeks (3,102 patients out of 4227 referred).
- At least 198 patients (5%) who were assessed as 'routine' had to wait longer than 12 weeks to start treatment.

## What do the results show (2016 – 17 Q4)

- 69% of patients who were assessed as 'urgent' accessed treatment within 1 week. 6% who were assessed as 'urgent' had to wait longer than 4 weeks to start treatment.
- 79% of patients who were assessed as 'routine' accessed treatment within 4 weeks. At least 34 patients who were assessed as 'routine' had to wait longer than 12 weeks to start treatment.
- An improving picture? ... need to treat data with caution (under-reporting).

## What do the results show (2016-17 Q4)

#### Patients who hadn't started treatment at end of Q4

- 47 patients (58%) who were assessed as 'urgent' had been waiting longer than 1 week.
- 223 patients (43%) who were assessed as 'routine' had been waiting longer than 4 weeks.
- Missing the net?

## What do the results show (2016 - 17)?

#### **Significant local variation**

- 49 CCGs only met the one week target for 50% (or less) of their urgent referrals.
- 21 CCGs only met the four week target for 50% (or less) of their routine referrals.
- Whereas 65 CCGs met targets in 75% or more of cases (average of urgent and routine cases).

## Are people receiving early intervention?

#### Time before seeking help (2015 survey)

- Immediately = less than 3%
- Less than a month = approx. 5%
- Between one and six months = approx. 20%
- Between six months and one year = approx. 20%
- Over a year = over 45%

## Are people receiving early intervention?

#### **GP Experiences (December 2016 Survey)**

- Half rated their GP care as poor or very poor
- 3 out of 10 did not receive a referral to a mental health service
- 1 in 6 were forced to change GP (with most receiving better care when they did)
- "It seems a disease which peaks and then largely 'burns itself out' and sometimes the best option is simply to support the person and family until it does so" – RCGP comment to NICE Guideline

## Are people receiving early intervention?

#### **Need to improve self-referral**

- Access and Waiting Time Standard very clear on the importance of self referral...
- 44% of Trust who responded don't accept self-referral.
- 46% of Trusts who responded don't accept referrals via parents/carers.

## Where do we go from here?

- Initial results are promising
- Increased pressure trends suggest more people seeking treatment and a need for adult standard
- It is possible to improve treatment without increasing funding? can we develop more effective treatment more research (MQ £1,517 spent per year on cancer research per patient in comparison to 15p spent per year on eating disorders research per patient).
- Improved early intervention to save money? (£90k per inpatient)
- Role of the third sector?

## Prevention vs. Early Intervention

- Facilitated a recent self support group discussion on this subject
- Prevention is always better than cure
- But the impact of this is far more profound with Eating Disorders

"Had I been more self-confident and better equipped to manage life's challenges, I may not have developed an eating disorder as a way of coping. But one my eating disorder became a reliable distraction from my troubles (albeit subconsciously), it took years to undo. Nobody could help me, until I was ready to be helped."

#### Prevention

- Young people struggle to manage life search for a way to cope.
- Eating disorders, OCD, self-harm, depression, alcohol abuse, drug abuse, unsociable behaviour, disassociation, etc.
- Early stage identification of stress factors that could manifest themselves as mental health coping mechanisms will help prevention of all of the above.

### Prevention In Schools

#### Holistic PSHE:

- Managing stress, dealing with bereavement, developing self esteem, balanced nutrition, positive exercise, social skills, mind/body connection, mental health awareness.

#### Identifying high risk individuals:

- -Consider use of wellness assessment
- -Understand potentially traumatic events
- -Consider home environment and family mental health
- Identify autism, young carers, family addictions, PTSD, anxiety, depression.

## Early Intervention

- School would benefit from further training to support their position.
- GP's need more education on eating disorders:
  - Some received as little as half a day in 7 years education
  - BMI criteria can be unhelpful and often extremely damaging
- Easier referral system e.g. GP to ED Team
- Access to community support for sufferers and carers to avoid hospitalisation at crisis point
- Greater funding and collaboration with community based services

## Early Intervention (continued)

- Early intervention may not stop an eating disorder from developing...
- But a lack of support may encourage it to take hold
- Inappropriate intervention often results in the development of more serious and complex issues:

Increased/ repeated trauma, latrophobia (fear of doctors), feeling of unworthiness or not being 'ill enough' to warrant help.

Multiple visits, assessment, referrals, measurement and use of scales can often be as bad (or worse) than no help at all.

## Other Considerations

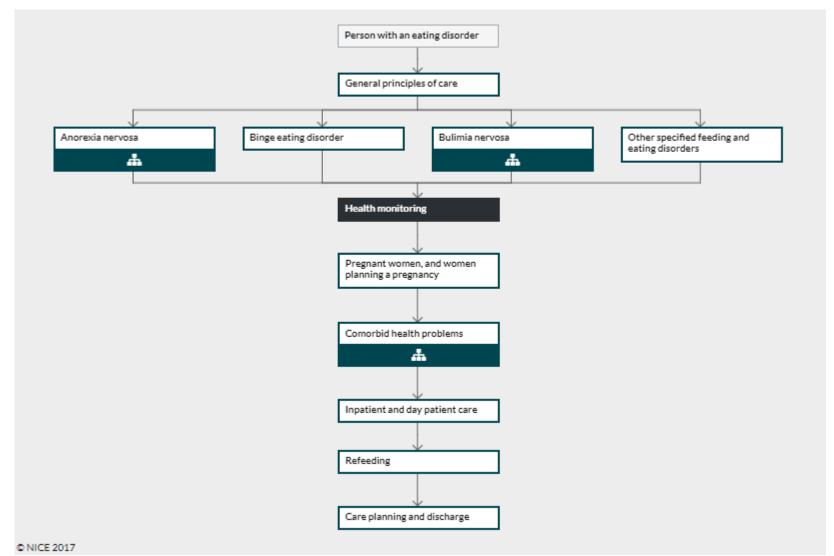
- Ultimate aim is to understand and treat underlying issues in the community.
- Shelley's personal example sexual abuse, dysfunctional family dynamics, violence in the family, alcoholism in the family, disassociation, depression, bulimia, attempted suicide lack of support inhibited recovery, further self harm, anorexia and anxiety.
- Appreciate importance and social connections, good communication and community support to avoid a snowball effect.
- Imperative to provide education and support to loved ones supporting the person affected by an eating disorder.

## Conclusion

- Prevention is possible with appropriate PSHE, support and appropriate treatment interventions.
- Identification of potential traumas/increased risk factors allow for prevention
- An eating disorder is often a side effect
- Long term recovery only possible is treatment is appropriate to cause.
- Early assessment = less traumatic treatment experience
- Appropriate support = less complex and traumatic recovery

## What Do the NICE Guidelines 2017 say?

Managing eating disorders



"Do not use single measures such as BMI or duration of illness to determine whether to offer treatment for an eating disorder"

- NICE, May 2017

## Questions?