Obsessive Compulsive Disorder (OCD)
Information Event

(Notes taken by Deryn Sparrow, Mental Health Involvement worker)

Wednesday 9th March 2017

Speakers: -

Dr Davis Mpavanenda –, Principal Cognitive Behavioural Psychotherapist, Hertfordshire Partnership University NHS Foundation Trust (HPFT). Part of his role is to support/advice staff teams throughout NHS England with treatment resistant OCD, he works with very few individual cases.

Jenny Robinson is a qualified counsellor who facilitates a support group for carers of people suffering with OCD, as well as a support group for OCD sufferers. Jenny has personal experience of caring for her son who had OCD until the age of 23 and is now in remission from the disorder. She also introduced **Jim** tell us about his experiences of OCD

Carers in Hertfordshire invited the speakers to talk to the group and to cover the following information:-

- What is OCD?
- How to recognise the signs
- What treatment is available
- Where to find support
- The best ways in which carers can support people with OCD

Davis spoke first and asked carers present what they would like to know. I've included copies some of the flip charts notes recorded during the presentation.

Carers Questions

- Is it true ADHD, Autism and OCD go hand in hand
- Is OCD likely to come out of nowhere,
- Risks to having OCD
- Conventional Medication treatment/counselling treatment/trauma treatment
- Alternative treatments
- OCD and stress, vulnerabilities
- Dealing with family members when they are not willing to get treatment
- OCD & Hoarding
- OCD/Anger/Learning difficulties
- Rituals and OCD

*See appendix 1

OCD has 2 elements –

1. Thinking - ”What if”, doubts, compulsive thoughts
2. Behaviours – we see the behaviours but cannot hear the “what ifs”.

*During his presentation, to highlight some of the difficulties people have Davis walked constantly from side to side, at times asking people to stop what they were doing (e.g. nodding, coughing) because it meant he had lost concentration and had to start again before moving on. We see him pacing, we hear what he says but we don’t know what he is thinking!

Treatment Themes

a) Thoughts can often be doubts i.e. “am I really awake or is this a dream”? Need to keep checking this. This can become very compulsive leading to frustration/anger because others do not understand. Thoughts/Compulsion/Actions.
b) OCD can make decision-making difficult/impossible – e.g. “what if” I choose orange over apple, should I have both.
c) The person knows it is senseless but cannot stop.

d) People are not always aware of thoughts, usually work with behaviour rather than compulsion.
e) There are often links to OCD rather than causes, it can start in early years or later in life. The links may be genetic, environmental, infection, trauma, threats or other. Family history of Anxiety disorder sometimes affects OCD. Many things can impact on OCD i.e. Depression, Post-Traumatic Stress Disorder (PTSD), Drug/alcohol misuse, these are all links rather than causes. People become consumed with intrusive thoughts (intruders). Treatment always focuses on the trauma. Example:- If I achieve I'll be fine, but "what if" I don't achieve. Just the thoughts of non-achievement cause anxiety, the person then feels anxious.
f) Stress may not affect OCD or it could make it worse. No hard set rules.
g) OCD works in waves and sometimes it returns, sometimes not, maybe the symptoms go away. You can have a trauma and recover. Helping to have the tools to have management

*see appendix 2

Dealing with family members who are reluctant to get treatment

Try to imagine what it is like to have some of these thoughts

- I know it's affecting me, if I report it how you can help me.
- "What if treatment makes it worse" changes can be very difficult
- Fear of pain – too risky

People can get preoccupied with thoughts, get stuck and it becomes a habit. Try a change of environment, do something different!

Medication may help, but not always
Maximise things that need improvement, encourage the person to have a go e.g. try the medication, it may work but you won't know if you don't try.

OCD can destroy families, friendships and confidence – medication/therapy may reduce things, give it a go!

Is medication a sticking plaster? – Davis does not believe it is. Need to remember you cannot leave OCD, it is with the person 24/7. Medication may help but not everyone benefits.

Cognitive Behaviour Therapy (OCD)

- Standard treatment is ERP exposure & response prevention
- Davis described this as putting your head in a lion's mouth when it had not eaten for 10 days!
- Person needs to be ready for treatment; it may be good while with the therapist but doesn't work when you get home if not ready.
- What is the behaviour impacting? (* demonstrated this while pacing.) Target is to reduce behaviour, how to do this in a gradual way. It is important to work on this every single day.
- Anger doesn't cause OCD but interrupting the sufferer during rituals may cause them to be angry. "I was just about to finish this ritual, now I have to start again, you don't listen!" (*demonstrated while pacing)

Q. How common is it for OCD to manifest in different ways? To demonstrate this Davis used an example carer had shared.

Person compelled to hold his breath affecting

- Eating,
- reading (stuttering)
- compulsive spitting (not wanting to swallow)

This becomes a ritual trap

- Treatment Target is Behaviour – holding of breath
- Impact of holding breath (consistent?)
- identify the fear – sensory? Fluff from jumper in mouth
- Aim – to show that nothing will happen if fluff in mouth.
- Encourage person to try this and then to repeat – Tough love is needed

*see appendix 3

Media Coverage

Q. Do you think the media trivialises OCD? –

A. It can show how OCD impacts on all, not sure if this trivialises it. It can raise awareness of how this affects family members and friends as well as the sufferer, which is important.

TV hoarders – Often negative exposure but good that it raises awareness. Always need to remember it sells TV, encouraging people to watch.

Jenny told us a little of her background as a carer and her experiences facilitating separate support groups for those suffering from OCD and also those caring for people suffering from OCD.

She spoke about how her support groups are run, the format of them and the benefits of meeting others in similar circumstances

OCD carer support groups:-

- Groups are a good way of sharing experiences, to hear what has helped others and to gain information
- The importance of hope
- Opportunity for carers to share how they really feel, the relief of being able to talk to others who have a real understanding of their situation, i.e. understanding the stigma around OCD
- It's a social event

OCD sufferer support groups have similar benefits to the carers support groups plus:-

- Sufferers in recovery help other members and give hope
- Have a common understanding about how it feels to have OCD and the impact of having it
- Members can share experiences, with each other about what has helped them most and support and encourage each other with their recovery.
- It's a social event

Whilst preparing for speaking at the meeting, Jenny asked her son what he felt had helped him most? His reply was, "You never gave up in your belief in me and that I would be able to manage my OCD, you saw me as your son not the condition". He felt nothing could be done about his OCD until he wanted to work on it. Jenny's son suffered severely from OCD between the ages of 16 – 23 at the age of 25 he wrote a few notes about his own self-help and engaging with therapy. See appendix 4

Jenny said those suffering from OCD can also help themselves (apart from medication and CBT) by having counselling for the underlying issues that drive their OCD, exercising regularly, eating healthily, socialising and talking to others in a similar situation (attending support groups).

Jenny finished by reminding us that as Carers we often lose sight of our own needs, it's important to have outside interests and normality. We need talk to people about OCD, not keep it hidden, it's nothing to be ashamed of.

To find out more about Jenny and the services she offers by visiting her website http://feellighter.co.uk

Jim – who attends Jenny's OCD group for sufferers and agreed to speak about his experiences:-

- He first experienced OCD aged 29 years, it was a complete surprise. He had intrusive thoughts and many "what ifs". He thought he was going crazy and eventually had a breakdown and told his wife who supported him to get help and go for counselling
- He felt better with the label of OCD, it allowed him to move on.
- He has had 3 relapses, always having negative thoughts – "what if I'm a bad person". Contamination, I try to solve mistakes, often misremember, OCD always remembers the negative!
- Counselling for the underlying issues that drive his OCD

Alcohol (a beer) sometimes seemed to be the answer, but it's not and he has found other ways to escape his anxieties.

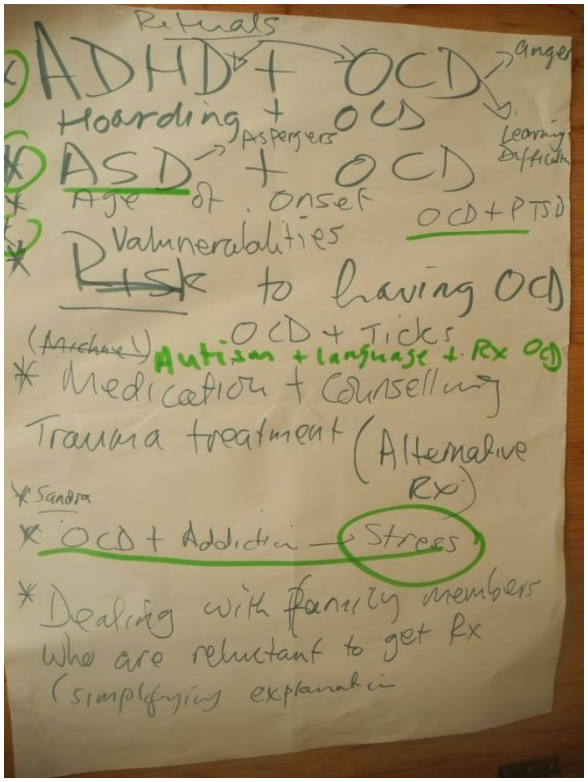
- Mindfulness training – pay attention to the here and now, not judgementally, eventually the anxiety passes
- Exercise is a big part of his life and really helps

A big thank you to Davis for providing us with an informative, interesting and inspiring afternoon, carers who attended said it has given them all a better understanding of OCD. Here are some of the important points that came up during the session

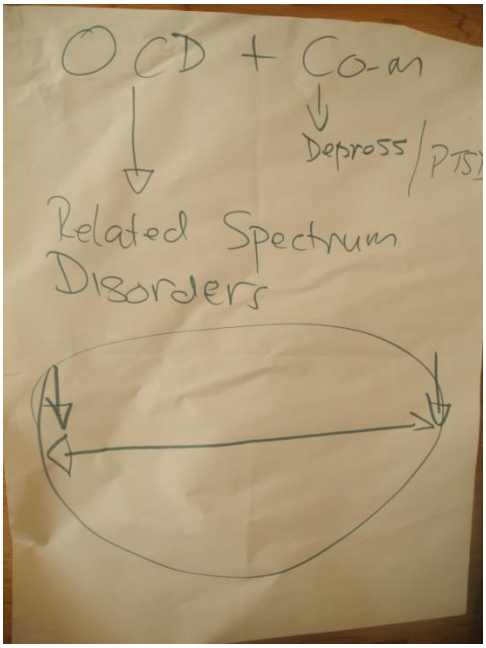
- All cases need to be looked at individually and treatment for everyone is different.
- Importance of helping person affected to have the tools to have better management
- Tough Love is difficult but often needed

Thanks also to Jenny for sharing her own experiences of caring for an OCD sufferer and running OCD support groups and how they can help. Huge thanks to Jim, who was brave enough to share his experiences with us. A big apology that we overran and many were not able to stay and hear what he had to say.

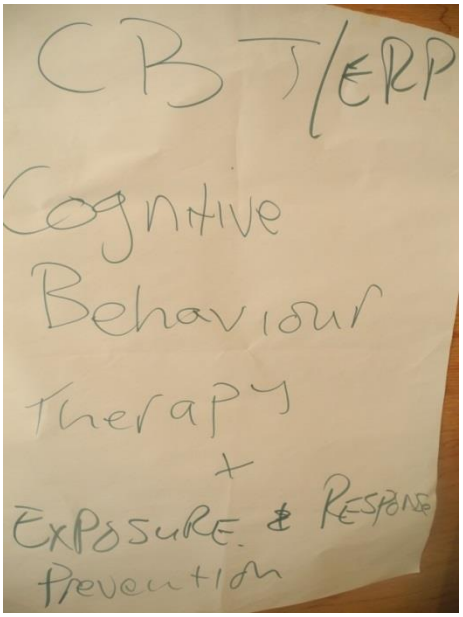
Appendix 1



Appendix 2



Appendix 3



Appendix 4. Written by son of Jenny Robinson , aged 25 who suffered from OCD between the age of 16 – 23 he is now in remissio from the disorder.

SELF HELP

- Therapists are only able to help those who are fully willing to accept help.
- By the same token you can only gain the help necessary if you are fully honest with your therapist.
- I lied to my black therapist saying I had racist thoughts as I felt this was better than telling the truth but it just slowed progress.
- Lack of sleep, poor eating and alcohol only perpetuates the OCD symptoms in the same way that giving into the thoughts and carrying out rituals perpetuates OCD behaviours.
- OCD is an anxiety based disorder thriving upon extremely high anxiety levels, sufferers believe the rituals reduce anxiety, however this is just a 'quick fix'.
- Ignoring the compulsive thoughts/ fighting rituals will eventually reduce anxiety over time.
- By ignoring the thoughts or resisting carrying out a ritual you will rewire your brain teaching yourself that this actively works to reduce anxiety. This teaches and rewires the brain in a similar way to the 'naughty step' technique used on badly behaving children.
- Sufferers will notice a reduction in the frequency of compulsive thoughts through the above 'ignoring' method spurring on progress.
- This results in a slow but steady snowball effect which gathers momentum as you reach your goal of an OCD free life,

ENGAGING WITH THERAPY

- Start with achievable OCD thoughts to ignore or small rituals to tackle (exposure therapy).
- Never 'keep' an OCD comfort behaviour as a safety blanket as this is a weak point for relapse.
- Make sure you have a therapist you trust.
- Trust is essential for exposure therapy to work.
- OCD is not individual to the sufferer, everyone has compulsive thoughts, it is how we react to them that defines us as having OCD
- The therapist will have heard about the symptoms and manifestations of the sufferers OCD many times before with other patients, so do not be afraid to be honest.
- I was told my therapist's wife had thoughts similar to mine but just dismissed them making me feel more comfortable with my therapist.
- Most people with OCD often think they are bad because of the thoughts in their head. However the reduction in frequency of the thought when starting to ignore them will help you realize that you are not a bad person and have just been caught up in a cycle of OCD.