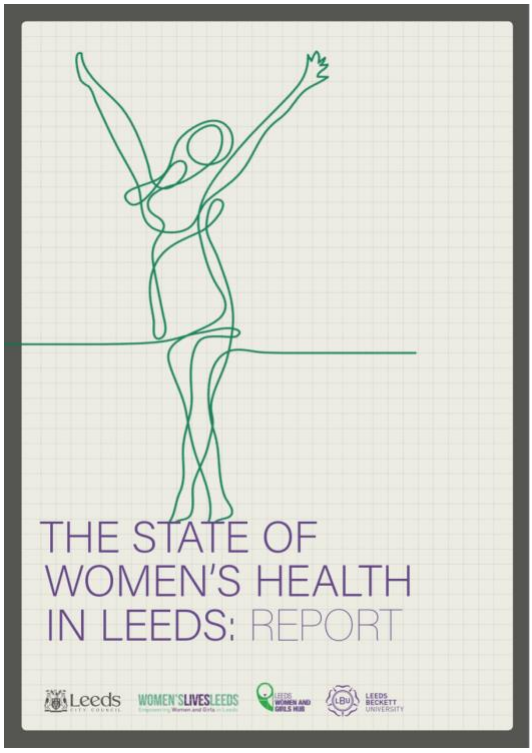

White A., Erskine S., and Seims A (2019) The State of Women's Health in Leeds, Leeds City Council, Leeds

8. Mental Health

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8.1 Introduction

The Adult Psychiatric Morbidity Survey (APMS) is a population survey of mental health disorders in adults, carried out every 7 years in England. The most recent report (McManus et al. 2016) highlights a number of key issues concerning women. Rates of common mental health disorders (CMHD) across England have remained relatively stable over last 10 years, however, proportional rates of moderate/severe CMHD have increased – this is driven by the deteriorating mental health of women. Young women (aged 16 – 24 years) were identified in the APMS as a group particularly 'at risk' of a range of mental health problems. Rates of self-harm amongst young women have tripled since 1993, and today's young women are three times more likely than young men to experience post-traumatic stress disorder and eating disorders (McManus et al. 2016).

The percentage of women and men with serious mental illness (schizophrenia, psychosis and bipolar disorders) is similar in the population overall, although the pattern across the life course may be different, with men tending to develop psychosis at a younger age and women later on in life (McManus et al, 2016).

Some women appear to be at greater risk of mental illness and may struggle to access treatment and support that meets their needs. Black women have significantly higher rates of CMHD than White British groups, but as a group are less likely to receive mental health treatment (McManus et al. 2016). Asylum seekers and refugees, Gypsy and Traveller groups, women who are homeless and street sex workers are also at significantly increased risk of mental ill health (Davies 2015; McManus et al. 2016).

The reasons for the poor mental health of women is complex but may include: increasing levels of domestic violence/abuse and the pressures associated with online culture, social media and pornography. Austerity has also had a disproportionate impact upon women, with 86% of the burden for recent cut-backs falling on women (Stewart, 2017) .

The apparent deterioration of women's mental health occurs within a context of a reduced national policy focus on the mental health of women and girls. The Mental Health Foundation, in its report '*While your Back was Turned: How mental health policymakers stopped paying attention to the specific needs of women and girls'* (MHF 2017) recommends increased attention to gender across mental health policy including:

- Clearly identified government structures for sustained leadership and action to improve young women and girls' mental health.
- Action for young women and girls' mental health using a whole community's approach.
- Systematic collection of disaggregated (gender, age and other protected characteristics) data on mental health outcomes.

Local analysis of the experiences of specific groups of women in Leeds highlighted high levels of mental ill health/morbidity in some parts of the city's female population.

- Of the 126 people who took part in the LGBT Leeds LGBTQ+ Mapping Project, 30% said they had a 'mental health condition such as depression, schizophrenia or anxiety disorder' and 90% reported having a mental health experiences(s) that impacted severely their day to day functioning in the last five years (Stewart, 2017).
- A recent health needs assessment of sex workers (commissioned by BASIS in Leeds), found that over 85% of the 63 women involved had a mental health disorder (Finnigan, 2015).
- A qualitative survey carried out by Leeds Beckett University into the mental health needs and experiences of Black women born outside of the UK found that's stigma, loneliness, language barriers, previous trauma and stress associated with asylum process impacted significantly upon their mental health and that his was compounded by: *'limited access to culturally appropriate mental health services'* (Woodward et al. 2016).
- University counselling services note the increasing levels of emotional distress in the student population (Erskine, 2018).

Case study 1 Mary

I came to Women's Counselling and Therapy Service (WCTS) after a recommendation from my CPN. I had been hospitalised for a physical illness from which I was not recovering as expected, luckily my GP realised that there was not only an underlying physical cause but also a psychological one.

I was diagnosed with a form of PTSD and gradually admitted that for the last five years of my marriage I had been physically, mentally and emotionally abused. I didn't realise this at the time as it was 'normal' for me, I abhorred such things when I heard of it happening to other people but could not recognise it in my own life.

When I first came to WCTS I was awaiting surgery to repair the physical damage that had been done and thought that this would be the panacea, unfortunately I had to have operations that have left me with constant physical reminders.

Counselling not only got me through this time but took me back through previous relationships and taught me that there had been a pattern of abuse going back to my childhood. I learnt that it wasn't me hiding what was happening in these relationships I expected this behaviour because I have never known any different.
Now I choose to be single and I'm actually happy finding out who the real me is. I was made redundant last year and this has been a great opportunity to leave the past behind. I have gone back to study to do counselling in community settings; this will be my way of giving something back to those people who enabled me to start my life.

[1]Name Changed

1.1 Common Mental Health Disorders

Common mental health disorders (CMHDs) cause marked emotional distress and interfere with daily function. They comprise different types of depression and anxiety including: generalised anxiety disorder (GAD), panic disorder, phobias, and obsessive compulsive disorder (OCD). Symptoms of depression and anxiety frequently co-exist, with the result that many people meet criteria for more than one CMHD. If left untreated, CMHDs can lead to long term physical, social and occupational disability, and premature mortality.

Locally, twice as many women are recorded as having a CMHD in Primary Care as men. When individual CMHDs are considered, this pattern remains, with the exception of Post-Traumatic Stress Disorder (PTSD) where rates are similar, and OCD where differences are less marked.

There has been an increase in the number of males and females affected by depression and anxiety across the city over the past year (Figure 1), with the biggest increase seen in anxiety for females.

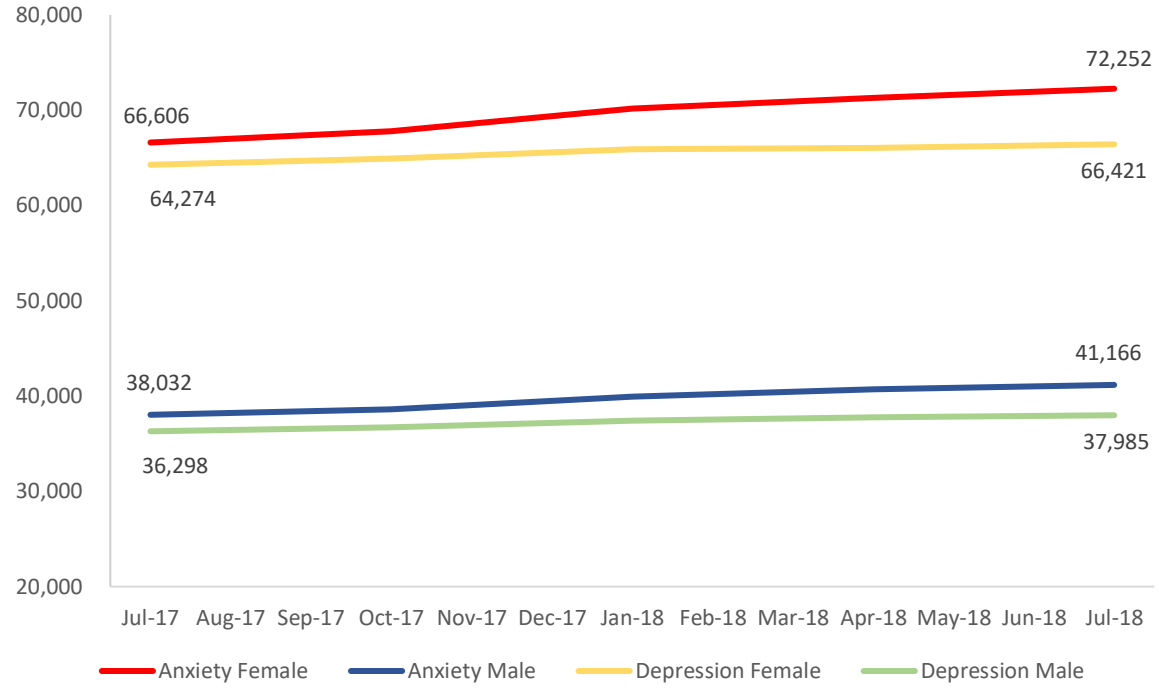

Figure 1 Trends in anxiety and depression for females and males 18+ years, 2017 - 2018, Leeds

1.2 Serious Mental Illness

Serious Mental Illnesses are usually defined as Psychotic Disorders (including schizophrenia, schizoaffective disorder, and affective psychosis) and Bipolar Disorder. Psychotic disorders produce disturbances in thinking and perception severe enough to distort understanding of reality. People with a psychotic illness can make a full recovery, although some will have repeated psychotic episodes over their lifetime and/or some degree of persistent disability. There is significant comorbidity between these types of mental health problems and physical health conditions such as diabetes. Mechanisms for this comorbidity are complex, although are broadly related to: lifestyle factors, medication side effects and barriers to healthcare.

Evidence shows that people with Serious Mental Illness (SMI) die, on average, 15 – 20 years younger than the general population (Davies 2014).

The APMS did not report variation in rates of psychotic disorder across other ethnicities or between the sexes that met statistical significance – this does not mean that these differences might not exist, but rather that the sample size was too small to be able to detect them. Locally, recorded rates of SMI within Primary Care are broadly comparable.

1.2.1 First Episode Psychosis

First episode psychosis (FEP) is defined as the first time someone experiences disturbances in thinking which may include delusions or distort reality. Early intervention in psychosis is a key service/intervention which can reduce the early negative impacts of FEP and improve longer term outcomes.

National incidence modelling of FEP via www.psymaptic.org underestimates local service need consistently in the North of England – for reasons that are not entirely clear. Therefore, NHS England has advised local areas to review service use and pathways and use a specific formula to inform decisions about likely future incidence. Mental Health Service providers, NHS Leeds Commissioners and Public Health have worked together to agree an incidence in Leeds of 32/100,000, which is much higher than the figure of 24/100,000 estimated by www.psymaptic.org.uk.
The onset of psychotic disorders in women tends to be later in life than in men, with a peak post menopause. Reasons for this are unclear, although there is developing consensus that decreasing levels of oestrogen (which operate protectively on the brain) around the time of the menopause increase the risk of psychosis (Ochoa et al. 2012; Falkenburg and Tracy 2014).

1.2.2 Dual Diagnosis

Dual diagnosis is defined as co-morbid severe mental illness and substance misuse. People with dual diagnosis often have other co-existing physical health problems. Forward Leeds data indicates that a higher proportion of women than men have a diagnosed mental health condition when they first access treatment (Table 1).

Table 1 Episodes in Treatment for dual diagnosis: Forward Leeds

	Yr 16/17			
	Dual Diagnosis	No Dual Diagnosis	Total	Total with DD
Female	613	1367	1980	31%
Male	970	3213	4183	23%
Total	1583	4580	6163	26%

	Yr 17/18			
	Dual Diagnosis	No Dual Diagnosis	Total	Total with DD
Female	611	1464	2075	29%
Male	917	3404	4321	21%
Total	1528	4868	6396	24%

(Source: Forward Leeds)

The relationship between having a substance use disorder and a mental illness is complex. Studies have shown that co-morbidity varies by substance type, severity of substance use and psychiatric disorder. There is often a relationship with trauma which can lead to an increased likelihood of someone experiencing substance use/mental ill health. In turn, having a 'dual diagnosis' increases risk-taking behaviour and risk of harm (Schulte and Hser 2014). Young women in particular have been shown to be more susceptible to comorbid substance use and mental illness, rates.

In a primary care population of young people aged 14 – 18 years old, girls with substance use problems or substance use disorder had increased odds of reporting symptoms of mania, attention deficit disorder, and conduct disorder (Shrier et al.

2003). Girls with substance use disorder were also at increased risk for symptoms of depression, eating disorders, and hallucinations or delusions

In comparison with men, women with co-occurring substance use/misuse and mental health disorders are more likely to stay in treatment for longer (Choi et al. 2015).

1.3 Eating Disorders

Eating disorders are a group of serious mental health conditions, characterised by persistent food intake disturbance. They can cause people to adopt restricted eating, binge eating and compensatory behaviours (such as vomiting and excessive exercise). They are associated with high morbidity, and sufferers have a significantly higher mortality rate than those without the disease from malnutrition, suicide and physical issues (such as electrolyte imbalances) (NICE 2017a).

Eating disorders predominately, but not solely, affect women, and commonly develop in teenage years. They are often comorbid with other physical and mental health disorders (including anxiety disorders) that are reported to affect the wellbeing and recovery of people with an eating disorder and raise the cost of treatment (NICE 2017a).

The 2007 national Adult Psychiatric Morbidity survey (APMS) highlighted the likely gap in epidemiological data due to under-reporting and under-diagnosis of eating disorders (McManus et al. 2009). In the 2007 study the 'SCOFF' survey tool[1] was therefore used in order to detect attitudes and behaviours associated with possible eating disorders in a large population sample. 20.3% of young women (6.1% of men) aged 16 – 24 years scored two or more (the clinical threshold for diagnosis of an eating disorder) on the SCOFF scale within this survey. The APMS reports that the prevalence derived from this tool likely to be an overestimation

[1] **The SCOFF questions** (Morgan F et al. 2000)

- Do you make yourself **S**ick because you feel uncomfortably full?
- Do you worry that you have lost **C**ontrol over how much you eat?
- Have you recently lost more than **O**ne stone (14 lb) in a 3-month period?
- Do you believe yourself to be **F**at when others say you are too thin?
- Would you say that **F**ood dominates your life?

Applying this percentage to the female Leeds resident population aged16 – 24 years suggests there may be 13,000 young women with a possible eating disorder in the city.

1.4 Self-Harm and Suicide

Self-harm (non-fatal intentional self-poisoning or self-injury, irrespective of degree of suicidal intent or other motivation) is a key risk factor for suicide. It is suggested that at least half of people who die by suicide will have engaged in self-harm at some stage in their lives, often shortly before death (Davies 2015). However, the relationship between suicidal ideas, self-harm and suicide is not straightforward. The overall profile of people reporting suicidal thoughts, attempts and self-harm is very different (in terms of age and sex) from that of people who take their own life, and the great majority of people who engage in these thoughts and behaviours do not go on to die by suicide (McManus et al. 2016).

1.4.1 Self-Harm

The National Institute for Healthcare and Clinical Excellence (NICE) define self-harm as any type of self-poisoning or self-injury irrespective of motivation (NICE 2013). A range of behaviours constitute self-harm, including cutting, burning, punching, swallowing objects, head-banging, pulling out hair or eyelashes, and inhaling harmful substances (Laye-Gindhu and Schonert-Reichl 2005; Stänicke et al. 2018). As a behaviour, self-harm is associated with a range of mental health problems, including borderline personality disorder, depression, and schizophrenia (NICE, 2013).

The APMS (2016) reports a sustained increase in reported self-harm between 2001 and 2014. This increase was evident in both men and women across all age groups, however, young women were noted as a particular risk group. 25.7% of women in this population survey reported ‘ever’ self-harming,

Using this rate and applying it to the Leeds female population aged 16 – 24 suggests there may be 16,000 young women who have 'ever' self-harmed.

1.4.2 Suicide

Suicide is considered as mainly a male issue, but it is still a significant cause of premature death in women and is just as devastating for all concerned (Mallon et al. 2016). Suicide is the leading cause of death in women aged up to 34 years (ONS 2018i), and in Leeds resulted in 30 female deaths between 2014-2016 (a rate of 2.4 per 100,000). The Leeds Audit of Suicide and Undetermined Deaths (Everitt et al. 2016) assesses coroner's records every three years for the previous triennium. Results indicate that since 2008 there have been more male (176) than female suicides (37). The rate of male death has increased from the 2008-10 audit; however, the rate of female death has not changed.

Data from the ONS show that Leeds has a female suicide rate of 10.3 per 100,000 for the years 2012 to 2014; this is comparable to both the Yorkshire and Humber rate (10.3 per 100,000) and the rate for England as a whole (10.0 per 100,000).

For females in England and Wales, between 2001 and 2007, poisoning was the most common suicide method. In 2017 it is now hanging (42.8%), with poisoning at 36.8%, then drowning (5.2%), fall and fracture (3.1%), and other causes (12.1%) (ONS 2018j).

There are a number of key factors which increase the risk of a woman taking her life. Women most at risk are those who have been abused, either as adults (Trygged et al. 2014; Wolford-Clevenger and Smith 2015; Palm et al. 2016; MacIsaac et al. 2017) or as a child (Bedi et al. 2011). Bereavement, and motherhood (Mallon et al. 2016) have also been associated with suicide in women, with a specific link found between suicide and motherhood, especially for those with existing mental illness (Mallon et al. 2016; Gressier et al. 2017).

Women with gynaecological cancer are at greater risk as compared to women with other forms of cancer (Ward et al. 2013). There are also lifestyle associated risks, including alcohol (Gomberg 1989) and substance abuse (Foster et al. 2016; Stenbacka et al. 2017).

Sexual minority women are at greater risk of suicide than heterosexual women (Tabaac et al. 2016), as are those who are trans (Barboza et al. 2016). Ethnic minority women are less visible in the suicide data, but evidence from America suggests that Asian women are less likely to seek help with emotional difficulties (Augsberger et al. 2015).

Whilst women may have borne the financial impact of austerity, there is no clear link between the recent recession and suicide in women (Coope et al. 2014).

1.5 Adversity and Mental Illness

There is increasing recognition of the link between adverse childhood experiences (ACEs) and the harmful effects that these have on health have throughout life. ACEs include: having parents with mental health problems and/or substance abuse disorders; having experienced violent, abusive or neglectful relationships as a child; bereavement; and divorce. Individuals with multiple ACEs are at increased risk of poor health outcomes, with the strongest associations being between multiple (defined as four or more) ACEs and sexual risk taking, problematic alcohol use and mental illness (Hughes et al. 2017).

A summary of recent research (Sara and Lappin 2017) on trauma concludes:

- Trauma is a common risk factor for a broad range of mental health disorders. These include personality disorders, bipolar disorder, mood substance misuse and psychosis.
- It is associated with reduced responses to treatment in mood disorders.
- Childhood adversity is associated with a 1.5 – 3 x increased likelihood of psychotic experience.

The Centre of Expertise on Child Sexual Abuse Scoping Report 2017 (Kelly and Karsna 2017) reports that 15% of girls (compared to 7% of boys) experience sexual abuse before the age of 16. Modelled Leeds estimates based on this prevalence figure and Leeds GP Registered Populations Mid-2018, suggest that 11,777 girls may have experienced sexual abuse in the city.

There are evidenced, causal relationships between, unemployment, debt and financial strain, having caring responsibilities, being in a violent or abusive relationship, living in built up areas and mental ill health (FPH/MHF 2016).

The Power Threat Meaning (PTM) Framework published by The British Psychological Society (Johnstone et al. 2018) goes further than reviewing such associations. It suggests that: 'emotional distress and troubling behaviour are intelligible responses to social and relational adversities and their cultural and ideological meanings' (p8). It foregrounds the central role that power and narrative play in the development of coping strategies or survival mechanisms, which are often termed mental illness within a psychiatric diagnostic system. The PTM framework may be a useful resource/perspective to employ when considering levels of distress in the female population given its focus upon understanding inequality and the effects of trauma and abuse.

The Visible partnership is a project in the city that brings together a number of key organisations to 'make visible' the impact of child sexual abuse on adults. The focus has been to support organisations in Leeds to be more trauma (or psychologically) informed, this includes statutory, third sector and others within the business community. The partnership has developed a policy statement for organisations to use in order to enable them to better support adults who have experienced childhood sexual abuse, this has now been approved and is being considered for adoption or already implemented by organisations across the city. The project is also achieving wider outcomes including improved information for the public and training/networking events for practitioners.

There is a broad consensus in the city amongst practitioners and commissioners that there is both *a gap in practice* – with mental health services needing to improve how they respond sensitively to trauma, and *a gap in provision* for people who have levels of need above that met by IAPT, but who may not have a psychiatric diagnosis.

Case study 2 Sonia

Sonia[1] referred herself for counselling to address difficulties dating back to her childhood. She had grown up in poverty, being forced to beg round her neighbours as a child. She had been raped as a young child, then sexually abused by a family member until he died when she was an older teenager. After this she was also emotionally and sexually abused by her older brother. She had been in a physically and emotionally abusive relationship with the father of her children for twenty years.

At the initial meeting Sonia was shaking, hyper-ventilating, and barely able to speak. She gave little eye contact. She spoke fast when able to, was in frequent physical pain, and was too afraid to visit a doctor, due to what later emerged was shame. She had poor ability to make choices or ask for anything for herself. She spoke of having no capacity to set boundaries, was constantly exploited by others, particularly her neighbour, and manipulated by her adult children. She rarely left the house and was terrified of anything new.

"I mean nothing to my family and friends. I am never able to say no. Put up and shut up was my way of being a child"

The work of counselling involved establishing a sense of safety, stabilisation and slowing down, working through breath, relaxation and art making. Sonia became able to voice her internal critical voices, learning to manage them and to make better choices for herself. Gradually she began to face her history of multiple abuse, fully understanding the impact this had had on her life, processing the trauma and associated shame. She overcome her fear of doctors, and developed a good relationship with her GP practice, receiving much needed treatment.

Due to concerns regarding the extent of exploitation Sonia was experiencing from her neighbour and the numerous practical difficulties in her life, she was referred to Women's Lives Leeds receiving support from a complex needs worker.

Through this partnership work, her practical needs, including debt management, multiple housing crises, social and medical needs were met in parallel with the psychotherapeutic work supporting gradually increasing self-awareness, esteem and assertiveness**.**

By the end of counselling Sonia's confidence had increased significantly, she was saying "no" appropriately to her exploitative neighbour and children and could identify abusive behaviour and protect herself from it. She was about to move house and planning to find work.
Sonia's feedback
If hadn't been able to come I don't know where I'd be to this day. That's scary to say. I can't praise it highly enough. I could open up in trust and security and I have never been able to do that before. It lifted the guilt and shame I'd carried around with me for SO many years. I learnt how to respect myself from within. I realised it's not my fault what happened to me. I understand now why people took advantage of me. "My sense of being cared for. Now I have learnt to take help and this is HUGE. Once I get my house move, I want to look to the future and go back to work.
[1]Name changed

1.6 The Mental Health of Girls and Young Women

It is estimated that 75% of mental health problems in adult life (excluding dementia) start by the age of 18 years (DH 2015). The APMS (McManus et al. 2016), identified young women (16 – 24 years) as a high-risk group, with high rates of common mental disorders, self-harm, post-traumatic stress disorder and 'likely bipolar disorder'. Young women in the survey had the highest score of any demographic group in terms of prevalence of common mental disorders, with over 25% reporting symptoms in the last week. The gap between young women and men is growing significantly. In 1993, 16 to 24 year old women (19.2%) were twice as likely as men of the same age (8.4%) to have symptoms of CMHD (CIS-R score 12 or more). In 2014, CMHD symptoms were three times more common in women of that age (26.0%) compared to men (9.1%) and a report on student mental health reveals similar findings (Thorley 2017). In 2009/10 first-year male and female students were equally likely to report a mental health condition (0.5% of students surveyed). By 2015/16 this had risen to 2.5% of women but only 1.4% of men.

Research suggests that rates of self-harm in the UK have increased over the past decade within the younger cohort of girls and are thought to be amongst the highest in Europe. An analysis of hospital self-harm presentations reported a 68% increase in 13-16 year old girls between 2011 (45.9 per 100,000) and 2014 (76.9 per 100,000 (Morgan et al. 2017).

Patterns of self-harm in Leeds reflect the national picture. Self-harm hospital admissions data for Leeds indicates that young women aged 15-19 have the highest incidence of self-harm admissions: 297 young women were admitted in 2016–17 compared to 78 young men (Cameron, 2018).

There is evidence to suggest that there is a link between mental illness and social media exposure (Primack et al. 2009) and that excessive use of computers and mobile phones maybe linked to a higher risk of mental disorder in young women, possibly mediated by sleep loss (Thomée 2011). The notion of the 'idealised' body image has also been shown to have detrimental impacts on self-esteem. This is

most notable in young women (RSPH 2017). There are also robust associations between cyber-bullying and mental health, specifically in terms of suicide and self-harm (Daine et al. 2013).

Two local Third Sector organisations (Women's Health Matters[2] and The Marketplace[3]) worked with young girls aged 13 – 19 years old in the city during 2011 - 12 to gather insight about their self-harming behaviour (WHM 2012). It was found that this behaviour was an alternative way of coping with what was happening to the girls. Workers observed that many of the girls experienced low self-esteem and complex emotional situation in their home lives. The WomenSpace service, which is funded by Leeds NHS CCGs, works with those with severe and enduring self-harming behaviours. An evaluation of their services interviewed 12 users of the service (aged 18-60 years) and found that although they did not ask specifically about the nature of their trauma that some spoke of abuse in childhood and experiencing domestic abuse as key factors in their self-harming behaviour (Beckett et al. 2016)

1.7 Social isolation

Social isolation and loneliness are problems that exist across all ages and can have serious health impacts, both physical and emotional. The Government recently launched their first loneliness strategy and appointed a Minister for Loneliness (HM Government 2018), which is following on from the Jo Cox Loneliness Commission (Jo Cox Commission on Loneliness 2017). There are differences that exist between being socially isolated and suffering from loneliness, with social isolation "usually characterised as an objective lack of meaningful and sustained communication, while loneliness more often refers to the way people perceive and experience the lack of interaction" (Poscia et al. 2018); one can live alone and not feel lonely and yet others can feel lonely even when living with a partner.

[2] http://www.womenshealthmatters.org.uk
[3] https://www.themarketplaceleeds.org.uk

There are a number of different reasons for feeling lonely, but the main factors include (ONS 2018k):

- Widowed older homeowners living alone with long term health conditions.
- Unmarried, middle-agers with long term health conditions.
- Younger renters with little trust and sense of belonging to their area.

Being socially isolated and lonely have been shown to be linked to both physical and mental health problems and an increased risk of mortality (Zebhauser et al. 2014; Courtin and Knapp 2017; Leigh-Hunt et al. 2017; ONS 2018k). One of the largest studies undertaken in the UK on mortality and social isolation and loneliness (Elovainio et al. 2017) found that for loneliness, there was no excess mortality other than those mostly associated with depressive symptoms. However, the higher numbers of deaths in those socially isolated as compared to non-isolated individuals could mostly be attributed to differences in lifestyle, socioeconomic factors, and mental health problems. In a study by Liu & Floud (2017) they also found that excess mortality in socially isolated and lonely individuals was associated with socioeconomic status, unhealthy behaviours such as smoking, mental health problems and self-rated health. When social isolation is linked to food insecurity, the risk of mental health problems increases, with women more affected than men (Martin et al. 2016a).

With women generally living longer than men, there are many more women who are at risk of social isolation as with increasing age comes the risk of greater morbidity and multiple morbidity that can lead to difficulty mobilising and retaining old social networks (Pettigrew et al. 2014). Women report more loneliness than men, but this may be because they are more willing to report their experiences (ONS 2018k). There is also an increasing number of divorces over the age of 60 years (ONS 2013b).

Case study 3 Maymoona

Maymoona[1] was a 70 year old Indian woman referred to the Leeds Women's Counselling & Therapy Service by an Asian women's support organisation for individual counselling in the community. She presented with anxiety and memory problems, difficulties sleeping, feeling confused, overwhelmed, tearful and frightened.

Maymoona attended regularly. Her anxiety gradually decreased and her memory appeared to be less debilitating as she told me her fears of growing older without anybody she could depend on. She had four adult children with their own families, and with sadness she told me how she had become separated from them when her husband took a 16 year old wife from India and she was made to leave the family home. Her children remained with their father, and she was ostracised by the community as the divorced woman. Whilst she had recovered contact with some of her children in their adult lives these relationships remained fragile. When she retired she had become isolated and depressed, made several suicide attempts and ended up in psychiatric care. Again, she was considered to have brought shame on the family for having mental health issues.

She explored her fears of growing old on her own, with her increased dependency needs and sense of vulnerability. She gradually became more active, contacting friends, accepting neighbour's invitations, going back to Temple and attending GP and hospital appointments for a range of physical health issues. As her confidence and sense of self- worth increased she initiated more contact with two of her children and although the contact was minimal she started to appreciate the relationships that were still possible.

[1]Name Changed

1.8 Dementia

Dementia is an increasingly common condition that has a major impact on the lives of those affected and those who care for them. It predominantly affects those over the age of 65 years but can occur in earlier life. It was estimated that approximately 850,000 people was affected with dementia across the UK in 2015 and this is projected to rise to over 1 million people by 2025, costing over £26.3billion (Prince et al. 2014).

It is not one disease, but has many different forms, including vascular dementia and Alzheimer's disease, with the common feature of causing memory problems, difficulty with planning, thinking things through, struggling to keep up with

conversations, and sometimes changes in mood or behaviour (Alzheimer's Society 2017). It is a most debilitating disease and a significant cause of mortality and morbidity, with dementia and Alzheimer's disease the overall highest cause of death in women across England and Wales, with 44,532 deaths in 2017 (a sixth of all female deaths) (ONS 2018i). In Leeds the mortality rate in 2016 was 942.8 per 100,000 for women and 856.1 per 100,000 for men, with the rate increasing over time (Figure 2). The rate is also higher in deprived areas, where men have the highest death rate.

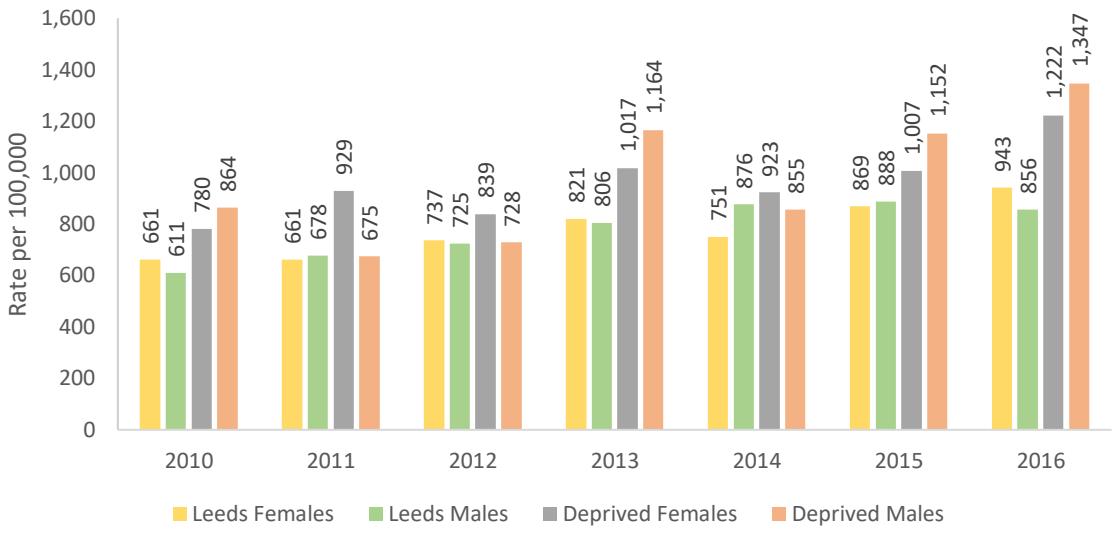

Figure 2 Alzheimer's diseases and dementia mortality DSR per 100,000, Aged 65+ years, by sex and deprivation category, Leeds, 2010 to 2016

Across England the number of people over the age of 65 years with dementia was estimated to be 645,507 in March 2018 (NHS Digital 2018b), with 450,509 actually diagnosed (284,661 females, 165,848 males) (Figure 3). Across Leeds, in July 2018, the rate of dementia in women aged 55+ was 3,096 per 100,000 population and for men 2,463. In 2016 there were 741 female deaths as a result of Alzheimer's diseases and dementia as compared to 402 male deaths.

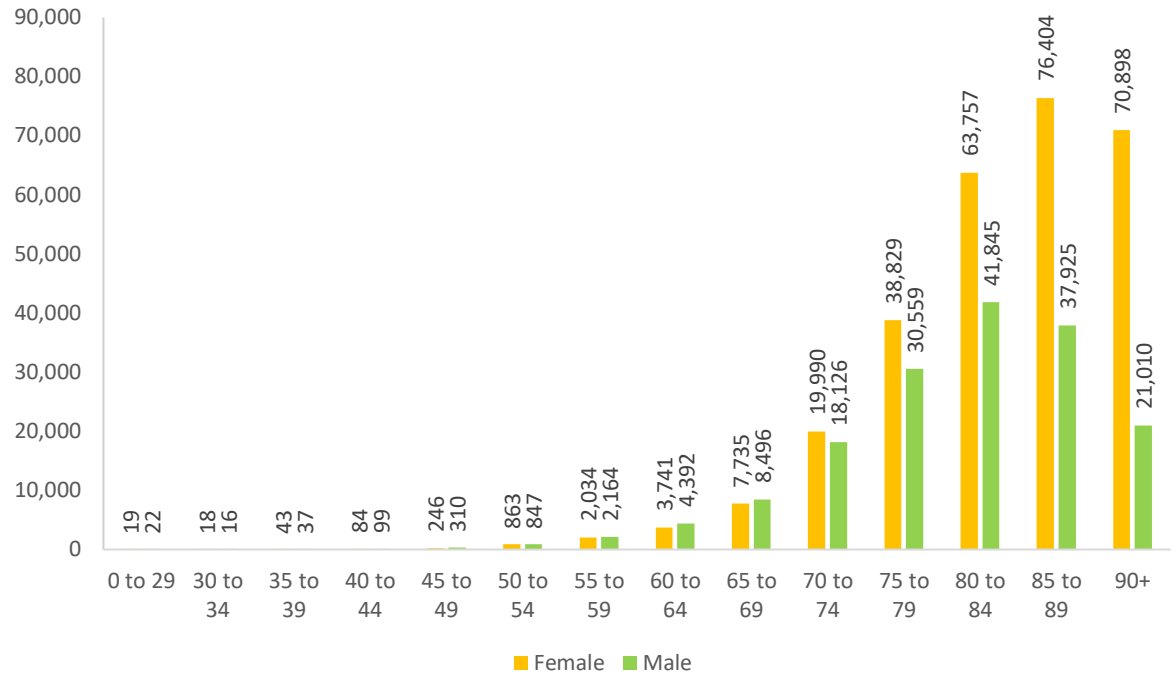

Figure 3 Observed prevalence of recorded dementia, by age group and gender, England, March 2018

There is a link between dementia and deprivation (Figure 4), with the highest prevalence rates found in Harehills (8,185 per 100,000), Meanwood 6 Estates (6,705 per 100,000) and Hunslet Green, Stourton, and Thwaite Gate (6,385 per 100,000). In part this higher prevalence is due to the higher incidence of risk factors in the more deprived areas, such as depression, hypertension, physical inactivity, diabetes, obesity, hyperlipidaemia, smoking and lower educational attainment (Beydoun et al. 2008; Deckers et al. 2015; Chatterjee et al. 2016; Neergaard et al. 2016; Albanese et al. 2017; Sabia et al. 2017; Cadar et al. 2018; Schiepers et al. 2018; Singh-Manoux et al. 2018). There is also a link between being more cognitively active during the working years and the rate of cognitive decline, which is again linked to socio-economic status (Rusmaully et al. 2017).

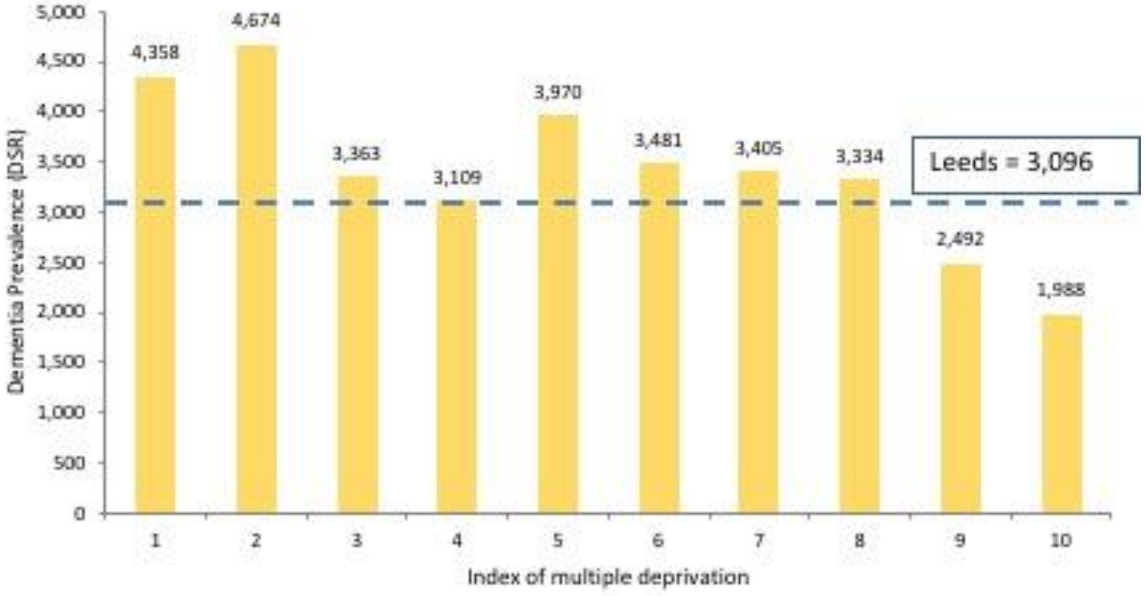

Figure 4 Prevalence of dementia, by deprivation, Leeds, July 2018

Those women with osteoporosis were found to have a higher incidence of dementia (although this might be that a fall in this group of women results in a diagnosis) (Amouzougan et al. 2017). There is also a risk of more advanced cancer at the point of diagnosis in women with dementia through difficulty in seeking help and their recognition of the warning signs and symptoms (Hopkinson et al. 2016; McWilliams et al. 2017).

Age-related hearing loss has been found to be a possible warning sign of further cognitive decline, cognitive impairment, and dementia (Loughrey et al. 2018), with hearing loss being a cause of depression in older women (Li et al. 2014). It is also associated with a greater risk of falling which can add to a woman's fear of frailty and unwillingness to socialise and to maintain important networks (Viljanen et al. 2009).

Women with Alzheimer's tend to have a worse outcome as compared to men across a range of cognitive outcomes (including language and semantic abilities, visuospatial abilities, and episodic memory) (Laws et al. 2016), possibly as a result of the loss of oestrogen in post-menopausal women or a greater protective cognitive reserve in males. In addition to these two factors, there is a growing appreciation of the possible sex and gender differences in Alzheimer's disease that warrant further attention (Nebel et al. 2018). These include lifestyle risk factors such as education,

exercise, and marital status, along with biological risk factors and a result of disease states such as cardiometabolic risk factors, depression and sleep patterns.

For some, there is a steady decline into dementia; for others a more rapid process, but for all there is a marked change in the person who once was, which can put a huge strain on the individual and those now having to take a care-giver role. This can lead to a high level of care-giver stress in those looking after the affected individual, which can impact negatively on their own health and wellbeing and also affect their ability to offer longer-term support.

Lesbian and bisexual women can experience specific difficulties if their partner has dementia, especially in relation to stigma, social marginalisation, and if residential care is required (Westwood 2016; Butler 2017; Fredriksen-Goldsen et al. 2018). A very moving local account of the realities of being a lesbian with dementia and the impact it has on her partner can be found in Rachael Dixey's book (Dixey 2016) "Our dementia diary: Irene, Alzheimer's and me".

Currently Leeds has a relatively small population of elderly women from the BME communities (5.5% of all women over the age of 65 years), but they are at a high risk of developing dementia and the BME population in Leeds is ageing. In a recent national study (Pham et al. 2018), Black women were found to have a 25% greater chance of receiving a dementia diagnosis as compared to White women. Prevalence in the South Asian community was found to be lower, but there was uncertainty as to whether this was a reporting issue.

It is important to recognise that with advances in care, more women and men with learning disabilities are living longer and increasing their likelihood of developing dementia (Alzheimer's Society 2015), with an estimated 1 in 5 over the age of 65 affected and a third affected whilst still in their 50's. This can be particularly challenging for them and their carer's.

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