

West Yorkshire and Harrogate
Health and Care Partnership



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A Scoping study on Maternal Mental Health Services:
Loss, Tokophobia, Birth trauma and
Assisted Reproductive Technology

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1. Introduction

The Chief Medical Officer in her 2014 annual report “The Health of the 51%: Women” (1) highlighted the missed opportunities to support women who had severe

mental health problems as a consequence of their pregnancy and early parenthood. This was picked up in the 2016 Better Births report (2), which was based on a national review of maternity services, as they identified a key area that needed attention was perinatal mental health provision (see Box 1). How this was to be achieved was outlined in the 2019 NHS Long Term Plan (LTP) (3), where it was proposed by 2023/24:

- Extending community services from preconception to 24 months after birth.
- Expanding access to evidence-based psychological therapies within specialist perinatal mental health services so that they also include parent-infant, couple, co-parenting and family interventions.
- Ensuring partners of women accessing specialist perinatal mental health services and maternity outreach clinics receive evidence-based assessment of their mental health and are signposted to support as required.
- Implementing 'maternity outreach clinics'.

Box 1

Better postnatal and perinatal mental health care, to address the historic underfunding and provision in these two vital areas, which can have a significant impact on the life chances and wellbeing of the woman, baby and family.

- There should be significant investment in perinatal mental health services in the community and in specialist care, as recommended by NHS England's independent Mental Health Taskforce.
- Postnatal care must be resourced appropriately. Women should have access to their midwife (and where appropriate obstetrician) as they require after having had their baby. Those requiring longer care should have appropriate provision and follow up in designated clinics.
- Maternity services should ensure smooth transition between midwife, obstetric and neonatal care, and ongoing care in the community from their GP and health visitor.

There is a conservative estimate that there are one in four women who experience mental health problems through their pregnancy (3). Within this number there are women who face particularly challenging and complex mental health difficulties as a result of their pregnancy or birth experience and yet may not be covered by current services. These include those women who have experienced perinatal loss (including miscarriage, termination of pregnancy due to fetal anomaly / or for medical or social reasons, stillbirth, neonatal death, and child removal at birth), severe fear of childbirth (tokophobia) birth trauma. The NHS LTP proposed that these women will be supported through a separate service to be known as Maternal Mental Health Services (formally called Maternity Outreach Clinics).

The purpose of this service is to:

- Integrate maternity, reproductive health and psychological therapy.
- Provide support (or additional support) for women not meeting the threshold for current specialist provision.
- Support women with moderate / complex mental health difficulties arising from, or related to, their maternity experience.

The service would also aim to be inclusive of parent-infant, couple, co-parenting and family interventions where necessary. In addition it would recognise the negative

mental health experienced by 5-10% of fathers and that ‘families’ affected by mental health problems in the perinatal period will include lesbian / bisexual couples (4–7), gay men (8–12), and trans men (13–16)¹. This new service is not meant to replace existing perinatal mental health services (including bereavement services), but to work alongside them. It is also important to note that assessment and signposting to onward support for partners of those accessing services should be equitable with the offer made by specialist Perinatal Mental Health (PMH) teams to minimise variation of service provision.

With the advent of an Integrative Care Systems² approach it opens up the possibility of having a more coordinated means of supporting women and their partners through their maternity and early parenting experience. This could create a new model whereby provision extends to involve a wider range of support services and helps link midwifery services, mental health services and social services with the wider third sector to provide a more holistic and joined up provision.

1.1 Economic case for action

The cost of perinatal depression, anxiety and psychosis was estimated as a total long-term cost to society nearly £8.1 billion for each one-year cohort of births in the UK (17). They further estimated that perinatal mental illnesses carry a cost to the NHS around £1.2 billion for each annual cohort of births, which they compared to the extra £280 million a year to bring the whole pathway of perinatal mental health care up to the level and standards recommended in national guidance. Taken at a per-birth level they suggest that the estimated cost of extra provision is equivalent to about £400 per average birth but left unmanaged perinatal mental health problems can lead to a cost of £10,000 per birth for society as a whole, with costs of around £2,100 per birth being picked up by the public sector.

1.2 Impact of the COVID-19 pandemic

During the writing of this literature review the world has been experiencing the most significant pandemic of the last 100 years. Currently (mid August 2020), there have been globally nearly 20m confirmed cases and nearly 730,000 deaths (18) as a result of the SARS-CoV2 coronavirus. It is too early to know all the ramifications of the virus on pregnancy and childbirth, but its effect will extend beyond the risk of infection into the psycho-social impact of the lockdown and disease impacting on the mental and emotional health of the mother and family on all aspects of this report.

1.3 Methodology

This report offers a comprehensive review of the academic journals, national reports and other desk-based available sources. The report is separated out into the four main areas of concern: Loss, Tokophobia, Birth trauma and Assisted Reproductive

¹ Through the report I will use the term co-mother to represent the experiences of the partner to the birth mother within a lesbian relationship.

² <https://www.england.nhs.uk/integratedcare/integrated-care-systems/>

Technology³. The area of Loss has been separated out into two separate sections, one dealing with loss through bereavement and another focused onto loss as a result of child removal.

Local demographic data is provided to give context and an indication of prevalence, but more detailed analysis of the West Yorkshire footprint is provided elsewhere.

1.4 Local demographic profile

Across West Yorkshire and Harrogate Health and Care Partnership (WY&H H&CP) there are currently 606,728 girls and women aged 13 to 44 years (Table 1), of which 133,720 live in the lowest decile of deprivation (Table 2). There is a large variation in the demographic profile of mothers across WY&H H&CP. With areas of high deprivation across the footprint, with Bradford, Kirklees and Leeds having the highest levels of population from ethnic minority backgrounds (Table 3).

Table 1 Female population, by age, West Yorkshire & Harrogate, 2018

	13-19 years	20-25 years	26-44 years
Bradford ⁴	26,490	20,133	72,952
Calderdale	8,051	6,367	25,048
Harrogate	5,943	3,536	16,529
Kirklees	18,066	15,731	53,282
Leeds	32,376	47,891	101,042
Wakefield	12,212	11,133	42,867
Total	103,138	104,791	311,720

Source of data: ONS Mid-2018 population estimates (19)

Table 2 Female population by age, 1st deprivation decile, 2018

	13-19 years	20-25 years	26-44 years
Bradford	10,240	7,751	26,891
Calderdale	1,435	1,245	4,135
Harrogate	29	14	124
Kirklees	2,799	2,505	7,712
Leeds	8,699	8,847	26,856
Wakefield	2,101	2,005	7,316
Total	25,303	22,367	73,034

Source of data: ONS Mid-2018 population estimates (19)

³ This report includes a section on those women who have conceived through assisted reproductive technology (ART), although not mentioned specifically within the national guidelines for this service it was included as part of the specifications for this study to explore if gaps existed in existing provision.

⁴ Bradford data includes Airedale, Wharfedale, Craven

Table 3 Proportion of mothers giving birth in population characteristic groups by CCG, 2017

	Asian or Asian British ¹	Black or Black British ¹	Mother's Age <20 years ¹	Mother's age >39 years ¹	Top quintile of child poverty ¹	Multiple births ¹	Born at 24 to 31 weeks ¹
Airedale, Wharfedale and Craven	19.1	0.4	2.1	3.6	16.2	2.9	1.3
Bradford City	66.8	3.6	3.5	2.8	60.1	1.90	2.1
Bradford Districts	36.1	1.8	3.3	3.3	32.9	3.2	2
Calderdale	17.2	0.6	3.4	3.1	26	1.9	1.1
Greater Huddersfield	18.7	3.4	2.9	3.9	22.8	1.8	1.4
Harrogate and Rural District	1.1	0.6	1.6	4.9	0	3.1	0.7
Leeds	11.4	7.2	3.4	3.9	35.8	3.1	1.2
North Kirklees	35.6	0.7	4.2	2.7	18.1	2.7	1.6
Wakefield	5	1.5	4.4	2.7	18.1	2.5	1.1

¹Percentage of all births in each commissioning organisation which fall within this category
Source of data: MBRRACE 2019

Across West Yorkshire and Harrogate 32,436 women were booked into maternity services in 2019 (Table 4).

Table 4 Bookings across West Yorkshire & Harrogate, 2019

	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec	Total
Airedale	626	572	574	551	2,323
Bradford	1478	1455	1371	1427	5,731
Calderdale & Huddersfield	1509	1437	1391	1309	5,646
Harrogate	497	421	450	426	1,794
Leeds	2891	2505	2441	2523	10,360
Mid Yorks	1626	1510	1604	1842	6,582
WY&H	8627	7900	7831	8078	32,436

Source of data WY&H dashboard

In 2018, there were 28,020 live births at 37 weeks or more, of which 938 were of low birth weight (Table 5)

Table 5 Live births at 37 weeks or more weeks gestation, 2018

	Live births with known birthweight	Live births with low birthweight (less than 2500g)
Bradford	6,659	277
Calderdale	2,104	66
Kirklees	4,499	153
Harrogate	1,276	29
Leeds	8,946	324
Wakefield	3,598	89
Total	27,082	938

There are a substantial number of women requiring specialist support through their pregnancy as a result of existing or emerging mental health problems (Table 6).

Table 6 Estimated numbers of women with Mental health illness in the perinatal period, 2017/2018

	Bradford	Calderdale	Kirklees	Leeds	Wakefield	Total
Chronic Serious Mental Illness in perinatal period	12	4	8	15	6	44
Severe depressive illness in perinatal period	174	55	120	227	91	666
Adjustment disorders and distress in perinatal period (lower estimate)	870	275	599	1,134	453	3,331
Adjustment disorders and distress in perinatal period (upper estimate)	1,740	550	1,199	2,267	906	6,661
Mild-moderate depressive illness and anxiety in perinatal period (lower estimate)	580	183	400	756	302	2,220
Mild-moderate depressive illness and anxiety in perinatal period (upper estimate)	870	275	599	1,134	453	3,331
PTSD in perinatal period	174	55	120	227	91	666

Source of data PHE Public Health Profiles (20)

It was proposed in the Five Year Forward plan that there should be an incremental rise in those accessing perinatal mental health services (PNMH), for WY&H [based on the 2016 ONS Birth rates] this equates to 3,159 women by 2023/24 (Table 7).

Table 7 Proposed referrals to perinatal mental health services, increment 2019/20, 2021/22, 2022/23, and 2023/24 (based on 2016 births)

	Bradford	Calderdale	Kirklees	Harrogate	Leeds	Wakefield	Total
Births (2016)	7,930	2,470	5,408	1,475	10,250	4,061	31,594
2019/20 (Target 4.5% of births)	357	111	243	66	461	183	1,422
2021/22 (Target 7.10% of births)	563	175	384	105	728	288	2,243
2022/23 (Target 8.6%% of births)	682	212	465	127	882	349	2,717
2023/24 (Target 10% of births)	793	247	541	148	1,025	406	3,159

2. Summaries of the sections

2.1 Loss - Bereavement

- Pregnancy loss can be a consequence of miscarriage; termination for fetal anomaly, medical or social reasons; stillbirth; or neonatal death.
- 43% of women will have had one or more 1st trimester miscarriages. Across West Yorkshire⁵ it is estimated that there were 5,616 first trimester miscarriages and 221 second trimester miscarriages in 2018.
- One in three females in the UK under the age of 45 years will have had a termination of pregnancy, which equates to 173,216 females in the West Yorkshire and Harrogate area, with 8,063 terminations in 2018.
- There are an estimated 165 terminations of pregnancy due to fetal anomaly / or for medical reasons across WY&H, with an estimated prevalence of 27 mothers at risk of PTSD at 14 days and 12 mothers at risk at 12 months.
- Across West Yorkshire there were an estimated 119 stillbirths and 54 neonatal deaths in 2017.
- Risk increases with deprivation, with a 72% higher risk of stillbirth and a 57% higher risk of neonatal death in the most deprived areas compared to the least deprived.
- The risk of stillbirth is over twice as high in Black and Black British babies as compared to White babies with a 73% greater risk of neonatal mortality in Asian and Asian British babies.
- Smoking is associated with a higher risk of stillbirths, with an estimate 22 stillbirths across West Yorkshire in women who smoke through their pregnancies.
- Risk of miscarriage and stillbirth increases with age, a previous history of loss, obesity, diabetes, hypertension, and conception through assisted reproductive technology (ART).
- The risk of miscarriage and stillbirth is higher in lesbian and bisexual women, those women who have been in abusive relationships, consanguineous couples.
- Loss can also be associated with deficiencies in care surrounding the birth.
- The emotional impact on the woman and partner vary greatly depending on the circumstances of the loss, with the risk of complex grieving, PTSD and depression that can still be present at subsequent pregnancies.

⁵ Harrogate data not available at the time of writing

- Careful advanced planning is required by the maternity services to ensure all staff are trained to offer support and to help with decision making. In addition, there should be specialist support available.
- There should be an early referral on to the Bereavement midwife for those women who are post 16 weeks at the time of loss.
- Support upon discharge from hospital should include the opportunity to have a counselling session with a psychologist, with support for both the mother and the father/co-mother.
- Mindfulness intervention support should also be available.
- For those parents with more intense and protracted grief an assessment using the Perinatal Grief Intensity Scale (PGIS) should be considered, with referral on to a clinical psychologist for a more formal assessment and support.
- Continuity of care is important to ensure transition to the bereavement services does not leave the bereaved parents missing their named midwife.
- All women should have the option of a consultation with a senior obstetrician to discuss the possible causes of their loss and the implications for future pregnancies.
- There should be signposting to on-line support services, including SANDS.
- It is important to recognise that how women and men deal with the loss may differ, with each needing support to meet their needs if longer term negative effects (such as relationship breakdown) are to be avoided.
- For those women booked for a subsequent pregnancy early assessment of mental health status should be undertaken and on-going support provided.

2.2 Loss - Child removal

- A child removal at birth is a very rare occurrence, based on a fear for the safety of the child and requires a court order.
- Based on Broadhurst et al estimate of 36 mothers per 10,000 births there would be 107 mothers facing a child removal, local data suggests this is more like 150.
- As with other forms of baby loss a mother who has a child removed at birth needs considerable support, both in its aftermath and in prevention of reoccurrence.
- The women who have their child removed are living very difficult, chaotic lives.

- Planning for a child removal should begin early and involve the mother as much as possible, with the removal seen as palliative.
- There are considerable emotional consequences following the child removal.
- What appears central to success for the women is early, consistent and empathic help coupled with concrete guidance on birth control to help break the cycle.
- The postnatal mental health team should be working closely with the woman in collaboration with social services, the Futures / Pause / Positive choices programmes, drug and substance abuse programmes, and other community support networks.
- A caseload approach would help the midwife form a stronger bond with vulnerable mothers.

2.3 Tokophobia / Fear of childbirth

- Many women have a fear of childbirth (FOC), which is different from tokophobia, which has been defined as a severe anxiety disorder characterized by an extreme, irrational fear of childbirth, which provokes a physiological response(21).
- Tokophobia is either primary when it occurs before or during the first pregnancy (primiparous women) or secondary in women who are pregnant again (multiparous women).
- Based the 2018 birth numbers and using O'Connell et al's prevalence estimate of 14%, 3,923 women are at risk of tokophobia across West Yorkshire and Harrogate.
- Tokophobia can be caused by previous negative experiences of childbirth, having heard of others experiences or through a deep feeling of loss of control and anxieties over the potential outcomes of the pregnancy.
- Women with a history of mental health difficulties and those women who have experienced sexual violence, previous loss and previous surgeries are also found to be at greater risk.
- Tokophobia can lead to perinatal depression, anxiety and an increased risk of developing PTSD, it can also lead to difficulties with mother-child bonding.
- Key support mechanisms for women include an early assessment of risk in the pregnancy initially through the Whooley questions (for depression) and the two-question GAD-2 questionnaire (for anxiety).

- In women deemed to be at risk the assessment guidance offered by the new Wakefield Tokophobia Pathway or the Pan-London tokophobia toolkit reflects best practice and includes general detection questions coupled with the risk the Fear of Birth Scale (FOBS) scale or the Wijma Delivery Expectancy/Experience Questionnaire [WDEQ] for primary tokophobia and the Impact of Events Scale-Revised [IES-R] for secondary tokophobia.
- Forming a strong and therapeutic bond with a known midwife is very important, with most papers preferring a continuity of carer / caseload management approach.
- Face to face interventions appear to be most beneficial.
- Formal counselling, whether by the midwife (as seen in some countries) or a psychologist have been found to be effective.
- Educational support to normalise the pregnancy and birth planning to address fears has also been found to be beneficial.
- For those without good partner support the use of a doula should be considered.
- Guidance on external support, such as internet support groups or local organisations should be given early in the pregnancy.
- For those women who report (or appear) distressed by having a birth contrary to their expectations they should be supported as per the guidance in the traumatic birth and other sections of the report to help prevent tokophobia in subsequent births.

2.4 Birth trauma

- Having a traumatic birth can increase the risk of postnatal depression, post-traumatic stress disorder (PTSD), and have implications for parent-infant relationships.
- It has been estimated that about 4% of women will develop PTSD, which amounts to 1,121 across West Yorkshire & Harrogate, rising to between 18 and 19% in high risk mothers (for example, having had a previous traumatic birth).
- Much of the PTSD women experience is iatrogenic, in-so-much that it has occurred as a result of negatively received medical interventions or poor communication, such that by changes in the way the woman and her partner are supported through the pregnancy and birth could prevent the onset of PTSD in many.

- Prevention should be a key goal over the pregnancy with pelvic floor exercises and a more proactive approach to protecting the pelvic floor during the birth.
- Women often prefer to see their own midwife when they are experiencing difficulties, so it is important that all the staff in the maternity services should have at least minimum training in supporting women with birth trauma with a referral system onto more specialist services – the continuity of carer approach would be of benefit here.
- Women who are pregnant again following a previous traumatic birth or had adverse childhood events / other trauma should be picked up at initial screening and assessed for existing PTSD and offered a care pathway to help manage emerging issues through their current pregnancy.
- Partners who are present at a traumatic birth (including, but not limited to, eclampsia, post-partum haemorrhage, maternal admission to ICU, NICU, stillbirth) should be offered support.
- Services should be advertised sensitively to ensure stigma and fear of consequences of usage are minimised. This should include information relating to the Birth Trauma Association.
- All women should be allowed to re-visit their experience of birth, with the opportunity to make an appointment with midwife or obstetrician.
- Formal psychological debriefing should not happen whilst an in-patient but if required be offered in the 4-6 weeks post birth and again at 6 months to allow for normal adjustment to occur.
- Women identified as having signs of PTSD (sub-clinical or clinical) should be referred through to specialist services for a clinical interview to assess the best way forward in terms of support and / or treatment.

2.5 Assisted conception

- The road to pregnancy may be stressful and very challenging for women and their partners seeking conception through assisted reproductive technology.
- Once pregnant, according to the literature, there are contradictory findings related to perinatal mental health problems, with the majority suggesting there is not a greater risk of perinatal mental health problems as compared to spontaneous conception.
- There may be other mothers and partners experiencing complex emotional and mental health challenges.
- There is the possibility that the woman and her partner need greater preparation for parenthood.

- Support for both partners is needed if there are relationship issues, to help keep the family unit together and able to function as a supportive unit.
- Links could be made with Assisted Reproductive Technology counselling service providers such that there is a more seamless move into pregnancy care.

3. Loss - Bereavement

3.1 Introduction

Across England and Wales there were an estimated 839,043 conceptions in 2018, with 656,925 births (22,23). The impact of losing a baby through miscarriage⁶, stillbirth, neonatal death, or through the need to have a termination for fetal anomaly / or for medical or social reasons can be both physically and emotionally traumatic and is a time of great need for the mother and her partner (24–26). The loss of a child can also have a wider effect on the women's family that is not always recognised (27,28). It is a special kind of loss, with any other death being accompanied by social grieving, support and the opportunity to say a final public goodbye through a funeral. The loss of one baby within a multiple birth can bring very complicated psychological difficulties for the women and her family due to both the loss of a child and a surviving sibling (29,30). For a perinatal death there is often feelings of blame, or of the death being inconsequential and that the women should 'move on' and it remain hidden (31). This form of sudden death also means little time to prepare and on leaving the hospital with no child can leave a lifetime of lost parenthood and grief. For some, however, a pregnancy carries a significant burden and a miscarriage (32) or the option of a termination brings great relief (33).

Often a miscarriage occurs early in the pregnancy with no problems in subsequent pregnancies, however for other women there can be repeated miscarriages, which can have a very negative effect on the emotional and mental health of the women and her partner. Even the threat of a miscarriage can result in an increased risk of antenatal depression (34), which can have an impact through into subsequent pregnancies (35). Stillbirth and neonatal deaths are an extremely traumatic event, and there has been a concerted effort to help support a healthy pregnancy from pre-conception (36) through to better perinatal maternal health and enhanced surveillance and support for women through their pregnancy to try and minimise the risk of loss (37). There have also been both national and international guidance on the management of stillbirth, including the American consensus on stillbirth care (38) and in the UK (39).

There is a significant financial cost of stillbirth in the UK (40), estimated to be £694m across the UK through the NHS care required to support the women through her experience and also the personal cost due to loss of earnings, funeral costs, and clinical negligence claims. There is also the loss to society of a child, who would have grown to be a productive adult. A stillbirth has been estimated to require more cost than a livebirth, due to the wide range of personal implications of losing a child and the care needs both following the loss and increased support for subsequent pregnancies (26).

3.2 Prevalence

⁶ Miscarriage is classed as a death before 24 weeks, after this time a death is classed as a stillbirth (delivered after 24 weeks, but showing no signs of life) or a neonatal death (NND) (born alive, but died before 28 completed days after birth) (52).

3.2.1 Miscarriage

Early pregnancy loss is a common occurrence, with an estimated 43% of women having had one or more first trimester spontaneous miscarriages (41). There were 35,987 conceptions reported across West Yorkshire in 2018⁷, with a reported abortion rate of 23.6% (22) (Table 8). Early pregnancy loss (prior to 12 weeks) has been estimated at 13.5% - 15% (41,42), taking the lower figure of 13.5% would give approximately 5,616 spontaneous miscarriages across West Yorkshire.

Table 8 Conception number, conception rate, abortions, first trimester miscarriages West Yorkshire, 2018

	Conceptions ¹	Conception rate per 1,000 women in age-group	Percentage of conceptions leading to abortion	First trimester miscarriages ²
West Yorkshire	35,987	78.4	23.6	5,616
Bradford	9,326	89.2	21.1	1,456
Calderdale	2,837	76.7	24.8	443
Kirklees	6,302	77.0	23.3	984
Leeds	12,575	72.6	26.1	1,963
Wakefield	4,947	79.1	22.0	772

Data from ONS Conceptions Workbook

Harrogate conception data is not separated out from North Yorkshire - data requested from ONS

¹Conception statistics are estimates derived by combining numbers of maternities and abortions.

²Calculated from conceptions and estimate of 13.5% miscarriages

The rate is higher in women over the age of 45 years, estimated at 56.9%, with the lowest risk in women aged 25-29 years (9.8%) (43). The rate also varies by previous pregnancy, with age adjusted odds ratios of 1.54 (95% confidence interval 1.48 to 1.60) after one miscarriage, 2.21 (2.03 to 2.41) after two, and 3.97 (3.29 to 4.78) after three consecutive miscarriages (43).

For second trimester miscarriages, numbers have been calculated using data from the estimates created by Tong et al. (44) and Cullen et al. (45). In 697 asymptomatic Australian women with a singleton birth presenting for their first antenatal visit between 6 and 11 weeks had a risk of miscarriage of 1.58%, with the risk decreasing over the length of pregnancy - 9.4% at 6 (completed) weeks of gestation, 4.2% at 7 weeks, 1.5% at 8 weeks, 0.5% at 9 weeks and 0.7% at 10 weeks (44). Cullen et al (45) in an Irish prevalence study of second trimester miscarriage estimated a risk of 0.8% of all deliveries. With the first booking for women in England & Wales at 10 weeks applying the 0.7% estimate to those women booked across WY&H LMS there would be 221 mid trimester miscarriages (Table 9).

Table 9 Estimated number of second trimester miscarriages, 2018

	Number of Bookings	Estimated number of miscarriages (0.7%)
Leeds	10,020	70

⁷ Data for Harrogate are included in 'North Yorkshire' and cannot be extracted.

Bradford	5,820	41
Airedale	2,258	16
MidYorks	6,040	42
CHFT	5748	40
Harrogate	1684	12
Total	31,600	221

3.2.2 Termination of pregnancy due to fetal anomaly, medical or social reasons

It has been estimated that one-in-three women in the UK will have had a termination of pregnancy by the age of 45 years (46). Across West Yorkshire & Harrogate there are 519,649 females aged between 13 and 44 years, which would equate to 173,216 that might have had a termination of pregnancy. For England and Wales there were 3,269 terminations of pregnancy due to fetal anomaly / or for medical reasons in 2018, which equates to 2% of all terminations of pregnancy (47). Across West Yorkshire & Harrogate (48) there were 8,228 legal terminations performed and applying the 2% equals 165 terminations of pregnancy that were due to fetal anomaly / or for medical reasons, with 8,063 for social reasons. In a recent literature review of studies exploring PTSD following termination due to fetal anomaly found prevalence varied from between 45% at 14 days post termination up to 67% at six weeks, falling to 50% at six months, with 20.5 to 41% still with pathological levels of PTSD at 12-16 months post termination (49). Using the lower prevalence estimate this would mean that 27 mothers at risk of PTSD at 14 days and 12 mothers at risk of PTSD at 12 months.

3.2.3 Stillbirth and Neonatal death

Stillbirth prevalence has been estimated at between less than 1% in developed countries through to 3% in less developed regions (50). Across England and Wales there were 2,520 stillbirths in 2018 (51), this equates to a rate of 4 stillbirths per 1,000 births (4%). Although this rate is falling it is still above international comparable countries. There is an ambition to get the rate below 2.6 per 1,000 births by 2025⁸. Across West Yorkshire there were 3.94 stillbirths per 1,000 births in 2017 (52). Based on the MBRRACE estimates there were 119 stillbirths (>24 weeks gestation) and 54 neonatal deaths in 2017 (Table 10). The male child has a greater risk of major congenital anomalies, miscarriage and stillbirth (53). In a 2014 review (54) of global data from over 30 million births the crude mean rate (stillbirths per 1,000 total births) was 6.23 for males and 5.74 for females, with a 10% higher risk of male stillbirth.

Table 10 Estimated number of Stillbirths and Neonatal deaths across WY&H, 2017

	Total births§	Stillbirths			Neonatal deaths		
		Crude rate ¹	Stabilised rate (95% CI)	Number ²	Crude rate ¹	Stabilised rate (95% CI)	Number ²

⁸ <https://www.gov.uk/government/news/new-maternity-strategy-to-reduce-the-number-of-stillbirths>

Airedale Wharfedale and Craven	1,569	2.55	3.61 (2.69 to 4.94)	6	1.92	1.70 (1.15 to 2.60)	3
Bradford City	1,618	6.8	4.13 (3.08 to 5.60)	7	4.36	2 (1.29 to 3.18)	3
Bradford Districts	4,907	4.48	3.98 (3.13 to 5.09)	20	2.46	1.91 (1.32 to 2.85)	9
Calderdale	2,413	3.73	3.75 (2.83 to 4.98)	9	3.33	1.96 (1.32 to 2.99)	5
Harrogate and rural district	1,401	*	3.58 (2.68 to 4.85)	7	*	1.65 (1.10 to 2.47)	2
Greater Huddersfield	2,653	3.77	3.73 (2.88 to 4.97)	10	3.41	2 (1.40 to 3.10)	5
Leeds	10,052	3.58	3.69 (2.95 to 4.59)	36	1.3	1.53 (1.10 to 2.13)	15
North Kirklees	2,556	7.04	4.38 (3.28 to 6)	11	1.97	1.73 (1.21 to 2.59)	4
Wakefield	4,013	2.49	3.44 (2.62 to 4.47)	14	1.75	1.70 (1.18 to 2.48)	7
Total	31,182			119			54

Data from MBRRACE, 2019(52)

§Excluding terminations of pregnancy and births <24+0 weeks gestational age

* entry suppressed because of small number of deaths

¹ Rate per 1,000 births

² Calculated from the stabilised rate (stabilisation of the mortality rates is a statistical method which allows for the effect of random variation and produces estimated mortality rates which are closer to the underlying mortality rate)

3.3 Risk factors for perinatal loss

For those women who have had a previous stillbirth there is nearly a five-fold increased risk of a subsequent perinatal loss (55). If there was no explanation for the death Lamont et al. suggests there is a minimal risk in subsequent pregnancies, however the evidence for this is weak. Women who face a higher risk of recurrent fetal loss are those with diabetes or hypertension and those women who have had previous obstetric complications such as placenta abruption (55).

Neighbourhood deprivation is directly linked to perinatal loss (52,56), with the rate of stillbirth increasing from 2.81 per 1,000 births in the least deprived areas to 4.84 per 1,000 in the most deprived (72% higher risk) and neonatal death increasing from a rate of 1.32 in the least deprived areas to 2.07 in the most deprived (57% higher risk) in 2017 (52).

Ethnicity also raises the risk of stillbirth and neonatal death (Table 11). In 2017, there was a 108% increased risk of stillbirth for Black and Black British babies as compared to White babies, 73% greater risk of neonatal mortality for babies of Asian or Asian British Ethnicity as compared to White ethnicity, and a 67% higher risk of neonatal mortality for babies of Black or Black British ethnicity (52).

Table 11 Stillbirth and neonatal mortality rates (per 1,000 births) and ratio of deaths, by ethnicity, England & Wales 2017

	Stillbirth		Neonatal death	
	Rate per 1,000 births	Ratio	Rate per 1,000 births	Ratio
White	3.59	Reference	1.66	Reference
Mixed	4.56	1.27 (1.1 to 1.47)	1.34	0.81 (0.62 to 1.06)

Asian, Asian British	5.7	1.59 (1.44 to 1.75)	2.86	1.73 (1.50 to 1.98)
Black, Black British	7.46	2.08 (1.83 to 2.36)	2.77	1.67 (1.35 to 2.06)
Other	3.68	1.02 (0.81 to 1.29)	1.62	0.98 (0.69 to 1.36)

Data source – MBRRACE, 2019 (52)

There has been more work on the impact of race and ethnicity on stillbirth in America. Sharma et al. found a three-fold increase in the risk of a recurrent stillbirth in African Americans as compared with Caucasian women (57). In part, this increased risk has been attributed to other known risks, such as socio-economic deprivation impacting on access to health services, or the increased incidence of obesity and hypertension. The Gypsy and Traveller community have also been found to have higher incidence of loss. To support women as this community we need to be innovative and employ different methods of reach and recognise that their lifestyle can result in them accessing services later and in a multitude of locations (58).

In an Australian study (59) of migrant women and stillbirth using registry data from 260,997 births found an increased risk of stillbirth, but this was reduced in those women who had access to an interpreter and early booking. They suggest the need for a culture-oriented educational programme or campaign to help get migrant women into midwifery care earlier in their pregnancies.

A higher rate of intrauterine death is seen in consanguineous couples, which was estimated at 8.62% from a study in Pakistan (60), an Australian study had the rate lower at 2.4% vs 1%, with a higher rate of threatened premature labour (5.6% vs 4.7%) as compared to non-consanguineous parents (61).

Women who are pregnant through after IVF or intracytoplasmic sperm injection, are at two to three times heightened risk of miscarriage and stillbirth (62) – this is also addressed later in the report in Section 5.

Obesity is linked to a higher rate of stillbirth and with the number of women who are obese or morbidly obese growing across society this may become more of an issue (63–65). A Swedish register-based cohort study (66) found a rate of 1.6/1000 stillbirths in normal weight women and 2.6/1000 in obese women. In the UK, where the stillbirth rate is higher in the overall population, an analysis of 44,600 births between 1994 and 2013 showed that being overweight increased the odds ratio of a stillbirth by 1.37, rising to 5.04 in obese women with a BMI over 50 (67). Jacob et al. do note that it is still a rare occurrence, but management of weight may help those women who are vulnerable to stillbirth – which has added mental health issues as weight loss is an emotional issue for many women, especially those with mental health difficulties.

Women who smoke also have a higher risk of stillbirth (68), which can also add to the mental health challenges facing pregnant women. The stigma associated with smoking during pregnancy is already recognised (69) as well as the increased psychological challenges women face when trying to quit smoking (70). According to the prevalence data supplied by the 2019 MBRRACE-UK report of the number of stillbirths by mother's smoking behaviour calculated against the 119 estimated

stillbirths in West Yorkshire and Harrogate there will be 22 stillbirths in mothers who smoke (Table 12).

Table 12 Stillbirths, by mother's smoking behaviour, 2017

	%	Number of stillbirths
Never smoked	62.2	74.0
Non-smoker at booking (history unknown)	3.5	4.2
Gave up before pregnancy	9	10.7
Gave up during pregnancy	4.5	5.4
Smoker	18.5	22.0
Not known	2.3	2.7

Women who have a twin pregnancy have also been found to be at an increased risk of miscarriage and stillbirth, with a 276% increased risk of stillbirth for teenage mothers as compared to a singleton pregnancy (dropping to a 38% increased loss in mothers over 40 years). There is a reversal of risk by deprivation, with women in the wealthiest decile having an increased risk of 168% as compared to a 29% risk in the poorest. This is presumed to be due to the cost of assisted conception (52). Risk of neonatal death is also greater in younger mothers (311% increased risk), with the lowest risk in mothers from the most deprived quintile of deprivation (155%), with the highest risk in the second least deprived quintile (351%) (52).

Women who have a second pregnancy soon after birth are also at greater risk of perinatal loss as the body has not had time to recover (71). Guidance on birth spacing now suggests a two year gap is optimal (72). The most vulnerable women are also those who are most likely to have short birth-to-pregnancy intervals (73).

Lesbian and bisexual women have been found to be at greater risk of miscarriage and stillbirth. In an American study (4) of 19,955 pregnancies from 2006 to 2015 reported in the National Survey of Family Growth, 5% of which were in bisexual women and 1% in lesbian women. Bisexual and lesbian women reported 30% of pregnancies ended in miscarriage as compared to 19% of the heterosexual women. Further, 0.8% of pregnancies reported by heterosexual women who have sex with men ended in stillbirth, compared to 1.6% of heterosexual women who also have sex with women, 2.6% of bisexual women, and 4.1% of lesbian women. There is also a higher risk of preterm birth in both bisexual and lesbian women. They suggest this may be due to discrimination or increased stress during the pregnancy, but no definitive reasons were presented.

Women who have been the victims of intimate personal violence may have a higher risk of miscarriage, leading to additional likelihood of traumatic stress, especially those who have an existing post-traumatic stress disorder (PTSD) diagnosis (74).

There are also incidences of perinatal death where a healthy child is lost through complications during the labour, which can add additional stress especially where there have been service failings. Serious failings such as seen in the Morecambe Bay and the Furness Hospital in the Barrow maternity services may make bereaved

parents more likely to look at the quality of the service they have received more closely. In 2015 there were ~ 500-800 babies that died or were left severely disabled during labour nationally (52). There will also be significant mental health implications for parents with a child living with disabilities as a result of intrapartum harm.

3.4 Mental health problems following perinatal loss

Termination of a pregnancy can be for social or medical reasons or due to the identification of a fetal anomaly. The majority of terminations have to occur before the 24th week of the pregnancy, unless there are significant medical reasons that put the life of the mother at risk or because there is a substantial risk the child would suffer from serious fetal anomalies (75).

Studies that have explored the emotional impact of deciding to have a termination recognise that it is a very personal matter and that for some it is a choice that they do not regret, for others it can be a more profound experience. An American study that explored the evidence for post-traumatic stress disorder (PTSD) or post-traumatic stress symptoms (PTSS) found that in the majority of cases those that exhibit difficulties the cause was not related to their pregnancy decision, but due to the surrounding life events, such as violence, abuse of unlawful activity (44%) or non-violent relationship issues (17%). In 14% of cases it was related to the pregnancy or the abortion experience or decision (76). A Swedish study found that pre-existing mental health difficulties were the most likely to experience PTSD or PTSS (77).

In a longitudinal study over 5-years, which followed 667 women who had an abortion with no known fetal anomaly, found that there was about an equal split between those that found the decision difficult and those that did not. Those that found the decision difficult were more likely to report sadness but the intensity declined significantly over the first and second year before stabilising. At five years relief was the most common emotional response, but for some it remained a difficult decision (33). A Finnish study investigating the mental wellbeing of women during the first year after a first trimester termination of pregnancy found that for the majority of women their quality of life score increased and anxiety levels fell by 3 months post termination (78). Forty percent of the women showed no increase in anxiety throughout the study period, suggesting the decision to have a termination was a rational choice. For those with pre-existing mental health problems, or for some with high base-line anxiety there was a more persistent impact both on anxiety and quality of life. Smoking was also predictive of a poorer outcome.

Felt community level stigma and fear of social judgement is an important source of distress in women who have had a pregnancy terminated, (33,79,80). When it is internalised, it can have a lasting impact on the longer term recovery following a termination (81).

In a study exploring the differences in reported grief, post-traumatic stress and depression in 158 mothers and 109 fathers following a diagnosis of anencephaly leading to either termination of pregnancy or carrying the child to full term. There were marked individual differences in psychological outcome, but overall 24% of women and 11% of men scored in the pathological range for grief, and 20% of

women and 13% of men scored in the pathological range for PTSD. Thirty four percent of women and 19% of men were in the range for depression. Of note, the study also showed that those that had a termination had a higher level of distress than those that carried their child through to term (82).

Mental health problems following perinatal loss have been widely studied (28,79,83–98). The most frequently identified are focused onto grief, guilt, blame, difficulty in coping and death attribution (79,84,92). Bereavement during pregnancy has also been found to have a negative effect on maternal self-esteem (99). These emotional responses are compounded by wider societal difficulties in knowing how to respond to the loss, with parents feeling isolated and hurt by other's responses to grief as they come to terms with being a parent without a child. There are also issues with regard to women facing stigma as a result of their perinatal loss (92,100).

There can also be difficulties with how both parents may respond to the death, with fathers being found to suppress their grief leading to longer term difficulties. Relationships can be strengthened, but also there is an increased risk of breakdown, with a stillbirth having a longer term impact. For women with a stillbirth the risk persisted up to 10 years, whereas for miscarriage there was still an effect, but over the shorter term (1.5-3 year period) (101).

For those women who do not already have children, have fertility difficulties, or have experienced dissatisfaction with the health care they received experience a greater grief response over the longer term (84,90,95). In a study of 311 mothers in Michigan, USA, nearly half of the respondents blamed their medical team for their loss (84). This study also found that depression persisting at either 9 months or 15 months was a strong predictor of greater guilt over the loss, with 17% of the mothers reporting that other people blamed them for the death.

In a longitudinal survey (83) of mothers in Michigan who had either a stillbirth (above 20 weeks of gestational age and at least 400 g) or an early infant death in the first 28 days of life 609 mothers responded to the questionnaire. At 9 months bereaved mothers were found to have twice the odds for general anxiety disorder and social phobia.

The impact of a miscarriage or stillbirth can follow through to after the birth of a subsequent live-born child. A Norwegian study (85) of 901 pregnant women, 172 of which having had a previous stillbirth, found that women with a previous stillbirth more often experienced anxiety (22.5%) and depression (19.7%) compared with women with previous live births (4.4% and 10.3% respectively) and previously nulliparous women (5.5% and 9.9% respectively). Post birth the prevalence of anxiety and depression fell significantly and was similar to those who had not had a previous stillbirth, however at 36 months the prevalence of anxiety and depression had again risen and was above that seen in women with previous live births, but not above that seen in the nulliparous women. Suggesting that there is a residual psychiatric morbidity from the stillbirth that is only temporarily relieved by a subsequent live birth. This is contra to the findings of an earlier study in Australia, which found that although women with a previous stillbirth were more likely to carry sadness or low mood, and excessive worry through to a subsequent pregnancy, this was not evident postpartum (93).

A meta-analysis conducted in 2017 of studies from 1995 through to 2016 on mental health difficulties in mothers and fathers who had experienced a previous pregnancy loss on their subsequent pregnancies found that there was a significant increase in anxiety and depression, but no effect on stress (86). A systematic review and meta-analysis of the psychosocial impact of stillbirth (92) found that many parents found themselves unable to relax and enjoy their new pregnancy or to engage in antenatal classes due to fear of what others might think of them. The parents reported a range of emotions from hopeful optimism to panic attacks, isolation and a lack of normality.

There are other studies that focus onto the risk of post-traumatic stress disorder (PTSD) as a result of the bereavement (97,102–106). The recent prospective cohort study (97) conducted across 3 Early Pregnancy Assessment Units in London found that of the 737 women who had an early pregnancy loss (537 women with miscarriage and 116 ectopic pregnancies) 29% met the criteria for PTSD at 1 month, with 24% meeting the criteria for moderate-to-severe anxiety and 11% meeting the criteria for moderate-to-severe depression. At the 3rd month, 86 of 418 women (21%) met criteria for posttraumatic stress; 96 of 426 women (23%) reported moderate/severe anxiety, and 32 of 426 women (8%) reported moderate/severe depression. At the 9th month, 59 of 336 women (18%) met the criteria for posttraumatic stress; 58 of 338 women (17%) reported moderate/ severe anxiety, and 21 of 338 women (6%) reported moderate/severe depression. There was a drop off in responses over the time period, such that the percentages may not reflect all the women's experiences.

In an earlier study (98) by the same authors similar findings on prevalence were found, with re-experiencing the most commonly found symptom, followed by avoidance, and then hyperarousal. Importantly for subsequent care needs, 41% of those who were trying to conceive again at 3 months still met the criteria for probable PTSD, with 23% meeting the criteria for moderate to severe PTSD. In this same study 20% of the women experienced moderate-to-severe anxiety following the loss at 1 month compared to 10% in the control group, but this dropped between 1 to 3 months, as compared to the PTSD symptoms, which persisted.

Both living with the threat of a miscarriage and the actual loss can have serious effects on the mental health of the woman and her family (34). With a high level of anxiety seen in women who have experienced perinatal loss during previous pregnancies in their current pregnancy which requires on-going support from the clinical team (35,86,107,108).

Farren et al's (96) narrative review of research relating to early pregnancy loss found between 25% and 39% of women reached the threshold for a diagnosis of PTSD at 1 month and between 18% and 20% of women experiencing symptoms of depression, which can persist for up to a year. Those women with a previous history of mental health morbidity and those with low marital satisfaction or support were most at risk, with those women with no previous children, a history of infertility or have had previous miscarriages also vulnerable to mental health difficulties post miscarriage. Fathers were found to have a lower intensity of depressive and anxiety reactions, but these too were evident for up to a year.

3.1 Assessment tools

In addition to the more standard measurement scales, such as the Hospital Anxiety and Depression Scale (HADS) there are some that have been used more exclusively with this cohort of mothers. Hutti et al,(87) have developed the Perinatal Grief Intensity Scale (PGIS) (87), which is a 14-item questionnaire created for clinical use to screen for grief intensity and predict future grief intensity and need for follow up after miscarriage, stillbirth, or neonatal death⁹.

In their prospective cohort study of early pregnancy loss, Farren et al. used the Post Traumatic Diagnostic Scale and HADS (97). The Revised Impact of Miscarriage Scale was used in the study undertaken by O’Kane & Cassidy (109). This comprises 16 items on a 4-point Likert scale in the O’Kane & Cassidy study, with the original being a 24 item scale by Swanson (110).

3.2 Interventions and approaches to care

Although termination due to fetal anomaly, miscarriage and stillbirth has been found to have an overall very negative effect there have been studies that have shown that with the right support women and their families can come through the experience with personal growth (92,111). Unlike many of the mental health challenges facing women through a miscarriage or stillbirth is nearly always unexpected, so there can be no anticipatory preparation. Care of the women and her family starts at the time of death, with most of the research into the longer term effects showing that the support and management in those first few hours can be crucial. However, for those women with a high risk of another stillbirth or miscarriage earlier preparatory support may be warranted to help set up a solid relationship in case the worst outcome is realised. Guidance in this section therefore covers both support in the labour ward as well as the care needs as time progresses. However, it should be noted that there is a still a lack of intervention research on this difficult area of practice (112).

Nationally there is an agreed pathway of support available for women and their partner who have experienced a miscarriage, stillbirth, neonatal death, or sudden infant death (113). The NICE guidelines (39) recommend that following a perinatal death the women, her partner and family should be given the option of 1 or more of the following:

- Having a photograph of the baby
- Having mementos of the baby – footprint, handprint, hair lock
- seeing the baby
- holding the baby.

They also recommend that this should be facilitated by an experienced practitioner and the woman and her partner and family should be offered a follow-up appointment in primary or secondary care. They state that it is important that if it is known that the child has died pre-birth that support should be available before delivery and be continued after discharge.

⁹ available from <http://uoflnursingpgis.org/pgis/>

This need for very well managed care over the perinatal period has been reiterated in other guidance, as how the family are managed at this time can have a lasting impact on the psychological adaptation to the loss (28,114). Practitioners who are trained in confirming the loss and in skilfully managing the communication needs of the woman and her family need to be always available.

In a recent global consensus Delphi Study (114) to determine best practice for bereavement care after a stillbirth the RESPECT study identified 8 guiding principles:

- Reduce stigma experienced by bereaved women and families by increasing awareness of stillbirth within communities.
- Provide respectful maternity care to bereaved women, their families, and their babies.
- Support women and families to make shared, informed, and supported decisions about birth options.
- Make every effort to investigate and identify contributory factors to provide an acceptable explanation to women and families for the death of their baby.
- Acknowledge the depth and variety of normal grief responses associated with stillbirth and offer appropriate emotional support in a supportive environment.
- Offer appropriate information and postnatal care to address physical, practical, and psychologic needs, including a point of contact for ongoing support.
- Provide information for women and their families about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up.
- Enable the highest quality bereavement care by providing comprehensive and ongoing training and support to all members of the healthcare team.

The American consensus on the management of stillbirth acknowledges that support is needed, but that it should be tailored to the parents personal, cultural and religious needs (38). They go on to re-iterate the importance of good communication and that a referral onto a counsellor, peer support group or mental health professional may be needed. They also recognise that the psychological burden extends from the grief of the loss of their child onto the possible consequences for future pregnancies and this may require the mental health team working in partnership with the medical team advising on the causes of the current loss and implications for the future (38). If no definitive reason for the loss can be found this may give more reassurance than if a genetic or other factor has been identified, which will moderate the intervention plan for the women and her partner. Women who have a pre-existing medical condition that increased the risk of stillbirth and miscarriage such as diabetes or hypertension or in those with obstetric problems such as placental abruption will need additional support (38,108).

There may be difficulties for the women to discuss previous stillbirths or miscarriages if they are holding feelings of guilt (84), With sensitive questioning and counselling for those with maladaptive grief they may be helped come to terms with their loss and be able to move on.

Different hospitals have varying levels of support available for managing perinatal loss. At the hospital in Cork they have a bereavement team comprising representatives from obstetrics, midwifery, medical social work, chaplaincy,

sonography, management and perinatal pathology, they also have a dedicated postnatal bereavement ward, where midwives are trained and experienced in perinatal bereavement (115). If the women are able to access this service they have the highest levels of satisfaction in their care, showing how important it is to have the right staff in the right environment.

3.2.1 Stillbirth memento photography

The use of stillbirth memento photography is one of the recommendations laid out in the NICE guidelines. With studies now looking at best practice (116) and whether it is better to be done professionally or informally by the staff or parents as it is important that this is done sensitively.

3.2.2 Holding the baby

Decisions made over the perinatal period need to be carefully managed, such as method of delivery, analgesia and whether a postmortem is required. In relation to memory making, there is some still uncertainty over whether holding the baby is wise. Partners have been found to have greater mental health difficulties if they held their stillborn child, with the suggestion that this might create more tactile experiential memories that can lead to longer term distressing memories (117). A similar finding was also found for mothers holding their stillborn child, with increased risk of depression (118). However, other studies have found no difference (28,119)

3.2.3 Cold cot

The use of the cold cot has been found to be a useful way of enabling a longer time for the parents and family to spend with their lost child, by delaying the onset of body deterioration, along with colour and olfactory change (120). In an interview based study based in Bath, 33 midwives who had used the cold cot gave positive reactions to their use. It needed careful management with regard to how the technology was introduced to the parents and it was most useful when parents wanted to stay with the baby in the hospital or wanted to take the baby home with them. It was also useful when the mother was unwell and needed more time to recover before they could start the grieving process. They also reported the need to warn the parents that their child would be cold. The use of the technology was found to be straightforward and overall a very positive development.

3.2.4 Counselling support

In a London based prospective study (121) women who had miscarried in early pregnancy were allocated to one of three groups, a bereavement group (n=33), [which included discussions concerning the role of factors such as fetal abnormality, stress, personal, and other people's behaviours and characteristics in causing the miscarriage, and clarification of women's misconceptions], this bereavement group with additional psychological counselling (n=33) and a control group that had no specific post-miscarriage support (N=66). The counselling comprised a 50 minute consultation with a psychologist. Anxiety, depression and grief decreased

significantly with time in all three study groups. The intervention groups both saw a decrease in self-blame, with the intervention group coupled with the psychological counselling also seeing a greater decrease in grief. The biggest decrease in worry about future pregnancy was seen in the counselling group.

Mindfulness interventions have been found to be beneficial to those who have suffered a traumatic bereavement (122), but overall there is little in the way of research that has explored its use with parents bereaved through perinatal loss. A preliminary study of an internet-based Mindfulness intervention that was linked to online yoga is underway in the USA (123). This study is focused onto women who had experienced a stillbirth over the previous 24 months. Following a baseline assessment via self-report the 74 consented women have been asked to participate in 60 minutes of online streamed yoga videos per week following a week-by-week prescription with videos selected by the research team. In addition The Mindful Health study is also underway to assess the effectiveness of a 12 week home-based yoga intervention for mothers after stillbirth (124). The use of Mindfulness may have benefit for women due to its effectiveness elsewhere in managing difficult emotions. Local groups or online interventions may be beneficial.

The use of Interpersonal psycho-therapy (IPT) to help women who have experienced loss was explored in a pilot randomized controlled trial (125). Fifty women who had experienced loss were allocated to either the intervention group or a normal practice control group. The intervention comprised a pre-group individual session, 12 group sessions, and a 1-month individual booster session (a total of 14 sessions). The women enrolled in the study had a mean of 10 weeks from their loss (range 2-49 weeks) with 54% with a diagnosed PTSD (19 related to the recent perinatal loss, 3 from another trauma only, and 5 from both traumas). Some of the women had generalized anxiety disorder (12%) and others panic disorder (12%). The control was a Coping with Depression (CWD) group based on a cognitive behavioural treatment which did not focus on perinatal loss nor social support. The focused IPT group was found to be more effective at supporting the women to recovery with reduced symptoms, more improvement in social support, social functioning and grief symptoms. It also enabled a faster recovery (11 weeks compared to 24 weeks in the CWD group). The key element here might be that it was focused onto the specific needs of bereaved parents and not just a general bereavement therapy.

Cognitive behavioural therapy (CBT) has been advocated for women who have had a termination of pregnancy due to fetal anomaly (111). In a study of 178 women who had experienced a termination between 11 and 34 weeks of gestation (88.2% before 24 weeks), 65.84% (n = 106) of the women scored above 34 for "active grief," 44.72% (n = 72) above 30 for "difficulty coping," 52.17% (n = 84) above 27 for "despair" and 55.28% (n = 89) above 91 for "overall grief. The majority of the women demonstrated adaptive coping, but the high level of grief suggests that CBT may help the women in re-framing their experience and managing their distress.

3.2.5 Support groups and social media

Having the opportunity to meet with other bereaved parents through face-to-face or internet support groups should be offered to the parents. In a study exploring mothers use of these approaches Gold et al. (106) used an online anonymous

survey posted on message boards and a paper version for in-person pregnancy or infant loss support groups in Michigan USA. There were 416 usable internet survey questionnaires and 60 face-to-face usable questionnaires returned, of which 64% of the women in the face-to-face groups had an EPDS score of 10 or higher compared to 60% of the online support group users. Both groups found benefits from reaching out to other affected mothers. Nearly all (95%) the mothers who attended the face-to-face group had also used online groups, suggesting that they needed face-to-face support as there were perhaps issues they did not want to share online, or that they found additional benefit from the personal contact. The survey did reveal that it was mostly white and well educated women that responded, which may reveal an issue that needs addressing about how a more diverse range of women can be helped to use these kinds of services.

With the rise in social media there has been a growth in on-line support for women who have experienced perinatal loss. One study from America undertook a qualitative study of how Instagram was used to share and receive support (126). They assessed 200 Instagram messages under #ihadamiscarriage in 2019. They found that there were a wide range of emotions expressed and that the problems many of the women experienced showed the effects had gone on for years. It is a resource that many women will turn to and the authors of the paper recommend that health care providers should see this as part of the parent's support mechanisms following their loss as part of their overall care.

The Stillbirth and Neonatal Death (SANDS) charity has a well-developed set of support mechanisms in place to help bereaved parents. Parents should be directed to their webpage (<https://www.sands.org.uk/>) for access to their information and helpline.

3.3 Women's experiences

Cullen et al. undertook a qualitative study in Dublin, interviewing 14 bereaved parents (9 mothers, 5 fathers) to explore their experiences of a second trimester miscarriage (24). The policy at the hospital was that they would be administered mifepristone and allowed home for 48 hours, which some found difficult, but most valued the time to come to terms with their loss. Some form of contact by a midwife during that time would have been welcome. Both the mothers and fathers found it very difficult if they were treated on the antenatal ward, with seeing other pregnant women or hearing babies very distressing. Both mothers and fathers noted a lack of facilities for the father, such as a male toilet or the ability to stay overnight. There was a need for clear information and good communication and if possible a reason for the miscarriage so they can move to further pregnancies. There was also an issue as to what constitutes good pain relief.

An Irish study (109) undertook a postal survey of 232 women who had experienced a miscarriage between 5-30 months previously to explore their experiences of loss and the care they received. They found that there was a definite link between the care the women received at the time of their loss and their subsequent recovery. They note however, that if they have had a previous miscarriage or if they have had another child since the miscarriage it leads to a more positive view of care had received. Whilst the recency of the miscarriage as well as a longer gestation before

the time of miscarriage are associated with a more negative view of care experienced.

In a Swedish longitudinal study 103 women and 78 men completed a postal questionnaire at one week and four months after miscarriage (90). The women reported felt more guilt over the loss than their partner and that this was still present at 4 months. Previous children made the miscarriage easier to endure while a previous miscarriage or a history of infertility had the opposite effect.

A systematic review of parent's experiences of stillbirth was undertaken by Ellis et al. (127) covering all studies from 1996 up to 2014. Which was condensed down to 40 articles relating to parent's experiences. The key findings were that:

- Behaviours and actions of staff can have a memorable impact on parents.
- Clear, easily understandable and structured information given sensitively at appropriate times, helps parents through their experience.
- Parents want privacy not abandonment.
- Research and multi-professional training are important for all staff to improve standards of bereavement care.
- Parents wish for increased awareness and acknowledgement of stillbirth.
- Fathers may have different needs to mothers; they want to be involved in decision making and often focus on practical tasks.
- Continuity of care and carer is important to parents.
- Parents with a baby who died in-utero may feel that their care is not appropriately prioritised by staff.

Using a postal survey to 21 mothers and 15 fathers an Irish study (115) explored experiences following a stillbirth. One of the most durable memories for both the mother and the father was the way they were cared for over the loss. From the way the news was given and the subsequent labour through to discussions over the autopsy and support post-discharge were remembered in detail. The most important aspects for the parents were the importance of being kept informed of what was happening, having choice and control, medical management, investigation of the stillbirth, time with the baby, creation of mementos, support with the funeral. With the one area where every respondent agreed was with regard to the kindness and sensitivity of the staff. Half of the respondents were very affected if they were not visited by the consultant obstetrician at the birth or afterwards.

3.4 Father / co-mother & family

Persistent anxiety & depression has been found in fathers following perinatal loss (86,90,128,129). Many of the studies that have explored men's reaction to perinatal loss highlight that there are difficulties in expressing their grief or avoidance (31,92). This can be misinterpreted as not caring but has been found elsewhere to be a defence mechanism against extreme emotions in men (130) and needs to be handled with care. Often the men are confused over how they should react and try to deny their own feelings to support their partner (131). The review by Ellis et al. (127) also found that fathers wanted to be involved in decision making and have a need for information they can base decisions on. They also noted that the men wanted to protect and support their partner but can feel frustrated and helpless. Relationship

breakdown, employment difficulties and increased substance abuse have been seen in bereaved fathers as a longer term impact of the loss (92).

There were no studies found that directly addressed the experiences of co-mothers following a bereavement.

Grandparents are also very much affected by perinatal loss (27), great emotions are built in the anticipation of the birth and the happiness of the parents, with the potential for physical and emotional health problems as they try to support their children and come to terms with their own grief.

The emotional support needed by other children in the family should also be considered. Depending on how old they are there will be many complex issues for them to face, which can impact on both their short and long term emotional health (132). Difficulties can focus around their mixed emotions about another child coming into the family (and now not), parental relationships, and complex grieving for a child they have never met.

3.5 Midwives experience

There is little in the way of research on the midwife's experiences of caring for a mother who suffers a perinatal death. Ellis et al. (127) undertook a systematic review of parents and healthcare professionals experiences. They found that there were anxieties over their confidence to provide the care the women needed. They also reported issues with regards to hospital policies and protocols in being able to meet the women's needs. Although experience helped the staff in managing perinatal loss it did not diminish the emotional burden. There was a call for more training in bereavement care and for specific communication skills guidance so as to avoid fears over making matters worse for the parents.

A more recent qualitative study interviewing 7 midwives in Australia (133) on supporting women with a miscarriage found that the midwives were educated with regard to the practical management of the miscarriage, but not the emotional support needs of the mother and father. They also reported little or no follow up care. Pressures to providing good quality care included time issues, language barriers and limited availability of resources. They noted that some health professionals may choose not to provide comprehensive emotional support as a form of self-protection.

3.6 Summary

- Pregnancy loss can be a consequence of miscarriage; termination for fetal anomaly, medical or social reasons; stillbirth; or neonatal death.
- 43% of women will have had one or more 1st trimester miscarriages. Across West Yorkshire¹⁰ it is estimated that there were 5,616 first trimester miscarriages and 221 second trimester miscarriages in 2018.

¹⁰ Harrogate data not available at the time of writing

- One in three females in the UK under the age of 45 years will have had a termination of pregnancy, which equates to 173,216 females in the West Yorkshire and Harrogate area, with 8,063 terminations in 2018.
- There are an estimated 165 terminations of pregnancy due to fetal anomaly / or for medical reasons across WY&H, with an estimated prevalence of 27 mothers at risk of PTSD at 14 days and 12 mothers at risk at 12 months.
- Across West Yorkshire there were an estimated 119 stillbirths and 54 neonatal deaths in 2017.
- Risk increases with deprivation, with a 72% higher risk of stillbirth and a 57% higher risk of neonatal death in the most deprived areas compared to the least deprived.
- The risk of stillbirth is over twice as high in Black and Black British babies as compared to White babies with a 73% greater risk of neonatal mortality in Asian and Asian British babies.
- Smoking is associated with a higher risk of stillbirths, with an estimate 22 stillbirths across West Yorkshire in women who smoke through their pregnancies.
- Risk of miscarriage and stillbirth increases with age, a previous history of loss, obesity, diabetes, hypertension, and conception through assisted reproductive technology (ART).
- The risk of miscarriage and stillbirth is higher in lesbian and bisexual women, those women who have been in abusive relationships, consanguineous couples.
- Loss can also be associated with deficiencies in care surrounding the birth.
- The emotional impact on the woman and partner vary greatly depending on the circumstances of the loss, with the risk of complex grieving, PTSD and depression that can still be present at subsequent pregnancies.
- Careful advanced planning is required by the maternity services to ensure all staff are trained to offer support and to help with decision making. In addition, there should be specialist support available.
- There should be an early referral on to the Bereavement midwife for those women who are post 16 weeks at the time of loss.
- Support upon discharge from hospital should include the opportunity to have a counselling session with a psychologist, with support for both the mother and the father/co-mother.
- Mindfulness intervention support should also be available.

- For those parents with more intense and protracted grief an assessment using the Perinatal Grief Intensity Scale (PGIS) should be considered, with referral on to a clinical psychologist for a more formal assessment and support.
- Continuity of care is important to ensure transition to the bereavement services does not leave the bereaved parents missing their named midwife.
- All women should have the option of a consultation with a senior obstetrician to discuss the possible causes of their loss and the implications for future pregnancies.
- There should be signposting to on-line support services, including SANDS.
- It is important to recognise that how women and men deal with the loss may differ, with each needing support to meet their needs if longer term negative effects (such as relationship breakdown) are to be avoided.
- For those women booked for a subsequent pregnancy early assessment of mental health status should be undertaken and on-going support provided.

4. Loss - Child removal into care

4.1 Introduction

Having a child removed is a deeply traumatic event for all involved, with often complex decisions made that will have a life-long impact on the child and the parents within weeks of a birth. There can be very good reasons why a baby has to be removed from a mother at birth. According to the Children and Family Court Advisory and Support Service (Cafcass) a local authority applies for an order to take a child into care when they are at risk of neglect or abuse (Box 2).

Box 2 Reasons for child removal

Neglect

When the local authority believes a child is being neglected. Neglect involves ongoing, serious failure to meet a child's basic needs and can include:

- not taking the child to see a doctor when they need to go
- not giving the child enough to eat or drink
- not ensuring the child receives an education
- not keeping the child clean.

Abuse

When the local authority is worried that a child has been, or is likely to be, abused either by their parents or carers, or other people they know. Abuse includes:

- physical abuse, which is inflicting pain or injury to a child and also includes giving a child harmful substances, such as drugs, alcohol or poison
- sexual abuse, when a child is pressured, forced or tricked into taking part in any kind of sexual activity
- emotional abuse, when a parent or carer behaves in a way that is likely to seriously affect the child's emotional development. This can include constant rejection, continual and/or severe criticism and witnessing domestic abuse.

For a pregnant mother to be considered at risk there must be grounds for concern based on her suitability to care for the child. It can be the consequence of previous convictions of child abuse, where the child is at immediate risk or it can be as a result of a chaotic lifestyle that is often a consequence of drugs, abuse, poor living conditions and young age. There is also a high proportion of mothers with learning difficulties whose child is taken into care at birth, due to concerns over their parenting capacity (134).

Children's early development is very important and it is imperative that they are safe and cared for in the very early life, such that key growth milestones can be met and the child has a chance both of survival and a healthy life. Difficult decisions therefore have to be made and they have to be justifiable. They also have to be the most limited action needed to ensure protection and based on a legal case *YC v United Kingdom* in 2012 [see (135)]:

'[F]irst, it is in the child's best interests that his ties with his family be maintained except in cases where the family has proved particularly unfit; and second, it is in the child's best interests to ensure his development in a safe and secure environment. ...

[F]amily ties may only be severed in very exceptional circumstances and that everything must be done to preserve personal relations and, where appropriate, to 'rebuild' the family.' (para 134)

A study conducted at Lancaster University (73) conducted by Karen Broadhurst into 72 vulnerable birth mothers found that there was a pattern of repeated care proceedings for some women, with the average age in 64% of the cases under 20 years of age, with 40% of the women having been in statutory care with half having multiple placement moves. For the majority, the pregnancies were also unplanned.

According to Masson & Dicken's socio-legal research study into care proceedings the risk of physical neglect and emotional abuse are the most common concerns (135). In first time removals a higher proportion had learning difficulties, a smaller proportion had mental health difficulties or drug addiction but alcohol abuse was much more common.

In a recent review of the literature relating to supporting mothers who have experienced a child removal Tantawi-Basra & Pezaro (136) identified a 'cycle of maltreatment'. This cycle incorporates:

- Adverse childhood experiences
- Diminished attachment
- Diminished self esteem
- Diminished parenting capacity
- Reinforcement through social stigma

This cycle reflects the traumatic lives many of the women had experienced and the difficulties they encounter in trying to get to a position where they can overcome their plight. The study also considers the distrust the women have of formal services and how important it is to be able to develop a trusting relationship.

In an Australian study (137) of the 171 mothers on an opioid treatment programme 56 women (32.7%) had a child in care, with nearly half (n=46) removed at birth. None of the 32 mothers who had their child removed at birth and gave birth subsequently retained the care of their new baby. Of this cohort, two-thirds (64.5%) had been physically or sexually abused as a child, 54% had recent psychiatric illness, 18% were currently the victims of domestic violence and most (87.1%) were receiving government benefits.

There are women who may not have had previous babies removed at birth, but still have experienced the loss of a child due to court proceedings or inability to cope. These women have also got a heightened risk of anxiety and mental health problems as a consequence and will be fearful if pregnant again of similar loss (138,139). The studies that have been done with women who have lost their children into care talk of the deep loss they experience, with the grief coupled with a sense of failure as a mother. The studies also reveal the chaotic and challenging lives these women lead and the need for intensive support (136).

A further consequence of not supporting vulnerable mothers is that those who have lost a child through court proceedings also have this as a legal record against their name, which can have significant implications for their life chances.

Despite the gravity of having a child taken at birth there are no statutory requirements in place in England to support the mother and so they are mostly left to fend for themselves (73,136,140). Morriss (140) in a review based on analysis of court proceedings relating to the Family Court notes the questions posed by a QC in relation to a young birth mother had a second child removed – a five-month baby girl – within a six-month period and placed for adoption, having experienced extreme abuse and deprivation herself but had never been offered therapeutic support.

- i) Is it right that this mother should not yet have been offered therapy, particularly bearing in mind that her first child was born three years ago and was himself the subject of lengthy proceedings?*
- ii) If she had been offered therapy at an early stage, is there not at least a possibility that the outcome of these proceedings might have been different?*
- iii) Even if the outcome would not have been different, would not an attempt at therapy make these proceedings more satisfactory?*
- iv) Has the money that has been spent on issuing proceedings [£2055 is the cost of issuing a care application] and on psychological evidence [over £2000] well spent when the expenditure is incurred before attempts at therapeutic support have been made in cases of this nature. (A Local Authority v. The Mother & Anor [2017] EWFC B59)*

Despite there being a legal requirement for a pre-birth plan, a review by Broadhurst et al found that for women whose child was taken into care as a neonate, or within 1-3 weeks pre-birth proceedings took place less than 4 weeks prior to birth in 50% of cases (141).

4.2 Prevalence

Broadhurst's study (73) showed that there were than 46,000 mothers with one or more children in care proceedings, 7,060 were repeat cases: 44% of the repeats involved mothers who first had babies as teenagers. They estimate that the probability of recurrence within 1-2 years of initial child removal proceedings is 13.2%,. Based on Broadhurst et al's Born into Care review in 2017 (141), prevalence estimates for Yorkshire & the Humber of 36 mothers with children taking into care per 10,000 births would mean there were 107 mothers affected (Table 13).

Table 13 Mothers with children taken into care as a newborn

	Total births§	Mothers - Child into care
Bradford	8,094	29
Calderdale	2,413	9
Greater Huddersfield	2,653	10
Leeds	10,052	36
North Kirklees	2,556	9
Wakefield	4,013	14
Total	29,781	107

Actual data seems higher. Data from Leeds suggests that in 2018 there were 50 mothers with a newborn child taken into care, with about 58 children under 7 days of age being taken into care in Bradford in 2018 and 2019 involving 51 mothers¹¹. There may be more than one child with a mother, but this approximates to about 50 mothers. If a similar rate went across the other areas this would amount to about 150 affected mothers.

Mothers with learning disabilities are more likely to have their child taken into care at birth. This is a difficult and complicated issue, with many women not declaring their learning disability status or not booking till later in their pregnancy (134,142–144). In 2012, across Leeds 13 of the 38 mothers who had a child removed had a confirmed learning difficulty, with another 7 suspected but not diagnosed (145).

4.3 Mental health impact of child removal

The impact of having your child taken has a profound effect on the women. For many the grief can lead to mental health difficulties and a greater likelihood of further negative life events. As part of Broadhurst's study she interviewed 72 women across 7 local authorities, she found that many of the women were already very vulnerable, leading the most complex and challenging lives; the study found that that 66% of recurrent mothers had experienced neglect in their childhood, 67% emotional abuse, 52% physical abuse, and 53% sexual abuse, with an ACE¹² score of 4 or more.

They found the women were consistently describing an acute sense of grief, loss and isolation following the removal of their child. Suicidal thoughts were common and, in the majority of cases, women described 'self-harming' behaviour such as excessive drinking, drug-taking and negative intimate relationships. Cases in which women had babies removed very close to birth (60% of repeat cases) were reported to be particularly traumatic. The study revealed a lack of preparation for the mothers during the latter stages of the pregnancy, with no shared plan of what was to happen.

¹¹ This may include more mothers as the ones with another child in care proceedings are not included in this figure.

¹² ACE - Adverse childhood experiences score is based on (a) physical abuse, (b) sexual abuse, (c) removal from a single-parent household, (d) exposure to community violence, (e) number of caregiver transitions, and (f) number of school transitions.

Chapman's study on mothers' experiences of child removal suggests that the grief, coupled with the acknowledgement and understanding from others can mothers to resort to coping strategies such as repeat pregnancies, suppression of feelings and searching behaviours. The desire to have a repeat baby may also be kept hidden from the health and social authorities, especially in young mothers aged 16-19 years— further reducing the opportunities to give adequate support.

4.4 Interventions

Prevention of child removal must be seen as a key goal for services. This can be done at the legal level, with a 'Pre-proceedings process' being found to reduce the number of babies being taken into care (135). By working early with the parents by both the clinical and legal teams gave the parents more time to demonstrate they could work with the professionals in preparing for the child and the health team had more time to assess their needs and to offer support.

Taplin & Mattick's study (137) exploring the experiences of Australian women who were heroin users found that those who were supported through an opioid treatment programme three-quarters (73.5%) reported that their parenting ability had improved, that most of their difficulties had reduced and that they had significantly reduced their substance use. However, many reported a reluctance to enter into rehabilitation as it made them more visible and they were frightened that it would impact on the risk of losing their child.

Following the child's removal many of the women Broadhurst interviewed were unable to access psychological support and were mostly left to their own devices to come to terms with their loss. For those who were able to form a more stable and supportive relationships with the father and had time to mature were able to turn their lives around for the good. They also suggest that working with the mother who has lost her child may enable the child to be returned, seeing the removal as an 'interim palliative' measure (146) that can give time for intensive intervention.

There have been successful programmes established to help support women who are at risk of child removal at birth. Pause¹³ an organisation that works with vulnerable women at risk of having their children removed at birth has been independently evaluated by The Department of Education (147). They found good results, but the initiative has strict criteria to follow for women and families to be accepted onto the programme, including mandatory use of long-acting reversible contraception. This has been criticised as it suggests the sole criteria for success in supporting women at risk of recurrent child removal is contraception (140).

In Suffolk there are two services, Positive Choices and M Power, for at risk mothers, both of which were evaluated by a team at the University of Essex. Positive Choices is run by the Suffolk County Council's safeguarding team and comprises one part-time manager and two full-time support workers and M Power is a voluntary organisation run by Oriminston Families, which specialises in working with families in challenging circumstances. Neither service works to a particular model, but offer a pragmatic, client-led approach, based on one-to-one support, self-care and trust-

¹³ <https://www.pause.org.uk>

building (148). Assisting them through encouragement and offering opportunities to participate in community based initiatives alongside supporting them to access long-term contraception. What was notable was that none of the mothers had a repeat pregnancy since in the following year from their child removal (based on Broadhurst et al's. 13.2% recurrence, this should have been 9 women of the 65 in their study). Another mother and her partner with their support were also able to keep their child born of a planned pregnancy.

4.5 Mothers experiences

The interviews conducted as part of Broadhurst's (149), Cox's (148) and Marsh & Leamon's (150) studies with women who have lost their child reveal the complexity of the lives the women were leading and the negative impact of losing their child. This was also shown in Morriss's court case papers analysis, where she describes the mothers being 'haunted' by the process and being deeply stigmatised by being judged as a flawed mother.

All the studies show the importance of the mother's relationship with the practitioners and wider social services. Having a caring service that was working for the women and her child was recognised as being a significant factor in coming through the experience. However there was also such vulnerability that they were not always truthful to the health care team for fear of repercussions and further stigma (150).

Claire Mason, a Senior Research Associate working with Broadhurst, has produced 'Turning Points'¹⁴, a film in which women share their stories of positive change. The film provides hope for other women in similar difficulties, who have also had children removed from their care.

4.6 Fathers experiences

No studies have been found as yet that have explored the father's experiences of child removal at birth. In many cases the fathers are absent, but not all. It's important to recognise that many fathers are affected by the experience, with anecdotal evidence of fathers sharing the complex grief and having difficulties accessing appropriate support services.

In a study of girls experiences of adolescent pregnancy the presence of a supportive father was important (151) and the greater the man's engagement in the pregnancy the greater the possibility of turning both lives around to the benefit of the child.

4.7 Midwives experiences

Having to take a child away from their mother at birth is a most distressing event for the midwife and has been likened to being present at a stillbirth (152). In an Australian study of 9 midwives who have been involved in an 'assumption of care' child removal due to fears for its health and wellbeing reported a need to mentally separate from the emotions of the event to be able to do justice to the complexity of

¹⁴ Turning Points video <http://wp.lanacs.ac.uk/recurrent-care/turning-points-documentary/>

all that assumption of care entails. They also reported, however, the emotional or the 'heart space' where they were faced with the emotional impact of what was happening and having to deal with the range of responses from anger through to deep grief and despair by the mothers. In a similar way to coping with a stillbirth the midwives created mementos of the child, through photos, hair locks and foot and handprints. The midwives reported a need for greater organisational support to help them through the process both so they can give the most appropriate care but also to help the midwives deal with the emotional impact.

A UK PhD study (153,154) exploring 8 midwives experiences of child removal identified 'moral distress' as the core theme as the midwives from moving from 'baby catcher' to 'baby snatcher'. Working against the ethos of 'mother-centred' care to 'child-centred' care and having to comply with a decision that they may not agree with the decision. There were also dilemmas as the midwives know they were not being open and transparent with the mothers in relation to sharing information with the authorities. They were also in conflict as they were not aware of any research that shows what benefit it accrues the baby to be taken away at birth or what damage it does to the mother. The midwives were aware they were delivering fragmented care and not meeting the women's needs for consistency. They felt that a caseload approach would have helped them form a stronger more therapeutic bond.

4.8 Summary

As a way forward Broadhurst (149) has argued:

- It is imperative that we provide a safety net for women in the immediate aftermath of child removal because crisis can lead to further difficulties with profound longer-term consequences.
- Grief is enduring and intersects with issues of socio-economic disadvantage and stigma. The scale of the difficulties women face needs to be recognized in services that aim to promote recovery.
- Given women's profound sense of isolation and social stigma, preventative projects should create opportunities for the collective sharing of experience and help women to gain a clearer sense of the multiple factors implicated in the loss of their children, including vulnerability which results from socioeconomic disadvantage.
- A number of professional services can potentially aid or undermine women's recovery, at present the plight of birth mothers within the welfare system and housing is insufficiently understood and requires urgent attention.
- Children's services, the courts and allied agencies must be attuned to women's deep mistrust of professional help and the impact of this on women's subsequent engagement with services.

In addition:

- A child removal at birth is a very rare occurrence, based on a fear for the safety of the child and requires a court order.

- Based on Broadhurst et al estimate of 36 mothers per 10,000 births there would be 107 mothers facing a child removal, local data suggests this is more like 150.
- As with other forms of baby loss a mother who has a child removed at birth needs considerable support, both in its aftermath and in prevention of reoccurrence.
- The women who have their child removed are living very difficult, chaotic lives.
- Planning for a child removal should begin early and involve the mother as much as possible, with the removal seen as palliative.
- There are considerable emotional consequences following the child removal.
- What appears central to success for the women is early, consistent and empathic help coupled with concrete guidance on birth control to help break the cycle.
- The postnatal mental health team should be working closely with the woman in collaboration with social services, the Futures / Pause / Positive choices programmes, drug and substance abuse programmes, and other community support networks.
- A caseload approach would help the midwife form a stronger bond with vulnerable mothers.

5. Tokophobia / Fear of Childbirth

5.1 Introduction

Pregnancy is one of the most physically and psychologically demanding periods of a woman's life and brings with it its own anxieties and fears of what being pregnant, giving birth and being a parent will mean. These are normal and demonstrate a healthy regard for their own and their expectant child's health and wellbeing. There can be times when these fears become overwhelming and damaging to the mother, the child and to the family.

These pregnancy-specific anxieties (PSA) can relate to many different aspects of the pregnancy experience for the woman, including anxieties over adverse pregnancy and infant outcomes (such as losing their babies), congenital abnormalities, premature delivery, low birthweight, pain, neonatal morbidity, problems with mother-infant bonding, and infant cognitive, behavioural, emotional, and psychomotor deficits (155,156). There are other anxiety disorders that may be present during pregnancy, such as needle phobia (trypanophobia) and fear of vomiting (emetophobia) (157). There is also a specific issue with regard to the actual birth that has now received specific recognition.

Fear and anxiety relating to childbirth has long been recognised as a significant issue affecting women's mental health during pregnancy, with references back into the 18th Century (21). The use of the term 'Fear of Childbirth' (FOC) as a specific concern emerged in the 1980's, with the term tokophobia¹⁵ first being used by Hofberg & Brockington in 2000 (158). The name tokophobia (or tocophobia) comes from the Ancient Greek 'τόκος (tókos) which translates to "birth" and φοβία (phobia), which means "fear"¹⁶. This is characterised by a morbid and irrational fear, which results in panic attacks, nightmares, insomnia, shortness of breath, tachycardia, trembling and a strong desire to get away (21). Tokophobia is either primary when it occurs before or during the first pregnancy (primiparous women) or secondary in women who are pregnant again (multiparous women) (159).

Women who are experiencing tokophobia can have marked physical and emotional difficulties, including panic attacks, trembling, insomnia, nightmares, stomach aches (160,161). They may also be experiencing co-morbid problems, such as agoraphobia, PTSD, perinatal anxiety or depression. There are many behavioural consequences of tokophobia that impact on the women's health and wellbeing¹⁷. For many women with tokophobia they will avoid pregnancy altogether through scrupulous contraception, those with secondary tokophobia may also have no wish for a further child and opt for contraception or sterilisation (158,162). There are others who might opt for adoption or have long delays between births as tokophobia does not mean that they do not wish to be a mother, just the thought of pregnancy and childbirth is more than they can cope with.

¹⁵ This condition is also known as maiusiophobia, which is a morbid dread of childbirth; parturiphobia and also lockiophobia (fear of pregnancy and childbirth)

¹⁶ <https://en.wiktionary.org/wiki/tokophobia>

¹⁷ Interestingly, tokophobia is not covered by the NHS Health A to Z (<https://www.nhs.uk/conditions/>)

For women who become pregnant some will have a termination (158) [or have a history of previous terminations (160,163)]. They may book late and being poor attenders at clinics (both infrequent or frequent at the clinic or with the GP), and are more likely to request an early epidural, a caesarean section (CS) or attempt to birth alone at home (21,163–166). There has been an association found between FOC and dystocia / protracted labour, but no evidence of fetal distress (167).

5.2 Prevalence

An attempt at identifying the prevalence of women affected was undertaken by O’Connell et al. (159) through a systematic review of 33 studies and a meta-analysis of 29 studies and was estimated at 14%. They add a note of caution as to its accuracy as many of the studies exploring the prevalence of tokophobia have been hampered by inconsistencies in the way the condition has been reported and measured. In a more recent study, which used researchers trained in undertaking a gold-standard diagnostic clinical interview found a reduced prevalence of 0.032%, with an overall prevalence for pregnancy related phobias at 1.5% (the majority being needle phobias). It is important to note, however, that the sample for this study was taken from those women who were identified at initial booking as having a positive Whooley response (see below for more details on this measure), but of those 882 were eligible, but 624 (71%) did not take part in the study (168). The nature of tokophobia may have been a factor in the low response rate. It is also worth noting that in Nath’s study (169) of the use of the Generalised Anxiety Disorder scale in pregnancy 8 of the women who refused to take part had already disclosed severe trauma earlier during the research interview which were related to being physically abused, sexual abuse/rape and witnessing violence – all of which are contributory factors for tokophobia.

The best estimate of those affected by tokophobia therefore comes from the work of O’Connell et al, which put the figure at 14% of total births – accounting for 3,923 women in West Yorkshire and Harrogate (Table 14).

Table 14: Estimates of Tokophobia based on estimated 6% and 14% prevalence

	Bradford	Calderdale	Kirklees	Harrogate	Leeds	Wakefield	Total
Total births (2018)	6,936	2,170	4,652	1,305	9,270	3,687	28,020
Tokophobia risk (14%)	971	304	651	183	1,298	516	3,923

5.3 Risk factors for tokophobia

Studies that have explored who is at greatest risk of FOC have suggested that women who are a first time mother (although some studies suggestion multiparous women are more at risk (160)), prior history of anxiety or depression, women who are lonely or with poor social support, low perceived informational support, history of abuse, and those with low self-esteem (170–175). Women with a history of obsessive-compulsive behaviour have also been found to be more at risk, due to the fear of cleanliness and contamination (21,169). The most common cause relates to previous mental health problems and lack of social support (171,176).

The issue of abuse by healthcare professionals has been found to be a contributory factor in developing a FOC (175,177,178). Elsewhere in the world there have been reports of more significant abuse and violence against women by health professionals during their pregnancy and through their childbirth, which has also contributed to a fear factor – this may be an issue for women who are new migrants or asylum seekers (179–185).

O’Connell et al. (21) identified the following as being key characteristics of women with tokophobia:

- Young maternal age
- Advanced maternal Age (>40 years old)
- High socioeconomic status
- Low level of education
- Unemployment
- Smoking
- Anxiety before or during pregnancy
- Depression before or during pregnancy
- Single marital status
- High risk pregnancy factors such as: IVF pregnancy, gestational diabetes or congenital anomalies
- A previous C-section
- More common in nulliparous women
- In nulliparous women, tokophobia is associated with smoking
- Witnessing birth at a young age with no explanation

Women who have experienced female genital mutilation may also be at greater risk of fearing childbirth (186).

Women’s fears were also driven by stories they have heard from friends and relatives, TV and media and through their searching of the internet (163). The most common concerns that drive the women’s fear of childbirth are pain (174–176,187), the possibility of the episiotomy, and having no control over the event (175,176). Younger mothers in a study of 201 adolescent girls found over 75% had a fear of childbirth, with one-in-three appraising their birth experience as ‘awful’ or traumatic (151).

In parous women the risk of FOC was found to be increased after birth, suggesting that moderate to severe fear of childbirth may occur as a reaction to traumatic birth experience (164,188).

Interestingly a Dutch study found that those women who had elected to have a home birth were found to have a lower rate of FOC as compared to those who wished to have a hospital birth (189). In the 2 month follow-up questionnaire, even those women who were not able to have their preferred home birth were still less likely to show FOC.

5.4 Mental health problems with tokophobia

Experiencing tokophobia may lead to longer term mental health problems for the mother as it has been associated with an increased risk of developing PTSD or perinatal depression or with worsening pre-existing mental health problems (169,170). The long term nature of FOC was seen in a Swedish study (190) that returned to mothers 7 to 14 years after their first childbirth. Of the 63 women who had been identified as having FOC during their first pregnancy they were less likely to have a subsequent child, were more likely to have a CS in both their first and any subsequent pregnancies, more often had a less positive birth, received more counselling in subsequent pregnancies and still had FOC 7-14 years after their first child as compared to the 172 in the reference group.

Tokophobia may impact on the mother-child bonding (160), but there are no specific studies that have explored a direct link with FOC [most references refer back to the original article by Hofberg & Brockington (158)], however there is evidence that mothers with perinatal depression or PTSD may have issues with bonding and this may be co-occurring with the tokophobia. There may also be issues for women with tokophobia who avoid antenatal classes and be less prepared for managing their new baby.

The possibility also exists of low birth weight in mothers who have opted for an earlier birth. Stress during pregnancy has been associated with developmental outcomes for the child, with some studies also making a link with FOC (191,192).

5.5 Assessment tools

Women at first booking are not formally assessed for signs of tokophobia. With tokophobia having a strong link with previous trauma and mental health difficulties, which many may not wish to divulge, it is important that all women should be carefully assessed for signs of mental health difficulties at first booking and throughout their pregnancy. The NICE guidelines (39) for antenatal mental health advise that the two-question Generalised Anxiety Disorder (GAD-2) questionnaire be used:

- Over the last 2 weeks, how often have you been bothered by feeling nervous, anxious or on edge?
- Over the last 2 weeks, how often have you been bothered by not being able to stop or control worrying?

They also advocate the use of the Whooley questions:

- During the last month, have you often been bothered by feeling down, depressed or hopeless?
- During the last month have you often been bothered by having little interest or pleasure in doing things?

These questions have been used in a number of research studies to identify women at risk of mental health problems (157,168,193–195). In many cases, however, the first clear sign of FOC is when the woman requests a caesarean section (196).

If a woman is identified as having either depression or anxiety disorder NICE advise the use of the Edinburgh Postnatal Depression Scale (EPDS) or the Patient Health Questionnaire (PHQ-9) and the GAD-7 scale (197). In addition, they advocate the

women should be referred on to their GP or to a mental health professional. They are not tools that will formally identify tokophobia.

The most common tool used to assess severity of FOC is the 33-item Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ in the original paper, shortened subsequently to WDEQ)(198). This has two forms, WDEQ A for use during pregnancy and WDEQ B to be used after childbirth. WDEQ is scored from 0-165 item with the recognised score for severe fear of childbirth at cut-off scores that varied between 66, 85, and 100 according to studies that aimed to measure high/severe FOC. A score below 37 shows low fear, with a score of ≥ 85 usually used to denote high fear (162) and it has been suggested that it is also important to identify women scoring ≥ 66 as they may also need specific support (199).

Although this is widely recognised as the most reliable and valid tool for identifying FOB it is also long and not very practicable in everyday practice (200,201). Alternatives include the Fear of Birth Scale (FOBS). The FOBS is a two-item scale, which assesses both fear of birth and worry over the pregnancy. This asks, 'How do you feel right now about the approaching birth?' by marking two crosses on two 100mm visual analogue scales, anchored by the words: worried/calm and strong fear/no fear. These two scores were averaged to give a FOBS overall total score (201). This measure has been used in a number of studies to explore fear and has been found that those women who score over 60 are highly predictive of scoring over 85 on the WDEQ scale and should be followed up (201–204). A Swedish interview based study on 31 women's views of completing the measure found it to be mostly acceptable (205).

The Pan London Tokophobia best practice toolkit (206) offers the following key questions to ask the mother:

- How do you feel about the pregnancy? (look for ambivalent or negative emotions, anxiety symptoms)
- What are your thoughts and plans for childbirth? (if she requests a caesarean section but there is no medical indication for it, explore the reasons why)
- What are your feelings towards the baby? (ask during pregnancy as well as postnatally; tokophobia and/or birth trauma are likely to make it more difficult to form a bond with the baby)
- What was your previous experience of childbirth like? (where applicable; look for symptoms of post-traumatic stress disorder such as frequent thoughts/images of the birth, flashbacks, nightmares, avoiding reminders of the birth)

They also advocate the use of the Wijma Delivery Expectancy Questionnaire and the Fear of Birth scale. For secondary tokophobia they advise the use of the Impact of Events Scale-Revised [IES-R] (207).

The Perinatal Anxiety Screening Scale (PASS), has been found to be a useful tool for identifying women at risk of pregnancy related anxiety, but it is not yet shown to be sensitive to specific phobias (208).

At the time of writing a Tokophobia pathway is being developed, which will be a welcome development.

5.6 Interventions

Supporting women to come to terms with their fears and anxieties can reduce the number of CSs and helping the women to have a more relaxed birth. This can help shorten the labour and to reduce the risk of a vacuum extraction (209). It can also reduce the possibility of going on to develop perinatal depression or PTSD.

A key feature from the literature is that the women have a deep sense of uncertainty over what is happening to them and their baby and they need for a safe, secure and consistent service which is focused onto their needs. Having good communication with the practitioners enables the woman to face her fears and have confidence in themselves and the service. For this to occur there needs to be a willingness on behalf of the clinical team to acknowledge the woman's concerns and to provide the women with a sense of control over the process. This empowerment of the women enables her to birth on her own terms and helps the women to both acknowledge her fears and to build her confidence in overcoming them.

NHS London tokophobia best practice toolkit¹⁸ offers a very comprehensive set of guidelines on how to support the women with tokophobia. It would be worth considering adopting their approach. All women identified as being at risk are referred through to a specialist mental health midwife / consultant midwife for assessment and put onto a tokophobia care pathway.

5.6.1 Caseload management

Having continuity with a known midwife has been found to be an important factor in helping women overcome FOC and go on to have a normal birth. In a small Swedish feasibility study (210) 10 women with a score of 60 or more on the FOBS received standard care with the addition of a known midwife through the pregnancy and an invite onto a psycho-prophylaxis course, all but one had their fears alleviated or disappear, with 8 having a vaginal birth with a positive or very positive birth experience. The benefit of a caseload model was also found in another small Swedish study (211), which found the creation of a 'trustful woman-midwife relationship' a key factor in helping the woman overcome her fears.

Women with severe FOC (WDEQ ≥ 90), but not those with levels ≥ 66 , were found to benefit from heart rate variability (HRV) biofeedback (StressEraser) programme at home in a Japanese study of 97 low risk women (212). This intervention was carried out each evening and was based on relaxation and deep breathing exercises linked to their heart rate via a finger monitor. It is suggested that severe FOC is associated with greater parasympathetic activity, which can be reduced through this intervention. For all the women who took part in the study there was a subjective improvement in their fear of childbirth, with a reduction in WDEQ scores and improved sleep.

5.6.2 Complementary therapy

¹⁸ <https://www.healthylondon.org/resource/tokophobia-best-practice-toolkit/>

An analysis (213) of the effectiveness of Haptotherapy, which is based on increasing self-awareness and helping to normalise the childbirth through series of 8 sessions with a certified healthcare haptotherapist who is specialized in the treatment of pregnant women with severe fear of childbirth. The study found that recruitment and retention was problematic, with 11 switching themselves to the haptotherapy group of their own volition. The comparator groups were psycho-education via the internet and care as usual. The study found that the intervention group showed a significant decrease of fear of childbirth. As the partner is also invited to the haptotherapy groups they suggest that there is an additional benefit in increasing their feelings of social support.

5.6.3 Interventions that have been structured around group work

A Finnish study (214) focused onto group work with 105 women identified as having severe FOC, which were run by a psychologist using the Nyytti intervention¹⁹. This comprises a 6 week programme and a follow-up session 6-8 weeks postpartum. They found a decrease in FOC over the duration of the sessions. There were some women who refused to take part in the groups due to not wanting to share their emotions, there were also some women who were not helped by the initiative.

5.6.4 Internet-based Cognitive Behavioural Therapy (ICBT)

In a study (215) exploring the differences between internet-based ICBT and standard care (face-to-face counselling) in Sweden, the ICBT comprised 8 treatment modules specifically designed to address fear in pregnancy, with written feedback from a psychologist. Of the 127 women recruited onto the ICBT there was a decrease from 34% wanting a caesarean section (CS) to 12% by the time of birth and from 24% to 20% in the face-to-face counselling group. In the postpartum 2 months' follow up, the preference for a CS had again risen to 20% in the ICBT group and 29% in the counselling group. The actual mode of delivery did not alter between the two groups, but the majority (65%) had a vaginal birth and 10 a planned CS. What was important to note from the study was that the women preferred the face-to-face counselling, with a high drop out from the ICBT intervention. The challenging nature of ICBT and the greater requirement for commitment may be a factor, or the preference for a more 'supportive' personal contact through face-to-face counselling.

The use of an internet based CBT self-help manual for women with FOC was evaluated by the authors of the report in a Swedish study (216) of 28 primiparous women. The women completed exercises over an 8 week period, with submitted homework and a mapping of their fear levels. At the start of the intervention the 28 women had a mean WDEQ score of 125. Of the 15 who completed the 8 weeks the WDEQ mean had dropped to 81.6. All women's score fell, but some more than others with 3 still having a mean score of 109, 8 women had dropped to below 65. Post-birth follow up interviews with the women suggested that the women found it a positive intervention, appreciating the home based work (although they were surprised by the volume of work involved), the feedback, and that it had helped with their fears. However, they did voice a preference to have seen their therapist face-to-

¹⁹ This comprises a group intervention and integrates psycho-education, the lifespan model of motivation and practices to support mentalisation and mind-body connection.

face. For those who did not complete the programme the researchers suggest they may have been put off by the exposure of what was to come too difficult and they advocate greater preparation of the women at the start of the programme as to what to expect.

The same authors undertook an narrative based study (217) of 15 nulliparous women with severe FOC (WDEQ ≥ 85) before and after an ICBT intervention. Each woman was asked to describe in writing their thoughts on five different scenarios pertaining to their pregnancy and birth during the first week and at the end of the 8 week programme. Between these two time points all the women had improved their attitude towards their birth with it now seeming more manageable.

In a ICBT randomised controlled trial in Sweden (218) 276 women who scored over 60 on the FOBS were recruited into either an intervention group receiving or standard care group. The intervention comprised a guided 8-session self-help programme based on CBT over the internet. The psychologist running the project made contact with the women both through a portal and via calls. There was a decrease in fear of birth in both the intervention and control groups – which they surmise is due to a natural reduction in FOC over time from when the initial screening took place. There was a larger reduction in fear of birth 1 year postpartum in the ICBT intervention group, which they could not explain. What was noticeable in the study was the high drop out from the ICBT group (over 50% drop out), which lead them to suggest it was not a feasible or well-accepted approach for treating FOC.

5.6.5 Counselling

Midwifery-led counselling for women with FOC has been found to have a positive effect. The key features found in a Swedish interview study of 27 women with a FOBS score above 60 at recruitment appear to be the building of a trusting relationship with the midwife and instilling a 'sense of calm and preparedness', which helps build confidence and empowerment in the woman (219). However not all the women found the counselling helpful and in an earlier study women who did not receive counselling tended to fair better (220).

A study into the effectiveness of crisis-orientated counselling to reduce the number of women requesting CS for FOC was undertaken in Norway (221). Eighty-Six women who had been identified as having a fear of childbirth received an individual crisis-orientated intervention with the team midwife, with 2 hours for the first session and then individual plans for follow up meetings. After the intervention 74 (86%) had changed their thinking about the birth. Of those with low obstetric risk 96% gave birth vaginally, of those with high obstetric risk 54% gave birth vaginally and 22 (46%) were delivered by CS for medical reasons. Twelve women (14%) with severe fear (2 of which were nulliparous) kept their request for a planned CS. A follow up questionnaire showed 98% were satisfied with the counselling service, with 46 who had a CS wanting a vaginal delivery in the future.

5.6.6 Psycho-educative group therapy

Group therapy has been used to help women with FOC. In a trial of psycho-educative group intervention in Finland (209) 90 women with a WDEQ score over 100 and their partners were recruited to take part in the groups, whilst the 240 women in the control group had usual care. This usual care included 106 requiring specialist support and the remaining 134 being cared for by the community midwife and GP. The intervention groups comprised 6 women, with 6 sessions each lasting 2 hours and run by the same psychologist. An additional session was run with the mums and their newborn's 6 weeks after delivery (details of the sessions are included in the paper). More women in the intervention group went on to have a vaginal delivery as compared to the control group (87.7% vs 77.4%), however this was not statistically significant. They note that women having the opportunity to share different and often contradictory feelings towards delivery and parenthood in the group helps normalise and diminish feelings of inferiority and indignity.

In a systematic review and metanalysis for reducing FOC, the majority [8] of the studies they focused on were educational, with two that had focused onto the use of hypnosis (222). They found that antenatal class education was more effective than psycho-educational approaches, with both more than twice as effective as self-hypnosis. Nevertheless, all approaches to tackling FOC were found to significantly reduce FOC.

5.6.7 Childbirth Education

A 2-hour enhanced childbirth education session held at the maternity hospital was found to be effective in reducing childbirth related fear than a control group who received normal care (223). There were 338 in the intervention group and 321 in the control group. They found the intervention was most effective for tackling fears over specific labour issues, such as how to push or what's involved in an episiotomy, though normalisation and discussion.

5.6.8 Yoga

Yoga has a long standing reputation for being good for both physical and emotional health. A single session of yoga was found to reduce both subjective and physiological effects of anxiety, with a course of yoga showing further significant improvements in 31 nulliparous low risk women as compared to the 28 women were recruited onto a treatment as usual group (224).

5.6.9 Art therapy

In an art based therapy study (225) aimed at women with severe FOC 39 women were recruited onto an art therapy intervention, with 43 in the control group who received normal care. The art therapy comprised 5 sessions of 1½ hours duration. Women from both the intervention and the control group reduced their WDEQ score, with no significant difference shown. The study was small scale and found recruitment difficult, with the length of the sessions being seen as a hinderance.

5.6.10 Doula support

Having continuous support through the childbirth has been shown to reduce the number of women needing a caesarean section. A Cochrane review (226) of continuous support suggests that having a person who is not part of the mother's own family, has experience of supporting women through labour and has had some training appears to be beneficial.

An evaluation of the benefit of having doula²⁰ support for disadvantaged women was undertaken by Spiby and colleagues (227). One hundred and sixty seven women completed a questionnaire and 13 women took part in focus group discussions with the findings suggesting that the service was highly valued and had a positive effect on the women's psycho-social wellbeing over the labour and was particularly welcomed by women from a disadvantaged background. This was evident even when the support was during the pregnancy, but not actually at the birth. Their on-going support also helped increase the number of mothers breastfeeding and helped the women access statutory services. One aspect of the service that was problematic was in relation to the ending of the relationship, which some women found upsetting and a loss, as they had valued their support, with the suggestion that the service should be extended beyond the six-week period to help get the women over the time of peak incidence for post-natal depression (228).

5.6.11 Internet support groups / information

There are a number of internet support options available for women who are struggling with tokophobia including:

- Tommy's website: which has a section on "Fear of childbirth"²¹
- NCT: Tokophobia: how to get over extreme fear of giving birth²²
- Netmums: 6 ways to ease your fear of childbirth²³
- VeryWellMind - Tokophobia: Fear of Childbirth and Pregnancy²⁴
- Tokophobia Support Network²⁵

5.7 Women's experiences

A recent meta synthesis (229) of qualitative studies on women with FOC found the common narrative running through the papers included was that the women were 'at a point of no return'. Having become pregnant, they were forced to confront their situation, with their anxieties fuelled by their own previous experiences or from hearing of other women who had traumatic childbirth. They also found the women felt they had lost control and were fearful of a painful birth or a pregnancy with no guarantee of a success, either for them or their child.

²⁰ The role of a doula (Greek for 'handmaiden') is regulated; to become a mentored Doula they have to complete a Doula UK approved Preparation Course and be involved in Doula UK's Recognition Process.

²¹ <https://www.tommys.org/pregnancy-information/im-pregnant/mental-wellbeing/specific-mental-health-conditions/tokophobia-fear-giving-birth>

²² <https://www.nct.org.uk/pregnancy/how-you-might-be-feeling/tokophobia-how-get-over-extreme-fear-giving-birth>

²³ <https://www.netmums.com/pregnancy/fear-of-giving-birth>

²⁴ <https://www.verywellmind.com/tokophobia-overview-4684507>

²⁵ <https://www.facebook.com/groups/tokophobiasupportnetwork/>

In a UK based interview study (230) with 10 women who were identified as having FOC through standard care and referred through to a consultant midwife. Three of the sample were primiparous and 7 were multiparous. Six themes were identified from the primiparous women: 1. Fear of inability to cope with the pain, 2. Fear of my body's inability to give birth, 3. Fear of harm or stress to the baby, 4. Fear of the unpredictability of childbirth, 5. Fear of my lack of ability to plan and 6. Fear of harm to self, 7. Fear of long-term implications of damage from labour and childbirth, and 8. Not being 'heard' during labour or having an ability to influence what happens. The interviews with the multiparous women also found these same themes, with the addition of three additional themes: 9. Fear of being abandoned/alone in labour and childbirth, 10. Fear of length of labour and 11. Fear of intervention (including any processes that made them feel 'done to'). This study included interviews with experienced midwives on what they thought were the women's main concerns. Fear of the unknown was a key feature from the two sets of interviews alongside the role of uncertainty and unpredictability in the birth process eliciting fear.

An interview based study with mothers and fathers in Northern Ireland found that fear of the pain and not being able to have a normal birth were the main fears (231).

How women saw midwives was the focus of a Norwegian study (232) of 13 mothers identified as having a fear of childbirth, with the key finding being the importance of creating a trusting and caring relationship. This was achieved through having a continuity of care.

5.8 Fathers / co-mothers and family

There is a growing literature on the impact of pregnancy and childbirth on fathers, with men experiencing PTSD, perinatal depression and other emotional difficulties (233–237). There are also fathers that are affected by fear of birth, both through their partner's difficulties with tokophobia and also their own fears (238,239). In an Irish study, fathers were anxious that their wives mental health would be affected by a traumatic birth (231), this was also a significant factor in a Swedish study of men who had portrayed intense fear over the pregnancy (238).

The experiences of lesbian co-mothers on fear of childbirth is under-researched. One team from Sweden that has explored this issue has found that tokophobia may influence the choice as to which partner will give birth and also both partners experiences both during the pregnancy, labour and postnatally (240,241).

5.9 Midwives experiences of tokophobia

With apprehension and a general anxiety about being pregnant and facing childbirth being a very common phenomena it is part of the midwife's everyday experiences with women. Facing a more morbid fear is less common.

From the Netherlands a study of 217 midwives on midwives knowledge and practice relating to FOC and PTSD found that their knowledge and awareness was greater for FOC than for PTSD (242). In part this was seen as a greater exposure of women with a FOC (most had seen more than 5 per year) as compared to PTSD (1-5 per

year). Also, midwives will have had more conversations with the women about their anxieties approaching this current birth than dwelling on previous traumatic births.

In a similar study from Sweden, 726 midwives completed a questionnaire on FOC, over 2/3rds thought that the prevalence had increased over the last 10 years, which they felt was both a greater awareness in both the public and the profession (243). The sample reported that they saw FOC as more of an issue for parous women, as a consequence of previous traumatic births, which might suggest they are not looking at nulliparous women as being at risk. The midwives working in antenatal care clinics mostly reported that the women did not need psychotherapy but should be referred through to their FOC team. Those working in labour wards were mostly (95.2%) of the opinion that women with FOC should have a vaginal delivery and not a CS. Both sets of midwives felt that they intuitively recognised when a woman has FOC.

A deeper view of how midwives see women with FOC was given in a Swedish qualitative study comprising 4 focus group with 13 midwives (244). The study was based on the experiences of the midwives running counselling sessions with the women. The common theme that emerged was that the midwives were trying to create a safe space where the women could explore their previous and present fears of childbirth. This involved creating a reliable and trusting relationship and showing a dedication to the women. The midwives had to work at regaining the confidence in the women, especially when previous labours had not gone well. They did acknowledge that the sessions could be difficult and emotionally challenging and there was a need for good supervision. They also note there were no guidelines on how the counselling should be provided and a lack of women focused care models sometimes created conflicts in supporting the women through their labour.

5.10 Summary

- Many women have a fear of childbirth (FOC), which is different from tokophobia, which has been defined as a severe anxiety disorder characterized by an extreme, irrational fear of childbirth, which provokes a physiological response(21).
- Tokophobia is either primary when it occurs before or during the first pregnancy (primiparous women) or secondary in women who are pregnant again (multiparous women).
- Based the 2018 birth numbers and using O'Connell et al's prevalence estimate of 14%, 3,923 women are at risk of tokophobia across West Yorkshire and Harrogate.
- Tokophobia can be caused by previous negative experiences of childbirth, having heard of others experiences or through a deep feeling of loss of control and anxieties over the potential outcomes of the pregnancy.
- Women with a history of mental health difficulties and those women who have experienced sexual violence, previous loss and previous surgeries are also found to be at greater risk.

- Tokophobia can lead to perinatal depression, anxiety and an increased risk of developing PTSD, it can also lead to difficulties with mother-child bonding.
- Key support mechanisms for women include an early assessment of risk in the pregnancy initially through the Whooley questions (for depression) and the two-question GAD-2 questionnaire (for anxiety).
- In women deemed to be at risk the assessment guidance offered by the new Wakefield Tokophobia Pathway or the Pan-London tokophobia toolkit reflects best practice and includes general detection questions coupled with the risk the Fear of Birth Scale (FOBS) scale or the Wijma Delivery Expectancy/Experience Questionnaire [WDEQ] for primary tokophobia and the Impact of Events Scale-Revised [IES-R] for secondary tokophobia.
- Forming a strong and therapeutic bond with a known midwife is very important, with most papers preferring a continuity of carer / caseload management approach.
- Face to face interventions appear to be most beneficial.
- Formal counselling, whether by the midwife (as seen in some countries) or a psychologist have been found to be effective.
- Educational support to normalise the pregnancy and birth planning to address fears has also been found to be beneficial.
- For those without good partner support the use of a doula should be considered.
- Guidance on external support, such as internet support groups or local organisations should be given early in the pregnancy.
- For those women who report (or appear) distressed by having a birth contrary to their expectations they should be supported as per the guidance in the traumatic birth and other sections of the report to help prevent tokophobia in subsequent births.

6. Birth trauma

6.1 Introduction

The risk of postpartum post-traumatic stress disorder (PTSD) has become recognised as a separate and significant cause of depression in women over the last 20 years. Those women who experience ‘the perfect storm of trauma’ of physical or emotional trauma prior to their pregnancy, along with difficulties through their pregnancy, a traumatic birth and then parenting difficulties were found to be at the greatest risk (245).

A traumatic birth has been defined as “The emergence of a baby from its mother in a way that involves events or care that cause deep distress or psychological disturbance, which may or may not involve physical injury, but results in psychological distress of an enduring nature” (246). An alternative definition of birth trauma has been provided by the Prevention and Treatment of Traumatic Birth (PATTCh) organisation “A birth is said to be traumatic when the individual (mother, father, or other witness believes the mother’s or her baby’s life was in danger, or that a serious threat to the mother’s or her baby’s physical or emotional integrity existed.”²⁶

Having an instrumental or assisted birth, caesarean section, employing general anaesthesia, performing the Kristeller manoeuvre (fundal pressure, third/fourth degree perineal tears, postpartum haemorrhage, and manual removal of the placenta have been identified as risk factors for PTSD at 4-6 weeks both for preterm or full term delivery even when the delivery is obstetrically straightforward (197,247,248).

There is also another definition of trauma, which recognises that it is not just the physical trauma of the birth that requires careful management. Experiencing adversity, whether it be a single event or multiple negative experiences, can have a significant impact on the emotional health of the woman during their pregnancy and into parenthood (248–252). Those who are most at risk include:

- Women who have had adverse childhood experiences (ACEs), whether it be sexual abuse, physical or emotional maltreatment
- Refugees / asylum seekers
- Women from Black, Asian and Minority ethnic communities
- Women who have had genital mutilation (FGM)
- Intimate partner physical or emotional abuse
- Women in prison
- Homeless women and those living in poverty
- Those with chronic ill-health or disability

A traumatic birth may be associated with negative short and long-term impacts for women including PTSD symptoms such as flashbacks, nightmares, hypervigilance, and also reduced self-confidence and self-esteem, mother-infant attachment difficulties, relationship difficulties with partners, breastfeeding discontinuation, social

²⁶ <http://pattch.org/resource-guide/traumatic-births-and-ptsd-definition-and-statistics/>

isolation, reduced take-up of healthcare and prevention or delay of future conceptions (253). An analysis of symptom presentation in 2009 found that in 1,423 women there were two principle symptom clusters, one on re-experiencing and avoidance (RA) and one on numbing and arousal (NA), with the later strongly associated with general distress, such that it can be difficult to separate out what are normal responses to childbirth and what can be seen as a sign of impending PTSD and warranting intervention.

Studies that have explored the impact of PTSD on mother-child bonding have suggested issues with regard to mother-infant interaction – but many of these studies are difficult to compare and have been seen to have weaknesses that make the findings less robust (254–258). The most recent review of PTSD and mother-baby bonding (257) suggests that it is likely that there may be issues for the mother's interpretation of the babies behaviour which may impact on their relationship. A study (258) conducted in Croatia on 603 mothers of infants aged 1-12 months using the City Birth Trauma Scale (CityBiTS), found that there were bonding issues when the general PTSD symptoms were considered on the CityBiTS scale, but not from the birth symptoms on the scale. The important symptoms were those related to arousal and most symptoms of negative cognitions and mood (such as feeling irritable and tense, having problems concentrating and feeling detached from other people). This led the women to feel detached from their baby and difficulty in bonding. There was also found to be an in-direct effect as a result of co-morbid depression.

There is evidence that women who are experiencing PTSD symptoms, both antenatally and postpartum are less likely to breastfeed (253,257,259,260), however the studies done so far have had low numbers of affected women. It has been suggested that the same mechanism which affects women with perinatal depression and breastfeeding are similar to those seen with PTSD.

6.1.1 Post-traumatic stress disorder

According to the 2018 NICE guidelines on PTSD (261) the symptoms for PTSD include:

- re-experiencing (such as spontaneous thoughts, flashbacks, nightmares of the event)
- avoidance (avoiding memories, thoughts, reminders of the birth)
- hyperarousal (including hypervigilance, self-destructive, anger and irritability)
- negative alterations in mood and thinking (disrupted memories, sense of blame, isolation from others, low affect)
- emotional numbing
- dissociation
- emotional dysregulation
- interpersonal difficulties or problems in relationships
- negative self-perception (including feeling diminished, defeated or worthless)

The Guidelines (261) recognise childbirth as a possible cause of PTSD. They recommend when assessing for PTSD that specific questions are asked relating to: re-experiencing, avoidance, hyperarousal, dissociation, negative alterations in mood

and thinking, and associated functional impairment. An individual with PTSD requires an assessment that takes into consideration their physical, psychological and social needs and a risk assessment.

In a 2019 study that undertook a synthesis of research papers on PTSD following traumatic birth they found that there were some predictors of those who might be at risk of PTSD (262). These included those women who had experienced prior trauma, such as childhood sexual abuse or partner violence and those with a history of psychiatric disorders. For PTSD following birth, those most at risk were those women with low levels of support during the birth itself (from partners, family members or from the clinicians), those who needed a caesarean birth (especially emergency CS (263,264)), and those who had a negative birth experience. They also found that there were papers reporting co-morbidity with postpartum depression.

The relationship between PTSD and perinatal depression was explored in a 2019 study of 685 women recruited through postpartum websites in relation to their childbirth experiences and psychological consequences (265). They found the majority of women with PTSD following a traumatic birth also had symptoms of depression, which they argue should be seen as a single posttraumatic stress-depressive response and not just another dimension of perinatal depression.

The majority of women who have a traumatic birth recover without intervention, but there are a high proportion of women who go on to develop longer term problems. In a Turkish study exploring 226 women's longitudinal trajectories at 4-6 weeks and 6 months following a traumatic birth found that 61.9% showed resilience (minimal/mild disruption or absence of elevated symptoms), 18.5% showed recovery (initial significant disruption and elevated PTSD symptoms which resolves after some time), 13.7% had chronic dysfunction (elevated PTSD symptoms that are maintained over time) and 5.8% had delayed-PTSD (worsening of symptoms over time) (188). They also found that resilient women were more likely to have been satisfied with their health professionals, had good social support at all time points as well as less depression, fear of childbirth and fewer traumas since birth. Affective symptoms (depression and anxiety combined) at 4-6 weeks postpartum emerged as strong predictors of birth-related PTSD trajectories. Poor satisfaction with health professionals was associated with chronic-PTSD and delayed-PTSD.

6.2 Prevalence

It has been estimated that up to 30% of women can experience their birth as traumatic, with between 20% and 48% of women who experience a traumatic birth experiencing some PTSD symptoms that can affect their life, but not lead onto a diagnosable PTSD (266).

Nath et al., in their detailed study of the prevalence of anxiety disorders, using a clinical interview in an inner city study in the UK found a prevalence of 0.8% of PTSD. However, the authors noted that there were women who refused to answer the questions relating to PTSD but had previously reported past histories of abuse. When the prevalence calculation was adjusted to make an assumption that they did have PTSD the number affected rose to 4% (169). This study has relevance as it demonstrates the number of women who may not be willing to disclose PTSD to

clinicians. This issue of non-disclosure within a study, despite previous trauma, was also found in the Howard et al., study into the validity of the Whooley questions (168).

A review and meta-analysis of 59 studies (267) into the prevalence of PTSD during pregnancy and postpartum found that there was a 3.3% chance of PTSD during pregnancy and between a 4% and 6% chance of PTSD as a consequence of birth in the normal community. These rose to 18.95% in high risk women who were pregnant (as a consequence of complicated pregnancy or re-triggering of previous trauma) and 18.5% following birth in women who are identified as 'high-risk'. These high risk women were those who had experienced a previous difficult or traumatic birth, had emergency caesarean sections, severe fear of birth, a history of sexual/physical violence or childhood abuse, babies that were born very low birth weight, preterm, or diagnosed with fetal anomaly, or who had severe pregnancy complications such as hyperemesis grvida, pre-eclampsia or HELLP²⁷ syndrome. This study also found that PTSD prevalence increases between one and six months postpartum and that self-reported questionnaire measures had a similar prevalence rates to clinical interviews.

Basing an estimate of prevalence on 4% there were 1,121 women at risk of developing PTSD as a result of birth trauma across West Yorkshire and Harrogate (Table 15) in 2018.

Table 15 Estimated risk of developing PTSD as a result of birth trauma across WY&H

	Bradford	Calderdale	Kirklees	Harrogate	Leeds	Wakefield	Total
Total births	6936	2170	4652	1305	9270	3687	28020
Birth trauma (4% of birth)	277	87	186	52	371	147	1,121

6.3 Assessment tools

There is still not a universally accepted measure of PTSD following childbirth. Ayers and colleagues (268) developed The City Birth Trauma Scale (CityBiTS), which recognises the criteria for PTSD as described in the latest edition of the Diagnostic and Statistical Manual (DSM-5) (269) and is structured to make it more valid for women during pregnancy and childbirth, as compared to trauma from other causes. The scale was found to be both reliable and valid in identifying women at risk. In two subsequent validation studies the scale was again found to be an effective measure (270,271). It is noted, however that all these studies have been self-completed by the women themselves and not accompanied by a clinical interview or with high-risk women.

An American scale (Structured Trauma-Related Experiences and Symptoms Screener for Adults STRESS-A), which was developed for PTSD in the wider community has been adapted for a perinatal context. It showed promise, but has had limited validation (272).

²⁷ A rare liver and blood clotting disorder that can affect pregnant women (343)

A Dutch evaluation (273) of two instruments (Traumatic Event Scale-B [TES-B] and the PTSD Symptom Scale-Self Report [PSS-SR], which are used within the maternal setting to identify PTSD, found limited agreement between the two scales. The measures also failed to confirm the DSM-IV three symptom categories, as the identified subdimensions distinguished only between childbirth-related factors (re-experiencing/avoidance) and more general symptoms of depression and anxiety (hyperarousal/ numbing). Thomson & Downe in their survey of emotions and support needs following a distressing birth had a narrative component alongside their modified PSS Scale (266). They found that their respondents had elements not covered in the instrument. These included on-going mistrust of professionals, health complications, negative self-internalisations of guilt and failure, and concerns over future conceptions.

It has been suggested that at the time of a traumatic event the brain “switches off” to help deal with the enormity of the stress (261,274,275). This peritraumatic dissociation can be both a protective factor but it can also lead to longer term problems through the interference with processing and memory formation around the event. There may be a need for women who have been through a traumatic birth to be assessed using the Peritraumatic Dissociative Experiences Questionnaire (PDEQ) to help identify those who may be at risk of PTSD (see Thiel & Dekker (275) for more details).

There were differences expressed between on-line completion and in-person completion with a practitioner, with the latter preferred by women with a previous history of mental health problems (276). They found women without a known mental health history who struggled with emotional problems were inclined towards less interactive approaches and reported a reluctance to share their concerns. They suggest that having a variety of approaches to screening and better awareness raising of the purpose of the screening and its outcomes is needed.

Self-report measurement of PTSD tends to lead to higher numbers being identified than through structured clinical interview. This might be due to the strict criteria used in the interview missing some women at risk, or that the self-report leads to a greater number of false-positive diagnosis and a label of PTSD that is not warranted and might be more damaging (263).

The timing of the assessment is also important, as many women who may be distressed at the time of birth recover without intervention. It has been suggested that assessment should not occur until 4-6 weeks post birth (277).

6.4 Interventions

There are many women who are suffering from PTSD but are not receiving any support. Some authors suggest this is due to self-blame and being uninformed about the nature of PTSD and how it can affect them (278). There are also issues with regard to women’s willingness to engage with mental health screening (169,278). A Canadian qualitative study of new mothers found that there were issues of health literacy and for some an lack of recognition of their own emotional states, but there was also fear of the consequences, such as being stigmatised, or seen as unable to cope or risking losing their child (276). In many cases, however, they were just not

aware that they were able to access support, or had long waits for referrals (245,266). There is a need for more research into how the barriers for many women to disclose trauma and trauma related symptoms can be overcome, with Nath et al. suggesting that more sensitive methods for asking women about trauma need to be found (169).

There may be issues with regard to the midwife's awareness of PTSD and what signs to look out for. In a survey of midwives knowledge and awareness of FOC and PTSD they were much less aware of PTSD and over 18% of the 257 midwives in the sample were unable to answer any of the knowledge questions relating to signs and signals, psychological risk factors or possible consequences (242). In part this was seen as due to their relative lack of exposure to women with PTSD (between 1 and five per year).

When women do access services there is still uncertainty as to what provision should be provided. A 2017 systematic review (279) exploring primary prevention of PTSD found no studies that had explored primary prevention, only secondary prevention. The papers that had explored secondary prevention were deemed to be inconclusive. The only intervention that they reported as having a stronger evidence base for was the use of expressive writing, where the women were asked two days postpartum to note down their thoughts, expectations and emotions related to the delivery.

A review has been undertaken by Thomson & Garrett (280) with 54 respondents representing 54 different NHS hospital trusts from all geographic regions of England of current provision for women post-traumatic/distressing birth. They found that the majority (n=46) had a formal afterbirth/listening service, with 8 having an informal service. Attendance was variable, but as it was not recorded in many of the services provided the estimates were given as between 30 to over 300 per annum. Over 50% received no specific funding or allocated hours. Over 83% reported the service had evolved out of a direct response to women's needs, with others as a Trust decision due to complaints received from women. Only 24.1% had based their delivery on scientific/theoretical best practice.

In the majority (59.3%) of cases it was the midwife who solely provided the care, the rest were in conjunction with doctors and/or psychologists. Over 40% of the services were provided by professionals with no specific training. In only 18.5% of services had all the professionals accessed any related training. For those that had received training it varied considerably, from a day course through to the Birth Trauma Resolution Practitioner Training (accredited by Royal College of Midwives).

The majority of women attending were informed of the service by their health professional as there was a reluctance to widely promote the service due to limited capacity. Some were developing new ways to advertise the service, such as posters, via a Facebook page. There were few referrals as a result of routine screening (11.1%) or for those women who had had a potentially traumatic birth (27.8%). The timeframe for appointments also varied from site to site.

The majority of the services focused their appointment around what the women requested to know, such as details of the birth and why certain decisions were made.

The practitioners sought to normalise the women's reactions and to discuss future pregnancies. Only 55.6% provided women with information on birth trauma. The majority (89%) would refer a woman on to more specialist mental health services as needed, fewer would provide information or encouragement to access wider support from personal networks (63%) or organisations such as the Birth Trauma Association (55.6%). The survey did not include a question relating to support for partners/family members. What was promising was that 83.3% of the afterbirth services provided the women with advice and guidance regarding future pregnancies.

There were more specialised services available in 39 NHS trusts: including perinatal psychiatry, clinical psychology, specialist midwives (i.e. mental health), consultations with other clinicians (i.e. consultant midwife, anaesthetist, neonatologist, obstetrician), counselling, perinatal mental health and bereavement services. With one trust having a multi-professional team reviewing each case.

The use of perineal ultrasound and a visual biofeedback for women in the second stage of labour such that they were able to see the impact of their pushing on the babies progress was used with 26 women in Israel (281). This was found to increase the women's feeling of maternal connectedness postpartum and decreased symptoms of acute stress 2 days postpartum as compared to a comparable control group.

6.4.1 Debriefing

In 2000 a randomised controlled trial of midwife led debriefing (282) using an intervention based on a 1 hour discussion prior to discharge where the women were given a structured opportunity to discuss their experiences. They found the intervention did not reduce the risk of depression, and in fact there was signs that it had made it worse for the women. At the time of the debrief the women reported that it was 'helpful', however it has been suggested that it prevents the woman from processing her own experiences, can lead to re-traumatization, and through medicalising the event it prolongs the recovery (283).

Despite these early warnings Ayers and colleagues (284) noted in 2006 that debriefing was commonly practiced, with three models evident:

- Structured psychological debriefing as proposed for use following traumatic events,
- Midwife or obstetrician led debriefing where professionals review the events of a woman's pregnancy and birth experience with her
- 'Birth Afterthoughts' services run by midwives to discuss the events of birth with the woman.

They noted that these approaches lacked an evidence base and was actively discouraged within the then current guidelines (285), which is still the case in the current 2018 guidelines (261). Similarly, a 2015 Cochrane Review (286) of debriefing for women following a traumatic birth found there was insufficient evidence that there was any difference with routine postnatal care. The reviewers did warn, however, that the studies tended to be of a small scale, with deficiencies in the study designs and larger more robust studies were needed.

Nevertheless, studies have shown that women have difficulty processing their birth memories and the trauma they experienced and that they have a need have an opportunity to review and discuss what happened (266,287). A literature review undertaken by Baxter et al. (288) on the current practice of debriefing in 2014 found no evidence that there was a decrease in morbidity, but the women were very positive about having the chance to discuss their experiences with a midwife. This helped prevent the women feeling that their expectations had not been met and a means of reassurance regarding future pregnancies, it was also suggested as a means of reducing the likelihood of complaints. The timing of this opportunity to discuss what happened may be the important factor, with a delay of 4-6 weeks giving time for the mother to have adjusted to the birth.

In an internet blog²⁸, Dr Alison Wright, vice president of the Royal College of Obstetricians and Gynaecologists, suggests that women should first be advised to process their thoughts with family and friends and then if necessary speak to a clinician. She reported that many hospitals now have 'Afterthought clinics' for the women to attend. First established in Winchester in 1992 (289) they are now used across the country and are normally led by a senior midwife and often at a site away from the hospital. For those women who are identified as having more enduring issues they can be directed on to other provision. These clinics can also be attended by women considering another pregnancy, or already pregnant, so may be many years after the first birth (290).

6.4.2 Trauma Focused psychotherapy

There is still little in the way of research that has tried to take treatment approaches developed elsewhere into the maternal setting. Effective approaches that are used with other forms of trauma include trauma focused psychotherapy, which is combined with either exposure therapy, CBT or Eye movement desensitising and reprocessing (291).

The NICE guidelines (261) for PTSD recommend the use of trauma focused CBT for adults with a diagnosis of PTSD or clinically important symptoms of PTSD more than 1 month after the traumatic event (birth). They cited evidence that offering 12 individual sessions was clinically and cost effective. There may also be a benefit in also offering psychoeducation (p56). The use of eye movement desensitisation and reprocessing (EMDR) preferably commencing 3 months after the trauma has also been found to be an effective intervention. The use of trauma-focused computerised CBT, both supported and done unsupported were beneficial with effects lasting up to a year post trauma, with more benefit in supported sessions. Drug management is also warranted in some situations but is not covered in this review. For patients with complex needs the principles outlined above still hold but will need to be adapted to the individual's specific needs. This approach is also supported by the NICE antenatal and postnatal mental health guidance (39). In addition, they suggest offering the opportunity for women who have had a traumatic birth or miscarriage to talk about their experience, but again warn against a formal psychological debrief where they are expected to 're-live' the birth.

²⁸ <https://www.youtube.com/watch?v=kaCh0JuDpiQ&t=52s>

The research on resilience and growth suggests that increasing women's positive emotions, mastery/control, active coping and encouraging a sense of purpose or meaning during pregnancy, birth and postpartum may increase resilience and therein prevent or reduce postpartum stress (292).

A study (293) that explored the experiences of 144 women who had a single perinatal trauma within the previous four years, either with loss of the child (through miscarriage or stillbirth) or with trauma but without loss. Counterintuitively they found that the women with trauma but no loss had greater levels of psychological distress than in those that had suffered a bereavement. This was the case when previous mental health difficulties were taken into consideration. The researchers surmise that this may be due to women without loss receiving less emotional support from their partners and health practitioners. They suggest that it is important for every woman to feel that she is supported post difficult birth.

In a Swiss study women who required an emergency CS were asked to undertake a visuospatial task (playing a tetris game) for 15 mins within the first 6 hours, which resulted in fewer traumatic memories than a control group that had usual care (294).

6.5 On-line and mobile support

The Birth Trauma Association is a UK charity dedicated to supporting those adversely affected by birth trauma. They have an active Facebook page and Twitter account

<https://www.birthtraumaassociation.org.uk> @birth_trauma_association_uk

The National Childbirth Trust (NCT) has guidance and a support service for mothers affected by trauma <https://www.nct.org.uk/labour-birth/you-after-birth/traumatic-birth-and-post-traumatic-stress-disorder>

MIND offers guidance and links to other support services

<https://www.mind.org.uk/information-support/types-of-mental-health-problems/postnatal-depression-and-perinatal-mental-health/ptsd-and-birth-trauma/>

PTSD UK is a national charity supporting those with PTSD and offers support and guidance to mothers and fathers <https://www.ptsduk.org/?s=birth>

Prevention and Treatment of Traumatic Birth (PATTCh) is an American organisation with a similar remit to the Birth Trauma Association - <http://pattch.org>

PTSD COACH is a developed downloadable resource for smart phones that contains self-help tips for those struggling with PTSD symptoms. It isn't specifically designed for women (it was created by the US Veteran Affairs for ex service personnel) <https://www.ptsd.va.gov/apps/ptsdcoachonline/default.htm>

Make Birth Better support service for parents and professionals (@birthbetter) <https://www.makebirthbetter.org>

Birth trauma support family peer support for those affected by birth trauma (@birthtraumasupportfamily)

<https://www.instagram.com/birthtraumasupportfamily/?hl=en>

Mumsnet – peer support for mothers <https://www.mumsnet.com>

6.1 Women's experiences

A qualitative UK study (290) based in Hull explored 9 women's experiences of a traumatic birth and its effect on their subsequent pregnancies. They found that their previous experiences had a profound impact on their early pregnancy as they dwelt on what might be to come. They felt a need to be in greater control of their delivery and were lacking in trust of the health professionals. There was a need for the midwife to work to establish a good relationship with the women and to be extra supportive of her during the pregnancy to help reduce the risk of further problems in the future. The impact of a previous traumatic birth and negative experiences of pregnancy were also found in a survey study (266) conducted in the North West of England with 106 women. In this study two-thirds of the women continued to experience, or re-experience, negative affects in their current pregnancy.

In a Dutch qualitative study (295) with 34 women who self-identified as having a psychologically distressing event during their previous birth found that a key aspect was the perception of exclusion from key decisions made during the delivery and the objectification of their body. This included the unilateral decisions made by the midwife without informed consent. There were also negative connotations when the birth was not as expected (called by others as an 'incongruent birth experience' (296)).

The impact of feeling separated from decision making during the birth was also found in a UK based study (297) based on four in-depth interviews with women. The women found the mis-match between what they were expecting and what happened to be traumatic, this included pain management, feeling invisible within the process of birth, especially if they felt that their feelings were dismissed and that they were part of a routine process for the staff. The women felt that better management of them as a person with fears and expectations would have helped. This was also a finding of a Scottish interview based study (298) of 6 women who greatly valued the practitioner who had a positive relationship, recognising their vulnerability and supported them through including them in decision making.

The use of a birth plan, using epidural analgesia, and performing skin-to-skin contact with the baby at birth have been advocated as protective factors in a Spanish study of 2,990 puerperal women (247,248). Similar findings were found in an interview study of 32 Spanish women who had experienced a traumatic birth (299). The main themes in this study related to compliance with their birth plan, the early establishment of the mother-baby bond through skin-to-skin contact, as was support with breastfeeding. A further theme related to feeling well supported in the post-partum period and the final theme related to the overall experience. A worrying finding was that "many parturients in this study felt they have been crassly objectified and deprived of their human dignity as individuals."

'On my terms' was the main theme in an Icelandic study (300) of 131 women relating to their birth, with the sub-themes 'being recognised', listening is paramount' and 'mapping the unknown' as associated with the experience. Under the theme 'moving on' there was the feeling that they could progress when they had been able to regain some control of their lives through being listened to and having their wishes respected.

A Cochrane Review (226) of continuous support during childbirth found that women who felt more supported through labour were more likely to have a spontaneous birth, require less analgesia, be more likely to be satisfied and have a shorter labour. They were also less likely to go on to develop postpartum depression and the babies were likely to have a low five-minute Apgar score. This support could be from the midwife, her family, or an experienced doula.

6.2 Fathers / co-mothers and other birthing partners

For those who are present at a traumatic birth (including, but not limited to, eclampsia, post-partum haemorrhage, maternal admission to ICU, NICU, stillbirth) there is also the risk of them going on to develop PTSD (235,301–304). For many this will be their first experience of significant trauma and this is compounded by it being a loved one and them not having any control over the situation. There is also an expectation that they will be the support for the mother and child, such that they will not receive attention in the same way as if they were in other traumatic events – such as observing a shooting or work related accident on a colleague. Being at a traumatic birth can lead to significant adverse effects both during the event and subsequently, which impact on the health of the birthing partner, their relationship with their partner and their baby.

6.3 Impact on midwives of a traumatic birth

A scoping review that explored how a traumatic delivery affected the midwife was undertaken in Australia, identified the event as both an opportunity for personal growth and also a risk of increased defensiveness(305). A Scottish study of 6 midwives experiences of traumatic childbirth found that the midwives were working under stressful conditions and that it was difficult to provide the level of care they wanted to give (298). There was a need to ensure that they were supported and enabled to make positive relationships with the women, especially in the immediate postnatal period. This required recognition of the stressful and 'toxic culture' that can exist whereby the midwives felt that they were not in a supportive environment with negative behaviour by both colleagues and management. They reported that this led to negative interpersonal behaviour by midwives towards the women, colleagues and other maternity care staff. [A harrowing read of cruelty in maternity settings is provided by Goer (178)].

6.4 Summary

- Having a traumatic birth can increase the risk of postnatal depression, post-traumatic stress disorder (PTSD), and have implications for parent-infant relationships.

- It has been estimated that about 4% of women will develop PTSD, which amounts to 1,121 across West Yorkshire & Harrogate, rising to between 18 and 19% in high risk mothers (for example, having had a previous traumatic birth).
- Much of the PTSD women experience is iatrogenic, in-so-much that it has occurred as a result of negatively received medical interventions or poor communication, such that by changes in the way the woman and her partner are supported through the pregnancy and birth could prevent the onset of PTSD in many.
- Prevention should be a key goal over the pregnancy with pelvic floor exercises and a more proactive approach to protecting the pelvic floor during the birth.
- Women often prefer to see their own midwife when they are experiencing difficulties, so it is important that all the staff in the maternity services should have at least minimum training in supporting women with birth trauma with a referral system onto more specialist services – the continuity of carer approach would be of benefit here.
- Women who are pregnant again following a previous traumatic birth or had adverse childhood events / other trauma should be picked up at initial screening and assessed for existing PTSD and offered a care pathway to help manage emerging issues through their current pregnancy.
- Partners who are present at a traumatic birth (including, but not limited to, eclampsia, post-partum haemorrhage, maternal admission to ICU, NICU, stillbirth) should be offered support.
- Services should be advertised sensitively to ensure stigma and fear of consequences of usage are minimised. This should include information relating to the Birth Trauma Association.
- All women should be allowed to re-visit their experience of birth, with the opportunity to make an appointment with midwife or obstetrician.
- Formal psychological debriefing should not happen whilst an in-patient but if required be offered in the 4-6 weeks post birth and again at 6 months to allow for normal adjustment to occur.
- Women identified as having signs of PTSD (sub-clinical or clinical) should be referred through to specialist services for a clinical interview to assess the best way forward in terms of support and / or treatment.

7. Assisted conception

7.1 Introduction

For women struggling to conceive spontaneously there is an increased use of ovarian stimulators (OS) and assisted reproductive technologies (ART), such as in-vitro fertilisation (IVF) to promote conception. These have developed greatly over the years and are now more commonly used.

There are also now an increasing number of women who are in a lesbian relationship that are turning to ART to enable childbirth and also solo women who are seeking ART as a means of getting pregnant without a male partner. For all treatment cycles in 2017, heterosexual partnerships made up the majority at 90.7%, while female same-sex partnerships made up 5.9%. Single patients or those acting as surrogates made up 3% and 0.4%, respectively (306). Treatment cycles for patients in same-sex partnerships have increased by 12% from 2016 to 2017 and 4% and 22% for patients with no partner or surrogates, respectively.

For most heterosexual couples the main issue is infertility, which is 'a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse' (307). Using data from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3) Datta et al. (308) estimate that across Britain one in eight women and one in ten men have experienced infertility with prevalence higher in women aged 35-44 years (17.1%) and lower in younger women. Less than one-third (32%) of young women (16-24 years) seek help, but this rises to 58% in women aged 35-74 years. Those who were most likely to have experienced infertility were women and men who settled later with a partner, had higher educational attainment and occupational status and, among those who did have a child, became parents at older ages (308). It is also important to note that those women aged 50 or younger who sought help were more likely to report recent symptoms of depression and had dissatisfaction with their sex life (which would impact on their relationships).

The causes of infertility can be found either within the mother, within the father or a combination of issues in both parents. Infertility in women can be caused by a number of different factors, including smoking (309), obesity (310), diabetes (311), pelvic floor problems and other reproductive disorders (such as endometriosis or pelvic inflammatory disease) (312). Increasing age can also be a limiting factor. In men total male sperm count has decreased by nearly 60% between 1973 and 2011 (313), older men may also have issues with the quality of their sperm which also affects their fertility (314).

There is a growing trend for women to postpone pregnancy until later in life due to following a career or through other personal reasons. An increasing age at which couples are attempting to have a child means that the woman's biological clock is ticking, resulting in a greater pressure to conceive. The average age for donor insemination is now 34.5 years and for IVF 35.5 years.

There is an increasing cohort of solo mothers that have conceived through ART. This is still an under-researched area with regard to their experiences. A Swedish study of

solo mothers found little difference in relation to the woman's experience post birth, but noted over 50% had a previous history of anxiety or depression and suggested that staff should monitor their mental health through their pregnancy in case the need for support arose (315). A Norwegian qualitative study (316) of solo mothers views on postnatal care found that their drive to succeed could leave them vulnerable and fearful that they would be negatively perceived by the midwives. It can be an issue if they do not feel they can ask for help. Having a supportive environment in the early days of delivery was seen as very important, with relaxation of the rules regarding visitors important in ensuring they had support.

There are also more lesbian women who have undergone ART to start a family. Whereas for heterosexual couples there is most likely a long history of infertility, this might not be present for the lesbian couple. In a study by Rubio et al. (317) of heterosexual and gay couples conceiving through ART few differences were seen in the needs of the different couples in terms of their experiences of transitioning to be a parent.

7.2 Prevalence

In 2017 there were 75,000 IVF treatment cycles carried out across the UK (306). According to the Department of Health costing tool for fertility treatment there are 98 attendances at a fertility clinic for every 10,000 population across Yorkshire and the Humber (approx. 4,000 to 5,000 attendances), with 1,450 couples likely to be assessed as eligible for IVF treatment. Across West Yorkshire there are 398,330 women aged 18-42 years, which means that there may be ~3,903 attendances and 1,257 women eligible for treatment.

The Leeds Fertility Clinic is one of three fertility clinics in West Yorkshire, the others are Orbit Fertility in Bingley, West Yorkshire and Yorkshire Fertility, based in Calderdale Hospital. The Leeds Fertility Clinic is a large centre and their data will also include women who have travelled from other parts of the country, however, using their data gives an indicative number within the West Yorkshire area (Table 16). The data on births over a three years period [2015-2017] (318) shows that there were on average 710 women per year pregnant through fertility treatment, with 623 live births, of which 41 were multiple births. There were on average 87 pregnancies that did not go on to a live birth.

Table 16 Births over 3 years 2015-2017, Leeds Fertility Clinic

	Pregnancies per cycle	Live births	Singleton	Multiple births
donor insemination	104/555	97	95	2
ICSI - Fresh embryo, patient's eggs	796/1970	707	657	50
IVF - fresh embryo, patient's eggs	760/2198	659	622	37

IVF & ICSI -fresh embryo, donated eggs	34/94	28	26	2
IVF & ICSI - frozen embyos, donated eggs	25/73	22	22	0
IVF & ICSI - frozen embyos, patient's eggs	412/1188	355	323	32
Total over 3 years	2131/6078	1868	1745	123
Average per year	710/2026	623	582	41

Source of data HFEA <https://www.hfea.gov.uk/choose-a-clinic/clinic-search/results/314/statistics/> accessed 13th July 2020

Of those 710 pregnant there were 1,316 unsuccessful cycles, with differences seen depending on many variables, such as age, weight, and technique used. As there may be more than one attempted cycle within each year it is not possible from the available data to determine the number of women who had previously unsuccessful attempts which had failed. For those women who have been unsuccessful through their fertility treatment it has been estimated that one-in-six go on to spontaneously conceive (319).

7.3 Mental health and Assisted Reproductive Conception

ART is a complex process, which requires considerable investment, both personal and financial, which can be very stressful on both parents. The current success rate for a healthy baby are improving, and currently stands at 22% for IVF treatment (but decreasing with age), but this still means that many will have experienced various treatments (such as intrauterine insemination) before what could be many cycles required before success. There are also fewer multiple births nowadays through ART, but this still stands at 10%, which is higher than seen in spontaneous conception (306). In England there has been a decrease in publicly funded treatments, which currently stands at 35% in England, with variation seen within localities and the criteria adopted.

Women who conceived with ART are more likely have greater obstetric risks, such as miscarriage, stillbirth, assisted delivery, preterm births and have infants of lower birth weight than those who conceived spontaneously. A Canadian case-controlled analysis of data from the Quebec Pregnancy cohort identified a 46% higher risk of pre-term birth than seen in pregnancies through spontaneous conceptions (320). In terms of actual proportions this equates into an absolute preterm birth risk of 6.71% among spontaneous conceptions and 9.72% among those conceived through ART or ovarian stimulators or both (nearly 1 in 10 women). This includes those having late preterm (34-37) weeks through to extremely pre-term (< 28 weeks), which has implications for the child's health and parental stress.

There has been a reported difference in the quality of life in women who have conceived through ART due to the more severe social and physical restrictions placed on them due to the greater risk of obstetrical complications (321). In a Swedish study of 468 sub-fertile non-pregnant women, 2,972 naturally pregnant women and 143 women pregnant through ART anxiety and depressive symptoms among sub-fertile, non-pregnant women (57.6% and 15.7%, respectively) were significantly higher compared to women pregnant after ART (21.1% and 8.5%, respectively) and spontaneously pregnant women (18.8% and 10.3%, respectively) (322). The authors suggest that women who have conceived through ART are not in

need of any specific preventative intervention with regard to depression or anxiety as compared to spontaneously pregnant women.

Prenatal maternal stress has been associated with difficulties for women during their pregnancies, both for the mother and for the child. It has also been associated with increased stress in the partner of the mother, which can have implications for the level of support needed for them and its impact on support for the mother and child (323). A study on the impact of twin parenthood between ART and spontaneous conception found a decline in marital relationships in the ART couples (324).

How much of this translates into perinatal depression once conception has occurred has been the subject of many studies both nationally and internationally, with contradictory findings (321). For the majority of studies there has not been a relationship found for perinatal depression between women who conceive naturally and those that use ART (322,325–330). A Canadian prospective cohort study (330) of 1176 women comprising women who had conceived through ART and a control of spontaneous conception and assessed during pregnancy and 6-10 weeks postpartum. Using the GAD, EPDS and State Trait Anxiety Inventory six item scale found women conceived through ART had lower levels of anxiety and depression throughout their perinatal period.

A meta-analysis of studies exploring twins and multiple births did find that ART mothers had higher rates of depression and stress than spontaneously conceived mothers (331).

A Swedish study (322) compared anxiety and depression in 496 sub-fertile non-pregnant women with 143 women who have conceived through ART and 2972 women naturally pregnant. They found that high levels of both depression (57.5%) and anxiety (15.7%) in the non-pregnant sample, but after pregnancy there was little difference between the ART women and those who had spontaneously conceived. They did note that women with a lack of regular physical exercise, tobacco smoking, high alcohol consumption, and overweight were each independently associated both with depression and anxiety symptoms.

There may be complex adjustment issues to being pregnant in women who have undergone ART as a result of self-protective delays in believing in the pregnancy, forming an emotional attachment to the fetus and preparing for life with a baby (332). There is an issue with regard to depression in women who have used ART who then go on to miscarriage (333), especially if there are repeated miscarriages experienced.

With the improvements in ART there are an increasing number of women conceiving in their later years. With the hormonal fluctuations that occur through the menopause women who conceive through ART over the perimenopause may be more vulnerable to postpartum depression (334).

There are other complex issues faced by South Asian couples relating to the cultural position regarding donor insemination, which is seen as taboo by some in the Bangladeshi and Pakistani communities. This can create a burden of secrecy for the parents. This issue of donor eggs or sperm can also become an issue later in the

child's life as parents come to disclose their origins. The Leeds Fertility Counselling service offer a 'Talking and Telling' guidance session for parents facing this challenge.

There can be complex grieving emotional issues for those women (and their children) who have used posthumous sperm retrieval or sperm frozen prior to death. Although this is a rare occurrence it is feasible that this will become a more common practice.

There is an issue of substance abuse in parents coming through fertility treatment. This is not routinely assessed for through the fertility treatment, but estimates based on population use suggest that around 1 in 11 people will have used an illicit drug in the previous year and that there may be a case for more regular screening to determine risk (335).

7.4 ART and transition to parenthood

Fisher suggests there may be an issue of women who have had a difficult time conceiving find it hard to complain or to express doubts, uncertainties or anxieties about motherhood and this leaves them lacking social or professional support (329). This was also the conclusion of a systematic review from 2008, which suggested that there was so much emotional investment in the birth that it could lead to idealization and un-realistic expectations, coupled with a lack of confidence and reluctance to seek help if problems emerge (332).

A systematic review (321) of psychological stress and adjustment following ART found a significantly more intense and protective emotional attachment to their unborn baby. There may be a risk of idealising the pregnancy and struggle with its realities and the challenge of multiple births (329).

In the Canadian study the women undergoing ART were wealthier than the spontaneously conceived group, so they may have had more support and better access to health care (330), however they found similar levels of depression, anxiety and stress when they controlled for maternal age and SES.

There is a greater likelihood of twins or multiple births with ART. Tendais and colleagues (324) found in their study of 41 couples expecting twins (25 spontaneous conception, 16 ART) that those who required ART found the transition to twin parenthood more difficult, with mothers struggling more than the fathers. They were also more likely to report relationship difficulties, with a decline in the relationship over the pregnancy and into early postpartum. This study also found that the ART mothers had lower psychological wellbeing from pregnancy through to the postpartum. However, a Canadian cohort study found no difference in measures of depression or stress between singleton and twin pregnancy (330).

An Australian cohort study of women being referred through to their residential early parenting services (REPS) found that of the 166 women recruited into the study that had been through ART at 3 months post birth 40% had already used one or more of the early parenting services, with 8% admitted to the residential service as compared to 5% of the general spontaneously conceived population (336). There were lower

levels of clinical depression seen in the ART women, but higher levels of distress, with the women more worried, and sensitive and less assertive. They were more likely to find difficulty in managing infant crying, sleeping and feeding. Their mood had deteriorated from the birth and they were less likely to have initiated breastfeeding and were less confident in their ability to care for their child. The authors suggest that the women have had a cumulative effect of pressure to conceive through the more intensive support and surveillance through the pregnancy, a more idealised expectation coupled with reduced confidence in their ability to be a good parent. They also consider that the older age of the mothers, and a lower sense of entitlement to support may also be factors.

7.1 Interventions and assessment

A review of the implications for baseline depression and anxiety and that which occurs during ART suggests that there is a more negative effect on the outcome of the ART if the depression occurs during the treatment. Suggesting more support for women during ART may have a more beneficial impact (337). Such preparation during the ART in managing anxiety and depression has been found to be successful. An Iranian study of 90 infertile women undergoing ART were split into a control group and a group receiving eight 120 minute mindfulness based group counselling sessions along with home based activities, such as yoga and other exercises (338). They found the intervention group had a significant decrease in their levels of depression from a score of 20.77 to 10.82 on the 2nd Beck depression inventory (BDI-II) and the control group depression increased from 17.95 to 21.33.

Once the woman is pregnant if they have experienced a long process of treatment or have had repeated miscarriages there is a higher likelihood that they will have already be experiencing anxiety and depression. Infertile women are also more likely to have a history of psychiatric diagnosis (322). It has been suggested that a brief screening measure such as the EPDS in early pregnancy is wise to help identify early problems and to assess progress through the pregnancy (329). In a similar way to women who have conceived spontaneously with previous mental health difficulties early psychological counselling and intervention might be advisable.

Stress reduction methods such as yoga, meditation, mindfulness, acupuncture, and cognitive behavioural therapy might be helpful for reducing stress in women have been suggested (322,338). Support concerning risky lifestyle behaviours could also be helpful, considering their higher prevalence in women who are sub-fertile.

What stands out from the review is the need for women having conceived through ART to be given greater preparation for parenthood and to support them postpartum. The emotional toll of ART coupled with the higher incidence of pre-term babies and operative delivery may add to the parenting stress the parents are under, especially if there are twins or multiple births (329).

Couple-based interventions may be helpful for those whose relationships are strained or are facing twins or multiple births (324).

7.2 Mothers experiences

In the study by Rubio et al. (317) of heterosexual and gay couples experiences of IVF found that the heterosexual couples conceiving children through IVF was an 'exhausting' and 'stressful process'. They also reported being anxious throughout the pregnancy, resulting in 'waiting to tell relatives and friends about the pregnancy', 'fear of having a miscarriage in the first trimester' and 'being afraid that pregnancy would be terminated prematurely'.

7.3 Fathers / co-mothers experiences

The majority of studies that have explored fathers experiences of pregnancy following ART suggest there are few differences to those seen in spontaneous pregnancy (339–342). There were no studies found that explored specifically the experiences of co-mothers.

7.4 Midwives experiences

There have been no studies found that have looked at midwives' experience of caring for families where pregnancy follows ART.

7.5 Summary

- The road to pregnancy may be stressful and very challenging for women and their partners seeking conception through assisted reproductive technology.
- Once pregnant, according to the literature, there are contradictory findings related to perinatal mental health problems, with the majority suggesting there is not a greater risk of perinatal mental health problems as compared to spontaneous conception.
- There may be other mothers and partners experiencing complex emotional and mental health challenges.
- There is the possibility that the woman and her partner need greater preparation for parenthood.
- Support for both partners is needed if there are relationship issues, to help keep the family unit together and able to function as a supportive unit.
- Links could be made with Assisted Reproductive Technology counselling service providers such that there is a more seamless move into pregnancy care.

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