Supporting mental healthcare in a maternity and neonatal setting

Good practice guide and case studies

July 2021

This resource has been produced by University of Liverpool, Department of Primary Care and Mental Health, Liverpool L69 3GB

Contents

A message from the experts by experience who co-produced this document

We are all involved in this project as part of our work supporting other parents who have been on journeys like ours. Despite the many amazing staff that we have come across, we have all also had the experience that at times healthcare professionals have focused entirely on our physical wellbeing, and that of our babies, with no consideration given to our mental health needs. All of us have experienced intense anxiety, sadness, grief, anger or the effects of trauma as a result of our experiences in maternity and neonatal services. For many of us (and the others we support), fear of stigma, along with feeling like we mustn't impose on staff, meant that we often put on a mask and that no-one ever questioned how we were feeling emotionally. We know this harm was not intentional and that staff themselves may not have had the support and training they need to understand perinatal mental health (PMH) needs.

Should the recommendations in this document have been in existence, we are certain that our experiences would have been different. The principles and recommendations written about here can pave the way for women and families in the future. No-one needs to endure having their emotional pain compounded by a system ill-equipped to support them. We are proud to have had the opportunity to be involved in this project, as we firmly believe it will lead to better services for the most vulnerable and thus improved outcomes for families.

This document contains a comprehensive approach to identifying those at risk as they enter the maternity service, to helping those enduring PTSD or depression due to or accentuated by their maternity experiences, to supporting those who experience a perinatal loss. Were all trusts to put into practice the principles detailed here, there would be vast improvements in services. No woman or parent should ever feel as if they have nowhere to turn, and this document details the ways in which other parents might begin to get the help they so desperately need. Communication is key, and you will see the vast amount of information given in this document to help empower women and families, as well as the staff caring for them.

We believe the principles detailed in this document have the power to change lives for the better. They are an essential tool for helping maternity and neonatal staff identify and support parents with mental health needs.

Rachael McGrath, Kirsten Mitchell, Terri-Lynn Quigley and Katie Hoult

Introduction

What this guide covers and offers

This guide is for commissioners and staff involved in maternity and neonatal care. It aims to guide thinking about how best **to provide services that will support mental health in the maternity and neonatal context**. It also considers **the role of specialist maternal mental health services (MMHS) in supporting this function**.

The guide describes the underpinning principles of and good practice for supporting good mental health and psychological wellbeing in maternity and neonatal settings. It also outlines why this is important. It does not cover direct provision by primary care staff such as GPs and health visitors, except where this involves liaison with maternity staff.

The perinatal period is a time of major transition for women, partners and families. This can make them feel vulnerable and, at times, overwhelmed. Support from healthcare professionals has an enormous impact on psychological wellbeing and mental health. In line with NHS England and NHS Improvement's Mental Health Implementation Plan, this support involves "identifying needs and intervening at the earliest appropriate opportunity to reduce the likelihood of escalation and distress and support recovery". This document therefore focuses on prevention as much as intervention; in other words, how we minimise negative outcomes by helping women, their partners and families feel safe, while providing a 'safety net' of therapeutic support where this is needed.

The guide contains:

- an overview of the underpinning ideas and ethos
- sections 1 to 6, highlighting the learning from each area that was considered
- a summary of how these ideas can be implemented in practice.

In each section, we introduce the psychological context of care, before presenting good practice that underpins service delivery. Sections 1 to 6 are illustrated with quotes from parents and case studies of good practice. Quotes are confidential but give the name of the organisation that supplied them. The case studies demonstrate some aspects of good practice in that area; they do not aim to be examples of a 'perfect' service.

Getting the most from the guide

Each section of the guide covers one area of work, which may be relevant to specific groups of staff. The overview of the underpinning ideas and ethos and the supporting information on practical implementation apply to all professionals.

When implementing the suggestions in this guide, teams should refer to their local policies and guidelines, including safeguarding, information governance and data protection, as these differ across services.

This guide should be used together with the following documents:

- Involving and supporting partners and other family members in specialist perinatal mental health services: Good practice guide
- Good practice guide for delivering trauma-informed care during the perinatal period
- NHS Long Term Plan
- Better Births: Improving outcomes of maternity services in England – A five year forward view for maternity care
- Implementing the recommendations of the Neonatal Critical Care Transformation Review
- National Bereavement Care Pathways.

How this guide was put together

NHS England and NHS Improvement commissioned the University of Liverpool to develop this guidance. It was produced by: Pauline Slade, University of Liverpool; Ruth Butterworth, Cheshire and Mersey Specialist Perinatal Service; Geraldine Scott-Heyes, Belfast Health and Social Care Trust; Ruth Bender-Atik, Miscarriage Association; Jane Fisher, Antenatal Results and Choices; Katie Hoult, Spoons; Rachael McGrath, Birth Trauma Association; Kirsten Mitchell, Spoons; Kate Mulley, SANDS; Terri-Anne Quigley, Liverpool Maternity Voices Partnership; Katie Balling, University of Liverpool; Rebecca Molyneux, University of Liverpool; Helen West, University of Liverpool.

An expert reference group was set up to represent relevant experts by experience and professionals. This group defined seven questions to be addressed by the guide (see Appendix 1). Evidence was gathered from three sources, with equal weight given to each:

- existing documents (eg guidelines)
- rapid literature reviews
- surveys of service users and healthcare professionals.

A note on language

The importance of language frequently came up during this project. The guide covers a wide range of scenarios, so a term that feels appropriate to one audience may not suit another. For this guide, we use the following broad terms, while recognising the importance of adapting language to meet individual needs in practice.

Woman or mother: The individual who is pregnant or who has given birth. We use the pronoun ‘she’, while recognising that not everyone in this position will identify as such.

Father or partner: The individual identified by the woman as her partner, including a same-sex partner or a non-biological parent of the baby.

Parent: Mother or father. We recognise that someone who has experienced the loss of a pregnancy may not choose to describe themselves in this way.

Fetus or baby: We have used these terms to refer to the child who is or was expected, or who has been born, respectively. We recognise that, in some circumstances, women and

fathers/partners differ in their preferred terms. It has been our aim to follow the guidance of those representing experts by experience in our process.

Family: Any other family members who the woman regards as significant, eg her parents, siblings or grandparents.

Equalities statement

Promoting equality and addressing health inequalities are at the heart of NHS England and NHS Improvement's values. Throughout the development of this guide, we have:

- given regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it
- given regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities
- used the term 'women' throughout this guide to refer to those using maternity, neonatal and/or perinatal mental health services during pregnancy, birth and the perinatal period. However, we acknowledge that not all people who use maternity, neonatal and perinatal mental health services are cis women, including trans men and non-binary people, and it is important that care for maternity, neonatal and perinatal mental health is inclusive of all birthing people
- used the terms 'fathers' and 'partners' to refer to the significant others of those using maternity and/or perinatal mental health services during pregnancy, birth and the perinatal period.

Overview of underpinning principles and key ideas

This guide is based on 14 key ideas and is underpinned by principles of psychologically- and trauma-informed care. These principles and ideas came up repeatedly across all our questions and sources of evidence. They underline the importance of providing care that promotes and supports good psychological wellbeing and mental health in women, their partners and families.

Psychologically- and trauma-informed practice

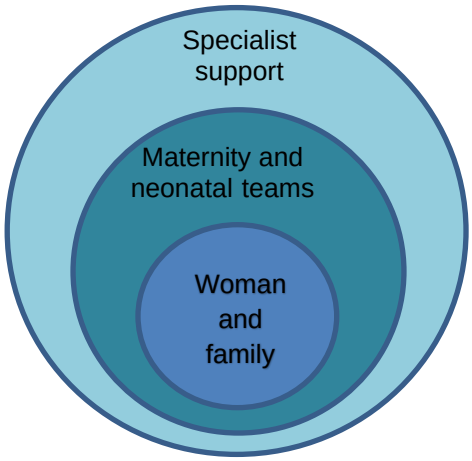
Psychologically- and trauma-informed care aims to promote feelings of psychological safety, choice and control. Every contact with a woman, partner and family member matters. It is important that staff put the woman at the centre of her care and consider the needs of the family – this can be done by ensuring all individuals feel seen, heard and cared for.

Seen
To feel acknowledged, valued and seen as an individual

Heard
To be supported to share how they feel, have their feelings acknowledged and play an active role in their care

Cared for
To feel protected, respected and supported when things are difficult

Wrapping care around the family



For further information on implementing principles of trauma-informed care in the perinatal period, readers are advised to review NHS England and NHS Improvement's system guide.

The vast majority of healthcare professionals place these principles at the heart of their values and practice. But their roles are emotionally charged and challenging. In particular, caring for women, partners and families who have experienced trauma, mental health difficulties or relationship difficulties can bring up powerful feelings for staff too. This can make it harder to understand an individual's needs and how best to meet them. Just as women and families need to feel seen, heard and cared for, so do

staff, to prevent burnout and to allow them to provide the responsive, attuned care that supports good outcomes.

Key ideas

These ideas apply to the way that care is provided and the support mechanisms, structures and processes that help to embed these values in practice.

1. **Accessibility, equity, equality, diversity**

    - Psychologically-informed care is consistently available, accessible, respectful, sensitive and equitable to all.
    - It considers the cultural and personal circumstances of people from diverse communities.
    - Staff may benefit from training and support to recognise their conscious and unconscious biases and improve cultural competence.
    - All women should have equal access to intervention for mental health difficulties, irrespective of where they live, their socioeconomic status, ethnicity or any additional needs (eg physical, sensory or learning disabilities). This is in accordance with the Equality Act, 2010.

2. **Attuned, compassionate care**

    Psychological wellbeing is underpinned by:

    - treating people with respect, dignity, compassion, courtesy, understanding and honesty
    - respecting confidentiality.

3. **Communication**

    Parents feel safer when staff:

    - communicate clearly and effectively with sensitivity, understanding and respect
    - listen to women and families and their preferences and concerns
    - involve the woman's partner or family where appropriate.

4. **Information provision**

    Information is likely to be most effective when it is:

    - accessible and understandable to all women

- in a format that women can understand, eg women with disabilities or vulnerabilities may need information in a non-standard format or different language
- clear, consistent, evidence-based, unbiased, tailored, complete and accurate (verbal as well written).

5. **Decision-making, preferences, control, informed consent**

    - Women feel safer and more confident when they actively participate in decision-making.
    - They need support from healthcare professionals who encourage them to express their needs and preferences.
    - Information, resources and time all impact on the experience of decision-making.
    - Women have the right to choose their care, treatment, tests and place they give birth.
    - Their perspectives on the balance of risks and benefits may be different to those of healthcare professionals, and their views should be respected.

6. **Individualised, person-centred care**

    Each individual is unique. The best quality care will be:

    - tailored to their needs and preferences
    - mindful of personal circumstances, perspectives and experiences.

7. **Family integrated or family centred care**

    - The needs of partners, fathers and families are important.
    - Including and supporting partners and fathers enables them to more confidently support women.
    - In the neonatal setting, the family integrated care model supports the mental health of families by putting them at the heart of the baby's care.
    - It is important to link services to local safeguarding processes and seek consent from women before involving family members in their care.

8. **Continuity of carer, including named contact**

   Women benefit extensively from having a named healthcare professional and knowing how to contact them. Continuity of care, and particularly carer, improves women's experiences by [1]:

   - reducing anxiety and stress
   - increasing the likelihood that women will discuss any mental health difficulties
   - improving safety and clinical outcomes.

9. **Referral, signposting, transitions**

   - The most effective care involves providing information about relevant services that families can access, including third sector, peer support and community organisations.
   - Clear referral pathways make it easier for professionals to provide this information and facilitate smooth transitions between services.
   - Outcomes are likely to be poorer for women who feel that they are left to cope on their own.

10. **Communication between services or professionals**

    - Effective care systems help healthcare professionals exchange patient information in an accurate and timely way.
    - Families appreciate it when care is joined-up between services, with close working relationships and collaboration.

11. **Peer support**

    - Peer support is often highly valued in the perinatal period, particularly by those who are experiencing specific challenges.
    - The best peer support is underpinned by high quality training, supervision and governance to ensure its effectiveness and the safety of both providers and recipients.
    - Parents benefit when staff are aware of what is available, locally and nationally.
    - This links to the peer support principles developed by Mind and the McPin Foundation.

12. Specialist mental health support

- Specialist mental healthcare professionals can support the maternity and neonatal system by providing training, supervision and support for staff, as well as direct support for families.
- There is evidence of benefit in embedding specialist mental healthcare professionals within maternity and neonatal services. Good PMH services can thereby provide an integrated care pathway with key professionals physically based in the maternity and neonatal setting.
- Maternity trusts can support excellence in psychologically-informed care by employing a specialist PMH midwife with a clear job description outlining their role, competencies and arrangements for clinical supervision.

13. Staff training

- Section 7 on practical implementation offers an overview of the training themes that emerged as being important for maternity and neonatal staff.
- PMH is key to the education of healthcare professionals working in, or interacting with, a maternity and neonatal setting.
- **Health Education England (HEE) has developed a competency framework for PMH skills to support all professionals working with women, partners and families during the perinatal period**.
- Developing communication skills is seen by families as a priority for all staff.
- **Where possible, training should be co-produced with experts by experience.**

14. Developing and improving quality data collection

All services aim to provide safe and high-quality care, with effective, professional and timely processes. Collecting data will enable services to monitor this and identify improvements required. **Development and review of a standardised core dataset** (incorporating maternity, maternal mental health and specialist perinatal services, for example) **will enable services** to:

- monitor care and identify improvements required
- support continuous learning
- develop effective mechanisms to receive and act on feedback.

1. General antenatal care: supporting mental health and psychological wellbeing

While pregnancy can bring great pleasure, it also brings physical, emotional and social changes. We know that these challenge psychological wellbeing and mental health for many women. Maternity services have a unique role in supporting women through this period and can limit the development or recurrence of mental health difficulties.

> "Asking questions at booking appointments is not enough. It's not easy to be vulnerable and open up to strangers. A relationship matters. Trust needs to be established before people will tell you their struggles." MVP

Good practice

1. Assessing and identifying problems

Mental health difficulties may develop or arise at any time during pregnancy. To identify problems at the earliest opportunity it is important that staff:

- make time to assess and discuss women's mental health and wellbeing at booking and at each antenatal contact. Allow time for comprehensive assessment and discussion in earlier appointments where possible
- inform women in advance of the number, timing and content of antenatal appointments, including mental health screening and support
- feel confident and supported to discuss emotional issues, listen to women, identify difficulties and refer to specialist mental healthcare staff for further assessment if needed
- consider the environment and ensure that this is a safe space, especially if partners are present.

Women value seeing the same member of staff at antenatal appointments and this helps identify emerging distress or mental health difficulties at an early stage.

Women want a focus on their needs as well as on the baby, and early interest in their psychological wellbeing can foster a sense of personalised care and connection.

2. Communicating information about mental health to women

Discussing mental health difficulties with women during pregnancy can instil hope and reduce stigma for those with existing or past symptoms. The following actions will encourage open, meaningful conversations:

- Provide a comfortable and private physical environment.
- Inform women that:
  - a wide range of appropriate support for mental health will be available as part of routine care in pregnancy and postnatally
  - everyone will be asked about their psychological wellbeing by staff with appropriate training
  - they will be listened to and their concerns acted on.
- Provide information in a range of community languages and media.
- Information should be up to date, consistent, clear and give opportunities for the woman or their partner to ask questions. Content could include:
  - reassurance that mental health difficulties are common and treatable
  - emotional and psychological changes in pregnancy
  - signs of psychological ill health or mental illness
  - where to go for help, including mental health services to which they can self-refer.
- Ensure midwives and other staff have time to address mental health needs, to prevent or reduce difficulties.
- Identify when referral to mental health support is needed. It is important that women with psychological or mental health difficulties can discuss possible treatments, and their benefits and risks, with appropriately trained staff. This can support them in making informed decisions.
- Integrate specialist PMH professionals into the maternity service. When other mental health services are involved, maternity services should work collaboratively with them, following clear pathways of care.

3. Potential barriers to identification

Women may face the following barriers:

- stigma, which may discourage women from sharing mental health difficulties or seeking support
- fear of the consequences, particularly having their fitness to parent questioned
- insensitive communication from healthcare professionals, which can make it more difficult for women to talk about any problems they may have.

It is important that maternity staff:

- are aware that active listening and acknowledging distress or information provided by women can be helpful in itself
- have training on how to hold sensitive conversations, using terminology that can be well received by women, partners and families with mental health difficulties
- feel confident and competent in supporting individuals with mental health difficulties
- have time to explore difficulties
- have a clear referral pathway
- receive support for their own needs.
- have an understanding of cultural differences that may pose a barrier to women disclosing sensitive information.

> "They need to be able to take time during appointments to really listen and understand our needs, concerns and history." MatExp

If there is inadequate time for a full conversation, it is important to consider offering a follow-up appointment, with the same midwife whenever possible.

GPs play a key role in identifying mental health issues in the perinatal period. Early identification and appropriate referral to mental health support is improved through provision of training by those with specialist mental health expertise, such as staff from MMHS or specialist PMH community teams.

4. Screening questions and scales

Universal mental health screening reduces symptoms of depression in women who are not clinically depressed, in the absence of any further provision. It also helps those diagnosed with mental health difficulties when it leads to evidenced-based intervention.

A range of screening scales and questions are available for assessing emotional wellbeing and mental health:

- Edinburgh Postnatal Depression Scale [2]
- Patient Health Questionnaire-9
- Generalised Anxiety Disorder scale – GAD-2 and GAD-7
- Wijma Delivery Expectation/Experience Questionnaire-A [3]
- Fear of Birth Scale [4]
- Impact of Events Scale – revised [5].

The Child Outcomes Research Consortium (CORC) has developed an implementation manual on the use of routine outcome monitoring.

These tools have the most benefit when:

- staff are appropriately trained to use and interpret them, to inform the delivery of care
- they are used as a guide for discussion, rather than as a checklist
- clinical judgement is also applied in assessment
- midwives can access in-house mental health staff to discuss any uncertainties or queries.

5. Assessing women with a history of mental health difficulties and/or previous adverse perinatal experiences

When maternity staff identify a woman with a history of mental illness requiring psychiatric care, it is important to establish if the woman is currently in contact with a mental health service and if not, to consider referring her to a PMH service. Even when women with a history of mental health difficulties are well, maternity staff are advised to be proactive in monitoring and assessing their needs. This involves communicating relevant information to other professionals involved in their care.

Obstetric history and previous experience of neonatal care are highly relevant when assessing any woman's vulnerability to mental health difficulties in the perinatal period. In particular, if past perinatal loss or a traumatic perinatal experience are affecting a woman's experience of pregnancy and mental health, it is advisable to refer her to, for example, perinatal clinical psychology or MMHS (see sections Section 2 and Section 3).

"Ask us about recurrence and past experiences of our pregnancies. There should be a note on your file to signify past losses so you are not constantly explaining yourself. A sticker so you don't have to explain to the sonographer." MC/EPT

Joint mental health liaison clinics may work in partnership with MMHS and PMH midwives to advise women with mild-to-moderate mental health difficulties. Community mental health teams or GPs can signpost women to these services.

For women with current or past severe mental illness, it is important to routinely provide access to preconception advice from specialist PMH services.

Consider that some women may go into preterm labour due to risk factors such as the use of non-prescription medication or alcohol dependency during pregnancy, and the timing of advice on community resources and support is important.

6. Support for the partner, father, family or carer

Support for families, carers and other supportive individuals will benefit maternal and infant mental health.

High quality maternity services will support the partner/father and/or family when the mother has a mental health problem. This includes:

- identifying partners/fathers and family experiencing mental health difficulties
- supporting them as far as possible in the context of maternity care
- supporting partners/fathers and other birth partners who have been present at a traumatising delivery, either recently or in the past, to minimise the risk of longer-term negative impact

"Support for partners seems scant. Other than the two scans we had, my partner didn't see anyone during the whole pregnancy. More appointments for men/partners where they are involved and given the right to feel. Did sense it was all about the birth mother." Dad Matters

- supporting partners/fathers who have had previous experience of being on a neonatal unit
- signposting to other mental health services if needed, especially if the woman herself has mental health difficulties.

Qualitative studies of partners' and new fathers' experiences have emphasised their conflicting emotions and the challenge of redefining roles. Maternity care that recognises their emotional needs may help partners and new fathers adapt to their new roles.

7. Mental healthcare provision

Psychologically-informed practice in maternity and neonatal services increases women's confidence in the care they receive. This can prevent or limit their anxiety and distress.

Maternity care can accommodate the psychological needs and preferences of women in the following ways:

- targeted increase of continuity of carer
- making adaptations for those with social anxiety attending antenatal appointments or during inpatient care
- adapting care for women with more complex problems or a history of trauma, such as difficulty trusting others or responding to anxiety with hostility or withdrawal. This may involve psychological formulation, which is a structure for the individual to work together with a psychologist to identify the causes of their mental health difficulties and how to move forward [6]
- specialist assessment and adaptations to address fear of childbirth (see Section 4)
- consider providing the opportunity to self-refer to MMHS or PMH services.

Integrating psychological provision within the maternity system is an effective way of supporting staff to adapt how they care for women to prevent distress developing or worsening.

There are some important considerations when a woman has a history of or new onset severe and enduring mental illness:

- Maternity services to:
  - enable prompt access to specialist PMH, with clear referrals and an integrated pathway of care – this ensures timely assessment and appropriate, evidence-based PMH at the right level
  - provide effective liaison between specialist maternity mental health staff, MMHS and PMH services.
- Women need:
  - co-ordinated ongoing support from maternity staff and specialist mental health services, with continuity of care – this will usually be supported by a care plan drawn up with PMH, maternity services and the woman herself
  - support from their GP or PMH professional to make an informed decision about treatment options – for those women who express preference for psychological support over medication, it is important to discuss the benefits, risks and possible harms of medication, and changing or stopping medication
  - timely access to psychological intervention, delivered by specialist staff at the right level of input to meet their individual needs
  - accurate and consistent information about their baby's condition, should they be too unwell to visit the neonatal unit.

8. Facilitating social support

Women, including those with perinatal mental illness, can benefit from access to social support via voluntary sector and community organisations.

With awareness of what is available locally and at national level, midwives can routinely advise women on how to access community resources and 'informed' perinatal peer support.

It is important for such peer support to have access to expert supervision, and to adhere to governance principles in keeping with the peer support principles developed by Mind and the McPin Foundation.

9. Intervention with a maternal bonding focus

Where there are persistent and significant concerns about a woman's emotional response to the pregnancy, fetus or baby, it is important for parents and staff to have access to a perinatal psychological assessment.

10. Communication between services and professionals

Good communication and information-sharing with GPs and health visitors is vital for co-ordinating care. This involves:

- prioritising GP referrals for women with prior mental health difficulties
- conducting a mental health assessment when a woman books directly with maternity services, to ensure her needs are met through signposting or referral to a mental health service
- providing women with copies of letters between healthcare professionals.

11. Staff training

Adequate training in PMH and communication skills is essential for all professional healthcare staff who come into contact with women in the perinatal period. This is particularly important for maternity and neonatal staff. It will enable them to effectively address the sensitive topics of psychological wellbeing and mental health and to provide psychologically-informed care.

To enable service delivery in keeping with the competencies in the HEE Perinatal Mental Health Competency Framework, ongoing training could include:

- effective communication skills
- how to implement recommended screening scales
- common emotional and psychological changes in pregnancy
- key signs and symptoms of emerging mental ill health
- identifying when emergency PMH is needed, including the red flags listed in Better Births
- the potential impact on the woman's life and relationship with her baby
- local PMH pathways.

Training for specialist mental health staff working in maternity settings may include:

- knowledge of mental health issues and their urgency in the perinatal period
- awareness of variations in the presentation and course of mental health difficulties during pregnancy and the early postnatal period
- prevalence, identification and management of mental health difficulties.

Some midwives could be trained and supported to provide psychological support for mild depressive or anxiety symptoms with appropriate supervision.

Staff in specialist PMH services or MMHS may be well placed to provide training and support to midwives, neonatal nurses and obstetricians in relation to assessment, maternity care adaptations to meet individual needs and mental health referrals.

12. Staff support

The work of maternity and neonatal staff is emotionally demanding. It is important that staff are supported through:

- adequate, dedicated time for training and supervision. Specialist midwives and specialist mental healthcare staff require regular supervision from a specialist mental healthcare professional who has an appropriate level of expertise – this can provide the clinical and personal support necessary to maintain psychological wellbeing
- integration of specialist mental healthcare staff into maternity services who can provide day-to-day clinical support/advice, timely consultation and guidance to support decision-making in relation to individual women
- a team approach – this is regarded as safer and more effective for staff and patients than single-handed specialist services.

Section 7 on practical implementation gives a summary of how change might be supported in practice.

Case study

This service-focused case study illustrates some of the best practice points identified from the evidence. Systematic ongoing assessment and monitoring of psychological wellbeing and mental health with strong links to PMH services are notable.

Wirral University Teaching Hospital NHS Foundation Trust PMH Service

This multidisciplinary service covers an area with approximately 3,200 births per year. Weekly triage meetings of specialist midwives and mental health staff focus on complex and high-risk cases, supporting midwives with any concerns and signposting patients to appropriate services.

Support for women

Mental health is monitored at the booking appointment and at every antenatal and postnatal contact using recommended questionnaires if indicated. Most referrals are made by the community midwife at the booking appointment, with other referrals accepted throughout the maternity episode to four weeks postnatal.

Referrals are reviewed daily and acted on within 5–10 working days. Women may be referred to the regional specialist mental health team or other mental health services, depending on individual needs. Otherwise the woman is seen by a member of the team. If the referral does not meet the criteria for the PMH midwife or the team, the community midwife is given advice, such as referral to the GP, Improving Access to Psychological Therapies (IAPT) or voluntary organisations for tailored support and monitoring. The team also liaises with social care regarding early help and safeguarding issues.

Maternity inpatients are checked daily by a PMH midwife. Those who are patients of the PMH midwife team are reviewed and new, urgently referred women are seen for assessment. When necessary, these women are referred to psychiatric liaison and the regional specialist PMH team.

Patients seen by the PMH midwives have a detailed assessment related to risk and care planning. In cases of severe mental illness or significant concern the PMH midwife will co-ordinate multidisciplinary teams (MDTs) and a care planning meeting with all relevant professionals. PMH midwife follow-up appointments are arranged based on individual needs.

Support for staff

The liaison psychiatry clinical nurse specialist provides monthly clinical supervision for the midwives within the team. The Band 7 PMH specialist midwife is responsible for staff training, midwives' annual updates and provision of advice/support/case supervision.

Hannah Horne, Perinatal Mental Health Specialist Midwife

2. Complex pregnancies: supporting mental health and psychological wellbeing when there is risk of physical complications, or complications are identified, in the mother or fetus/baby

Women and partners may experience stress and anxiety when the mother or baby has known physical complications. Even in the absence of confirmation of a complication, awareness of heightened risk can challenge their mental wellbeing. For example, in a multiple pregnancy, the mother and babies may remain physically well, but awareness of the associated risks often leads to increased anxiety. This can continue throughout investigations and often through to delivery.

How individuals express fear and distress varies within and between cultures. These behaviours may cause concern and highlight a need for support, but it should not be assumed that this reflects a mental health problem.

Women and staff can benefit from:

- having a specialist clinical psychologist as an integral member of the maternity service to promote high quality, psychologically-informed care and to work directly with women and partners when needed [7]
- well trained maternity staff who are supported to provide psychologically-informed care – this is particularly important when there are complications of pregnancy, as women have a greater emotional and practical dependency on maternity services compared to those experiencing a low-risk pregnancy.

Some women are aware of a degree of risk to themselves or the baby before they become pregnant. This may be due to a chronic health condition or their obstetric or family history. They may have taken advice and weighed-up the risks before deciding to get pregnant but this may still affect their experience of pregnancy and psychological wellbeing from the outset.

For others, the possibility of complications in maternal or fetal health arises for the first time during pregnancy. This can lead to parents having a sense of grief for the loss of a normal pregnancy experience, and of hopes and dreams. Risk related to pregnancy outcome can also impact on the early development of parental attachment.

Good practice

1. Support and communication with parents

Highly skilled, thoughtful communication is essential in supporting the emotional wellbeing and mental health of women and partners when there is risk of maternal or fetal complications and when complications are confirmed.

It is helpful to:

- see the woman and partner together when possible, as this will enhance their ability to support one another
- repeat information, as anxiety can make it hard for women and partners to remember
- provide information in writing, where possible.

Good practice could include providing women with:

- a member of professional staff as a point of contact or key worker to ensure the smooth handover of information throughout pregnancy and into the postnatal period
- repeated opportunities to communicate with familiar staff and to have queries or concerns addressed in a timely way
- additional appointments and scans if they have been diagnosed with complications in pregnancy, while being aware that regular monitoring can lead to increased anxiety
- personalised guidance on self-monitoring of fetal movements – with regular hospital reviews women can feel self-monitoring is less needed
- referral for support with anxiety management.

- a discussion about the possibility of a neonatal admission, and offer the opportunity for both parents to visit the neonatal unit and meet the neonatal team, with written information where possible.

The unpredictable nature of the situation can reduce parents' sense of control, which has implications for mental health. The evidence from service users emphasises how important it is to listen carefully to their concerns and ensure they are well informed to facilitate them in having an active role in decision-making.

"Parents need opportunities to ask follow-up questions and receive additional support. It can be really hard to think of things on the spot." MMHA/TAMBA

It is best to provide potentially challenging information, including test results, in a face-to-face meeting. This information may increase or decrease anxiety so it is important to be particularly sensitive to timing and location. Where possible:

- provide a quiet waiting area separate from the general antenatal clinic
- provide a private, comfortable consulting room
- plan sufficient time without interruption to give personalised support
- give information and test results promptly.

"For tests and diagnosis to happen promptly after concerns are raised. It is really difficult emotionally waiting. A day or two may not seem like a long time in normal circumstances but it is torture when potentially facing heart-breaking news." ARC

2. Investigations and tests including fetal diagnosis

Women and partners will benefit from clear information about:

- which antenatal screening tests are available to them and what they involve
- why the screening tests are being offered
- the risks and benefits of the screening tests
- the process and timescale for receiving test results
- what the results might mean, including an explanation of relative risk
- how to ask questions or request an appointment, including a contact number.

Continuity of carer throughout the screening and diagnostic process will improve trust and communication, particularly where complications or anomalies are suspected or confirmed.

3. Risk and uncertainty regarding the outcome for the baby

Continuity and high quality, psychologically informed care are especially important when the antenatal diagnosis carries a high risk of significant morbidity or death for the baby.

What may be regarded as a relatively 'minor' fetal anomaly by maternity staff can cause parents great distress.

Parents will benefit from having:

- test results or information about an uncertain outcome sensitively communicated by a familiar professional in a confidential setting
- clear, simple and honest communication, avoiding or explaining medical jargon
- non-judgemental, non-directive co-ordinated care
- complete information about the situation and what is likely to happen.

4. Specialist referrals and support

Women experiencing pregnancy complications need timely access to specialist mental health and physical care.

Asking a woman what help she may need, explaining the reason for any specialist referral and fully involving her in related decision-making will indicate respectful care and help her have a sense of control which can ease anxiety.

> "With mental health sometimes you as an individual don't know or realise so I say make it a part of antenatal care for high risk pregnancies especially if not possible for all…. I suppose if asked back then I would have said I'm fine but I really wasn't, however I didn't know that." MatExp

When a fetal anomaly or diagnosis is confirmed it is good practice to offer parents the following:

- a meeting with a neonatal or paediatric consultant who has expert knowledge of the baby's condition. This can help parents prepare and understand what the diagnosis means and what treatment may be possible. It also enables antenatal planning to feed through to the neonatal unit or paediatric care
- a tour of the neonatal unit (see Section 5)
- referral to genetic services or counselling when the condition may be inherited. These can provide specialist support and clarify understanding of the diagnosis and any implications for future pregnancies.

Consider routinely offering referral for psychological support.

5. Lifestyle advice

Women with complex pregnancies will usually receive the same advice and support as other pregnant women, promoting the importance of mental as well as physical health and wellbeing.

Individualised, non-judgemental advice encouraging healthy behaviours might include face-to-face discussion, written information or telemedicine.

Professional emotional and social support are crucial when lifestyle factors may have contributed to a maternal and/or fetal complication.

6. Preparation and care: labour and childbirth (see also Section 3)

Women with complex pregnancies benefit from detailed, collaborative and sensitive planning for care around delivery. This is vital for:

- building trust in staff
- easing anxiety by reducing uncertainties as far as possible
- encouraging a sense of empowerment.

A good service will:

- provide continuity of carer
- actively involve women in decision-making
- ensure women are fully informed of their options
- seek consent from women for care given to the fetus, including the mode and timing of delivery
- involve women in discussions about what will happen during labour and at delivery – this includes keeping women informed during labour
- provide women with a record of the decisions made.

To reduce anxiety, women and their birth partners should be made aware in advance that additional medical and nursing staff may be present at delivery to provide care for the mother and/or the newborn.

Involving the woman's birth partner in planning can help meet their psychological needs and allow them to provide effective support before and during delivery

Some parents may feel anxious about seeing their baby when it is known that a fetal condition affects physical appearance. It is important for staff to discuss parental wishes sensitively in advance to understand how they feel and provide support. Adapting usual procedures can help ease anxiety and support parents when they meet their baby.

7. Mental health and equal priority to physical health

Maternity professionals are in a strong position to support mental and physical health, particularly for those women experiencing complex pregnancies. They can do this by:

- asking women regularly about their emotional wellbeing
- providing women with advice and support promoting the importance of mental as well as physical health and wellbeing
- supporting women to recognise that their own wellbeing is as important as that of their baby
- acknowledging and providing support for the potential psychological impact of fetal complexities, such as guilt or feelings of failure.

Women can benefit from being able to access mental health support in the same hospital as their physical health appointments. This can be important for women who need inpatient care during pregnancy.

A clinical psychologist with perinatal experience is well qualified to play a preventive role by supporting psychological wellbeing directly and indirectly through staff. They can also provide assessment of mental health needs and appropriate follow-up.

> "I had PTSD in my second pregnancy. No one asked how I felt … I was an inpatient for a long time on the antenatal ward. It was really awful witnessing women suddenly being rushed to labour ward … they became very sick usually quickly. Psychologically that's so hard. Maybe a psychologist on an antenatal ward to see long term patients?" MatExp

Best practice may include:

- routine specialist clinical psychology support for women with complex pregnancies
- integrated care, eg a consultant-led obstetric clinic or fetal medicine as part of the MDT, offering streamlined appointments
- assessment of mental health needs and appropriate follow-up.

It is important to consider the mental health needs of partners in relation to maternal and fetal outcomes. Together with the family, they can provide invaluable support to the

woman. This may reduce the risk of mental health difficulties, especially when they are involved and supported by maternity services.

8. Support for parents

Women and partners would benefit from a holistic support plan, which:

- is informed by their views on what support they would find helpful
- ensures the availability of support at points of transition in care
- is regularly reviewed.

A specified key worker can play an important role in signposting and co-ordinating care, which could include peer support and professional intervention. The plan can be especially useful to ensure availability of support at points of transition in care.

9. Communication and co-ordination between services

Women experiencing complex pregnancies should be a priority for continuity of carer to enable effective care co-ordination.

A personal care and support plan can:

- address the risk of fragmented care between different medical specialties, community services and the antenatal clinic
- be developed collaboratively by the woman and key professional staff – this could include the partner and family if appropriate. It is important for the woman to have control over her decisions with the family collaborating only as she feels appropriate
- discuss place of birth if the baby is going to be delivered in a specialist unit away from home.

The role of the key worker is to co-ordinate care. All relevant primary and secondary care staff should have a copy of the woman's care plan and contact details for the wider network of services involved.

Women largely understand the need to share information and want professional staff to understand their history and context to reduce the need for repetition. Appropriate information sharing is encouraged but it must be done sensitively, discreetly and respectfully, with women fully informed about what is being shared and who with.

10. Staff training

Staff benefit from training to help them meet the needs of women and partners when there are complications of pregnancy.

A good service will consider training staff in:

- high-level communication skills, specifically sharing difficult news and how to explain the balance of risks in decision-making
- recognising and understanding common parental responses to complexities of pregnancy
- how to support women and fathers/partners in this situation
- when to refer on for specialist mental health support
- awareness of the impact of the health professional on this process
- how to be resilient to the emotional content of this work.

MMHS staff may be well placed to provide training for staff and input for women with complex pregnancies, to prevent worsening of normal anxieties.

11. Staff support

In addition to standard support (see Section 1), staff supporting women with complex pregnancies will benefit from the offer of emotional support and debriefing as required. This includes trainees and students who may be witnessing or hearing about traumatic events for the first time.

Individualised support will be most effective if provided when needed, without making assumptions about timing or frequency.

Regular MDT support may also be of value.

Section 7 on practical implementation gives a summary of how change might be supported in practice.

Case study

This case study illustrates the benefits of providing a fully integrated clinical psychology service within maternity services, in particular high quality care for women, fathers and partners when there are maternal or fetal complications of pregnancy.

Specialist Clinical Psychology Obstetrics and Gynaecology Service, The Hillingdon Hospitals NHS Foundation Trust

The specialist service is located in the women and children's directorate in an acute hospital providing care for approximately 4,300 births a year. The service provides a 0.8 whole time equivalent (WTE) Band 8b principal clinical psychologist to the maternity and gynaecological service, receiving approximately 180–250 referrals a year.

Support for women

The aim of the service is to promote psychologically-informed care for all, with ready access to specialist psychological therapy when needed.

Referrals from medical consultants and specialist midwives or nurses based in the hospital are not restricted by GP or location. Reasons for referral include a wide range of psychological issues, eg when medical conditions such as ME, fibromyalgia or diabetes complicate pregnancy. Women are offered psychological therapy during pregnancy and into the postpartum period if needed, to ensure continuity of care. This can include direct work with couples and partners and group work.

The clinical psychologist may also act as care co-ordinator with other professionals within the MDT to ensure that maternity care is individualised and psychologically-informed. A psychology care plan is developed with the woman to support psychologically-informed intrapartum care. Similar psychology input is offered to women with diagnoses of fetal abnormalities and those who have medical terminations of pregnancy. A 'green sticker' is placed in the woman's file to indicate to the MDT that there is psychology involvement.

Support for staff

As a member of the maternity MDT, the clinical psychologist contributes to service development, including input to steering groups. Staff consultation, staff training and debriefs are also provided.

The service liaises closely with the perinatal lead in the local IAPT service and provides supervision to perinatal IAPT leads in the North West London sustainability and transformation partnership. The service also works closely with the local PMH team. This ensures that women and their partners receive appropriate psychological interventions at a level to meet their needs.

An individual case example

A woman and her partner were referred to the service in their second pregnancy following the stillbirth of their first baby at 28/40 weeks. The baby had severe fetal hydrops and had not been expected to survive. The woman became pregnant again a few months after the stillbirth and understandably she and her husband were very anxious. Unfortunately, the same condition was identified at 12/40 weeks. The woman chose to continue with her pregnancy. The clinical psychologist worked therapeutically with the couple to facilitate adjustment and with the specialist midwives to support psychologically-informed care. Maternal depression and a complicated bereavement reaction prompted liaison with the PMH team.

Following the death of the second baby, psychological therapy continued and the clinical psychologist acted as care co-ordinator to ensure continuity of care from relevant professionals. Despite having experienced two tragic losses, the woman and her partner felt well supported by the team around them, which has helped in their adjustment to their loss.

Sarah Finnis, Principal Clinical Psychologist

3. Birth preparation: supporting mental health and psychological wellbeing

Childbirth can be stressful and unpredictable for some women. High levels of distress during labour and birth can adversely affect women's psychological wellbeing and mental health postnatally.

Approximately 6% of women experience post-traumatic stress disorder (PTSD) after being exposed to an event that felt life-threatening for them or their baby. This can result in symptoms such as:

- increased anxiety
- feeling constantly tense and alert (hypervigilance)
- an increased emotional response (hyperarousal)
- avoidance of triggering situations
- flashbacks to the event
- nightmares.

When women are highly distressed in labour this can make it more difficult for staff to provide best care. In addition, women with pre-existing mental health difficulties need care that takes their specific needs into account to avoid making their symptoms worse.

Women who have clear, realistic understandings about labour and birth are more likely to feel positive about their birth experience and less likely to feel disempowered. Appropriate preparation for birth and support during la bour is crucial for preventing mental health difficulties developing or worsening.

"Prepare women and their partners for a variety of scenarios, the most common ones (induction, instruments, planned and emergency caesarean section). It should be made clear when there is no longer choice such as baby too low for a caesarean section." Birth Trauma Association

Support from a birth partner, if available, and from staff is important for a woman's psychological wellbeing, mental health and her ability to cope. Birth partners also benefit from staff support, to help them in their role and for their own mental health.

It is important that preparation for birth and parenthood begins early in pregnancy and this is seen as an ongoing process. This can reduce anxieties, eg if the baby is born prematurely. This is not just the province of the third trimester.

Good practice

1. Information on physical aspects of labour

Women need to feel prepared for what labour may involve, to empower them and reduce anxiety. Services could consider providing high quality, evidence-based information, which includes:

- how to recognise labour and what action to take
- what happens physiologically during labour and birth
- what might help during birth, such as positions and pain relief
- what happens procedurally, such as different locations, when/who to call, who will be there, pain relief options, ‘general rules’ in each setting
- potential risks and interventions, to ensure informed consent if needed.

The 'expectation–experience gap' can be a major cause of postnatal distress. Women and birth partners will benefit from information that:

- is individualised and realistic
- acknowledges that, although birth is generally safe, it is not always straightforward or without intervention
- addresses the possibility of neonatal care
- is tailored to the maternity service where they are booked.

It is important that women understand their rights and choices. An emphasis on collaboration is key to prevent women feeling that they’re working against staff.

2. Psychological strategies for management and coping

Services could consider offering education on methods of preparing for and coping with labour and childbirth, including caesarean birth. This would help women and birth partners access information in a way that is meaningful for them, when offered in different formats. It could include information on:

- active birth
- breathing
- hypnobirthing
- use of pain relief
- what might be difficult
- how to manage anxiety.

> “More talk please about active birth and breathing as standard. I don't think it is fair that only people who can afford to pay for antenatal education have access to this vital information.” Dad Matters

Staff can help women feel confident about their ability to cope with the uncertainties of labour, rather than aiming for a specific type of labour and birth. This flexibility can help women feel ‘at ease’ with the ebb and flow of labour and its unpredictability, knowing that however they give birth they will be well supported.

3. The postnatal period

Parents would benefit from information about the postnatal period as a key part of their antenatal preparation. This may include information on:

- physical recovery
- baby care and feeding
- role transition
- getting to know your baby, physically and emotionally
- relationship changes
- normal worries and concerns
- mental health and wellbeing.

Promoting realistic postnatal expectations can be useful, recognising the challenges as well as the positives of their new role as parents. This includes being clear about what may be involved in birth and discussing how their experiences might impact mental health.

Antenatal preparation helps parents understand the psychological transitions they will face. For example, they may experience grief over the loss of their former life or independence. Normalising these feelings can and does help women understand what is happening and allows them to recognise changes in their mental health.

4. Managing birth anxieties

Maternity services could consider beginning conversations about birth anxieties or preferences from booking or 16 weeks.

Routinely asking women how they feel about labour can identify severe fear of childbirth (tokophobia). Services could consider offering additional support to women with significant anxiety in terms of birth planning and specialist mental healthcare within the maternity system.

5. Birth preferences

Discussions about birth preferences happen best over time and with continuity of carer, where a woman feels known and has established a trusting relationship with her midwifery team. Changes to give greater continuity of care already in progress through implementation of Better Births will support this. To enable flexibility, it may be helpful to discuss ‘birth preferences’ rather than a ‘birth plan’.

Women benefit from having as much control as possible over where and how they give birth. Their documented birth preferences could include:

- what is most important to them
- psychological support
- physical aspects of care
- consideration of more complex circumstances
- the need for flexibility with changing circumstances.

Feelings of failure about the birth can contribute to poor mental health. Staff can help minimise these feelings by supporting women to:

- view mode of birth flexibly, minimising the sense that one mode of birth is ‘better’ than another
- understand that, while early opportunities for skin-to-skin are supported and desirable, this is not essential for bonding – it is good practice for staff to gain informed consent for skin-to-skin, with an awareness of cultural differences.

It is good practice for services to:

- consider the role of the birth partner and how healthcare professionals can work collaboratively with them to support good psychological outcomes
- communicate honestly and openly if there are specific service limits on what is available
- ensure that birth preferences:

  - are documented in collaboration between parents and staff and can be updated or changed – good communication is important to ensure that this document remains live and can be updated/changed
  - become a routine part of intrapartum care
  - are read and respected
- consider how women with ongoing mental health difficulties can complete their birth preferences in collaboration with maternity and mental healthcare professionals involved in their care
- have checks for whether birth preferences are followed and provide women with a clear explanation when this has not been possible.

6. Information, communication and informed consent

It is good practice for services to consider both physical experiences and psychological needs when deciding whether to advise a woman to go to hospital or stay at home in early labour. Good antenatal information and preparation for women and birth partners may help women stay at home for longer.

> "It would have helped to know that not having skin-to-skin, breast feeding, etc is unlikely to cause the baby harm and these things can be done later if the mother wishes." MMHA/Tamba

Positive birth experiences are supported by:

- good communication and partnership working between women and healthcare professionals
- clear and consistent explanations of what is happening and options going forward, with regular updates, taking women's individual needs into account and checking back to ensure information is understood.

Sensitive use of language can minimise adverse psychological impacts. For example, women may interpret 'a failed induction', 'incompetent cervix', 'failure to progress' or 'high risk' as their own failings or incompetence or their circumstances being more dangerous than they are.

Women and their birth partners benefit from:

- feeling cared for during labour and birth
- being treated with compassion and dignity

> "Reassurance by the midwifery team so parents do not feel like they are on a conveyor belt and 'just another birth'". MMHA/TAMBA

- feeling both physically and emotionally respected and supported.

The needs of birth partners are important and staff can reduce their anxiety by:

- supporting them to feel involved
- offering them emotional support
- considering their needs in an emergency – it is important that both parents, if they are both present, can speak to a specific member of staff when an obstetric emergency occurs.

"Emotional support for the partner could be useful, especially if it is a tricky birth. Someone to talk them through procedures and answer any questions. When a partner sees the mum suffering and doesn't know what's going on, that creates its own trauma in that partner." Birth Trauma Association

7. Managing transfer from labour ward to postnatal ward and postnatal care

Some women will be discharged home from the delivery suite, but many will move from receiving individualised 1:1 care in labour to the postnatal ward where one midwife is caring for six or more women. This is a huge transition for women at a time when maximum support is needed and it can leave them feeling isolated and abandoned.

Parents benefit from being actively introduced to the postnatal ward and neonatal unit, including what happens there, the midwives and facilities. Good services will:

- have systems for handover to postnatal ward staff, which alert them to the woman's experiences (such as induction, long labour or blood loss) so they can tailor support to the parents' needs
- be aware of women's considerable vulnerabilities at this time, providing dignity and ongoing support so women are not left alone, feeling fearful and unsure of how to manage their new role
- provide additional support to women on the postnatal ward, such as:
  - pastoral or emotional support
  - pain relief monitoring
  - feeding support
  - help with baby care
- ensure that both parents are taken to see their baby as soon as possible. Make sure that parents are regularly kept up to date and fully involved in all decisions about the plan of care for their baby or babies.

A good service may involve midwives, support staff, infant feeding specialists and peer supporters.

Women benefit from their partners being able to stay on the ward whenever possible to provide support and reduce isolation. Services could also consider how to provide for those who do not feel comfortable being on a ward where partners are staying. Good services will be guided by principles of care that routinely support mother–infant and family closeness, maintaining contact and avoiding separation wherever possible.

> "Most first-time mums don't have a clue what to do when they're handed a newborn baby but are expected to know everything. I think a little more time making sure mum is managing and coping with everything would help. Asking are you ok? Do you have any questions? Not to take over looking after the baby which is what I found. Also including the partner in the care of the new baby to make them feel just as important as mum." Spoons

It is good practice to ask all parents about their experience of birth while on the postnatal ward and offer follow-up support as appropriate.

Women who are discharged from hospital soon after the birth need access to support from community midwifery. Women benefit from seeing community midwives at home on the day following discharge.

Maternity services could consider how to provide physical and emotional care to women when their babies are on the neonatal unit. It is important to support the recovery of women who have been discharged while their babies remain on the unit, as this may not be covered by community midwives.

8. Support for parents

Maternity services could consider providing comprehensive antenatal education for parents, such as:

- accurate and relevant information
- 1:1 midwife appointments or team-based small group antenatal education, where the continuity model of carer is in place
- tours of the labour ward
- tours of the neonatal ward for higher risk families (if it is a planned delivery, it is helpful to invite them to come along at least a week before if possible).

Information resources could include:

- reading materials in languages relevant to the local population
- online content including videos and parent perspectives in different languages
- information for birth partners.

Group provision could:

- be community based
- be flexible, to allow for working parents
- be offered free or at low cost
- involve other professionals, such as obstetricians, maternity support workers, health visitors, mental health team members and physiotherapists, where appropriate.

All women benefit from being able to ask questions in a safe space. It is important services consider how to ensure this works equally well for all individuals and may be particularly important for women from minority or disadvantaged groups.

Many pregnant women access information on the internet or social media, which may not reflect the care in the hospital where they are booked. Enabling women to access reliable local information could be achieved by:

- signposting to trustworthy sources
- answering questions and supporting care via maternity-led Facebook groups – this could include information that is tailored to local provision and routinely available to all women from second trimester regardless of parity
- supporting them to make links with other pregnant women from the second trimester.

9. Continuity of carer and communication

Continuity of carer is an important and effective way to improve antenatal preparation and enhance the experience of birth.

Women benefit when staff can get to know them as individuals and build trust, as outlined in Better Births. Trust, compassion, empathy and sensitive use of language are all important for women to feel safe and well cared for.

> "It feels like there's a huge gap between some of the antenatal classes, which suggest women have 'natural births' with as little intervention as possible, and the realities of the Westernised risk-averse medicalised hospitals that women give birth in. Some middle ground would mean women feel less of a failure when their birth doesn't go to plan." Dad Matters

10. Staff training

Staff will benefit from training in the psychological aspects of pregnancy, birth and parenthood and in responding sensitively to those with additional needs, including ongoing mental health difficulties. This is of equal importance to physical aspects of care.

Midwives will also benefit from training in: the provision of antenatal preparation; supporting women to use their own coping resources in labour; and obtaining informed consent for all procedures.

11. Staff support

Where mental healthcare professionals are embedded within the maternity system, they can provide psychological training and support for staff and reflective practice opportunities for managing challenging situations.

See Section 7 on practical implementation for a summary of how change might be supported in practice.

Case study

This case study illustrates how one service has tackled providing trustworthy information, a safe place to ask questions and a sense of community

Facemums: Bringing relational continuity to the home through social media

What's new?

Continuity of care and easy access to reliable information during pregnancy is essential to the health and wellbeing of pregnant women. Widespread use of the internet is changing the way people obtain health information and communicate with health providers. Pregnant women are particularly motivated to look for information and support online.

At the forefront of developments in online maternity services, an innovative social media-based intervention called Facemums is giving pregnant women the opportunity to join private online discussion groups, organised and moderated by qualified midwives. Funded by a development grant from HEE, Facemums allows pregnant women to develop their own virtual communities of care where they can support each other and share their personal experiences and information.

How does it work?

During the first appointment with a midwife at their local maternity unit, pregnant women are given the opportunity to join a Facemums group, hosted on Facebook. These groups usually involve a maximum of 20 women and are 'secret', which means they are accessed by invitation only. Each group is assigned two Band 5 midwives who act as moderators. Their job is to regularly monitor the comments and discussions posted on their group and be available to answer any maternity-related queries. Importantly, they can step in to clarify misunderstandings or correct any inaccurate and misleading information that may be shared. Facemums is highly inclusive. Currently, pregnant women who want to take part only need to be booked for care at a participating hospital maternity unit, be willing to use Facebook and be over 15 weeks' gestation.

Facewives (for the midwives) funding is withdrawn when the last woman in a given group is six weeks postnatal and the midwife moderators withdraw at this point. However, the mothers in a group can decide if they want to maintain contact as a support for each other.

When necessary the midwife moderators can refer a woman to community midwives, community team leaders, mental health specialist midwives or mental health teams. They also have ongoing support from their own midwife mentors.

Facemums was developed during extensive pilot work conducted in two NHS trusts during 2017 and is now being trialled in a further 12 trusts across the North of England. It is hoped that a nationwide rollout in maternity units across the UK will take place. The initiative is proving to be a highly effective way of delivering professionally verified information and social support to women in pregnancy. Early evaluation data indicates that taking part in a group can improve perceived levels of relational continuity, which is one of the key aims of maternity care provision. It can also reduce levels of stress and help women cope with the feelings of isolation and uncertainty that may be a feature of pregnancy.

Find out more

McCarthy R et al. Midwifery continuity: the use of social media. *Midwifery* 2017; 52: 34-41.
http://hub.salford.ac.uk/facemums/
Twitter: @facemums www.salford.ac.uk
Instagram: @Facemums1 Facebook: Facemums

4. Traumatic birth: supporting mental health and psychological wellbeing

Trauma results from an event, or series of events, that an individual feels is harmful or life-threatening and that has long-lasting effects on their mental, physical, social, emotional or spiritual wellbeing [8].

Where birth is experienced as traumatic, women and their birth partners are at risk of developing PTSD. This is highly distressing and debilitating and can become chronic if it is not recognised and treated.

PTSD following childbirth can also affect a woman's relationships with her baby, partner and family.

Sensitive care in childbirth can minimise the risk of women experiencing birth as traumatic. It is important to recognise that trauma is subjective and may be experienced by women who have had an obstetrically straightforward birth. It is for the woman and her partner to decide if her birth has been traumatic, not the professionals caring for her.

Good services will consider putting in place strategies to reduce the risk that birth is experienced as traumatic as well as screening and intervention systems for PTSD.

Good practice

1. Care on the postnatal ward

Good services would consider how to actively support women on the postnatal ward in relation to their birth experience. This could include routinely giving women and their birth partners an opportunity to talk, privately and independently, with a member of staff about their birth experience and to ask questions.

2. Postnatal follow-up in relation to childbirth experience

Good services will support community midwives to routinely provide an opportunity for women to discuss the birth. Staff can be supported to:

- actively engage with each woman to ask how she feels about her birth experience – women will benefit most from an active discussion, rather than a tick-box exercise
- listen with interest and without making assumptions – women will often hide their true feelings unless there is a demonstration of genuine interest
- facilitate discussion, eg by recording a free text description of what was discussed on discharge sheets.

"Someone to talk to just to check in and ask how you are (Dad as well!)." MMHA/Tamba

Where possible midwives should discuss the birth with the birth partner separately. When they are seen together, women and birth partners may not feel able to talk openly and may try to protect each other.

Good maternity services can support care by training midwives to screen women for birth trauma and for acute stress symptoms. They will consider how to offer this input to all women, including those whose babies are admitted to neonatal care.

For women who find giving birth traumatic, a good service will ensure they are made aware there is an opportunity for follow-up at a birth review clinic. This follow-up if needed can be about any aspect of the birth experience and the woman should be given a number to contact so this can be at a time right for her.

"Increase awareness of birth trauma and make sure it's part of usual conversation that is handled immediately. Acknowledging birth trauma has occurred is the first step to healing, moving forward or getting answers. When you tell someone who does nothing with that information it enables the trauma to become a deeper, harder mental scar." Smallest Things

3. After midwifery discharge

The onset of trauma symptoms can be delayed and may arise following discharge from community midwives.

Good maternity services provide outreach training for health visitors and GPs in screening for birth trauma and PTSD symptoms. Mental healthcare professionals can train staff to use screening measures combined with clinical judgements to inform care.

Staff could consult MMHS or PMH services and make appropriate referrals when necessary.

4. Trauma intervention

A good service will consider providing a birth review clinic. This could involve:

- community midwives, obstetricians, health visitors or GPs referring women to the clinic
- self-referral without a postnatal time limit on this provision
- a stepped care process with midwives trained and supported in birth review and mental healthcare staff with specialist expertise in trauma-focused psychological intervention.

Where possible, seeing a woman and partner together and separately is of value.

It is suggested that the process is entirely separate from complaints procedures. With women's agreement, material could be fed back into ongoing maternity staff training to improve local services.

It may be helpful for provision to be incorporated in MMHS, which would facilitate integrated and maternity-informed care.

"Time and prompts for discussion with midwives, the health visitor and GP to discuss the labour, birth and feelings around this." MMHA/Tamba

"Being given the chance to talk through the experience when I felt ready." MMHA/Tamba

"Recognition of the PTSD that can come with traumatic birth and neonatal experiences. This has impacted on me for 8 years since the twins birth and I work in the NHS and have had to desensitise myself to noises, experiences and environments in locations I regularly come across. Plus anxiety every time my son is ill and when we need A&E. The PTSD has been low level at times and debilitating at others. My husband does not understand this at all and it has been isolating. Both of us needed help to understand this and it has not been available." Smallest Things

"CBT and EMDR saved me, and my relationship with my baby. I think they should be available to absolutely any mum who needs them." Birth Trauma Association

5. Care in a subsequent pregnancy

A good service will routinely consider women's previous experiences of birth in any subsequent pregnancy. In particular, staff could ask women how they feel about giving birth again so there is an invitation for them to talk about previous birth experiences.

When a prior experience of traumatic birth leads to a fear of childbirth, it would be helpful to:

- provide rapid access to MMHS psychological intervention from early second trimester

- take a woman's previous experience into consideration when discussing her birth preferences
- take the proposed birth partner's previous experience into account when identifying their psychological needs.

"Support for the father.. especially if he observed a traumatic birth." Dad Matters

Services could consider:

- signposting women and families to existing online peer support services via third-sector or community groups
- setting up facilitated online support for specific groups, such as women with third/fourth degree tears/obstetric anal sphincter injury, or partner groups.

6. Staff training

One in three women experience birth as traumatic, but in most cases, the early symptoms resolve with appropriate timely support and an understanding that this can be a normal response.

Good services will:

- consider providing training for maternity staff about:
  - the potentially more subtle or psychologically-focused issues that can make a birth traumatic
  - the signs of PTSD
  - the increased risk of PTSD in those who have experienced high levels of intervention, whose births differed greatly from their hopes, whose babies are in the neonatal unit or where a woman has experienced a stillbirth
- enable midwives to provide initial support and recognise when the trauma response is more serious or not resolving
- train staff to use trauma exposure and PTSD screening tools and to understand common post-trauma responses so they can provide screening and discussion
- support maternity and obstetric staff to acknowledge when they may lack confidence in supporting people experiencing psychological trauma issues
- support staff to seek advice and assistance from mental healthcare professionals whenever necessary to provide comprehensive care

- enable awareness that women may be reluctant to talk about any problems they may have, engage with healthcare professionals or attend hospital appointments following a traumatic birth.

7. Staff support

Maternity staff can themselves be traumatised by exposure to work-related events, whether in a single incident or as a consequence of repeated exposure. Good services would consider how systems can be put in place to provide trauma-focused intervention for maternity staff.

See Section 7 on practical implementation for a summary of how change might be supported in practice.

Case study

This case study illustrates an established birth review with integral psychology trauma service.

Sheffield post-birth stepped care model

Midwives offer a birth afterthoughts style service for women who want to talk through their experience of childbirth and make sense of events. This is a weekly clinic with five appointment slots.

The service is provided by three midwives (0.2 WTE Band 6 and 0.2 WTE Band 7, overseen by a Band 8b). All have other duties in the maternity unit, which provides care for 6,500 births per year.

Support for women

The approach is flexible depending on the needs of each woman. Some women want to make sense of their emotions and others want a factual account of what happened, often to fill in memory gaps and to understand implications for future pregnancies.

Midwives offer the service at 6–8 weeks postpartum as this has proven to be the best time period for women to feel able to recall events and synthesise information and discussion. It also allows us to screen for PTSD. The session focuses on the woman's story. It encourages her to express feelings and emotions, aims to help clarify events along her journey, offers discussion on future pregnancies and validates her lived experience.

Women self-select for the service, which is available to any woman who perceives her birth experience as negative or traumatic. Fathers and partners can attend with women if they wish.

Working alongside a hospital-based psychology service, midwives screen all women who attend for PMH issues including PTSD. For women showing symptoms of PTSD as a result of childbirth we offer referral to the birth trauma service for psychology assessment. The birth trauma clinic is staffed by two Band 8a clinical psychologists (total 0.2 WTE) who are supervised by a Band 8c with specialist knowledge and expertise in this area. Women are typically offered two assessment sessions and up to six treatment sessions, although this may be increased or reduced according to the woman's needs. Sessions last up to 90 minutes, as recommended for trauma-focused work.

Women are usually seen in the maternity unit's antenatal clinic. This allows the psychology service to integrate into the maternity service and begins to expose women to trauma-related stimuli. For some women, their avoidance symptoms would stop them accessing therapeutic intervention sessions in the maternity unit. In these cases, provision is made to see the women elsewhere in the hospital. Women are also offered support in their next pregnancy, including planning for labour and birth with a consultant midwife.

Support for staff

From our experience, providing a service 'in-house' ensures close collaboration between psychology services and maternity, allowing for a more seamless referral pathway and joined-up working, and providing women with more efficient and comprehensive care. It also ensures that each discipline informs the other. Midwives working in the birth afterthoughts service can discuss referrals with the psychologist and get advice on complex cases. Psychologists can seek advice regarding the obstetric details of a woman's experience or to understand whether a woman's perception of 'life-threatening' is a true appraisal. In addition, clinical supervision can be provided to the midwives working in birth afterthoughts.

Themes that emerge from women's narratives are often discussed at team meetings and fed back into education sessions and service provision with the aim of building a more psychologically-informed workforce.

Alison Brodrick, Consultant Midwife

Find out more

Williamson.E Pipeva A Brodrick A Saradjian A and Slade P (2021) The birth trauma psychological therapy service: An audit of The birth trauma psychological therapy service: An audit of outcomes Midwifery https://doi.org/10.1016/j.midw.2021.103099

5. Neonatal care: supporting mental health and wellbeing

The experience of neonatal care is individual. However, there are some common psychological challenges that families experience, which underline the importance of good psychological as well as physical care. A well delivered family integrated care model will positively influence the following elements, leading to improved mental health and other long-term outcomes for both baby and parents.

Attachment and bonding

The neonatal unit (NNU) can be an overwhelming sensory experience for babies who have come from the relative quiet, dark and warmth of the womb, often ahead of time. All babies need responsive, attuned care to help them regulate themselves physically and emotionally.

Parents are biologically primed to provide this care, so being physically separated can be a huge challenge for them. It can also be more difficult for parents to feel connected to their baby:

- when their role is unclear
- when they are struggling to regulate their own sense of threat
- where there are physical barriers both to being with their baby and to learning to read their cues.

Attachment security can have a significant impact on later child and family outcomes, so it is important to prioritise supporting parents with this.

Role and identity

The journey from conception to parenthood generally develops over 12 months – the ‘fourth trimester’ is when parents and their baby first get to know each other. This process is disrupted when babies are born early or sick and spend time in neonatal care. Parents often describe feeling that they are unsure of their role on the NNU and more like a visitor than a parent. This can have a significant impact on the parent’s sense of self, leading to

anxiety and low mood and potentially impacting on the emerging parent–infant relationship.

Trauma

Parents on the NNU have often experienced a traumatic birth and once arriving on the unit may continue to fear for their baby's wellbeing and often survival. This is not a one-off experience of trauma but may be experienced repeatedly. The alien environment, high levels of sensory stimulation, medical intervention and fear of the unknown compound this feeling of threat. Studies have shown that up to 50% of NNU parents will experience PTSD, with many more experiencing elevated traumatic stress responses. These symptoms can stay with parents for many months and years after discharge.

While therapy can help to reduce these symptoms, this is only likely to be effective once the danger has passed. Many parents describe not even recognising their difficulties until after the baby comes home. In the short term, the focus must be on supporting parents to feel seen, heard and cared for until the immediate threat has subsided.

Having a baby in neonatal care places parents and infants at significant risk of psychological and mental health difficulties and steps need to be taken to ensure that the psychological quality of the care provided reduces this risk whenever possible.

Good practice

The Neonatal Critical Care Review highlights the importance of supporting the psychological wellbeing of babies and parents and recommends use of the Bliss Baby Charter to deliver these aims. Our aim is to complement and enhance the charter's references to good psychological/psychosocial care for families while underlining the psychological significance of all aspects of care.

1. Transition from maternity to neonatal care

Preparation

Where there is a high risk that a baby will need care in a NNU, parents benefit from having:

- access to preparation, including information on what to expect

- an online or physical tour supported by staff
- an opportunity to meet an appropriate member of NNU staff
- signposts to online information from recommended local and national organisations.

"Prior to delivery time, explaining [the] possible plan of care … It reduced the stress once our baby was born and intubated. We knew how he was being cared for and why. He felt in very safe hands." Spoons

These can help reduce the traumatic impact of the admission.

Meeting mothers' needs too

When a baby is being cared for on the NNU, it is important that women continue to receive appropriate maternity care. This might include:

- offering alternative settings (eg a side room or room on an antenatal ward) to avoid contact with other women and their babies
- removing reminders of the baby's absence (eg an empty cot)
- wherever possible, keeping the mother in the same hospital as her baby, being transferred along with her baby if they continue to need inpatient care – or ensuring someone else is supported to go with the baby if this is not possible
- taking the baby's location into account in deciding when to discharge the mother.

"A new mum whose baby is in the NICU should never be put on the post labour ward to 'recover' while surrounded by other new mums and their babies… it was horrific and caused my PTSD to be even worse." Smallest Things

Keeping in touch

Effective systems of communication between the maternity (or wherever the mother is receiving physical care) and neonatal staff are crucial to maintain the connection between parents and their baby. This might include:

- providing photographs of the baby when mother and baby are separated, and where available use of a video link
- regular updates for parents and facilitating them to be with their baby as frequently as possible
- having a link midwife for parents with a baby on the neonatal unit to support the transition and ensure parents' needs are considered.

Orientation

To reduce the psychological impact of transfer, parents benefit from:

- being warmly welcomed onto the unit, introduced to key staff and given a clear description of what will happen next
- having the opportunity to spend time with their baby as soon as possible
- receiving information about how the unit works, how to gain access and any restrictions to access
- having an orientation to the sounds, equipment and activities of the unit.

> "A good welcome and introduction to the unit to understand how the ward works and the role of the parents within that – it is incredibly difficult to not be able to make decisions about your own child so to understand fully how things work is important." Spoons

2. Support from the neonatal team while on the unit

Physical environment

The physical environment has a huge impact on families' experiences of parenting on the unit. High quality care will include providing parents with:

- a welcoming, comfortable environment to spend time with their baby
- facilities to make food and spend time with other parents
- a private and comfortable space for breastfeeding and expressing
- a private space for discussing their baby with staff
- space for siblings to play and feel comfortable
- information on financial support, to reduce barriers to being with their baby on the unit
- wherever possible, the facility for parents to stay overnight on or near the unit.

> "Being able to stay on the unit. We couldn't do this until coming home and I feel this affected my mental health massively." Smallest Things

Infant psychological needs are also a priority: promoting closeness and connection with parents and minimising pain and overstimulation in terms of noise, light, and smell.

Emotional support

Good emotional support can go some way to mitigating the traumatic impact of the neonatal journey. The best care will allow staff to spend time with parents and build trusting relationships, so parents feel that:

- their experiences are acknowledged – it is ‘ok not to be ok’
- they are encouraged to rest and take care of their own needs as well as those of the baby by warm, compassionate and sensitive staff
- staff are attuned to when parents might be struggling in getting to know their baby and are there to offer support
- staff understand some of the key triggers for anxiety they might experience, such as:
  - the introduction of new members of staff
  - a change to their baby’s care
  - a transfer from one unit to another
  - their baby’s cot has moved
  - another baby has died.

Good communication will help to reduce the impact of these events. NNU peer support is an essential part of emotional support for families and is further described below.

Parents often find it hard to be separated from family, friends and other children while they spend time in the NNU. Supporting them to record physical memories and milestones of the time with the baby throughout their stay on the unit can support their emerging relationship with their baby and create a narrative about the baby’s role in the family that can help the wider family feel more connected.

Families may also benefit from being signposted to support for siblings that helps them make sense of the experience and promotes family relationships.

> “Some kind of intervention or questioning of us as parents while we sat in NICU would have helped us to express what we were feeling. We were there a lot but we weren't the patients so we didn't really matter. It's a missed opportunity to formally connect with traumatised new parents.” Smallest Things

Feeding support

Parents all want the best for their babies but for some mothers breastfeeding or expressing is particularly physically or psychologically difficult. It is good practice for staff to:

- be aware of the psychological significance for parents of feeding (in whatever form) and nurturing their babies

- empower parents to take the lead, eg by involving them in tube feeding or ensuring they are involved or updated on any changes to feed times
- sensitively explain the particular significance of breastmilk when a baby is premature or sick, offering information and practical support
- ensure the mother does not feel judged if breastfeeding or expressing is not manageable or is too psychologically aversive.

Communication and collaboration – family integrated care

Family integrated care (FIC) plays a significant role in addressing some of families' vulnerabilities. To do so, it must be embedded in the values and culture of the unit and the approach of each member of staff.

Where FIC works well:

- staff recognise the parents as their baby's primary caregivers and support them to be a lead partner in their baby's care, promoting collaborative decision-making
- parents receive appropriate education and support to confidently take on this role
- parents receive consistent messages about their role in their baby's care when transferring between different nurses or units.

"Help a parent to actually feel like a parent – you don't, you sometimes feel like a spare part who has walked into a room and isn't wanted. The guilt makes you feel like you have failed and when you have no clue what you're doing it makes you feel like a terrible mum." Spoons

Good communication in this context includes the key ideas outlined in this guide, as well as the points listed below.

- Providing up-to-date, consistent information about the baby's condition and their care in a format that is tailored to parents' needs.
- Being sensitive to parents' wishes regarding:
  - where (at the cot side or in a quiet space)
  - how (tailoring language to parents' needs, explaining key terms, avoiding euphemisms and acronyms, checking parents have understood)
  - who shares information with them, particularly with reference to their baby's condition or potential outcomes.

"Full disclosure – it really helped to have the doctors and nurses be honest about my babies care and their health. Sometimes it wasn't easy and we had to face some incredibly tough times but it felt like we were working together if we all knew where we stood." Spoons

- Providing written information for those who want it, with parents being encouraged to take part in creating resources about their baby's care.
- Collaborative decision-making with families throughout the neonatal journey. Additional psychological support may be helpful to support these conversations in difficult circumstances.

Transfer and transition

All transitions are a time of increased stress and anxiety, even if they are positive, eg transfer to less intensive care. Where FIC is well established, this will make transition easier. It is good practice to reduce difficulties where possible, for example, by:

- supporting parents prior to transfer, keeping them informed and involved
- orientating parents to the new unit in the same way as any parent first arriving
- actively communicating the needs of parents alongside those of the baby during shift handovers
- communicating effectively in the unavoidable situation of mother and baby separation
- supporting parents to understand and adjust to changes in their baby's physical condition, which may affect how much they take part in care
- having a mechanism, such as a care passport, to highlight the skills parents have developed and support conversations about the parents' role in caring for their baby and the eventual transition home
- ensuring families are signposted to appropriate local support groups and organisations.

3. Follow-up and aftercare

Preparation for discharge home

Although parents have waited a long time to take their baby home, it can also be very anxiety provoking to take home an often vulnerable baby without the support they have been used to. It is best practice for discharge planning to begin as early as possible, including:

- effective communication with primary care throughout the admission, including a meeting involving the health visitor and any community services to provide adequate handover of care

- involving peer supporters from within the parents' local community in this process where possible, to help the family transition home
- offering parents at least 24 hours of supported rooming-in with the baby before leaving hospital and support to acknowledge and address any anxieties
- effective communication is essential between teams and with parents where babies are being transferred to a paediatric service via a multidisciplinary discharge planning meeting.

Where babies are being discharged home or to hospice care with life-limiting conditions or for palliative care, it is good practice to provide a robust package of care for parents, co-ordinated by the bereavement team and including community support (see Section 6).

"Although on the one hand it was all we had been yearning for, I was actually scared to go home. So better preparation for your transition to home would be great." Smallest Things

Support once home

Parents often describe feeling 'abandoned' when they get home. They worry about their vulnerable baby and this is often also the time when they begin to acknowledge and process the trauma of their birth and neonatal journey. Good practice in supporting parents at this time includes:

- giving parents a named neonatal or community healthcare professional to call for support if they are worried about their baby or how they are coping
- providing written information to parents and their primary healthcare team about the baby's needs and listing possible sources of support – the baby's red book could be modified to identify that they have been on the NNU and alert primary care staff to this
- health visitors are a potentially huge source of skilled nursing support but would benefit from specialist training and support from the NNU to offer tailored follow-up care
- screening parents for psychological coping throughout the neonatal journey and continuing this following discharge via the GP or health visitor
- normalising the psychological impact of neonatal care on parents and encouraging them to share difficult feelings
- offering parents the opportunity to come back later to review their care and reflect on their experiences with maternity and/or neonatal staff – developing a coherent

picture of events can help reduce the impact of trauma when staff are trained to avoid retriggering traumatic memories.

4. Integrated sources of support

It is important that all staff see it as their role to offer psychological support in their day-to-day interactions with families. This is most effective when there are ready sources of support for parents, babies and staff.

Awareness raising

It is helpful for staff to routinely ask about parents' psychological wellbeing. Staff may benefit from training in how to identify those who need additional support and how to signpost accordingly.

Parents and staff benefit from information about identifying psychological and mental health needs, including:

- understanding low mood and anxiety
- recognising trauma and PTSD
- recognising when they are struggling in their relationship with the baby
- being aware of the 'red flags' for more severe mental health difficulties – see below
- knowing what support is available if these needs are identified
- contact details of appropriate local and national organisations that provide peer support, befriending, counselling, information and advocacy.

"I think the reality of the likely impact on mental health needs to be discussed with mums on the unit and again before leaving. To let them know just how likely they are to suffer and to seek help as quickly as possible and who to do this with." Smallest Things

Red flags in perinatal mental health:

- a history of bipolar disorder or severe depression
- reporting a belief that they have a mental health problem
- a significant change in mental health or new symptoms
- new acts or thoughts of violence or self-harm
- expressing feelings of being a bad mother
- feeling estranged from their baby.

Shakespeare J. Red flags for GPs in perinatal mental health. RCGP, 2016.

Peer support

Opportunities should be created for specialist neonatal peer support. Different parents will respond to different models and as such a range of options may be needed. These might include:

- drop-in support from trained peer supporters
- coffee mornings or regular meet-ups for parents on the unit
- FIC group sessions
- groups involving veteran NNU parents
- online support for those who prefer indirect contact.

There are now a number of models for providing effective and safe [9]. It is important that these principles are adhered to, to protect and adequately support all parties.

> "Speaking to other parents helps. Your own family's support is brilliant but nothing can compare to parents who have been through your experience." Dad Matters

Psychological support

There are a number of important specialist psychological support functions, both on the neonatal unit and following discharge. These include:

- staff training and support to create a 'psychologically-informed environment'
- counselling or a listening space for parents as they process what is happening
- assessment and signposting to other services, such as IAPT, counselling services, MMHS, specialist PMH teams and parent–infant mental health teams – specialists from the NNU might offer supervision or consultation to these services to ensure the support is tailored to neonatal needs
- evidence-based psychological therapies to support parent's mental health and their relationship with their baby, where a neonatal specialist is needed.

> "I think having a mental health professional on each NNU would be a good start. With maybe an initial assessment post birth and then each week and to be followed up going home. During the NNU stay, especially if your baby is very poorly, I think you are so determined to be OK you don't see the problems that a professional would help you identify and address before it hitting you once you get home." Smallest Things

Wherever possible, having a psychological or mental health professional based on the unit will maximise the degree to which psychological care is embedded in practice. This would enable

parents to see a known individual who understands the context. It would maximise effectiveness and avoid problems of external referral as well as reduce stigma and facilitate access for families.

5. Supporting and developing staff

Staff training

To effectively meet families' psychological needs, neonatal staff will particularly benefit from training in:

- understanding parents' experiences of neonatal care; the significance of milestones, normalising distress; and the process of adjustment
- perinatal and infant mental health, including how to screen for and support both
- understanding the longer-term impact of trauma and the neonatal journey on both parents and babies
- communication and basic counselling skills
- conflict resolution
- bereavement support.

Ideally, training would be provided in-house by the psychological or mental healthcare professional attached to the unit. This would ensure it is accessible, meets local needs and provides opportunities to develop local practice.

Maternity staff, health visitors and wider mental health teams, including IAPT, would also benefit from having information about the impact of neonatal care included in their training.

Staff support

Staff are doing a very difficult and emotionally demanding job. Supporting them well can reduce burnout, improve retention and positively impact on their care of families. Staff support might include offering:

- reflective supervision and reflective practice sessions
- 'debriefs' after loss or other traumatic events, which offer a space to reflect on the emotional experience of the event as well as the lessons learned
- access to individual psychological support and intervention for workplace trauma as required

- consultation with perinatal and infant mental health specialists with regard to their work with specific families.

See Section 7 on practical implementation for a summary of how change might be supported in practice.

Case study

This case study demonstrates the benefit of embedded psychological support.

Embedded clinical psychology service on the NNU: Evelina London

Level 3, 55 cot unit, neonatal intensive care unit (NICU), high dependency unit (HDU) and special care baby unit (SCBU).

Staffing

Two psychologists (1 WTE) plus doctoral trainees, an honorary assistant psychologist (0.4 WTE) and undergraduate placement student (0.4 WTE). Psychologists are based on the unit itself.

Support for parents and families

Referral to the psychology team is open to any parent while their baby is on the unit. Referral routes are flexible and often by brief email or conversation with the aim of reducing barriers to accessing psychology. Families are usually seen within a week. Referrals are prioritised by level of distress in parents, which is assessed in the first instance by a combination of information from the medical and nursing teams, questionnaires given to parents and factors relating to the status of the baby.

Parents are given the option to be seen together or separately or a combination of the two. Sessions are also offered to siblings if needed or this can be a focus of work with parents (eg managing behavioural changes in children and supporting their emotional needs). Psychologists also offer support at key transitions such as to PICU or another hospital and help prepare families for the emotional changes that can occur when they are at home. They may also become involved to help the team with complex care discussions, such as helping the family make decisions about their baby's care or end-of-life options. There is flexibility in appointment frequency, length and location to fit with the rapidly changing environment of intensive care.

After being seen on the unit, onward referrals are made to mental health services including perinatal and IAPT teams as appropriate. Psychologists on the unit will also often work with these teams to provide shared care for women who are already known to them and whose babies are admitted to neonatal care. Currently the team have limited follow-up facilities;

however, families in need will be seen up to three times post-discharge during which time liaison with local teams takes place to ensure ongoing care.

Other roles

Psychologists also contribute to running the EPIC (Empowering Parents in Intensive Care) programme on the unit, which is a series of sessions for helping parents adapt to the neonatal environment, learn to care for their baby and prepare for going home. A trauma group is also being planned on the unit comprising psychoeducation and components of the stabilisation phase of trauma treatment. Psychology is involved in leading the family and staff engagement work, which includes developing FIC, considering the NICU environment and ensuring that unit initiatives are regularly guided by family feedback. Psychologists run reflective practice groups for staff and contribute to training and teaching on the unit, eg teaching on the impact of trauma, managing anxiety in parents and communication.

Service evaluation

Parents are given an adapted version of the Experience of Service Questionnaire (ESQ) used by paediatric psychology. They complete this if they have been seen by the neonatal psychology team. The service receives consistently good feedback from families and is currently considering implementing meaningful outcome measures that can inform intervention and service development and design.

Rebecca Chilvers, Clinical Psychologist

6. Perinatal loss: supporting mental health and psychological wellbeing during and following pregnancy loss, termination after prenatal diagnosis, stillbirth and neonatal death

The National Bereavement Care Pathway (NBCP) brings together a wealth of information, tools and resources to support the provision of high quality care for women and their families who experience pregnancy or baby loss, as well as linking to free online learning. This section aims to complement the NBCP by highlighting some of the key features of care that will specifically support mental health and psychological wellbeing.

This section does not cover loss relating to removal of a baby for safeguarding reasons or termination of pregnancy for non-medical reasons.

The psychological process of perinatal loss

The experience of perinatal loss is unique to every individual. Pregnancy brings significant changes in identity that are then further impacted by experiencing the loss of a pregnancy or baby. This impact will be influenced by an individual's history of relationships, of loss, of pre-existing mental health difficulties, previous pregnancies or parenthood and by their wider sense of self.

Even when a woman and her partner have very ambivalent feelings about a pregnancy or baby, the loss can trigger a complex mix of feelings including guilt, shame, sadness, trauma, anxiety or numbness – all of which may be compounded by the physical pain

and trauma of loss. No assumptions or judgements should be made about the path that an individual's feelings or reactions might or 'should' take.

It is important that grief is seen as a natural and important process which each individual will navigate in their own way. Staff need to feel comfortable in supporting individuals who are distressed (or perhaps who do not show visible distress) without needing to 'fix' this. However, for some individuals, grief can become much more complicated and 'stuck', particularly when the way the loss happened was experienced as traumatic.

The universal and specialist care that an individual or couple receives on this journey can have a significant impact on their longer-term psychological wellbeing. For those who have pre-existing psychological vulnerabilities or who have had a particularly traumatic experience of loss or poor care, there is an increased risk of more complex and severe mental health difficulties developing.

Following loss, staff and parents benefit from:

- being aware of the psychological as well as physical recovery process
- having the skills, confidence and resources to identify more complex grief reactions
- accessing appropriate specialist support.

Good practice

1. Universal principles of care

Communication

"Language has a big impact on your state of mind. At our scans, our baby was referred to as just that, our baby. As soon as its heart stopped it changed to fetus or retained products of conception. It's so cold." MA/EPT

It is important that communication with women and their partners is:

- sensitive, respectful and supportive
- clear and tailored to individual needs.

Communication can greatly affect how parents process loss and their risk of trauma.

No assumptions can be made about how an individual will feel about their loss or the intensity and duration of grief or other reactions that they experience. Staff should be aware of the language that they use and aim to:

- communicate that they recognise the significance of the loss for the parents

- be attuned to how women/partners/parents[1] refer to their pregnancy/baby and choose their words sensitively to match personal perceptions of the loss. Some parents will hold and/or communicate a preference much more clearly while others might take their lead from staff. This is an individual process which will sometimes miss the mark – but the emphasis is on really listening and responding accordingly.

Staff can empower parents to make decisions about their own care and that of their baby but some parents may appreciate guidance and reassurance to do so. Feeling involved rather than 'done to' plays a key role in reducing trauma but the responsibility to make decisions alone can provoke a difficult emotional response without support.

Mechanisms to inform other healthcare professionals of a loss help them respond sensitively. This avoids parents having to unnecessarily repeat their story, which can re-traumatise them at a vulnerable time.

With parental permission, a sticker on maternity notes to highlight loss can alert staff to the need for sensitivity and avoid adding to parental distress.

Continuity

There are advantages to having a dedicated bereavement lead/team who can offer consistent support and guidance throughout (see Section 1). They might:

- offer enhanced support and signposting for those who have lost a pregnancy or baby
- be proactively involved in supporting families and staff
- facilitate transfer of information between settings and services
- support parents to make practical arrangements
- remain a point of contact for parents.

In doing so, they offer emotional containment and limit the escalation of difficult feelings. Such care may prevent the development of more sustained and complex grief reactions and mental health difficulties.

[1] In addition to the issues around language identified in the introduction, an even greater sensitivity around language is understandably required when referring to loss. Those experiencing the loss of a pregnancy or baby will refer differently to these experiences and this should be respected and supported. For brevity and to highlight the issues around identity following perinatal loss we continue to refer to 'parents' in this section but we are aware that this is not how all individuals would see themselves.

Timeliness

Women benefit from being offered assessment and information as quickly as possible to manage escalating anxiety. Having sufficient time and information available to make treatment decisions increases the likelihood of them feeling comfortable with their decision.

Once women have made a treatment decision, having access to physical procedures in a timely manner supports them to move forward with the process of grieving.

Information provision

Staff will benefit from training and support to deliver difficult or unexpected news sensitively. Ideally this will happen in a face-to-face discussion, in a private and appropriate environment with parents together if possible.

Parents are likely to have difficulty processing information and making decisions due to the emotionally challenging nature of the situation. They benefit from:

- being provided with sufficient, unbiased and timely information
- having information repeated if needed or receiving written information to back up key points
- another discussion opportunity once they have had time to think.

Many parents describe the unexpected events involved in a loss as being particularly traumatic. It is helpful for them to be made aware of:

- what they might feel physically during and following loss
- what they might see, eg the condition of or physical changes in the baby
- what medical and legal processes will happen
- what they might feel emotionally.

Parents need space to understand what has happened and why (where that is known), both in relation to this baby and potential future pregnancies.

> “I wish I was told what I can expect when the baby is born. I remember being shocked and terrified about the colour of her skin and the nose bleed, I didn't expect it. I didn't know what choices I had, whether I could see the baby, how it would look like, whether I could bathe it or dress it. These things were not communicated to me in advance and at the time I was so shocked and upset that I didn't think to ask. Now I have regrets about not spending enough time with my baby, which intensifies my feelings of guilt and sadness.” ARC

Private space

Wherever possible, it is good practice to provide separate waiting areas for those awaiting assessment for pregnancy loss or who have just received difficult or unexpected news. It is important that staff maintain supportive contact with parents while they are in a separate private area.

Memory making

The NBCP gives clear guidance for supporting memory making according to the stage of loss. Mementoes of remembrance can be important for some families to act as a link to their baby, to support the grieving process and to validate their role as parents, if this is how they see themselves.

> "Have separate waiting areas in hospitals when having to go to hospital during/ following a loss. It's devastating to be in a room of happy pregnant people when you know that your pregnancy has ended." MA/EPT

It is good practice for a trained and well supported practitioner to facilitate the discussion of options, making clear that there are no right or wrong decisions.

Whole family

The grief of parents, siblings and other family members and the potential impact on family relationships should be acknowledged. It is helpful for staff to be able to signpost to appropriate family support as required.

Where one baby of a multiple pregnancy survives, the baby or babies who have died should be acknowledged when parents wish it and a clear system, such as stickers on notes or the bedside/cotside, used to communicate this to staff.

Bereavement pathways

A series of clear pathways, based on the NBCP, will ensure staff feel confident in supporting families leading up to, during and following a loss at any stage. Pathways will ideally include provision of additional support services, including chaplaincy, psychological or mental health support, peer and third-sector support. There will be good awareness of how these can be accessed.

Communication with primary care

It is important that the woman's GP, midwife and/or health visitor (as appropriate) is informed of the loss, to:

- offer joined-up support
- avoid tactless or misinformed contact being made
- enable them to proactively offer support, according to the family's wishes.

2. Care in specific circumstances

Miscarriage, molar or ectopic pregnancy

This good practice guidance and the NBCP give a comprehensive overview of how to support psychological wellbeing in this context, including:

- management of pregnancy remains
- marking the loss in a way that parents find helpful
- sensitive use of language
- signposting to appropriate external sources of support.

In addition to these points, it is important to consider the following:

- Accessing triage via A&E can amplify an already distressing experience for a woman potentially losing a pregnancy. Wherever possible, being able to self-refer for assessment via a more direct route, such as an early pregnancy assessment unit, can help to contain anxiety. If women are repeatedly presenting in pregnancy this may also help to identify them as needing additional psychological support.
- Where a direct route is not available, staff providing the first point of contact would ideally have an awareness of the psychological impact of pregnancy loss to enable them to respond swiftly and sensitively.
- While women benefit from feeling empowered to make decisions about their care, this should be managed sensitively. For example, women agreeing to surgical or medical management of a live ectopic pregnancy or a miscarriage may feel guilty that they are 'choosing' a termination or feel responsible for the loss itself. Staff may need to offer support through this process.

Caring for parents making difficult decisions

- Where serious fetal anomaly or the potential benefit of selective reduction is identified, it is important that staff:
  - sensitively discuss the options for termination or continuing the pregnancy with parents

  - discuss the potential benefits and risks of either option without judgement
  - acknowledge the extra distress caused when there are time pressures on decision-making because of legal abortion time limits or the wish to avoid feticide.
- Where parents decide to have a termination of pregnancy for medical reasons staff should be aware that they may be sensitive to feeling guilty and judged. This can be a risk factor for complex grief and so compassionate and non-judgemental care is particularly important. Accommodating the woman's preferred method of termination where possible may also help to reduce the associated distress.
- Where parents decide to continue with the pregnancy, they are likely to need emotional support throughout. Promoting psychological wellbeing might include:
  - keeping them informed of what is happening or expected to happen next
  - providing options where these exist
  - equal partnership in decision-making regarding both the plan for the baby's care at and after delivery and the practical processes that will take place
  - having a clear multidisciplinary plan in place for the delivery of the baby and for palliative/neonatal care should this be needed – to include mechanisms to support the parents' psychological needs so as to reduce the risk of birth trauma and promote psychological adaptation to grief over time.

Stillbirth and death of a baby on the neonatal unit

The NBCP gives detailed and helpful advice regarding the importance of:

- dedicated and private space away from other families
- parents spending time with their baby
- memory making
- marking and acknowledging loss
- providing information on what might happen when the baby dies to reduce the traumatic impact of unexpected sounds, sights or smells
- preparing parents for processes after the baby's death and the role that they will take – the Perinatal Mortality Review Tool has a Parent Engagement Pathway, which supports staff to walk parents through this process.

Openness and honesty: It is important for any mistakes to be acknowledged and addressed as part of the duty of candour. Openness and honesty between professionals

and the family and a transparent system of resolution and learning can help families move forward in their grief.

Support for the wider family: Wherever possible, parents appreciate flexibility in visiting rules to allow the extended family to say goodbye to the baby.

Where necessary, parents would benefit from staff helping them manage the needs and expectations of wider family members. This could include acting as a gatekeeper or communicating sensitive information that parents might find hard to share.

Follow-up:

- The NBCP highlights the importance of parents receiving follow-up care to avoid them 'falling through the gaps'. Ideally this will include a proactive contact and the option for the family to make contact earlier if they prefer.
- Signposting families to a range of bereavement resources, including written information, gives them the opportunity to process their experiences in their own time. Ideally, they will have ongoing access to the bereavement lead/team to receive this triage and signposting at a later stage if needed as bereaved parents vary in terms of when they are ready to access further support.

Death of a baby on the neonatal unit: In addition to the points raised above and in Section 5, and the detailed advice in the NBCP document, the following practice points may be helpful.

Where the unit has access to specialist psychological support, it is helpful for parents to have met this individual at an earlier stage in their baby's life, to allow for continuity of care should they need it during palliative care or after the baby's death. Similarly, the bereavement lead/team will be introduced to the family at the earliest possible stage in the palliative care journey.

Some babies will have been delivered and cared for in NICU away from the parents' home, and it is important to ensure that there is good communication to facilitate continuity of ongoing bereavement support in the local unit. If the death of a baby from a multiple pregnancy occurs, confirm with the parents if they would like to continue to refer to the surviving baby as a twin. Neonatal staff must ensure that all are aware if the baby is a surviving twin.

Parents can be supported in their grief by being provided with an active role in planning end-of-life care. This could include giving them the option of transfer to a hospice or

home as appropriate and empowering them to make this process as comfortable as possible. Wherever possible, being cared for by a familiar nurse during and beyond end-of-life care can be experienced as very comforting.

Following the death of a baby on the neonatal unit, consideration must be given to when and/or how to communicate to other parents on the ward that a baby has died. It is generally very clear to other families that something has happened and this is likely to have a profound impact on their own wellbeing and sense of their baby's vulnerability. With the bereaved family's consent, it can be helpful to name this and offer support as needed.

3. Supporting families through repeated losses

- In addition to supporting women and partners through individual losses, it is important that staff are aware of and sensitive to the experience of repeated loss – and the potential impact of this on the severity of parents' grief reaction.
- Parents benefit from access to specialist maternity or psychological support, depending on the complexity of their presentation. This helps them make sense of their journey and their future options. According to individual need, this might be best offered at the point where a pattern of loss has been recognised or early in any subsequent pregnancy.

4. Wrapping support around the family

Creating and supporting a specialist bereavement team

The NBCP identifies the importance of continuity of care and of having a bereavement lead within each maternity and gynaecology setting.

This is a very emotionally demanding role, both in terms of meeting women and families who have experienced loss and 'holding' the anxiety and distress of the wider workforce.

Gold standard services might consider identifying a small team of gynaecology, early pregnancy, midwifery and neonatal staff with dedicated time and responsibility for bereavement care, to foster mutual support.

"Availability of staff to answer questions, even if it's over the phone. It can all happen so fast, and it's so traumatic that when you're in the moment you don't think of the questions you need to ask, but this comes later. Having a number to call for support, or ready information of charities that are ready to deal with these questions would have helped me enormously." Sands

This team might not meet directly with every individual experiencing loss but would take responsibility for developing pathways and supporting the skills of the wider workforce in relation to bereavement care.

The bereavement lead or team may benefit from supervision from a specialist PMH professional to:

- support their work with families with more complex needs
- help identify when parents might need additional therapeutic support.

Peer support

Many families benefit from having access to specialist peer support with others who have experienced perinatal or neonatal loss.

It is helpful for staff to signpost parents to recognised local and/or national support groups to access once they feel ready. Those peer support programmes that are promoted should follow recognised principles to support their safety and effectiveness.

It may be helpful for the bereavement team to consider facilitating peer support through the unit, for women and partners experiencing different types of loss. The time invested may be rebalanced by maximising the resources available to support families and reducing the need for professional support.

Providing specialist psychological or mental health support

It is important that staff feel they have sufficient training and supervision to identify when an individual's needs are more complex or might require specialist intervention.

Before leaving the unit, and at any follow-up appointments, it is important that parents' distress is acknowledged and that they are asked directly about how they feel they are coping. Immediately following loss, it may be hard for them to feel clear about what they are experiencing, so it can be beneficial to provide information to ensure that they are aware:

- that bereavement support is available and how to make contact
- of the range of recognised peer or community support options, including national helplines
- of the importance of self-care following bereavement

- how to identify more complex grief reactions and other mental health difficulties – and the sources of support available.

All parents who are identified as needing additional psychological support will benefit from timely and responsive access to assessment and therapeutic intervention from someone with a specialist knowledge of perinatal loss. Where the loss is predicted (eg following diagnosis of fetal anomaly or where the baby is on a neonatal unit) they would ideally have met this person earlier in their journey to provide continuity.

"IMMEDIATE access to support in a pregnancy after a loss. My second pregnancy was hugely traumatic – it was complicated as well as occurring after a stillbirth. I was having full-on PTSD symptoms and didn't get a mental health specialist until 16 weeks… I had nowhere to go out of hours until 18 weeks, except A&E, where they take your blood pressure and send you home as a threatened miscarriage." Sands

Section 7 on practical implementation outlines the role of mental health services in providing support. Where support is provided directly by the MMHS or PMH service, it is important to provide a mechanism for parents to reconnect with the service after discharge. Knowing there is support and psychological input available is often therapeutic in itself as it helps people cope and feel less isolated.

Where women experience a complex or severe mental health crisis in response to a perinatal loss, such as postpartum psychosis, severe depression or suicidality, a MMHS may be well placed to facilitate access to effective care. This is likely to involve supporting other agencies to understand the perinatal aspects of the woman's needs rather than offering ongoing care co-ordination if a multidisciplinary mental health intervention is required.

5. Staff training

All maternity and neonatal staff (including sonographers, community and ward-based midwives, obstetricians, neonatologists, neonatal nurses, healthcare assistants and receptionists) are likely to benefit from ongoing training in bereavement care, which might include:

- listening and communication skills – not making assumptions
- sensitive use of language
- breaking difficult or unexpected news compassionately
- enabling informed choice
- understanding the grief process sufficiently to offer support

- an awareness of cultural and religious factors in bereavement and the importance of not making assumptions about these.

A smaller group of bereavement care specialists would benefit from having in-depth understanding of procedures and processes associated with loss, including:

- the psychology of loss, grief and identity
- recognising the normal processes of grief and the diversity of these
- recognising when mental health difficulties have developed, including experiences of trauma, PTSD, depression, anxiety or psychosis
- how to support and signpost accordingly
- identifying any risk of hopelessness and suicidality, how to respond to this and manage risk appropriately
- the potential impact on different family members
- how to support other professionals to support families.

Services could consider providing training or consultation for other staff in the wider system, such as GPs, health visitors and reception staff, in how to sensitively support parents following loss. These staff members are more likely to have contact with families further down the line and this has the potential to facilitate joined up care.

See Section 7 on practical implementation for a summary of how change might be supported in practice.

Support for the wider team

The work of maternity and neonatal staff is extremely emotionally demanding, no more so than when caring for parents during and following perinatal loss.

Effective staff support might include:

- training, supervision and reflective practice
- routine confidential listening support after difficult events
- formal debriefing, which considers emotional as well as practical issues
- clear pathways for staff to access individual psychological support and intervention for PTSD related to workplace events where necessary.

To facilitate learning, skills and confidence all staff and students will need the opportunity to care for women experiencing loss. However, flexibility is important if individuals are

struggling so they are not allocated to these families inappropriately. Wherever possible, rotas would allow staff to take time out following a particularly difficult experience or loss.

Improving services

The NBCP offers a detailed model of best practice. Trusts are given a self-assessment and action plan as part of this process, which can help identify areas for improvement. They could also consider routinely using the Maternity Bereavement Experience Measure to encourage parents to feed back on their experiences.

Involving bereaved parents in designing resources, developing peer support and improving service quality can be helpful for improving service and supporting the parents themselves to heal.

Case study

This case study demonstrates the power of embedding the universal principles of care.

Perinatal Bereavement Service: Manchester University Hospitals NHS Foundation Trust

This service cares for over 320 families across two hospital sites. It supports families who have a pregnancy loss, termination of pregnancy, stillbirth or neonatal death after 16 weeks of pregnancy.

Staffing

3.0 WTE bereavement specialist midwives, 0.4 WTE support worker, 1.0 WTE neonatal nurses, 1.2 WTE perinatal bereavement counsellors. Close working with a miscarriage nurse specialist based in the gynaecology service.

The service is developed and supported by a MDT including chaplains from different faith groups, an obstetrician, mortuary staff, pathologists and bereavement support workers.

Training and support for staff

Bereavement team members provide education and support to staff on the delivery and neonatal units. The MDT approach has enabled staff to appreciate and modify care to suit the needs of parents from different communities in our diverse population. The team also provides specialist lectures to student midwives at two local universities, enabling wider dissemination of best practice. Providing bereavement care for parents and families is emotionally and personally challenging. Peer support is available within the staff groups and from the perinatal counsellor.

Support for parents and families

We provide parents and families with support from the point of diagnosis of fetal death, commencement of medical termination of pregnancy or, in the case of neonatal death, when a baby's condition indicates they will not survive. This includes:

- supporting families, including siblings, throughout their hospital stay
- support to:
  - see and hold their baby, such as through use of cold cots
  - make mementos
  - arrange funerals
  - register the birth and death if parents wish
- dedicated bereavement suites on hospital sites, which enable families to spend quality time with their baby in a supportive and holistic home-from-home environment
- ongoing support from the bereavement team by telephone, text messages, dedicated email and face-to-face contact – they also attend follow-up appointments with medical staff to discuss test results
- peer support from an online support group set up by parents with help from the bereavement teams – parents receive information about local peer support groups and are invited to attend a quarterly coffee morning and an annual service of remembrance
- care in Rainbow Clinic, a specialist antenatal clinic for expectant parents whose previous baby has died – this clinic is staffed jointly by the bereavement midwives so that women can have continuity of care if they wish.

Service development

We seek parents' input using patient experience questionnaires co-developed by professionals and parents. Responses show the importance of key areas such as sensitivity and kindness of staff and the time parents spend with their baby. Annual review of this data has facilitated ongoing quality improvement.

Professor Alexander Heazell, Professor of Obstetrics and Director of the Tommy's Research Centre

Case study

This case study demonstrates the benefit of integrated psychological support.

Bereavement Support Service: Royal Jubilee Maternity Services (RJMS), Belfast

The bereavement support service is based in the regional maternity hospital for Northern Ireland, which provides specialist regional obstetric services, including fetal medicine and the regional neonatal unit, for 6,000 women per year. The service is available to couples, fathers and partners.

Staffing

The bereavement support service is led by a specialist midwife (1.0 WTE Band 7). While all maternity staff contribute to bereavement care, the specialist midwife has a dedicated role in providing additional and bespoke care to women and families. She provides support to women and families who experience pregnancy loss, including those who attend the early pregnancy unit and following stillbirth or neonatal death.

The perinatal psychology service is integrated within RJMS, staffed by three clinical psychologists (0.8 WTE Band 8c, 0.6 WTE Band 8a and 0.8 WTE Band 7). They offer a comprehensive perinatal service including targeted interventions for bereaved families with: additional vulnerability due to a history of fertility problems; experience of multiple losses including recent loss of significant others as well as perinatal loss; or a history of mental health difficulties.

Staff training and support

The specialist bereavement midwife supports maternity staff via training and consultation to promote high quality bereavement care. She has monthly clinical supervision with a member of the perinatal psychology service, which enables consultation on complex cases and consideration of onward referral to perinatal psychology. This facilitates a stepped care approach to bereavement care and, when appropriate, co-working with families.

Perinatal psychology and the specialist midwife provide regular in-house bereavement training to maternity and neonatal staff. They also provide staff support, given the high exposure to loss and trauma in the workplace. For example, they facilitate Schwartz Rounds and, on occasion, direct referrals for staff.

Support for parents and families

Specialist bereavement support involves:

- enabling women who have experienced perinatal loss to self-refer to the specialist midwife or seek referral from any member of maternity staff, her health visitor or her GP at any stage during pregnancy and up to 52 weeks' post-delivery

- providing a childbirth review service for those who experience a difficult birth – this often overlaps with the bereavement support role.

Clinical psychology support involves:

- accepting referrals to the perinatal psychology service from maternity staff at any stage during pregnancy – these may relate to a history of obstetric loss or having received bad news, such as a diagnosis of fetal anomaly
- continuing postnatal follow-up to bereavement for 12 months
- accepting new postnatal referrals up to six months postnatally when there are concerns in relation to mental health
- providing inpatient support to bereaved families and consultation to staff as needed within one working day.

Andrew Lok, Consultant Clinical Psychologist and Barbara Gergett, Childbirth & Loss Midwife

7. Practical implementation

Here we provide an overview of the themes that emerged through our research on how change might be embedded in practice.

1. Staff training

Gynaecology, maternity and neonatal staff benefit from access to a broad training curriculum, tailored to meet the specific demands of their role. This could include the following:

Understanding psychological processes

- Awareness of the psychological aspects of pregnancy, birth and parenthood.
- Understanding the principles of trauma-informed care for all women but particularly those with a history of perinatal trauma.
- Understanding of what can lead to a birth being experienced as traumatic and how staff can influence the woman's and family's experience.
- Awareness of what makes some women and families more vulnerable in the perinatal period (eg current or previous loss, high levels of obstetric intervention, neonatal care).
- The psychology of loss, grief and identity and how to support families through 'simple' and 'complex' grief.
- Understanding parents' experience of neonatal care, normalising distress and the process of adjustment while recognising the longer-term impact of trauma and the neonatal journey on both parents and babies.
- The potential impact of the perinatal experience and particularly perinatal stressors on different family members.

Awareness of specific perinatal mental health difficulties

- Understanding low mood and anxiety.
- Recognising trauma and PTSD.
- Identifying when parents and infants are struggling in their relationship.
- Being aware of the 'red flags' for more severe mental health difficulties or risks and knowledge of how to respond.

Key skills in supporting families

- Listening and communication skills and sensitive use of language.
- Cultural competence.
- Sharing difficult or unexpected news.
- How to explain the balance of risks in decision-making.
- Empowering and involving women in decision-making.
- Effective provision of antenatal preparation.
- Supporting women to use their own coping resources in labour.
- Communication and basic counselling skills.
- Conflict resolution.
- Supporting women and families following loss or bereavement.
- Using mental health screening tools to sensitively discuss and routinely screen.
- Understanding how to navigate PMH pathways.

For greatest impact this would begin pre-qualification, be a regular part of core training updates and be as fundamental to training and service delivery as the physical aspects of care.

The best training will include the voices of experts by experience (who must be well supported) and be followed up with opportunities for support, supervision and reflective practice to enable staff to incorporate basic psychological care as standard throughout all aspects of their practice.

2. Support for staff

The work of maternity and neonatal services is emotionally demanding. Staff frequently experience trauma from being exposed to distressing situations involving risk or loss. Greater continuity of carer as supported by Better Births intensifies identification and therefore risk to staff. They are also required to respond sensitively to women and families who are often in a frightened and vulnerable state and who might express this in a range of ways, including hostility, withdrawal, anxiety or aggression.

Staff retention is a significant issue for the maternity and neonatal workforce. To improve retention and staff engagement, the system in which they work needs to be psychologically informed and responsive to staff needs – which will in turn positively impact on the experience of families. This might include offering:

- training, supervision and reflective practice
- consultation with perinatal and infant mental health specialists with regard to their work with specific families
- routine confidential listening support after difficult events
- ‘debriefs’ after loss or other traumatic events that offer a space to reflect on the emotional experience of the event as well as the lessons learned
- access to individual psychological support and intervention for workplace trauma as required.

Embedding mental health staff within the maternity system would support the delivery of these interventions as well as offering the opportunity to review process and policies to ensure that the system itself is more psychologically informed. This focus on staff support fits with the aims of the NHS Long Term Plan - NHS Mental Health Implementation Plan 2019/20 – 2023/24 to sustain a healthy NHS workforce and with the Stepping forward to 2020/1 report from HEE (2017), which emphasises “the NHS should be an exemplar in creating a mentally healthy workplace: reducing stress and improving wellbeing”.

3. Practical processes

Systems of care can build on changes delivered through Better Births and the move to ‘continuity of care for most women by 2021’. Such systems can be organised so women feel known and can develop supportive trusting relationships which allow opportunities to openly explore distress. Other practical processes that might help to alert staff to an individual’s or family’s needs so that they do not have to repeat their story too often include:

- stickers for maternity notes to indicate that the mother is psychologically vulnerable
- stickers such as those from Tommy’s or Sands to highlight those who are pregnant or parenting after previous loss
- stickers for antenatal notes or NNU (eg purple butterfly) to indicate when one or more babies in a multiple pregnancy has died.

4. Specialist mental health input and pathways

Psychological and mental health support is likely to have most impact where it is woven into the maternity and neonatal system and underpins effective pathways to specialist assessment and intervention where needed.

Appendix 1: Methodology

An expert reference group (ERG) was set up to represent relevant experts by experience and professionals (listed in Appendix 2). The group defined seven questions to be addressed by the guidance.

1. For general antenatal care, how best to identify specific mental health support needs including those related to previous maternity experiences? To include consideration of:

    - how and when to screen
    - staff training requirements
    - what support should be in place to provide care for mental health in pregnancy.

2. How to ensure psychological needs are routinely taken into account in more physically complex pregnancies (ie fetal and/or maternal health issues) by psychologically-informed and well-trained/supported maternity staff and what additional provision might be required?

3. What do staff need to enable them to best psychologically support women in labour and how can women and families be best prepared for birth?

4. How can we facilitate best care for women and families in a maternity and/or neonatal context, where a birth has been experienced as traumatic? This should include:

    - families where a baby is on the neonatal unit
    - support and training for staff.

5. How should care be provided to best support parental and infant mental health when a baby is admitted and discharged from a neonatal unit? Particular considerations should include:

    - ensuring family-centred care
    - training for staff
    - unit environmental factors.

6. What are the key components of care provision (provided in the gynaecology/ maternity setting) to support mental health during and following loss during pregnancy (ie miscarriage, ectopic pregnancy, molar pregnancy, termination for medical reasons, stillbirth)? To include consideration of:

    - what support should be available from who, when and where
    - how information can be effectively and sensitively shared with women/partners
    - what training and support should be available for staff.

7. What are the key components of care provision for supporting bereaved parents and the wider family in relation to neonatal death in a maternity/neonatal setting?

    - What support should be available from who, when, where and for how long?
    - What training and support should be available for staff?

Evidence was gathered from three sources, with equal weight given to each:

- existing documents, such as guidelines
- rapid literature reviews
- surveys of service users and healthcare professionals.

Existing documents, such as guidelines, were identified by the project team, ERG and NHS England commissioners. These were eligible for inclusion if they were currently in use in a maternity or neonatal setting and were published or updated in the past 10 years. Recommendations within the 72 included documents were identified, assigned to the guidance questions and organised into themes.

Relevant rapid reviews were conducted. 9,426 English-language papers were identified that were either individual studies from the last five years (January 2014 to April 2019) or reviews from the past 10 years (January 2009 to April 2019). 809 papers remained following title and abstract screening and 45 individual studies and 46 reviews were included after exclusion criteria were applied (eg combining perinatal periods, non-UK, discussion paper, other non-empirical paper). Individual studies were appraised for quality using the Mixed Methods Appraisal Tool (MMAT) [10] and review quality was appraised using a series of questions adapted from Noyes et al [11] Relevant results were extracted and a variation of framework analysis was used to organise data into themes.

Service users and healthcare professionals were invited to respond to a co-designed survey sent by relevant stakeholder organisations but returned directly to the team.

Respondents were asked the top three things that they thought would make the biggest difference to people's experiences of care in relation to mental health, and any staff training needs in relation to their points. Responses were received from 489 service users and 463 professionals. These were thematically analysed for each question.

Survey responses from service users (relevant questions were sent via each organisation as listed below)

	Total	Q1	Q2	Q3	Q4	Q5	Q6	Q7
MatExp (online maternity campaign)	28	✓	✓	✓				
Maternity Voices Partnerships (MVP)	25	✓	✓	✓				
Maternal Mental Health Alliance/ TAMBA*	56		✓		✓	✓	✓	
LGBTQ+ Parents	5	✓	✓	✓	✓	✓	✓	✓
Dad Matters	37	✓	✓	✓	✓	✓	✓	✓
Birth Trauma Association	56	✓	✓	✓	✓			
Spoons (Neonatal)	43				✓	✓		✓
Smallest Things (Neonatal)	50				✓	✓		✓
Miscarriage Association/Ectopic Pregnancy Trust (MA/EPT)*	118	✓	✓				✓	
Antenatal Results and Choices (ARC)	19	✓	✓				✓	
Stillbirth and Neonatal Death Charity (Sands)	52		✓	✓	✓	✓	✓	✓
Total	**489**							

* Two organisations are listed together where one individual had links to both and circulated the same survey link, making responses indistinguishable.

Survey responses from healthcare professionals (asked to answer all questions that were relevant to their practice)

Professional group	Number responding
GPs	27
HVs	65
Mental healthcare professionals	58
Midwives	145
Neonatal professionals	114
Obstetrician/gynaecologists	32
'Other' (specialist midwives, MVP chairs, IMH team, social work etc.)	22
Total	**463**

Tentative guidance for best practice was proposed based on the themes identified in existing documents. Evidence from the rapid reviews and stakeholder surveys was then used to expand, modify and develop these principles or generate new ones. The draft guidance was then discussed with the ERG, who further shaped the content and identified any additional sources of evidence. This led to further revision. Co-production panels of experts by experience provided feedback on the revised guidance and were actively involved in shaping the document before the ERG reviewed the final draft. Examples of good practice were sought and these were discussed with the ERG and co-producer panel.

Appendix 2: Expert reference group membership

Kieran Anders	Project Manager, Dad Matters/Homestart (service user representative)
Mark Barsoum	Consultant Psychiatrist, Mersey Care NHS Foundation Trust
Maria Bavetta	Champion Network Manager, Maternal Mental Health Alliance (MMHA) (service user representative)
Ruth Bender-Atik	Miscarriage Association (service user representative)
James Boyes	North West Coast Clinical Network (Maternity and Perinatal Mental Health)
Catherine Briars	National Childbirth Trust (NCT) (service user representative)
Alison Brodrick	Consultant Midwife, Sheffield Teaching Hospitals NHS Foundation Trust
Rebecca Chilvers	Clinical Psychologist, Evelina London Neonatal Unit, St Thomas' Hospital
Jen Coates	Sands (service user representative)
Sam Collinge	Lead Bereavement Support Specialist Midwife, University Hospital Coventry and Warwickshire NHS Trust
Sarah Finnis	Clinical Psychologist, BPS Perinatal Faculty
Jane Fisher	Director, Antenatal Results and Choices (ARC) (service user representative)
Janet Fyle	Royal College of Midwives (RCM)
Kelly Harvey	Quality Improvement Lead Nurse, North West Neonatal Operational Delivery Network
Alexander Heazell	Professor of Obstetrics and Director of the Tommy's Research Centre, University of Manchester
Hannah Horne	Perinatal Mental Health Specialist Midwife, Wirral University Teaching Hospital NHS Foundation Trust (WUTH)
Katie Hoult	Neonatal loss parent advocate, Spoons (service user representative)
Karen Mainwaring	Senior Lead Nurse, North West Neonatal Operational Delivery Network
Rachael McGrath	Birth Trauma Association (BTA) (service user representative)

Kirsten Mitchell	Neonatal parent advocate, Spoons (service user representative)
Rebecca Moore	Consultant perinatal psychiatrist, Royal College of Psychiatrists (RCPsych)
Kate Mulley	Director of Research, Education and Policy, Sands (service user representative)
Claire Noor	Royal College of Obstetricians and Gynaecologists (RCOG)
Catriona Ogilvy	Founder, The Smallest Things (service user representative)
Fauzia Paize	Consultant Neonatologist, Liverpool Women's Hospital NHS Foundation Trust
Terri-Lynn Quigley	Liverpool Maternity Voices Partnership (MVP) (service user representative)
Karen Selby	Consultant Obstetrician & Gynaecologist, Sheffield Teaching Hospitals NHS Trust
Judy Shakespeare	Royal College of General Practitioners (RCGP)
Avril Swan	Programme Delivery Manager (Children & Maternity), NHS Liverpool Clinical Commissioning Group
Victoria Walsh	Wirral Maternity Voices Partnership (MVP) (service user representative)
Andrea Watt	GP

References

1. NHS England. The NHS Long Term Plan, 2019.

2. Cox JL, Holden JM, Sagovsky R. Detection of postnatal depression: development of the 10-item Edinburgh Postnatal Depression Scale. *Br J Psychiatry* 1987; 150: 782–86.

3. Wijma K, Wijma B, Zar M. Psychometric aspects of the W-DEQ; a new questionnaire for the measurement of fear of childbirth. *J Psychosom Obstet Gynaecol* 1998; 19(2): 84–97.

4. Haines HM et al. Identifying women who are afraid of giving birth: A comparison of the fear of birth scale with the WDEQ-A in a large Australian cohort. *Sex Reprod Health* 2015; 6(4): 204–210.

5. Weiss DS, Marmar CR. The impact of event scale-revised. In: Wilson JP, Kean TM (eds) Assessing psychcological trauma and PTSD: a practitioner's handbook (Ch 15). NY: Guildford, 1995.

6. Johnstone L. Psychological formulation as an alternative to psychiatric diagnosis. *J Humanistic Psych* 2018; 58(1), 30–46.

7. BPS. Briefing Paper No. 8 Perinatal service provision: the role of perinatal clinical psychology. British Psychological Society, 2016.

8. SAMHSA. SAMHSA's Concept of trauma and guidance for a trauma-informed approach. SAMHSA's Trauma and Justice Strategic Initiative, 2014.

9. Hall SL et al. Recommendations for peer-to-peer support for NICU parents. *J Perinatol* 2015; 35 Suppl 1(Suppl 1): S9–S13.

10. Pluye P et al. Proposal: A mixed methods appraisal tool for systematic mixed studies reviews, 2011.

11. Noyes J et al. Synthesising quantitative and qualitative evidence to inform guidelines on complex interventions: clarifying the purposes, designs and outlining some methods. *BMJ Glob Health* 2019; 4: Suppl 1.

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