

Supporting Perinatal Mental health by improving maternity services.

'Prevention is key'



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UNFOLD YOUR WINGS
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Why Perinatal Mental Health Matters

For any family, emotional wellbeing matters. When it comes to mental health, the perinatal period can be a challenging time. Adjusting to life with a new baby is hard, but for some families, the transition to parenthood is complicated by depression, anxiety, OCD, PTSD, psychosis or a traumatic birth.

The impact on families can be devastating, especially if they are unable to access support. Coping day to day becomes hard, relationships can become strained and caring for their new baby overwhelming. For some families, so serious is the issue that it can mean not being able functioning at all, resulting in the need to stay in mental health facility, this can lead to a mum and baby sometimes being separated. Sadly, for some families the consequences are the loss of a loved one to the ravages of perinatal mental health.

Perinatal mental health conditions are diverse, complex and challenging to diagnosis. Families can find accessing help or treatment difficult. Often it is a 'postcode lottery' as to whether families get the right help. Some areas have excellent services to support families, but in other areas there are big gaps, with families not able to access the help they need. By failing to prevent, diagnosis, treat and support perinatal mental health issues, we are jeopardising the wellbeing of families now and in the future.

The estimated numbers of women affected by perinatal illness in England each year is staggering with up to 20% women developing a mental illness in pregnancy for the first year after the birth of their baby.¹ This doesn't include the impact to partners, siblings, wider family members and of course babies themselves.

The costs of perinatal mental health is estimated to be £8.1 billion per year in the UK or almost £10,000 per birth.² Despite this more than 40 per cent of women have no access to specialist services.³

It is not just the cost to society financially but also in human terms, because perinatal mental health affects a whole family, including extended family such as grandparents. It can put pressure on families that mean they struggle to cope.

Estimated numbers of women affected by perinatal mental illnesses in England each year



1,380 Postpartum psychosis



Postpartum psychosis is a severe mental illness that typically affects women in the weeks after giving birth, and causes symptoms such as confusion, delusions, paranoia and hallucinations.

Rate: 2/1000 maternities

1,380 Chronic serious mental illness



Chronic serious mental illnesses are longstanding mental illnesses, such as schizophrenia or bipolar disorder, which may be more likely to develop, recur or deteriorate in the perinatal period.

Rate: 2/1000 maternities

20,640 Severe depressive illness



Severe depressive illness is the most serious form of depression, where symptoms are severe and persistent, and significantly impair a woman's ability to function normally.

Rate: 30/1000 maternities

20,640 Post traumatic stress disorder (PTSD)



PTSD is an anxiety disorder caused by very stressful, frightening or distressing events, which may be relived through intrusive, recurrent recollections, flashbacks and nightmares.

Rate: 30/1000 maternities

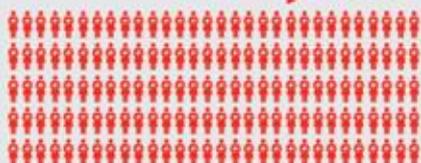
86,020 Mild to moderate depressive illness and anxiety states



Mild-moderate depressive illness includes symptoms such as persistent sadness, fatigue and a loss of interest and enjoyment in activities. It often co-occurs with anxiety, which may be experienced as distress, uncontrollable worries, panic or obsessive thoughts.

Rate: 100-150/1000 maternities

154,830 Adjustment disorders and distress



Adjustment disorders and distress occur when a woman is unable to adjust or cope with an event such as pregnancy, birth or becoming a parent. A woman with these conditions will exhibit a distress reaction that lasts longer, or is more excessive than would normally be expected, but does not significantly impair normal function.

Rate: 150-300/1000 maternities

* There may be some women who experience more than one of these conditions.

Source: Estimated using prevalence figures in guidance produced by the Joint Commissioning Panel for Mental Health in 2012 and ONS data on live births in England in 2011.

For many years investment in specialist perinatal mental health services has been lacking, this has led to many families 'Falling through the Gaps'.⁴ In England, many mental health trusts do not have a 'specialist' perinatal mental health service. There is currently a shortage of beds in mother and baby units nationally that provide a safe place for mothers to be cared for, with their babies, while they receive the treatment they need.

As well as a lack of specialist services, often those in place to care for families are not given the training, they need to support perinatal mental health. In fact, 41% of women reported that they were never asked about their mental health by their Midwife or Health Visitor. GP's too are often left without adequate training to support perinatal mental health, or without services to refer women to for treatment. This leaves families vulnerable and counting the cost emotionally.



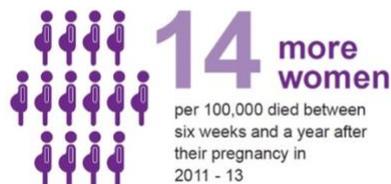
Early diagnosis, management and treatment of perinatal mental health helps prevent families reaching breaking point, or need inpatient care. For women or partners with previous mental health conditions, support during pregnancy enables them to be in control of their condition and prevent it escalating after birth, thus reducing the chances of more in depth intervention or admission to a mother and baby unit.

Sadly for 1 in 7 families⁵ affected by perinatal mental health, the result is a woman lost to suicide.

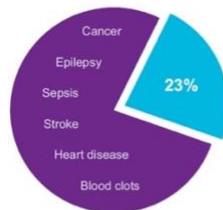
Key messages



from the report 2015



Mental health matters

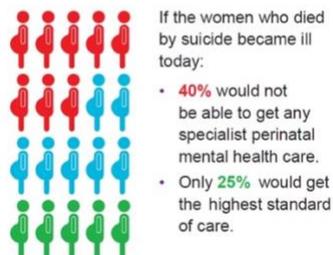


Almost a **quarter** of women who died between six weeks and one year after pregnancy died from **mental-health related causes**



1 in 7 women died by **Suicide**

Specialist perinatal mental health care matters*



It's OK to tell

The mind changes as well as the body during and after pregnancy.

Women who report:

- New thoughts of violent self harm
- Sudden onset or rapidly worsening mental symptoms
- Persistent feelings of estrangement from their baby



need urgent referral to a specialist perinatal mental health team

*Mapping data from the Maternal Mental Health Alliance (<http://everyonesbusiness.org.uk>)

With so many families affected and the costs so high can we support and improve perinatal mental health in families by improving maternity services?

Traumatic Birth and Perinatal Mental Health.

Between 24% to 37%⁶ of women consider their birth experience to have been traumatic.⁶ The impact of a traumatic birth on perinatal mental health, is long lasting and life changing. If we wish to support perinatal mental health we must start with supporting women and families to have a positive birth experience.

What is a positive birth experience?

A positive birth will be different for every woman, what matters is what her birth means to her. It is important that a woman's choice is supported and her wishes understood, and she is cared for in a kind, compassionate way, that respects her dignity and needs both physically but also emotionally.

Supporting a positive birth experience should include;

Good communication

A woman should always have clear honest information about what is happening to her and her baby. This gives the woman confidence and builds trust in those who are caring for her. It also allows her to feel in control of her birth. Understanding what is happening and feeling in control will ease anxiety and lessen fear. This is especially important if complications arise or birth becomes an emergency situation. Good communication helps reduce trauma and thus supports perinatal mental health.

Informed choice

During pregnancy, a woman should have unbiased information to help her and her family make informed choices that are right for them. Giving choice even in difficult situations means giving control back to the woman and her birth. The choice may be limited due to medical factors or complications, but choices should still be offered and discussed with the evidence based information given to allow for the making of informed decisions about her care and that of her baby. Any choices made should be done by the woman and not those over her care by the use coercion or force. Choice protects women emotionally in birth and thus protects perinatal mental health.

Dignity, respect and compassion

These feed positivity. A woman and her partner should feel that they have been treated with dignity by those caring for them. The language used, should be kind and never should a woman feel judged or labelled. Respect should be shown both her and her choices but also her concerns and fears. It may be that the decisions made are difficult for those caring for her to understand, but they are hers and should be respected. Never should a woman be treated unkindly or her needs ignored. Compassion should be the basis of any care given. This protects perinatal mental health.

Protecting perinatal mental health can also begin before conception with information given on supporting mental wellbeing along with the changes and challenges that pregnancy brings. Especially if a woman has a pre-existing mental health condition, conversations around medications and pregnancy/ breastfeeding will need to take place in order to protect her mental health.

During pregnancy, if complications arise, or a woman is suffering from a medical condition such as diabetes it should be acknowledged how this can impact on her mental health and support be offered.

If a woman has a pre-existing mental health condition this can resurface or worsen during pregnancy so support and communication is vital.

A pregnancy that is complex due to maternal illness or pre-existing mental health conditions also impacts on a birth experience. As can a previous traumatic birth.

The impact of birth on perinatal mental health.

When a birth experience is positive because a woman feels cared for and her choices supported, when she is treated with dignity, respect, kindness and compassion, the impact on her emotional health is profound.

For families left struggling with the effects of a traumatic birth and/or a poor maternity experience, it can be life changing.

If birth was traumatic the impact on a woman's mental health can affect her ability to care for her baby and her relationship with her baby. Bonding and attachment may be affected which can have long-lasting adverse effects on the child.⁷ The woman herself may feel isolated, guilty, ashamed and reluctant to reach out for help or tell anyone how she is feeling.

A difficult birth can damage relationships with partners, family members and friends as a woman can feel no one understands and in turn her loved ones may struggle to know how to offer support.

Depending on the nature of the trauma caused a woman may feel unable to access further medical tests such as smear tests. Sex may also be affected as a woman may fear further pregnancies, or even just the act of physical intimacy itself.

Others become overly anxious about their baby's health and wellbeing and constantly worry about every aspect of caring for their newborn.

"I felt like I was walking in a thick fog, every day was hard and I didn't know where to turn for help"

Many women will seek to hide their true suffering and 'carry on' as they try desperately to cling to normality. Everyday tasks become hard and just coping day to day can feel overwhelming. Their physical health too may suffer. Lack of sleep, trouble eating and the constant struggle all takes its toll. Flashbacks can result taking them back to the event, reliving moments, even smells, or conversations causing great distress and anxiety.

For women that are vulnerable due to economic, health, or social inequalities the risk of a poor maternity experience or traumatic birth affecting mental health increases.

Some families also find their babies need the special care of a neonatal unit. Research tells us that 15–53% of mothers and 8–33% of fathers⁸ will develop PTSD symptoms following having a baby in Neonatal.

Then there is the impact of the loss of a baby, whether it be during pregnancy, birth or soon after on perinatal mental health. The affect is profound, life changing and emotionally scaring for families.

***The loss of my baby is forever etched in my mind and heart.
There isn't a day goes by I do not think about my son or
think about the precious moments we could have shared.***
Jane

When we think of the impact that birth and maternity care can have on the emotional well-being of a family it is important that they are supported and

cared for in as many ways as possible that prevents trauma and supports emotional well-being, reducing the impact on their perinatal mental health.

The National Maternity Review Report 'Better Births' and supporting perinatal mental health.

In March 2015, Simon Stevens, Chief Executive of NHS England announced a major review of maternity services as part of the [NHS Five Year Forward View](#). Baroness Julia Cumberlege was asked to independently lead the review working with a panel of experts and representative bodies.

The scope of the review was to assess current maternity care provision and consider how services should be developed to meet the changing needs of women and babies. The national maternity review published its report 'Better Births'⁹ which had seven key recommendations.

Throughout the report, perinatal mental health is mentioned 19 times, with many of the key recommendations having a clear link to perinatal mental health. By improving these key areas and improving the care given women during pregnancy, birth and in the postnatal period we also support the emotional wellbeing of families.

The review has presented the opportunity for each trust to look at their maternity provisions and evaluate what is offered to women and families. It also gives us the opportunity to look at how improving maternity services can also support perinatal mental health.

The report recommended;

Personalised care *that is centred on the woman, her baby and her family, this would be based on their needs and their choices. They should have unbiased information that allows them to make informed choices as to their care and place of birth. Every woman should develop a personalised care plan with their midwife and other health professionals, which sets out her choices about her care reflecting her wider health needs.*

Personalised care enables women to make choices that support them in their circumstances and considers their other needs, be they physically or emotionally.

Choice is noted to be a major factor in women feeling safe and supported. When choice is given, respected and supported in birth it protects emotional well-being and maternal mental health. Many women report that a lack of choice or not having their choices supported was a major factor in feeling their births to be traumatic.

Continuity of carer *that enables safer care based on a relationship of mutual trust and respect. Every woman should have a midwife, who is part of a small team of four to six midwives. This team would be based in the community, know the women and family, and provide continuity throughout the pregnancy, birth and postnatally.*

Continuity of care enables the building of a trusted relationship with caregivers. It allows caregivers to get to know a woman and her family, their circumstances and needs, thus supporting them to receive more personalised care.

This can be especially beneficial for women who have suffered previous trauma during birth, miscarriage or stillbirth or may have long-term health conditions.

For women affected by maternal illness having someone over their care that knows their history, care plan and choices can be invaluable. It provides a relationship that is supportive because the complications are known and the management of them can be closely monitored and reviewed. Trust is important because decisions will need to be made, and when all parties know the relevant history, as well as the individual's circumstances, it can help alleviate much frustration and time for all involved.

Contact with the same person and having the knowledge that care provided will be by the same staff both before, during birth and after, can do much to help their maternity experience to be positive and supports emotional wellbeing. It also means that any advice or support would be in line with their

medical needs and be consistent, reducing confusion or the need for constant explanations regarding their physical health.

When it comes to perinatal mental health conditions it can be isolating, frightening and overwhelming. During pregnancy, a woman can be especially vulnerable to developing anxiety, depression as they adjust to their feelings, hormonal changes and worries about approaching parenthood. Pregnancy too can cause pre-existing conditions to worsen. Continuity of care means relationships are built, it allows for honest reflections on how to manage difficulties and allows those caring for a woman to know them well so they can pinpoint when they may be struggling and need extra support. This can be especially important after the birth when mental health issues can surface. Having someone trusted, that a woman and her family know well and can approach to seek support from, can make a massive difference to early intervention. It also provides a 'gatekeeper' so to speak, someone that can help a family find support as well as liaise with other healthcare professionals or services. This can especially be useful when questions regarding safeguarding may arise. Continuity of care provides a stable support when a woman feels at her most vulnerable.

Continuity also matters for families that have suffered a previous stillbirth or miscarriage/s and are now pregnant again. This can raise understandable anxiety and worry. Continuity of care allows for much-needed discussions on ways to support the current pregnancy and birth in ways that help alleviate some of the anxiety and concerns. It means that all those caring for the family are fully aware of their previous loss and so can offer care that protects the family's emotional and mental wellbeing.

For a woman and her partner that have had a previous traumatic birth, continuity of care is vital. Women can struggle to talk about their experience, so having someone that knows their history mitigates the need to re-tell this at every appointment which can be distressing. It also means that trust can be built or sometimes rebuilt, as trust is often shattered by a difficult birth experience. This is desperately needed for families to feel supported and confident.

Having continuity of care can go a long way in both reducing trauma but also in helping those with previous painful experiences to have a positive maternity experience.

Safer care, *with professionals working together across boundaries to ensure access to the right care in the right place. A safety culture through open honesty, communication and data that enables learning when things go wrong. This would include women being given information on risks, rapid referrals across organisations for specialist care when needed, professionals that work and train together, plus data on quality and outcome measures.*

The report also recommended there should be a national standardised investigation process for when things do go wrong, ensuring honesty and learning so that improvements can be made.

While all efforts are made to keep women and babies safe during pregnancy and birth sometimes things do go wrong. Providing the needed support, making sure that specialist care is accessed as quickly as possible, and that families are treated with compassion, honesty and respect, reduces the impact that these situations can have on their mental health. When birth is traumatic or results in the injury of a mother and/or her child, be that physically or emotionally, the impact on the whole family is life changing. Allowing for learning from mistakes can mean improving services that protect other families.

Increased funding for postnatal care *so women can access their midwife and other services as they require after giving birth. This includes a smooth transition between midwife, obstetric and neonatal care, to ongoing care in the community from GPs and health visitors.*

Postnatal care is vital to protecting a family's mental health and wellbeing. On perinatal mental health, the report calls for 'significant investment' in specialist perinatal mental health services in the community. This strongly supports the recommendations contained in the recent Mental Health Taskforce report and Five Year Forward View Report, that at least 30,000 more women each year should have access to evidence-based specialist mental health care by 2020/21. This would include access to Mother and Baby units for those who need it, to prevent the separation of babies from their mothers. Support also for breastfeeding was highlighted due to the significant impact this can have on mental wellbeing for women who wish to breastfeed but lack support to do so.

When women and families receive good postnatal care by multi-agencies that work together it supports perinatal mental health. Good postnatal support provides help with bonding, relationships, parenting, breastfeeding and coping with the challenges parenthood brings. When postnatal care is poor it leaves families struggling, vulnerable and at risk of long-term damage. By improving postnatal care, we also improve perinatal mental health.

Closer working, across boundaries, *enables multi-professional working by multi-professional teams to work effectively across organisational boundaries to provide seamless, high-quality, responsive care to women and their babies.*

This includes training for shared learning and reflection, which encourages teams to proactively ask for help and follow a consistent process for serious incident investigation. A nationally agreed set of indicators to assist collecting data on marking and improving the quality of maternity services. To support this would be a national maternity digital record for easy sharing of information.

Protecting perinatal mental health includes the support of multi-professional teams that work together, sharing information including data and providing services that support families.

The recently released guidance for 'implementing better births' for local maternity systems highlighted, "Perinatal mental health networks have already been established across England to support strategic joint working and aid service improvement, with a focus on including all key system partners and women with lived experience." Local maternity systems need to consider how they can engage with these networks, and others, to enable delivery of high-quality care.

By considering the key recommendations of the Better Births maternity review, and by supporting staff we protect the mental health of families. We also must make families co-producers of services. Their voices have much to share and provide valuable insight. Engaging with families can be done via mediums such as [Maternity Voice Partnerships](#) (MPVs) and grassroots movements such as [Matexp](#).

Five Year Forward View

As we have already stated one in five women will suffer from depression, anxiety, PTSD, psychosis or another form of perinatal mental health condition during pregnancy or in the first year after childbirth. Suicide is the leading cause of maternal death in pregnancy and the first year after giving birth.

Perinatal mental health problems not only affect the health of mothers but can also have longstanding effects on their children's emotional, social and cognitive development.

In March 2015 NHS England set up The Mental health taskforce to publish a 'Five Year National Strategy' for mental health in England, aligned to the Five Year Forward View. It was chaired by Paul Farmer, Chief Executive of Mind and co-chair Jacqui Dyer, expert by experience. The Taskforce heard from people with lived experience of mental health problems, carers, professionals, providers, voluntary organisations as well as NHS England (NHSE), Public

Health England (PHE), Care Quality Commission (CQC), Health Education England (HEE), NHS Improvement³ and the National Institute for Health and Care Excellence (NICE).

The Taskforce published its report¹⁰ in February 2016 with recommendations to help deliver the FYFV. The NHS in England committed to the biggest transformation of mental health care across the NHS pledging to invest more than a billion pounds a year by 2020/21. Included in this was the provision for perinatal mental health.

Five Year Forward View for Mental Health



THE FIVE YEAR FORWARD VIEW FOR MENTAL HEALTH

Simon Stevens: "Putting mental and physical health on an equal footing will require major improvements in 7 day mental health crisis care, a large increase in psychological treatments, and a more integrated approach to how services are delivered. That's what today's taskforce report calls for, and it's what the NHS is now committed to pursuing."

Prime Minister: "If you suffer from mental health problems, there's not enough help to hand."

The report in a nutshell:

- 20,000+ people engaged
- Designed for and with the NHS Arms' Length Bodies
- All ages (building on Future in Mind)
- Three key themes:
 - High quality 7-day services for people in crisis
 - Integration of physical and mental health care
 - Prevention
- Plus 'hard wiring the system' to support good mental health care across the NHS wherever people need it
- Focus on targeting inequalities
- 58 recommendations for the NHS and system partners
- £1bn additional NHS investment by 2020/21 to help an extra 1 million people of all ages
- Recommendations for NHS accepted in full and endorsed by government



The report recommended that by 2020/21 there would be increased access to specialist perinatal mental health support in all areas of England, allowing at least an additional 30,000 women each year to receive evidence-based treatment, closer to home, when they need it. This would include a range of specialist community and inpatient care.

Next Steps on the Five Year Forward View

In March of this year (2017) the next steps¹¹ on the five-year forward view report was released that outlined the key improvement targets for 2017/18 and 2018/19.

Under perinatal mental health, improvement targets included four new **Mother and Baby Units** which would boost current bed numbers so that capacity is increased by 49%. Meaning treatment for 2,000 more women with severe mental health conditions.

To implement this the implementation report outlined the needed investment and workforce requirements.

Local sustainability and transformation plans (STPs) are how the Five Year Forward View would be delivered. The idea being the bringing together of all the agencies needed, including patients, to deliver the services needed following the local STP footprint.

For a long time, perinatal mental health has been missing on the national agenda and this had led to significant suffering for families. Many families have not had access to specialist services or even basic services for supporting their mental health. Mothers and babies have been separated due to a lack of mother and baby units or in some cases faced travelling many miles to access help. While we know the financial cost, sadly awareness of the emotional cost that not providing for perinatal mental health means for families has often been overlooked.

By addressing the recommendations outlined in the five year forward view for mental health it is important that in this is included the improvement of maternity services and how this aligns with mental health service provision.

However, the question is, are we tackling perinatal mental health at the right time?

Are we addressing perinatal mental health too late?

If we wish to impact perinatal mental health this must begin with supporting women before and during pregnancy, as well as during and after birth. Waiting until women and families are already affected to support their mental health is too late.

We need to be looking at the prevention of perinatal mental health conditions.

If the birth experience, care given in pregnancy and postnatally are all risk factors for impacting on perinatal mental health supporting and our maternity services and improving them must be alongside developing specialist perinatal mental health services if we wish to reduce the suffering of families.

While funding and development of perinatal mental services that will support those who meet the criteria of severe perinatal mental health conditions are moving ahead, there are large numbers of families who are classed as having a perinatal mental health condition that is mild to moderate. For these families' life is greatly impacted also and they can struggle every day. By addressing the care and support given during pregnancy, birth and after, by improving our maternity services we can reduce the risk of developing or escalating a perinatal mental health condition.

By addressing only, the services in place once perinatal mental health is affected, means starting at the end instead of the beginning. Rather, we need to start at the beginning looking at prevention and reduction.

How can this be achieved ?

At a National level, there is the NHS Maternity Transformation Board and the NHS Perinatal Mental Health team. Each area will have a Local Maternity System and STPs with mental health transformation work streams. Most have task groups, some are clinical, and some are stakeholders. This raises two questions.

- Are these work streams working together, feeding into the same work streams and looking at how the outcomes can be reached together?
- Is the addressing of perinatal mental health being done in the context of our maternity services, as well local adult mental health services?

Perinatal Mental Health services and maternity services need to work together as each stream of work tries to achieve the same thing.

The Five Year Forward view discusses how in the future, services will be commissioned by single providers and hubs. These too will need to link into local maternity units and to also address prevention rather than just treatment.

All providers and commissioners need to collaborate with both local maternity systems and STPs to co-design services. Regional networks can bring together professionals, providers, commissioners and service users to share information, best practice and learning to provide support and advice. This should include maternity services.

By doing so we address prevention of perinatal mental health conditions as well as the building of services to provide specialist support for families when it is needed.

Included also in this would be training for all who care and support families in perinatal mental health and the impact it has. This means that staff are given the tools they need to care for families, reducing it where possible while also being supported themselves.

Summary

Supporting perinatal mental health also means improving maternity services.

It includes providing support pre-conception, during birth and postnatal.

To support perinatal mental health in families everyone must work together to implement the Better Births report recommendations and The Five Year Forward View for Mental Health.

The work streams in place to implement the recommendations need to support, link together and share good practice both locally and nationally. They must also include the voice of families, so that services can be co-produced, families must be at the heart.

Acknowledgement is needed too that birth and the care received in our maternity services can greatly impact on perinatal mental health. That when things go wrong they are an opportunity to learn, to improve. When good practice is evidenced this should be celebrated and shared.

Despite everyone trying we must go further, this can be hard as all who care for women and their families in these services are trying to give the best they can in the current challenging times of our NHS. We must however do more.

Improving maternity services often focuses on the safety aspect of care, mostly medically. Yet it is just as important that women and their partners are kept just as safe emotionally. Honest, open communication with families provides invaluable insight into providing services that does more than just support perinatal mental but prevents, and reduces, the risk of a perinatal mental health condition.

Prevention is key, we should not wait until a family is struggling to intervene. Instead let us begin in our maternity services, setting the foundation for good perinatal mental health of families everywhere. Perinatal mental health is 'everyone's business'.¹²

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