

Hidden harm in families living with dementia

- Bracknell Older People's Mental Health Services (CMHT OA)
- (BHFT and BFC)
- Vicki Brown and Mari Longworth

Personal history:

- Octogenarian male born in Caribbean into a large family. Agricultural background
- Married with younger wife (20years) and 3 children and one son from extramarital affair

Premorbid personality:

- Sensitive to perceived threats of direct social control (when punishment is threatened or applied for wrongful behaviour and compliance is rewarded by parents/family/authority figures). He often mentions feeling “persecuted” by those he sees as authority figures (police, doctors, DVLA).
- Mr X saw himself as a head of House

Psychiatric history:

- Referred to memory clinic with memory issues in 2018
- Seen in February 2019 and diagnosis mild cognitive impairment and review in 6/12
- In August 2019 review given dementia diagnosis and referred to dementia advisor (DA) for post diagnostic support
- During DA review – wife reported to DA how husband can become very angry and argumentative
- Referred to CPN due to increased risk, paranoid thoughts about his wife, which included thinking she was being unfaithful, becoming irate when she is on the phone and following a police incident. Paranoid thoughts about what he considered “social authority” – refused to engage with Consultant Psychiatrist but agreed community Psychiatric Nurse (CPN) engagement
- He had been told not to drive due to his dementia which exacerbated the risk towards wife.

- Incidents with son's who were protective towards mum
- Wife was furloughed during Covid lockdown and it was noted that Mr X's behaviour eased as he was able to monitor wife
- June 2020 - > wife returned back to work and soon after Mr X started to become more agitated and paranoid of her whereabouts and wanted to start to drive the car. He attempted to drive off; however, the car stalled due the battery been not been charged and the attempt failed. This caused anger in Mr X
- Grandchildren frequently visited the house and there was an incident with a knife

Psychological factors influencing behaviours

Pre-existing relationship

History of controlling/ coercive relationship/ jealousy/ paranoia and suspicion around relationship

Dementia

Brain changes that may increase risk

May include brain changes (damage) that mean behaviour is harder to inhibit/ less resources to problem solve or manage emotions/ memory issues

Changing over time as dementia worsens

Risk of coercive behaviour / verbal and physical aggression

Person with Dementia

Maybe historical issues of fear of authority figures / previous trauma

Awareness that their life is changing Vs lack insight

Loss of self esteem/ sense of control

Fear

Time shifting – poor memory

Partner

Have lived with risk for a long time

Issues of guilt/ shame/ low self esteem/ fear/ feels loyal towards partner

Sense of responsibility to care for other person

Difficulty trusting others including services – can feel risky to engage

Hard to tolerate very mixed feelings fear, love

**Cohort issues – beliefs ‘get on with it’, stiff upper lip
Physical health difficulties, dependency, changing roles**

Actions:

- CPN to engage with wife by phone call during her work time to avoid confrontation by husband due increasing concern of the risk of domestic violence
- Home visits were then changed to telephone contact due to COVID-19 due Mr X receiving shielding letter to monitor his mental health
- But also CPN to engage with wife by phone call during her work time to avoid confrontation by husband due increasing concern of the risk of domestic violence
- During every call, brief risk assessment of her wellbeing and also crisis numbers provided as well as Berkshire Women's Aid
- Safeguarding concern discussed with wife; however she did not wish pursue. Plan to monitor by CPN interventions.
- Information about dementia was provided to the family members (wife and son's) and Life Story work
- Mr X was referred to psychology for behavioural support planning
- Children's service contacted and information shared
- Complex Case Forum with multidisciplinary attendance
- Started on antipsychotic treatment (covertly) – was deemed to lack capacity
- Referred to Multi-Agency Risk Assessment Conferences (MARAC)
- Professional meeting with wife – risks discussed and reviewed. Since medication has been able to manage the behaviours by walking away.

Outcome:

- Mr X's mood stabilised with appropriate treatment and family having more understanding on dementia
- Wife did not wish to continue to engage with the services
- Referred to BHFT Positive Risk Panel Forum to support decision to discharge from services

Psychological input to help manage situations

Education

- Understanding of brain changes and how these impact situation – different to before the dementia
- Appreciating it is a dynamic changing process – responses need to change as brain changes

Carer support

- Helping the carer understand, comes to terms with changes
- Address unhelpful beliefs that contribute to guilt, shame and not accepting support

Minimising risk and changing responses

- How to minimise risks and triggers - how to keep the person with dementia settled
- Considering alternative responses to the past eg not confronting / asserting and managing the emotional difficulties associated with this

THANK YOU!

Any Questions?