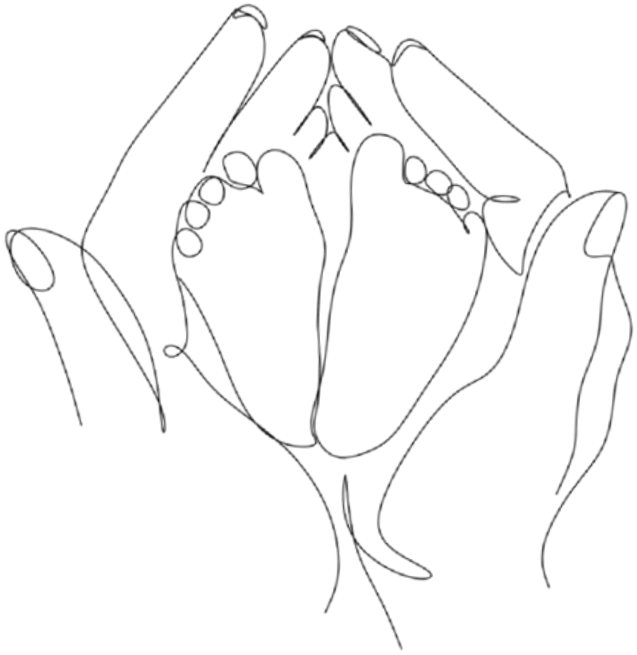
Leo's Perinatal Service

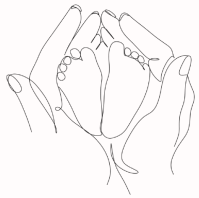
Leo's Perinatal Service - Supporting families through pregnancy and baby loss



REDCAR AND CLEVELAND 0 to 19 Family Hubs Helping Families thrive

Middlesbrough Family Hubs

Introduction



In 2023, Leo's was awarded a two year contract as part of the Department for Education's Family Hubs Transformation Programme, by both Redcar & Cleveland and Middlesbrough Council, to produce a bespoke perinatal baby loss pathway and service.

This service is the first of its kind in the region, addressing a powerful need to support families through the turbulence of pregnancy or baby loss.

Leo's is an award-winning lived-experience provider for neonatal mental health, and is now expanding its expertise to cover a wider scope of perinatal work with a core focus on pregnancy and baby loss.

This pathway marks a pivotal moment in perinatal mental health within the region, fulfilling a need to hold and care for families during one of the most traumatic life events imaginable, whilst providing a combined approach of therapeutic interventions, lived experience and trauma informed care to aid recovery.

Families living within Redcar and Cleveland and Middlesbrough postcodes who have experienced a miscarriage, termination for medical reasons, stillbirth or neonatal loss will now be able to receive specialist support within the first 12 months of their loss.

Perinatal mental health is defined as a mental health problem which occurs during pregnancy up to the first year after birth.

This can include, but is not limited to, postnatal anxiety, postnatal depression, postpartum psychosis, OCD, pregnancy trauma, birth trauma and PTSD.

The MBRRACE report outlines that perinatal mental health issues result in a cost of £8.1 billion for each one-year cohort of births in the UK.1

Suicide is currently the leading cause of death for women during pregnancy and in the first year after birth, with the cost to the public sector of perinatal mental health problems being five times the cost of improving services.2

It is unknown if those who have faced loss during the perinatal period are included in these statistics.

Introduction

The team will be using the following pyschometric questionnaires to understand the wider impact on the parents accessing this service:

- PHQ9/GAD7
- PCL5
- Birth Trauma Scale (City of London) (where relevant and appropriate)
- Maternal Attachment Scale (for a subsequent pregnancy whilst in our care)
- Leo's internal pregnancy anxiety questionnaire (for a subsequent pregnancy whilst in our care)

The newly designed service will be routinely guided by the voices and experiences of its community, whilst being firmly underpinned by trauma informed practices to ensure a robust, adaptive and nurturing care model is in place at all times.

Leo's have created a framework working within these key principals, which combine person-centered care, a trauma sensitive approach, with added goal setting capabilities to allow families to be held and cared for during the post-traumatic growth period.

Overview of Service

What does the service offer?

Offering a life-line of support, nurture and compassionate care within the immediacy of pregnancy or baby loss for families within the Redcar & Cleveland and Middlesbrough postcodes.

Talking Therapies, CBT, EMDR, Flash and Creative Therapies

Using a myriad of approaches to be flexible and adaptive to the needs of the families accessing the therapeutic counselling services. All parents entering the service will be assessed and paired with the most suited therapist. Therapists will work in a person-centered approach, and will offer 10 sessions of counselling interventions.

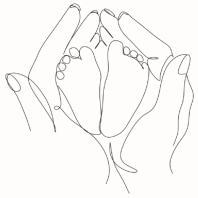
Lived Experience Peer Support

Using direct lived experience support of pregnancy or baby loss to help validate the feelings of families accessing mentoring care. Combining both practical and emotional support, mentoring support will offer hands-on care to families during their grief.

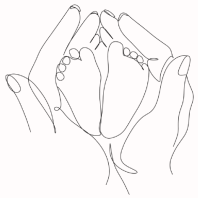
Specialist Sibling Therapy (Redcar and Cleveland)

Thanks to recent additional funding, we will now we able to offer dedicated child therapy support for siblings who are affected by the loss of a pregnancy or baby. This will be delivered by one of our BACP therapists who is qualified and experienced in this area.
Pathways are currently being designed

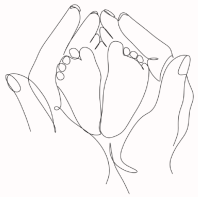
Service Aims



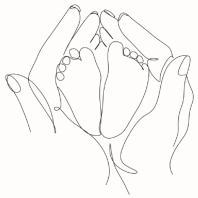
To reduce the risk of escalating perinatal illnesses during the perinatal period



To provide trauma-informed practice approaches to families within the service



To provide care for both parents



To work in line with local policy, frameworks and national frameworks and reports including the National Family Hubs Initiative, Better Start, The Pregnancy Loss Review Report, the NHS Long Term Plan, The Ockenden Report, MBRRACE, The Neonatal Critical Care Review and Better Births.

Scope of work

Who will it be supporting?

Families who have experienced miscarriage, TFMR, stillbirth and neonatal loss within the first 24 months of loss / birth. Referrals are currently being accepted from any losses that have taken place from April 2022.

Where will it take place?

Families within Redcar and Cleveland & Middlesbrough postcodes.

When will the service start?

Launching in July 2023, the service will run until March 2025

How will it support?

A combined approach of therapeutic counselling interventions and peer support.
*Wider funding bids have gone out to provide additional support.

Why is the support needed?

There is currently no specialist perinatal infant loss provision within the region which combines lived experience and therapeutic interventions, families are often left with no support, limited support, or have to pay privately for care.

Themes we expect to support

Through the current work Leo's undertakes within the neonatal mental health community, which includes loss, and research, below are the key themes we anticipate will be treated and supported within the service.

- Birth Trauma
- Grief
- Neonatal Trauma
- Diagnosis support
- Maternal and Paternal Mental Health
- Anxiety
- Depression
- PTSD
- Intrusive Thoughts
- Nightmares
- Auditory Hallucinations
- Visual Hallucinations
- Pregnancy Related Trauma
- Low self esteem
- Self-blame / Guilt

Criteria: Accepting referrals where a loss has occured from April 2022 onwards

Miscarriage:

Any early loss, up to 24 weeks gestation
Both parents
Living in the Redcar & Cleveland postcodes and Middlesbrough postcodes

Termination for Medical Reasons:

Diganosis support
Induction and birth
Both parents
Living in the Redcar & Cleveland postcodes and Middlesbrough postcodes

Stillbirth:

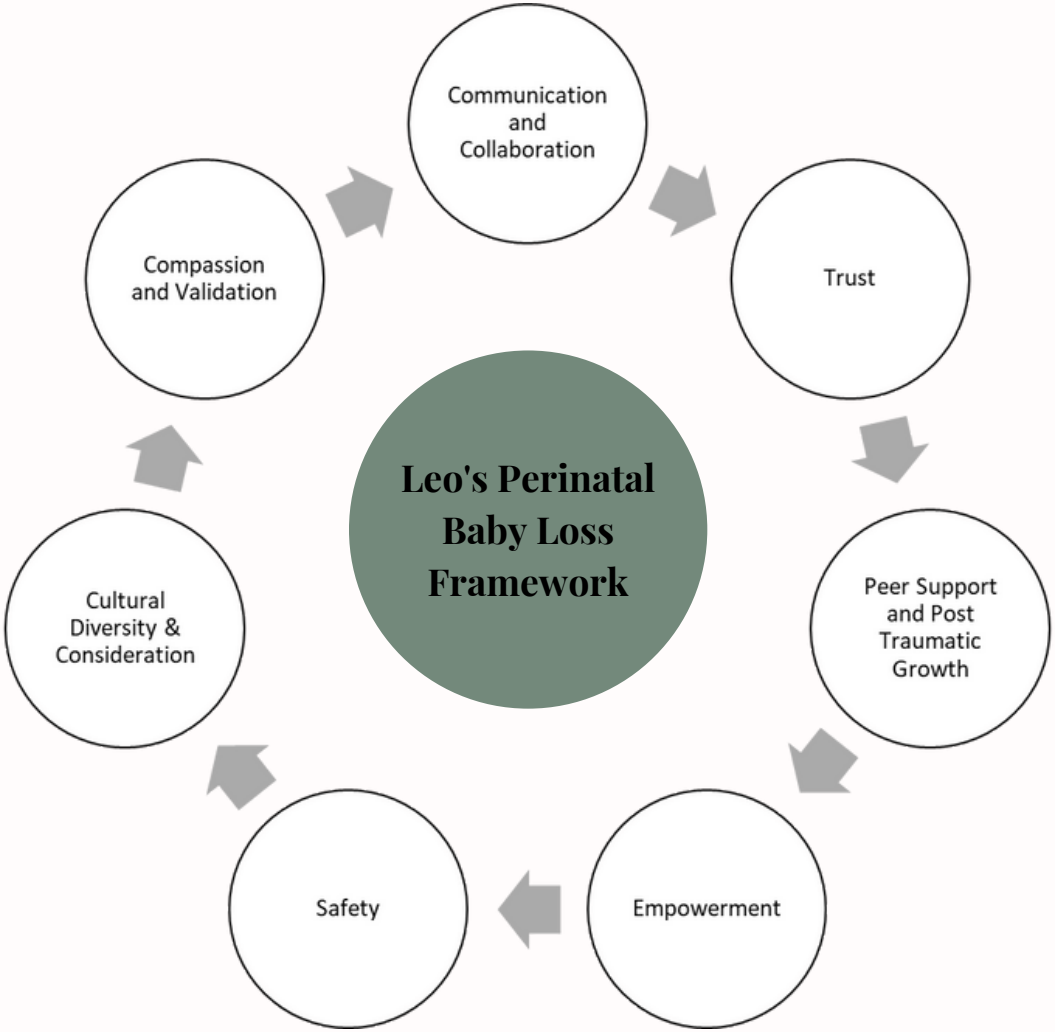
Diagnosis, induction and birth
Comfort care
Both parents
Living in the Redcar & Cleveland postcodes and Middlesbrough postcodes

Neonatal Loss:

Palliative care diagnosis, loss due to infection or sudden death where resuscitation has failed, rare genetic conditions etc
Baby / Babies must have passed away within the neonatal unit.
Hospice care (where this has been transferred for end of life care from the NICU and not longer term palliative care due to parent request)
Both parents
Living in the Redcar & Cleveland postcodes and Middlesbrough postcodes

Leo's Perinatal Trauma Informed Framework

Leo’s have created a framework working within these core principles, whilst adding new ones in, which combine person-centered care, a trauma sensitive approach, with goal setting to allow families to held and cared for during post-traumatic growth.



Referral Process: Adults

Referral

- Parent refers into Leo's Perinatal website / Professional working with the family refers in via the Leo's Perinatal website
- Initial assessment undertaken by a peer mentor, this may happen in the family home, or via the phone (depeding on parent preference)
- All relevant clinical, social care, VCSE teams including referer notified of commencement of support via letter (email).

0-6 months post loss

- Trauma Informed Care plan created in collaboration with the parent
- Initial stabilisation done by peer mentor. Mentoring to stay in place, unless the parent self-discharges, or disengages in the service. Parent is able to re-refer back in if required.
- Escalate care to the internal counselling team if risk increases. If risk to life is planned, escalate to the Crisis team.

6-24 months post loss

- Counselling assessment submitted at 6 months. Assessment to take place to determine support.
- Therapist assigned and theraputic intervention begins, if parent is stable enough to undertake theraputic intervention. If parent is not ready, mentoring to continue
- 10 sessions of care begins
- Wrap around mentor care where needed
- Parent discharged from counselling service
- Parent to continue with mentor or be fully discharged from provision depending on need

Additional Information

Additional care includes:

- Advocacy support
- Birth reflections support
- Debrief support
- Where required, birth planning and post termination for medical reason support
- Memory making
- Signposting to wider support services, both locally and nationally

Where to refer

All bereavement referrals made by staff must go to:
www.leosperinatal.org and use the **'staff referral'** button

Questions for the team:

Please email the team on lottie@leosneonatal.org or via phone on 07824353130

Appendix

Detail into the pillars of the Leo's Trauma Informed Care Model

PCL5

Birth Trauma Questionnaire

Leo's Perinatal Baby Loss Model

Compassion and Validation

"Trauma is when we are not seen and known." Bessel van der Kolk

During the perinatal period, the importance of compassion and validation is crucial in acknowledging a person's trauma. Working on the simple question of 'what happened to you?' We can understand the impact of the traumatic event on the person, their views and how it affected them in all ways. This includes their verbal and non-verbal cues and communication.

Trauma impacts the body in both a physiological and psychological way and is a full body experience. The impacts can be felt across the limbic system, Hypothalamic–pituitary–adrenal axis gland, the sympathetic nervous system and the vagus nerve

Showing an understanding of the gravity of the situation in that person's world can build trust, rapport and allow the parent to feel less isolated.

Using compassionate language, being mindful of your own verbal and non-verbal cues and communication offers a gateway to create a safe environment for sharing emotions, feelings and experiences.

Offering phrases which can confirm a parent's feeling "I can see that it feels hard for you." allows the parent to feel seen, heard and understood.

Leaving parents to feel unseen or lost in their emotions can compound emotional trauma, and add to the 'trauma load'.

Leo's Perinatal Baby Loss Model

Communication and Collaboration

The way we communicate counts. When supporting a parent in a high arousal state, or who has recently endured trauma, first impressions are the first building block to gain trust.
Words and facial expressions cause emotions, and equally emotions and words can cause our facial expressions.

It is imperative that during all interactions, especially the initial interaction that we create the impression that we are there to offer healing support.

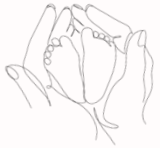
First encounters may occur in person, and also over the phone.

Ensuring that volume patterns, pitch and empathetic language to communicate are used, is important when making that first contact via a phone call.

Equally as important, making sure the way we communicate when in person with a parent in a vulnerable situation upon first contact is vital.

Considering everything from body language, words, pitch, tone and microexpressions, the mentor and therapist should be open, present and focussed to support.

Microexpression are seven facial expressions which are universal across all races, genders and cultures and cannot be faked.
These include:
Happiness
Sadness
Anger
Disgust
Contempt
Surprise
Fear



Emotions are highly contagious, emotions are communicated very easily. It is important that during all encounters, the team providing care offers the right emotional response to support the parent in need. This allows for the ability to forge relationships, ones that will need to be nurtured, trust gained, and opportunities offered for attunement and collaboration.

Leo's Perinatal Baby Loss Model

Communication and Collaboration

Considering the types of language we use (sterile / clinical vs understanding and validating) and the way people are identified can play a substantial role within self-identification during trauma.

As an example:
Incorrect language: The parents of the 28 weeker in cot space 1. The mum in side room A who's miscarrying. The palliative baby.

Trauma Informed Language: Sarah and Michael, mum and dad of Oscar who was born at 28 weeks gestation in cot space 1.

Emma, in side room A is sadly losing her baby from an early miscarriage.

Ted, Charlotte and Mark's little boy who is off home today has just been diagnosed as needing end of life care.

The use of non clinical, non sterile language is needed to allow a parent to feel seen and their experiences respected.

Communication is also vital for those where a learning disability is present or of parents who may have ASD, and the way they need to be communicated with, and the way they communicate with others is another area to be considered.

Ensuring that parents where English is not their first language it is important to understand and create a way to communicate effectively in a trauma informed way, which can be bespoke to them.

Collaborative care spans a number of disciplines, this includes allowing the parent to feel informed and in control of their own care, and decisions surrounding this.

Using the mentor and / or therapist in an advocacy role creates a person-centered approach, meaning that despite the number of care teams that may be involved, or NHS staffing where shift rotations occur, there is always the opportunity for collaborative working and care throughout.

Leo's Perinatal Baby Loss Model

Communication and Collaboration

The creation of co-produced care plans, multidisciplinary team meetings, and family support meetings, placing the parent and their well-being at the heart of care will provide positive and beneficial outcomes.

Making sure these fundamentals are included throughout the time caring for the parent is paramount to the success of their recovery.

Consistency & Continuity

Better Births, the report of the National Maternity Review, set out a clear recommendation that the NHS should roll out continuity of carer, to ensure safer care based on a relationship of mutual trust and respect between women and their midwives.

The continuity of carer model is a way of delivering maternity care so that women receive dedicated support from the same midwifery team throughout their pregnancy.

This relationship between care giver and receiver has been proven to lead to better outcomes and safety for the woman and baby, as well as offering a more positive and personal experience; and was the single biggest request of women of their services that was heard during the National Maternity Review. (NHS England)

Ensuring that within our workforce, the continuity of carer model is provided ensures that parents and families within our care feel safe, secure and have a single point of contact throughout their time within the service. The aim is to reduce feelings of overwhelm and confusion during a vulnerable period.

Leo's Perinatal Baby Loss Model

Consistency & Continuity

It also allows the core workforce to feel safe and secure with key designated mentors and / or therapists in place working in collaboration with wider NHS and Local Authority Teams where needed.

The Leo's 'Wrap Around Care' model will be implemented within this framework also. This is a tried and tested model of care which sees mentors and therapists and / or wider NHS, Local Authority Teams working together for positive outcomes.

The continuation of this well known model with our stakeholders will provide consistency and continuity across both neonatal and perinatal services.

The development of new pathways and clinical guidelines will offer succinct continuity and consistency across all services when referring into Leo's.

Trust

Trust is earned in the smallest of moments.It is earned not through heroic deeds or even highly visible actions, but through paying attention, listening and gestures of genuine care and connection.

Brene Brown

By creating care plans in collaboration with the parents in our service, and continuing to have a transparent workforce that effectively communicates treatments and what that entails will offer options for trust building to parents in our care.

Leo's Perinatal Baby Loss Model

Peer Support and Post Traumatic Growth

The power of telling your story can change, and save a life. We aren't meant to be alone, we need each other.

Peer support is rapidly becoming an integral part of trauma informed care and practices, acknowledging that the sharing of lived experiences can have a powerful and profound impact on a person in the midst of trauma, whilst contributing to post traumatic growth.

Working through a trauma informed peer support framework, allows the mentors to utilise a wide range of skills, whilst being imprinted on by every family member they care for. Every unique story and experience, shaping the next person they care for. This is known as lived expertise.
"When you speak to me about your deepest question, you do not want to be fixed or saved; you want to be seen and heard, to have your truth acknowledged and honored." Parker Palmer

Empowerment

Working towards goals allows for a post traumatic road map recovery to be built and developed.

The road map will be highly nurtured by all care teams involved, offering different tools to foster recovery which will empower the parent in our care to be the person they want to be, by reaching their full potential.

It also offers itself up as an effective reflective tool, allowing teams working with the parent to highlight key personal development and growth along the way.

Leo's Perinatal Baby Loss Model

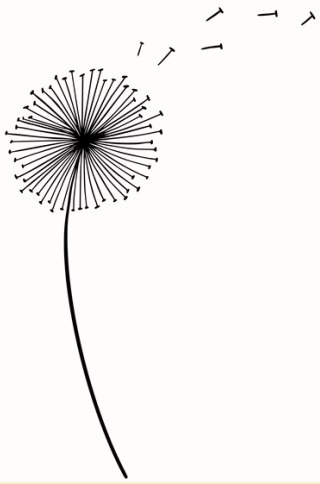
Safety

What does a safe space look like? To some people that's a cosy chair in the corner of the room with a good book, for others it's sitting by the sea, or a walk within the woods.
In order to support post traumatic growth it is imperative that teams working with parents help facilitate safe physical and emotional spaces.
This will be done in collaboration with the therapy team, and led by the parents themselves.
It will be done through a trauma and sensory informed lens, ensuring that spaces - be that physical or emotional - stimulate the parasympathetic nervous system, and provide opportunities for calming, regulating support.

Cultural and Diversity Consideration

The team actively acknowledges and moves past any cultural, gender and historical stereotypes and biases and offers person-centered responsive services and support.

It will incorporate policies and protocols / processes which will be respectful and fully inclusive / responsive to the needs of the racial, ethnic, gender orientation, religious and cultural parents within our care, whilst addressing historical trauma.



PCL-5

The PCL5 will be initially filled in by the parent upon entry to the service, it will then be completed by the therapist at the start, middle and end of sessions, and completed again upon discharge.

In the past month, how much were you bothered by:	0	1	2	3	4
Repeated, disturbing, and unwanted memories of the stressful experience					
Repeated, disturbing dreams of the stressful experience?					
Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?					
Feeling very upset when something reminded you of the stressful experience?					
Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?					
Avoiding memories, thoughts, or feelings related to the stressful experience?					
Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?					
Trouble remembering important parts of the stressful experience?					

Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?					
Blaming yourself or someone else for the stressful experience or what happened after it?					
Having strong negative feelings such as fear, horror, anger, guilt, or shame?					
Loss of interest in activities that you used to enjoy?					
Feeling distant or cut off from other people?					
Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?					
Irritable behavior, angry outbursts, or acting aggressively?					
Taking too many risks or doing things that could cause you harm?					
Being “superalert” or watchful or on guard?					
Feeling jumpy or easily startled?					
Having difficulty concentrating?					
Trouble falling or staying asleep?					

Birth Trauma Questionnaire

The Birth Trauma Questionnaire will be amended sensitively for each parent in our care who notes birth trauma as an area they want support in. We are aware the standardised questionnaire will not be appropriate for every parent and the varying levels of loss we will see. We are also aware that this will affect the scoring outcomes. This questionnaire is to guide us in understanding the role birth trauma plays in bereaved parents.

CITY
UNIVERSITY OF LONDON
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City Birth Trauma Scale scoring information

This questionnaire asks about your experience during the birth of your most recent baby. It asks about potential traumatic events during (or immediately after) the labour and birth, and whether you are experiencing symptoms that are reported by some women after birth. Please tick the responses closest to your experience.

What date was your baby born?_____

During the labour, birth and immediately afterwards:	Score 1	Score 0
Q1. Did you believe you or your baby would be seriously injured?	Yes	No
Q2. Did you believe you or your baby would die?	Yes	No

The next questions ask about symptoms you may have experienced. Please indicate how often you have experienced the following symptoms in the last week:

Symptoms about the birth*	NOT AT ALL	ONCE	2 - 4 TIMES	5 OR MORE TIMES
Q3. Recurrent unwanted memories of the birth (or parts of the birth) that you can't control	0	1	2	3
Q4. Bad dreams or nightmares about the birth (or related to the birth)	0	1	2	3
Q5. Flashbacks to the birth and/or reliving the experience	0	1	2	3
Q6. Getting upset when reminded of the birth	0	1	2	3
Q7. Feeling tense or anxious when reminded of the birth	0	1	2	3
Q8. Trying to avoid thinking about the birth	0	1	2	3
Q9. Trying to avoid things that remind me of the birth (e.g. people, places, TV programs)	0	1	2	3
Q10. Not able to remember details of the birth	0	1	2	3
Q11. Blaming myself or others for what happened during the birth	0	1	2	3
Q12. Feeling strong negative emotions about the birth (e.g. fear, anger, shame)	0	1	2	3

* Although these questions refer to the birth, many women have symptoms about events that happened just before or after birth. If this is the case for you, and the events were related to pregnancy, birth or the baby then please answer for these events.

Birth Trauma Questionnaire

City Birth Trauma Scale © Ayers, Wright & Thornton 2018. Frontiers in Psychiatry 9:409. Page 1

Symptoms that began or got worse since the birth	NOT AT ALL	ONCE	2 - 4 TIMES	5 OR MORE TIMES
Q13. Feeling negative about myself or thinking something awful will happen	0	1	2	3
Q14. Lost interest in activities that were important to me	0	1	2	3
Q15. Feeling detached from other people	0	1	2	3
Q16. Not able to feel positive emotions (e.g. happy, excited)	0	1	2	3
Q17. Feeling irritable or aggressive	0	1	2	3
Q18. Feeling self-destructive or acting recklessly	0	1	2	3
Q19. Feeling tense and on edge	0	1	2	3
Q20. Feeling jumpy or easily startled	0	1	2	3
Q21. Problems concentrating	0	1	2	3
Q22. Not sleeping well because of things that are not due to the baby's sleep pattern	0	1	2	3
Q23. Feeling detached or as if you are in a dream	0	1	2	3
Q24. Feeling things are distorted or not real	0	1	2	3

Q25. When did these symptoms start?	
Before the birth	0
In the first 6 months after birth	1
More than 6 months after birth	2
Not applicable (I have no symptoms)	

Q26. How long have these symptoms lasted?	
Less than 1 month	0
1 to 3 months	1
3 months or more	2
Not applicable (I have no symptoms)	

Q27. Do these symptoms cause you a lot of distress?	Yes 2	No 0	Sometimes 1
Q28. Do they prevent you doing things you usually do (e.g. socialising, daily activities)?	Yes 2	No 0	Sometimes 1
Q29. Could any of these symptoms be due to medication, alcohol, drugs, or physical illness?	Yes 2	No 0	Maybe 1