



"I'm not fine."

Little Miracles UK Parent Mental Health Report 2016

This report explores the mental health experiences of 338 parents who have had a premature and/or sick baby in the UK.

Little Miracles UK
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Foreword



Neonatal services in the UK are among the best in the world. On a daily basis they save lives that in other parts of the world would be lost. As a mother of four babies born premature I am personally eternally grateful and appreciative of every single person working in all units across the country.

The main focus of the units is rightly on the babies. And that is where it should remain.

However, giving birth to a premature or sick baby can be devastating; a scary, lonely and painful experience. Mentally crushing.

From my personal experience I found mental health support to lacking to the point of non-existent. Little Miracles is almost 4 years old at the time of writing this report, and I have found, by listening to the experiences of other parents of premature or sick babies over those years, that many echo mine.

Recent industry reports have revealed a severe shortage of trained mental health support on NICU's across the UK. And it is from that multiple perspective that Little Miracles UK decided to undertake this research.

One of our aims is to see mental health support made available to all parents of premature or sick babies. We started a petition to the UK Government in October 2016 and as you read this report, we ask that you take a moment to sign that petition online. <https://petition.parliament.uk/petitions/169168>

However, to prescribe and design a mental health support service, the users need to be consulted to ensure that any service is fit for purpose, and designed around their needs. Hopefully the findings and parent comments will provide some initial guidance, which can be built on going forward.

The best possible outcome for any NICU is for the baby to leave in the best possible health, with parents who in the best possible frame of mind to care for them.

When asked how you are feeling, how many answer with a simple "I'm fine." Maybe it's time we created an environment where people were encouraged to be honest, simply tell the truth....and say it like it is, **"I'm not fine."**

Best wishes,

Marsha Davis
CEO and founder of Little Miracles UK

Summary of Findings

Background:

- In 2014 90,253 sick or premature babies were born in the UK
- Parents of a premature baby are 10 times more likely to suffer depression after the birth, than parents of babies born at full term.

Some preliminary findings:

- 338 parents took part in the survey, making it the biggest sample of parents of sick or premature babies reviewed in the last 12-24 months
- Just under 95% of respondents said they were not offered any mental health support whilst their baby was in hospital.
- Approximately 94% of respondents felt that there was insufficient mental health support offered by the NHS

GP experience:

- Almost 60% of respondents said they were scared to see their GP in case the GP thought badly of them.
- More worrying is that just over 50% were concerned their GP would inform social services about their depression, with the risk of losing their child.

Of real concern were the more extreme, or less helpful, GP responses which included the following:

"First doctor laughed, it's obviously my baby and I don't need to give birth again, you're probably depressed but not the most depressed person I've seen, come back in 2 weeks! (Safe to say I didn't go back for ages)"

Talking about anxiety and depression:

- Only 49.85% of respondents were honest with neonatal staff when asked how they felt. One reason given was:

"Scared about being told can't cope, child being taken away."

- Only 36% felt able to speak to family and friends. One reason given was:

"They didn't seem to understand how serious it was. Kept being told how so and so baby was earlier or sicker. When given congratulation cards how can you explain that you don't feel like celebrating."

- Only 60.06% felt able to confide in their partner. One reason given was:

"I was told to stop moaning and that I'd be a rubbish mother if I couldn't cope with things now"

- **18% of all respondents said that they have felt suicidal at some point since the birth of their premature baby.**

Introduction

In 2014, 90,253 premature and sick babies were admitted to a neonatal unit in the UK (figure does not include Northern Ireland). [Source: Neonatal Data Analysis Unit, 2014 report]

Many parents of premature and sick babies suffer mental torture, often in silence. The anguish is incredible; the not knowing can be painful and mentally crushing. These parents need care and support immediately. But all too often it is not forthcoming. This cannot be right.

This report looks into the experiences of parents who have had a premature and/or sick baby, in the UK. It follows in the footsteps of a number of studies that have been undertaken in recent years.

Important points:

[Source: Bliss baby Report 2015, England only]

- (1) Parents of a premature baby are 10 times more likely to suffer depression after the birth, than parents of babies born at full term.
- (2) Up to 40 per cent of mothers of premature babies are affected by postnatal depression soon after birth
- (3) 41% of neonatal units said that parents had no access to a trained mental health worker – either on the unit or via referral to services outside of the unit.
- (4) At 30% of units, parents have NO access to psychological support all.

Of particular concern, even parents with the most critically ill babies are often not able to access this vital support.

- (1) One third (10 out of 30) of neonatal intensive care units (NICUs) were not able to offer parents access to a trained mental health worker
- (2) Around one in eight NICUs (4 out of 30) were unable to provide any psychological support.

Additionally:

“Critically, one of the most challenging aspects of PPD is how covertly women suffer; up to 50% of all cases of postpartum depression go undetected.” [Source: Ramsay R. Postnatal depression. Lancet. 1993;341:1358]

This Little Miracles UK study explores deeper the mental health experiences of parents of babies born premature or sick, both whilst on the ward and also after they have left hospital.

Methodology

In October 2016 Little Miracles UK made the online survey available; initially via the Little Miracles Facebook page. The survey questions were available for 4 weeks.

In order to encourage respondents to be as open and as frank as possible, we decided to make the survey completely anonymous.

The survey questions were phrased and prepared based around the real-life experiences of parents of a sick or premature baby, who have spent time on a neonatal ward.

A series of closed and open questions were used to allow us to capture not just raw facts and figures, but also the personal and emotional experiences of parents.

To remove any potential barriers to participation, all questions were optional.

In total 338 parents responded to the survey.

To put this into context, the Bliss Baby Report 2015 surveyed 224 parents. The Tommy's report, released in early November 2016, on the relationship between suffering a miscarriage and PTSD focused on 113 women.

This 2016 Little Miracles UK Parent Mental Health Report is based on a statistically significant sample size.

The Findings

Little Miracles UK canvassed the views and experiences of 338 parents, 97% mothers and 2.38% fathers. Quite possibly making it the largest survey conducted with parents of premature or sick babies in the last 12-24 months. Over 75% had a premature baby at 32 weeks or less.

Early stage support

Initial mental health support received by parents whilst they were in hospital gives rise to concern.

Just after delivery only 2.38% of respondents received support from a mental health practitioner and this increased only slightly to 5.64% when asked if they received assistance from any support organisation.

Once on the ward only 7.10% were offered professional mental health support.

Unsurprisingly 94.28% felt there was not enough mental health support available via the NHS after the birth of their premature baby. With a slightly higher figure (95.82%) stating that more should be done to support parents.

Parent suggestions on what should be done/offered will be covered later in the report.

The GP experience:

The experience with their GP throws up a mix of issues and points.

Whilst in hospital, 85.21% chose not to contact their GP regarding any concerns about depression. This is not really surprising as it can be assumed they would have been pre-occupied with concerns for their baby.

However, once they left hospital that figure increased significantly, with 44.48% making contact with their GP in relation to their feelings of anxiety or depression. This is good but not great, as we would hope the GP would be the first place one would go. However the reasons for this lack of take up might become clearer later in the report.

The responses and courses of action offered by GP's were in the main standard. Medication was offered in 42.99% of cases and referral to a specialist in 9.35% of cases. These figures should however be read with a small amount of caution as it is very possible that a GP might offer multiple solutions.

Almost 60% of respondents were concerned about speaking to their GP about mental health issues relating to their premature birth, for fear of being thought badly of.

Of greater concern is the fact that 52.73% feared being reported to social services by their GP if they brought up the anxiety or mental health issue. Having just gone through a traumatic experience it's understandable that a parent might have serious concerns about having that child taken from them.

Concerns about being seen as a bad mother and feelings of guilt are recurring comments throughout this consultation. A list of parent comments can be found later on throughout this report.

Of real concern were the more extreme, or less helpful, GP responses which included the following:

"First doctor laughed, it's obviously my baby and I don't need to give birth again, you're probably depressed but not the most depressed person I've seen, come back in 2 weeks! (Safe to say I didn't go back for ages)"

Talking about anxiety, depression and mental health

In hospital:

Only 49.85% of respondents were honest with neonatal staff when asked how they felt. Some of the reasons given for not being honest about how they felt are given below:

“Scared about being told can't cope child being taken away.”

“I didn't want to feel like a failure and that I was a bad mum.”

“I didn't realise myself until I got home that there was something wrong.”

“Because it was an off the cuff are you okay while walking past, rather than sit down next to you and ask and actually listen.”

“Trying to make out I was brave when in fact I was shitting myself!”

“I was ashamed”

With friends and family

It is widely known that people struggle to talk about mental health because of the stigma attached to it. Data from the mental health awareness campaign “Time to Change” states that “9 out of 10 people with mental health problems experience stigma and discrimination.” So whilst only 36.80% of our sample felt able to speak to family and friends, that in itself is not a bad figure and should be seen in that context.

Reasons for not speaking out and sharing with family and friends were varied and included:

“I felt pressure to be positive and happy because my girls were alive and doing well”

“My mum died when I was 5 months pregnant (60 days before my baby was born) so nobody dared to raise feelings with me except my Dad”

“They didn't seem to understand how serious it was. Kept being told how so and so baby was earlier or sicker. When given congratulation cards how can you explain that you don't feel like celebrating.”

“Whilst in hospital I had no contact with anyone really and by the time we came home everyone thought we should be over it as he was ok now”

“No one understands what it is like to go through a 5 day labour then emergency c section to a 25 week old baby.”

“My mum called my youngest a live miscarriage”

It is clear that a lack of understanding by friends and family can be attributed to the reluctance by a parent to discuss how they are feeling.

With their partner

Only 60.06% felt able to confide in the partner. Reasons for not being able to confide included:

“He was struggling too”

“I needed to be the perfect mother. I had “failed” my baby during pregnancy and I had to be perfect to make up for it.”

“Not supportive when I needed him to be, now in the process of separating”

“He was working a lot and say I was over-reacting so stopped speaking to him”

“I was told to stop moaning and that I'd be a rubbish mother if I couldn't cope with things now”

“I can't explain why. I just felt completely alone. Maybe some shame felt too.”

Some of the above comments are shocking. The feeling of shame and guilt is recurring. Probably compounded by the fact that in general people don't know how to talk about mental health issues, and just as importantly the partner (assumed male) is so poorly prepared and advised. As we can also see the situation can put an immense strain on parents' relationship in many cases, at a point when one would argue they need to be strong for each other.

It should be noted that 75.91% of respondents felt that something as basic as an information leaflet, which explains what to expect and what signs to look out for regarding anxiety and depression would encourage them to seek help sooner.

Anxiety, depression, PTSD...how do you feel?

The majority, 80.47% did not have any mental health issues prior to the birth of the baby.

For those that did, we asked “*if they were monitored closely*”. Below are a few responses. The experiences are mixed:

“Yes I had bad depression and was monitored closely.”

“Unexpected, unknown midwife appeared on my doorstep asking if I was taking drugs!”

“No I wasn't monitored at all even though I had previously suffered postnatal depression and anxiety.”

“Yes, I suffered with anxiety/depression following the death of my father so was kept on a low dose of antidepressants throughout the pregnancy.”

“No, there was virtually no support with anything, in fact staff made accusations about me which enormously worsened my mental health.”

“No, it was in my medical notes but I was never asked about it and no support was offered.”

29.45% of respondents said that their feelings of anxiety or depression got worse after they left hospital. This figure is higher than for those who felt worse whilst in hospital (25.15%).

Whilst the first stage of trauma took place whilst they were in hospital (the birth), they were surrounded by a full team of highly skilled medical professionals. Once they return home, they are on their own which would understandably heighten any feeling of anxiety.

38.81% of respondents claim to have been formally diagnosed with anxiety.

25.67% of respondents claim to have been formally diagnosed with postnatal depression.

15.13% of respondents claim to have been formally diagnosed with post traumatic stress disorder (PTSD).

18.10% of all respondents said that they have felt suicidal at some point since the birth of their premature baby.

Parent suggestions

An important aim of this consultation is to explore ways in which mental health support services could be improved for parents of premature or sick babies. Canvassing the opinions of parents is key and below are a few suggestions:

“Access to support straight away - consistent follow up when home”

“Specially trained NICU staff, counselling sessions whilst baby still in hospital”

“I would make it routine for the parents to have a one on one chat separately with a councillor soon after birth. I know it can't be compulsory but if it was made 'routine' people like myself wouldn't have to pluck up the courage to talk to someone.”

“One on one counselling to explain all feelings that are about to come are normal.”

“I think mental health should be spoken about more and feel that parents should attend a routine follow up appointment to discuss only their wellbeing without having to discuss baby's needs...”

“Maybe someone who specialises in mental health on the neonatal ward. If a mother feels happier it helps support breast feeding/milk production.”

“Even groups with previous mums that have been through it would help I think it would just be nice for parents to be able to sit and have coffee with someone who has been through something similar and gets how your feeling.”

“Automatic screening and follow up for 12 months post birth. Fathers and Mothers. Fathers are left feeling like a spare part!”

Conclusions and Recommendations

Conclusions

Within our survey parents widely felt that early stage mental health support on the wards was inadequate. The quality of any support was not brought into question, simply the lack of it.

In relation to GPs, we have to assume that in general support from GPs is good, when accessed. However, there was one notable lapse in standards reported and there can be no place for insensitive comments such as that reported by one respondent.

Additionally there appears to be a fear amongst some to be honest about their feelings with not just GPs but also neonatal staff on the wards. This is a cause for real concern and helps no one.

Some parents are concerned about having their babies taken from them, whilst others feel that they would be considered a failure. Fear and shame were also feelings expressed. Others found the whole experience to be terrifying. These feelings can only add pressure to parents who have or are already going through a traumatic time.

Family and friends should be a source of strength and support, but in so many cases they are not. There appears to be a lack of understanding of the emotional issues that a parent of a premature sick baby might have to face and deal with. This has resulted in cases where friends and family potentially add to any anxiety, rather than help to relieve it.

Just over 60% of respondents felt able to confide in their partner, this figure isn't great and it would be better if it were higher. But the more immediate concern is reserved for the rather awful experiences of those who were not able to confide in the partner. Placing stress on relationships and in one reported case leading to a break up.

For those who went into hospital with pre-existing mental health issues we note mixed experiences; ranging from full support, to not being offered any support at all. In one case notes on the patient records being ignored.

Feelings of anxiety increased for a large number of respondents, perhaps helping to make the case for standardised after-hospital mental health support.

Parents are, using business terms, the consumer. The most successful businesses and services are built and designed around understanding and then meeting the expressed needs of the consumer. The parent suggestions are revealing, in some cases practical and in all cases, worth taking serious note of.

It should never be ignored that 18.10% of all respondents said that they had felt suicidal at some point since the birth of their premature baby.

Recommendations

Little Miracles UK are campaigning for the provision of mental health assessment and practical support for all parents of premature and sick babies, from point of birth; within all neonatal units in the UK. As mentioned earlier a petition was started in October 2016. All readers and interested parties are encouraged to take a few minutes to sign it. <https://petition.parliament.uk/petitions/169168>

The main components of our recommendations are:

Part 1:

1. Funding and resources made available to support access to mental health support for all neonatal units in the UK
2. Mental health screening for all parents of premature and born sick babies; as close as possible to the point birth, with appropriately timed follow up assessments to ensure that any deterioration is picked up as early as possible
3. A trained mental health worker e.g. a counsellor, assigned to all neonatal units
4. After leaving hospital; care and professional support for as long as it is needed
5. Provision for peer-to-peer support, or similar, for parents whose babies were born sick or premature (possibly as part of a care package incorporated into Point 4)

Part 2:

As part of item 4 above, a standardised mental health care pathway plan, to be introduced. This could cover the following (suggestion only):

- Initial assessment (in hospital)
- Frequent follow ups
- Formal referral to GP
- GP actions and recommendations logged and as part of that formal mental health support plan

Fathers are often side-lined in discussions around mental health and prematurity, but they are just as likely as mothers to suffer PTSD. Recommendation: A partner support pack for fathers, as well counselling as required along with the mother.

On-the-ward information literature for parents to help them be as prepared as possible, before and after the birth.

Information pack for family and friends e.g. "Supporting parents of premature babies"

Maybe as part of the initial assessment, but as per one parent suggested "One on one counselling to explain all feelings that are about to come are normal."

Government funding to support all of the above recommendations.

Appendix 1: Parent comments

A number of questions we asked invited parents to comment and explain in more detail. These responses gave us a better understanding of what parents were going through and how they were feeling.

In this section we have provided a more extensive list of parent comments than provided in the main report. This is because it is hoped that for a parent reading this chapter it might be of some help to read the thoughts and experiences of others in a similar position.

Did you go to your GP about feelings of depression after your baby/babies came home? If you saw a GP what was the course of action?

“Referred to counsellor”

“Contacted health visitor to arrange support”

“Medication and PTSD Counselling”

“Telephone number for support”

“First doctor laughed, it's obviously my baby and I don't need to give birth again, you're probably depressed but not the most depressed person I've seen, come back in 2 weeks! (Safe to say I didn't go back for ages)”

“I went to GP for something different then just went into a flood of tears and couldn't stop crying. I talked it through with GP and felt a bit better.”

Were you honest with Neonatal staff if they asked how you are feeling?

Only 49.85% of respondents were honest with neonatal staff when asked how they felt. The majority were not, and below are a few of the reasons given:

“Don't recall them ever asking how I was feeling”

“Fear that I couldn't look after my child”

“Don't want them thinking you're not coping”

“Because it was about my baby, not me”

“I didn't want to feel like a failure and that I was a bad mum”

“Didn't want to come across as unappreciative or look a bad mum”

“Scared they thought I was weak and not up to it”

“I was scared but wanted to appear to be strong. I didn't want to be a problem”

“Scared about being told can't cope child being taken away”

“I was afraid to say how I felt, and I felt guilty that I wasn't coping as well

“I didn't realise myself until I got home that there was something wrong.

“Because it was an off the chuff are you okay while walking past, rather than sit down next to you and ask and actually listen”

"I was embarrassed and seen other mums coping so I felt ashamed that I was struggling..."

"Thought social services would be called for being unstable"

"I felt that I needed to be strong so they let my baby come home with me"

"I was trying to stay strong and did not want to show any signs of weakness. I felt if I voiced how I really felt I would crumble so I put my feelings aside. But it came back to bite me in the months following discharge. Two years on and I still feel I have not dealt with the emotions and feelings of that day but now feeling in a stronger place to discuss it."

"Trying to make out I was brave when in fact I was shitting myself!"

"I was ashamed"

Did you feel you could talk to your family or friends about how you felt during your neonatal journey?

Only 36.80% felt they could speak to friends or family about how they were feeling. The remainder did not. Below is a sample of the reason given for not being able to speak to those closest to them.

"They didn't seem to understand how serious it was. Kept being told how so and so baby was earlier or sicker. When given congratulation cards how can you explain that you don't feel like celebrating."

"My mum died when I was 5 months pregnant (60 days before my baby was born) so nobody dared to raise feelings with me except my Dad"

"We were all scared so didn't want to make it worse"

"Whilst in hospital I had no contact with anyone really and by the time we came home everyone thought we should be over it as he was ok now"

"I felt pressure to be positive and happy because my girls were alive and doing well"

"As no one had gone through it I didn't think they would understand."

"I didn't want anyone to touch my baby and it gave me anxiety. I felt like I could not say it so I had to walk away when people were holding her. (Including immediate family)"

"My mum called my youngest a live miscarriage"

"No one understands what it is like to go through a 5 day labour then emergency c section to a 25 week old baby."

Did you feel you could confide your feelings with your partner?

We would have hoped for a high positive response to this question but a rather worrying 60.06% felt able to speak to their partner. 5.33% of respondents did not have a partner, the rest (34.61%) did not feel able to confide in their partner. Below is a summary of the reason they gave for not confiding:

"He was struggling too"

"I needed to be the perfect mother. I had "failed" my baby during pregnancy and I had to be perfect to make up for it."

"As a mum and you carried the baby you just feel to blame and push everyone away"

"Not supportive when I needed him to be, now in the process of separating"

“He had to look after the other children at home the journey is a massive roller coaster and there should be more help for families.”

“He was working a lot and say I was over-reacting so stopped speaking to him”

“I was told to stop moaning and that I'd be a rubbish mother if I couldn't cope with things now”

“I can't explain why. I just felt completely alone. Maybe some shame felt too.”

Would you like to see more done to support parents with mental health following the traumatic experience of having a sick or premature baby/babies on a neonatal unit?

Unsurprisingly only 4.18% said that they would NOT like to see more mental health support on neonatal units. The remainder thought there should be and below is a summary of some of their suggestions:

“Access to support straight away - consistent follow up when home”

“Specially trained NICU staff, counselling sessions whilst baby still in hospital”

“Support or therapy for all parents of babies on neonatal units if they feel they need it. I was offered no support or anything during our neonatal journey and it took 11 months for me to build up courage to seek help myself.”

“I would make it routine for the parents to have a one on one chat separately with a councillor soon after birth. I know it can't be compulsory but if it was made 'routine' people like myself wouldn't have to pluck up the courage to talk to someone.”

“One on one counselling to explain all feelings that are about to come are normal.”

“I had a specific illness that meant my baby was premature and I was also dangerously ill, we both nearly died just 60 days after my Mam died suddenly, one of the hundreds of medical professionals I dealt with should have asked if I wanted to speak to someone and not one of them did.”

“I think mental health should be spoken about more and feel that parents should attend a routine follow up appointment to discuss only their wellbeing without having to discuss baby's needs...”

“Automatic screening and follow up for 12 months post birth. Fathers and Mothers. Fathers are left feeling like a spare part!”

“Even groups with previous mums that have been through it would help I think it would just be nice for parents to be able to sit and have coffee with someone who has been through something similar and gets how your feeling.”

“Maybe someone who specialises in mental health on the neonatal ward. If a mother feels happier it helps support breast feeding/milk production.”

Did you have any mental health problems before you had your premature/sick baby?

The majority, 80.47% did not have any mental health issues prior to the birth of the baby.

For those that did, we asked “*if they were monitored closely*”. Below are a few responses:

“Yes I had bad depression and was monitored closely.”

“Unexpected, unknown midwife appeared on my doorstep asking if I was taking drugs!”

“No my daughter spent 2 years in intensive care and constant fights with what is best for my daughter whether or not to turn that machine off that is keeping her alive is mental torture still battling on 7 years later and will not give up to get the best for my daughter.”

“No I wasn't monitored at all even though I had previously suffered postnatal depression and anxiety.”

“Yes - perinatal referral during pregnancy.”

“Yes, I suffered with anxiety/depression following the death of my father so was kept on a low dose of antidepressants throughout the pregnancy.”

“No, there was virtually no support with anything, in fact staff made accusations about me which enormously worsened my mental health.”

“No, it was in my medical notes but I was never asked about it and no support was offered.”

Acknowledgements

Little Miracles UK would like to thank the many parents who took the time to take part in this survey and share their experiences. We appreciate that answering these questions may have brought to the fore memories of difficult and challenging times.

We would also like to thank the Little Miracles UK team of regional coordinators who helped ensure that a wide range of parents were made aware of the survey.

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