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# Tokophobia Pathway

## Greater Manchester Mental Health NHS Foundation Trust

**To be read in conjunction with:**

Pan-London Perinatal Mental Health Best Practice Toolkit: Fear of Childbirth (Tokophobia) and Traumatic Experience of Childbirth

Greater Manchester & Eastern Cheshire Antenatal and Postnatal Mental Health Guide

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# Contents

# Introduction

This document is a guide for all professionals working with women throughout their pregnancy and postnatally who may present with tokophobia. This includes maternity services, psychological services and perinatal teams across Greater Manchester. This guidance is to be used when a woman/birthing person expresses a fear of childbirth/tokophobia.

## Aims

- Early identification of fear of childbirth (antenatally) and post-traumatic stress disorder after childbirth (postnatally)
- Increased signposting to timely interventions for fear of childbirth and/or post-traumatic stress disorder after childbirth

## Definitions

Tokophobia is defined as a marked fear of childbirth (and sometimes fear of pregnancy). Fear of childbirth is defined according to two categories:

1. **Primary tokophobia** is long-standing often since childhood
2. **Secondary tokophobia** is subsequent to a previous childbirth that was experienced as traumatic. Secondary tokophobia is therefore commonly conceptualised and treated as a specific form of post-traumatic stress disorder (PTSD) and is more common than primary tokophobia.

It is important to note that a previous childbirth that was experienced as traumatic relates to a person's subjective experience of childbirth independent of whether or not there were any obstetric complications. Evidence suggest that this can include the perceived risk of medical events such as maternal or infant death, but also perceived threats to integrity such as feeling violated, out of control or abandoned.

# Risks of tokophobia

**Baby/Foetal Risk**

During the early stages of a pregnancy, individuals with primary tokophobia are likely to be at increased risk of terminating pregnancies, including those which were previously wanted and planned, or resulting from assisted conception. During all stages of pregnancy there is evidence that ongoing anxiety as in primary and secondary tokophobia can impact on emotional and developmental outcomes for the baby in the longer term. Women/birthing people are likely to find it difficult to form a bond with their baby (known as the attachment relationship), both during pregnancy and postnatally. Sometimes they may develop negative thoughts or feelings towards the baby, because the baby maybe a link to their experience of childbirth. There could be other reasons why there are negative thoughts about the baby.

**Maternal Risk**

There is a very high risk of severe levels of anxiety and depression during pregnancy for women/birthing people with primary tokophobia. There will be symptoms of post-traumatic stress in secondary tokophobia and sometimes also in primary tokophobia. The risk of self-harm and suicide may be raised once a pregnancy progresses beyond 24 weeks' gestation (the legal limit for termination of pregnancy), as people may then feel trapped. It is also the case for many that increasing proximity to the delivery is associated with increasing anxiety.

# Assessment and Identification

On questioning, most women/birthing people will report some degree of anxiety in relation to childbirth and the challenge is to ascertain whether they require intervention. This is further complicated by the fact that many of the risk factors for tokophobia are highly sensitive topics (e.g. history of sexual abuse or rape), which people may hesitate to disclose.

Assessment and identification of tokophobia consists of initial screening followed by additional assessment by a perinatal specialist.

Early identification of tokophobia is crucial in order to allow time to access appropriate treatment before childbirth.

## Initial screening

Initial screening can be carried out by any health professional. The following assessment tools used either at booking or in clinic can act as a guide and support screening:

- **How do you feel about the pregnancy?** (Consider ambivalent or negative emotions, anxiety symptoms)
- **What are your thoughts and plans for childbirth?** (If a caesarean section is requested but there is no medical indication for it, explore the reasons why)
- **How are you feeling about becoming a parent** (explore with the parent how they are feeling, what they might be anxious or worried about)
- **How are you feeling about your baby?** (ask during pregnancy as well as postnatal; tokophobia and/or birth trauma are likely to make it more difficult to form a bond with the baby, explore what the parent might be feeling and thinking about their baby)
- **What was your previous experience of childbirth like?** (Look for symptoms of post-traumatic stress disorder such as frequent thoughts/images of the birth, flashbacks, nightmares, avoiding reminders of the birth)
- **Is there anything in your life (past/present) which might make the pregnancy/ childbirth more difficult?** For example, fear of birth, trauma, childhood sexual abuse, sexual assault?

A simple indication of severity can be gained by asking the following question concerning feelings about childbirth: On a scale of 0 to 10 where 0 is not at all anxious and 10 is extremely anxious, how anxious do you feel about childbirth?

If further information and clarity is needed in relation to the severity of symptoms, the Fear of Birth Scale (FOBS) (Haines, 2011) could be administered (see Appendix B).

If the screening questions indicate a significant fear of childbirth and/or the FOBS score is higher than 60, a referral should be made to a specialist mental health midwife for further assessment.

## Further assessment

The clinician carrying out an additional assessment, likely a specialist mental health midwife, will need to consider risk factors, observations, and psychometric tests.

**The following risk factors should be considered:**

- Previous adverse medical/surgical experience
- Previous traumatic experience of witnessing childbirth either personally (e.g. family member) or professionally (e.g. as healthcare staff)
- Pre-existing anxiety or mood disorder
- History of sexual abuse or rape
- History of sexual dysfunction
- Previous miscarriage, stillbirth or neonatal death

**Observable concerns or presentation to look out for may include:**

- Intense fear of childbirth, not amenable to reassurance and not at normal levels
- Thoughts that this is 'unnatural, wrong'
- Intense fear despite level of desire for child or forgetting the desire for a baby once pregnant
- Intense fear/discomfort regarding pregnancy
- Revulsion regarding 'something growing inside'
- Did not anticipate these feelings
- Avoidance of the pregnancy – discussion of the baby, sharing the news, concealing the bump
- Fear of negative physical consequences of childbirth (rupturing, injury to self or to unborn child, fear of death or of the unknown, losing control, or appearing silly)
- May have a history of remaining childless or delaying conception despite wanting children, or seeking out an obstetrician who will agree to perform a caesarean section pre-conception
- May have a history of terminating wanted/planned (including fertility assisted) pregnancies
- Shame and guilt may be strongly characteristic, perhaps associated with presenting to services late in pregnancy, late termination of pregnancy
- Stigma and embarrassment
- High levels of anxiety and low mood
- Negative thoughts about the baby or an absence of the baby
- Negative thoughts or severe anxiety about becoming a parent

The Wijma Delivery Expectancy/Experience Questionnaire (WDEQ-A) (Wijma, 1998) can be used as a psychometric measure of tokophobia. See appendix C for further details.

**A note on psychometric tests**
Measures can provide additional information on level of needs and inform decision making, but should only be used as part of a holistic assessment. Professional judgement should be made on whether onward referral is required (regardless of scoring) and to consider speaking to services to discuss concerns if unsure. If the clinical concerns do not match the test scores always use clinical judgment when making decisions about onward referral.

**Remember to take into account the common occurrence of parents minimising or under reporting their symptoms.**

### Post-Traumatic Stress (PTSD)/Birth Trauma

When a woman is identified as having symptoms of secondary tokophobia, there may be symptoms of post-traumatic stress from a previous birth. Professionals should be aware of key indicators of birth trauma:

- **Re-experiencing:** Frequent thoughts or images of the birth, nightmares, flashbacks, high levels of distress or anxiety.
- **Avoidance:** Avoiding reminders of childbirth e.g. hospitals, TV programmes about birth, friends who are pregnant, avoiding talking about or thinking about childbirth.
- **Hyperarousal:** Hypervigilance, exaggerated startle response, sleep problems. Some people report emotional numbing.

Using a measure (see Appendix D; Impact of Events Scale-Revised; Weiss & Marmar, 1996) in relation to birth may provide a useful indication of the severity of these symptoms.

**Additional risk factors for PTSD:**

- Previous childbirth experienced as traumatic
- History of childhood abuse
- A strong need to be in control

# Intervention

## Preconception

- Access to consultation e.g. Specialist Mental Health Midwife/Consultant Midwife.
- Information about tokophobia and care pathways.
- Access to discussion about previous delivery.
- If necessary, refer for psychological therapy in NHS Talking Therapies (if mild to moderate) or PETALS (if severe/complex).

Tokophobia information leaflet.

## Postnatal

- Postnatal follow up e.g. with Specialist Mental Health Midwife/Consultant Midwife.
- Screen for birth trauma/PTSD.
- Assess mother-baby relationship. If you have concerns, contact PIMH service for consultation.
- Access to information about birth/birth reflections appointment.
- If there are PTSD symptoms relating to the birth, please contact PETALS or Specialist Perinatal Service for further advice/support.

Birth Trauma Association Information.
Information about NHS Talking Therapies /Specialist Perinatal services/birth reflections.
Your Baby and You Leaflet: www.penninecare.nhs.uk/your-baby-and-you

# Pathway to intervention in pregnancy

**Screening**
- Key Questions
- FOBS

**NO**

Consider midwifery led interventions, for example:
- Signposting to self-help and information about tokophobia
- Arranging visits to birthing unit
- Continuity of carer
- Providing information on childbirth options
- Signposting to positive birth movement groups

**YES**

**Further Assessment**
- Key considerations
- Key observations
- WIJMA
- Consider PTSD (IES)

**Review**
- Take to supervision or case consultation if required/unsure

If you are unsure whether it would be appropriate to refer to PETALS or the Specialist Perinatal Service, please get in touch with the teams.

**Primary Tokophobia**

**In addition to the interventions described above, consider:**
- Support from specialist midwives
- Early appointments with obstetrics and specialists e.g. anaesthetist
- Psychological intervention from NHS Talking Therapies
- Psychologically - and trauma-informed birth planning by 32 weeks
- Consultation and possible referral to Parent Infant Mental Health Services

**Secondary Tokophobia**

**In addition to the interventions described above, consider:**
- Psychological therapy and/or care coordination from Specialist Perinatal Service or PETALS

**PTSD**

Psychological intervention (such as trauma-focused CBT or EMDR) from NHS Talking Therapies, Specialist Perinatal Service or PETALS

# Appendix

## Appendix A: My perinatal wellbeing plan

| Your details | | | |
|---|---|---|---|
| Name | | Pronouns | |
| My birthing partners name and their relationship to me: | | Pronouns | |

**Trauma-informed and compassionate care**

Most of us have had traumatic events in our lives. We know that 1 in 4 women have experienced trauma, and this traumatic experience understandably shapes the way in which we react. What happens during pregnancy, obstetric care, and childbirth can bring up powerful emotions - and make it hard to cope, but there are things we can do. Please help me feel safe and empowered by considering the following principles:

- Compassion and recognition
- Communication and collaboration
- Consistency and continuity
- Recognising diversity and facilitating recovery

**Understanding my story**

What has happened to you? What significant events have contributed to how you are today?

**What can sometimes trigger overwhelming feelings?**
Triggers can be internal such as bodily sensation, a thought/image or a emotion. Triggers may be external such as environmental, interpersonal, social, situational.

**What changes do I notice that signal to me that I am starting to feel overwhelmed?**
If you were to slow down and notice the early changes and signals that you are starting to feel unsettled, what would they be? What signals would indicate that you are feeling more intense emotion. You may notice signals from the changes in your body, thought patterns and your actions or behaviour.

**What helps me feel soothed and comforted?**
What helps calm down big and overwhelming feelings? What can you do for yourself? What can others around you do or not do? Consider key people who might be involved in your perinatal care.

## What I have learned and developed that can help me feel safe and soothed

## Being pregnant – next steps

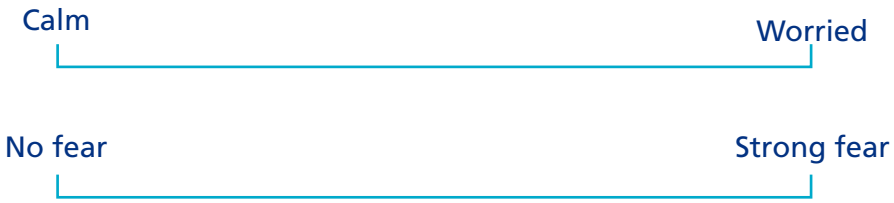
## Preferences for birth (If pregnant)

## If it doesn't work out as hoped

## Appendix B: Fear of Birth Scale (FOBS)

# "How do you feel right now about the approaching birth?"

Ask the respondent to place a mark on each of two 100mm VAS-scales with anchors defined as




Use a ruler to measure in millimetres where the woman marks each scale. The two scores are then averaged to create a total score ranging from 0 to 100, with high scores indicating higher levels of childbirth fear. Women scoring > 60 are identified as those who may require further assessment.

# Appendix C: Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ)

(min. score 0, max. score 165). A higher score indicates a more intense fear of childbirth.

This questionnaire is about feelings and thoughts women may have at the prospect of labour and delivery.

The answers to each question appear as a scale from 0 to 5. The outermost answers (0 and 5 respectively) correspond to the opposite extremes of a certain feeling or thought.

Please complete each question by drawing a circle around the number belonging to the answer which most closely corresponds to how you imagine your labour and delivery will be.

Please answer how you imagine your will be - not the way you hope it will be.

**1. How do you think your labour and delivery will turn out as a whole?**

| 0 | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| Extremely fantastic | | | | | Not at all fantastic |

| 0 | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| Extremely frightful | | | | | Not at all frightful |

**2. How do you think you'll feel in general during labour and delivery?**

0 1 2 3 4 5

Extremely lonely — Not at all lonely

0 1 2 3 4 5

Extremely strong — Not at all strong

0 1 2 3 4 5

Extremely confident — Not at all confident

0 1 2 3 4 5

Extremely afraid — Not at all afraid

0 1 2 3 4 5

Extremely deserted — Not at all deserted

0 1 2 3 4 5

Extremely weak — Not at all weak

0 1 2 3 4 5

Extremely safe — Not at all safe

0 1 2 3 4 5

Extremely independent — Not at all independent

0 1 2 3 4 5

Extremely desolate — Not at all desolate

0 1 2 3 4 5

Extremely tense — Not at all tense

0 1 2 3 4 5

Extremely glad — Not at all glad

0 1 2 3 4 5

Extremely proud — Not at all proud

0 1 2 3 4 5

Extremely abandoned — Not at all abandoned

0 1 2 3 4 5

Extremely composed — Not at all composed

0 1 2 3 4 5

Extremely relaxed — Not at all relaxed

0 1 2 3 4 5

Extremely happy — Not at all happy

### 3. What do you think you will feel during the labour and delivery?

0 1 2 3 4 5

Extreme panic — No panic at all

0 1 2 3 4 5

Extreme hopelessness — No hopelessness at all

0 1 2 3 4 5

Extreme longing for child — Not at all longing for child

0 1 2 3 4 5

Extreme self-confidence — No self-confidence at all

0 1 2 3 4 5

Extreme trust — Not trust at all

0 1 2 3 4 5

Extreme pain — No pain at all

### 4. What do you think will happen when labour is most intense?

0 1 2 3 4 5

I will behave extremely badly — I will not behave badly at all

0 1 2 3 4 5

I will allow my body to take control — I will not allow my body to take control at all

0 1 2 3 4 5

I will totally loose control of myself — I will not loose control of myself at all

# Appendix D: Impact of Event Scale

Below is a list of difficulties people sometimes have after stressful life events. Please read each item and then indicate how distressing each difficulty has been for you during the **past seven days** with respect to _____ , how much were you distressed or bothered by these difficulties?

| | Not at all | A little bit | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|---|
| 1. Any reminder brought back feelings about it | 0 | 1 | 2 | 3 | 4 |
| 2. I had trouble staying asleep | 0 | 1 | 2 | 3 | 4 |
| 3. Other things kept making me think about it | 0 | 1 | 2 | 3 | 4 |
| 4. I felt irritable and angry | 0 | 1 | 2 | 3 | 4 |
| 5. I avoided letting myself get upset when I thought about it or was reminded about it | 0 | 1 | 2 | 3 | 4 |
| 6. I thought of it when I wasn't meant to | 0 | 1 | 2 | 3 | 4 |
| 7. I felt as it hadn't happened or wasn't real | 0 | 1 | 2 | 3 | 4 |
| 8. I stayed away from reminders bout it | 0 | 1 | 2 | 3 | 4 |
| 9. Pictures of it pop into my mind | 0 | 1 | 2 | 3 | 4 |
| 10. I was jumpy and easily startled | 0 | 1 | 2 | 3 | 4 |
| 11. I tried to not think about it | 0 | 1 | 2 | 3 | 4 |
| 12. I was aware that I still had a lot of feelings about it but I didn't deal with them | 0 | 1 | 2 | 3 | 4 |
| 13. My feelings about it were kind of numb | 0 | 1 | 2 | 3 | 4 |
| 14. I found myself acting or feeling like I was back at that time | 0 | 1 | 2 | 3 | 4 |
| 15. I had trouble falling asleep | 0 | 1 | 2 | 3 | 4 |
| 16. I had waves of strong feelings about it | 0 | 1 | 2 | 3 | 4 |
| 17. I tried to remove it from my memory | 0 | 1 | 2 | 3 | 4 |
| 18. I had trouble concentrating | 0 | 1 | 2 | 3 | 4 |
| 19. Reminders of it cause me to have physical reactions such as sweating, trouble breathing, nausea, or pounding heart | 0 | 1 | 2 | 3 | 4 |
| 20. I had dreams about it | 0 | 1 | 2 | 3 | 4 |
| 21. I felt watchful and on guard | 0 | 1 | 2 | 3 | 4 |
| 22. I tried not to talk about it | 0 | 1 | 2 | 3 | 4 |

**Scoring**

1. Avoidance subscale: Mean of items 5,7,8,11,12,13,17,22
2. Intrusions subscale: Mean of items 1,2,3,6,9,16,20
3. Hyper arousal subscale: Mean of items 4,10,14,15,18,19,21
4. Impact of events - Revised score: Sum of the above three clinical scales

Note that the hyperarousal scale is made up of seven new items, (No's 4,10,14,15,18,19,21) added to the original impact of events scale (IES) For valid comparisons with scores from the IES, use just the sum of the avoidance and intrusion items.

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