

AIMS JOURNAL

RESOLUTION

Finding Closure Following Birth

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Association for Improvements in the Maternity Services

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Resolution – Moving forward from a bad birth

by Emma Ashworth



For years, AIMS produced a small book called “Making a Complaint about Maternity Care” which looked at the different ways that women and people who were unhappy with their maternity care could complain. With changes to the structures of the organisations involved, the book needed to be updated, but it became very clear from the experience of the volunteers on the [AIMS Helpline](#) that there is more to coming to terms with birth experience than just making a complaint. Making a complaint can be therapeutic for some people, but for others it can just add further trauma. What AIMS wanted was to provide information about the different options and to enable informed decision making in this aspect of the maternity journey too. We also wanted to help parents to understand better what they might experience when complaining or taking other actions. For example we often hear from parents that instead of receiving an apology they are dismissed, their experiences denied or even told that they are wrong. Phrases like, “I’m sorry that you felt that

We needed another way. In our new book, *The AIMS Guide to Resolution After Birth*, part of a new series of guides for women, pregnant people, birth workers and supporters, we look at a variety of ways that people can find Resolution about what happened to them during birth. This might be through the complaints process, but it might be through other ways. [Shane introduces the book in our first article](#), and we also have a diagram of many of the different options available to help women to navigate the various paths to find Resolution.

Regular readers of the Journal will recognise Beth Whitehead’s name as she’s previously written about her traumatic and abusive birth experiences. In this edition of the AIMS Journal, [Beth describes the ways that she attempted to find Resolution through the traditional channels](#), giving a clear picture of what is happening to so many women when they try to use the systems which are supposed to protect us but in fact so often deny us justice. We hope that by publishing this article it will give the organisations involved some incentive to change their ways.

Emma Svanberg of [Make Birth Better](#) has written [a fantastic explanation of two of the different treatments for birth trauma](#) which are available on the NHS. CBT and EMDR can both be helpful for many people who have experienced birth trauma – whether they gave birth themselves or witnessed it – and EMDR is often more appropriate for PTSD.

[Nija Dalal shares her experience of breastfeeding twins](#), and how she eventually resolved low milk supply caused by poor advice and support by the NHS as well as serious illness after birth. Thanks to the knowledge and support from her doula she was able to access someone who could help. She also had the Continuity of Care from the doula she knew

and trusted to support her and give her the confidence to keep going against the odds.

Many birth trauma experiences are caused by our rights being run roughshod over during our experience of labour, birth and postnatal care. Clinical negligence lawyer Stuart Bramley explains the “Montgomery V Lanarkshire” ruling which clarified the fact that medical staff are obliged to offer to share information that is important to each pregnant woman and person, rather than the doctor or midwife paternalistically making decisions FOR them. Knowing this can help pregnant women and people to feel empowered to ask more questions and not tolerate just being told what is going to happen if they’re not comfortable with that.

AIMS is excited to announce that we have a new Trustee who has just joined our team, long-time birth campaigner and doula Verina Henchy. We are delighted to have an interview with Verina in this issue, so do read it and get to know her a little better!

Also in this edition of the AIMS Journal, Dr Rehana Jawadwala explores an important health issue: why are “lifestyle” issues such as weight and smoking frequently a large part of antenatal care, whereas support for exercise has less focus, and sometimes a negative focus.

New AIMS Volunteer Emma Mason has written a beautiful account of her first birth for us. An inspiring story of a woman who took control and did what was right for her and her family. Finally, Marein Schmitthenner explores the life of a woman that we should all know about: Francis Oldham Kelsey. If you don’t know about her and how she saved thousands of babies from death or severe disability, click over there right now!

This is the third Journal of 2019, and the final issue will be on the topic of hormones. If you would like to contribute to that or any other AIMS Journal, or have any comments or feedback, please contact the Journal team at journal@aims.org.uk. We hope that you find the articles interesting and useful. If so, please, do share them widely!

Emma Ashworth

AIMS Journal Editor



A NEW SERIES OF
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The AIMS Guide to Resolution: A new AIMS book!

by Shane Ridley



I'm very pleased to introduce a book, *The AIMS Guide to Resolution*, which is being released shortly, in the new 'AIMS Guide to' series. We know that for some women whose births did not go according to any plan they envisaged, or who experienced actual physical abuse by the maternity services, giving birth may have been a traumatic, frustrating, devastating and frightening event. Often, there are no words that can describe the full extent of the trauma that some people experience.

The AIMS Guide to Resolution offers comprehensive and empathic advice about how to reach a satisfactory resolution to bad maternity experiences, however major or minor they are. It documents the practical steps you can take and the choices you have – how to approach the issue, who to talk to, and where to go. The illustration below gives an idea of the scope of those choices. There are chapters detailing how to make a formal complaint, with guest contributors writing about the legal aspects and consequences of making a claim as well as information on making decisions about which pathway(s) might be right for you.

And an important and new element to writing complaint letters is introduced – holding providers of services to account by quoting back at them what they are supposed to be achieving.

But we go beyond the formal complaint processes.

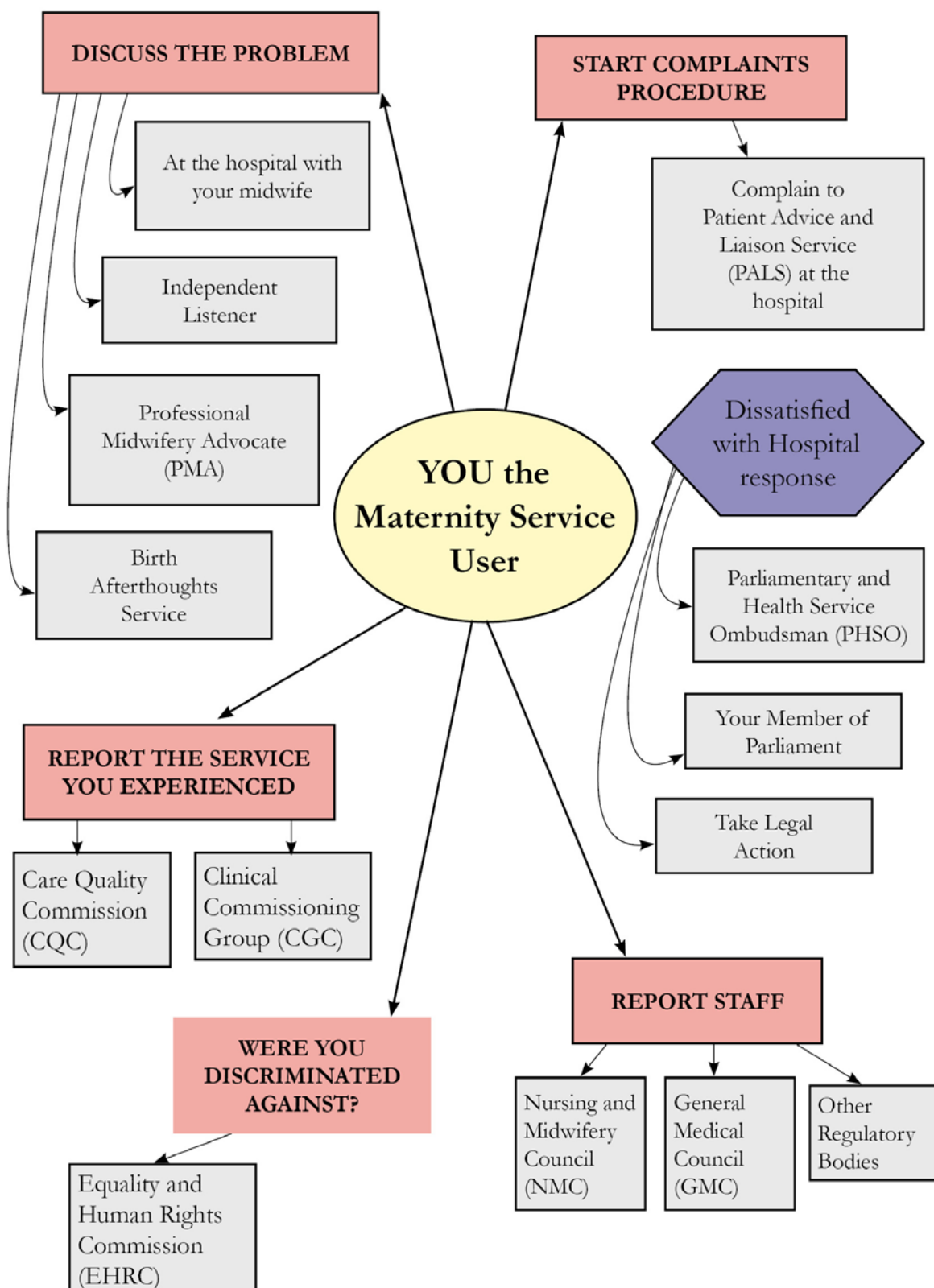
The AIMS Guide to Resolution has chapters on working through and understanding your feelings about your birth experience; information on birth trauma; stillbirth; and neonatal loss. Another chapter outlines what might happen with a referral to Children's Services and includes suggestions on how to manage this situation. There are lots of signposts to other organisations and places or websites to visit for further information. Finally, there is a chapter suggesting ways of preparing for another birth.

The AIMS Guide to Resolution is also **a book that can be read as part of preparation for pregnancy.** The chapters on your rights and what is meant by 'giving your consent' will help you to think about how to respond to the care and advice offered to you by your midwife and obstetrician. Birthing partners or helpers will also benefit from understanding how to respond to these two particular aspects.

We understand that complaining or raising a concern is only part of the journey after a bad experience, hence this new book which goes much further than our previous book, "Making a Complaint". We're really hoping that *The AIMS Guide to Resolution* will be a very useful resource to help women find a path to recovery and to avoid the pitfalls of the maternity services, thus preventing unnecessary trauma.

Shane Ridley

Practical steps to resolution after a bad maternity experience



Failures in Maternity System Regulation

by Beth Whitehead

After a difficult birth, it is natural to feel overwhelmed and exhausted. What I found the toughest part to deal with was my experience of abuse at the hands of healthcare staff, as well as the sense that they should not have treated and spoken to me the way they did, in their professional positions. I tried hard to push these feelings aside, at times I even tried to justify them as people liked to say they were just doing their jobs. They were not. Their job was to support, listen to, care and protect me but that was not what they did. They assaulted my body, caused severe mental and physical injuries and insulted me with degrading comments.

I did not want what happened to me to happen to other women, which was why I made a complaint. As I spoke to other women with similar experiences, I found that they decided to complain for the same reason. While sharing our frustrations of how poorly our complaints were dealt with, we soon realised we were also uncovering a system protecting the healthcare staff, our abusers. We need to put the regulatory bodies that are supposed to protect us under the microscope to understand what is failing and compromising safety for women and babies.

We need to put the regulatory bodies that are supposed to protect us under the microscope to understand what is failing...

The effectiveness of a regulator or the profession it is regulating is reflected by how well they deal with complaints i.e. when things go wrong or when professionals break codes of conduct. In the case of healthcare or maternity services, it is also a reflection of safety and how well the profession practices in respect of human rights laws. I will examine each of the common issues or systemic inadequacies I and many women have encountered in the complaints process.

Power Imbalance

Despite the legal requirement on informed consent, it is not always possible to prove its violation on paper because what is written by healthcare providers in a woman's maternity notes (a legal document) can be different to what actually happened and her experience. Furthermore, the maternity notes are often considered to be "expert opinion" and more credible evidence than a woman's own account of what happened.

The hospital setup is fragmented, with women being pushed from triage to the assessment room, then labour ward or birth centre, meeting various staff for the first time who have no knowledge of their clinical history nor understanding of their birthing decisions. These are examples of the structural power imbalance in place that disempowers women from the start. However, this is just the tip of the iceberg.

Dismissive Attitude

When I, and many others, complained to the hospitals about maternity services, the standard replies were denial and a minimisation of our experience, pathologising pregnancy and birth (including addressing women as patients). The harm or injuries caused by their staff's interference and negligence are framed as faults of our bodies, dismissing abuses as one-off events rather than acknowledging wrong-doing, improving practices and safety. It is a systemic issue. Institutionalised obstetric violence against women has been reported in a national newspaper recently.¹ Women who have experienced harm and their birthing partners (including birth workers) who have witnessed abusive practices, need to speak up and speak out about what happened behind closed doors.

Women who have experienced harm and their birthing partners (including birth workers) who have witnessed abusive practices, need to speak up and speak out about what happened behind closed doors.

Complaints about midwives are considered on an individual basis by their regulator, the Nursing and Midwifery Council (NMC). This means if you have experienced abuse from three midwives at your birth, the combined compounding effects of all their actions are not acknowledged and the obvious cultural issue in the team is also not dealt with. This means your complaint is structurally minimised and made easier to dismiss as each midwife's words and actions are considered individually.

Failures of Fitness to Practise

The NMC is tasked with investigating complaints of midwives in the interest of public safety. It has a process to assess 'fitness to practise'. However, in complaint responses, I have seen assessments of midwives' fitness to practise used to dismiss abuses carried out by them as one-off events that somehow the NMC believed will not happen again. Other complaints were found not to meet their "seriousness" threshold, even when they were obvious incidents of assaults.

What does this actually mean? What I can see is the NMC's unwillingness to acknowledge and address registered midwives' abusive behaviours. Abusing a person once can cause substantial lasting damage to them and their babies. The baseline should be that abuses should not happen, NOT EVEN ONCE! There should be NO free passes to abuse handed out to midwives by their regulators and employers. A person cannot attack another person on the street and claim it as their first offence to justify dismissal. Laws that apply outside of the birth rooms should also be applied inside them. No excuses and no exclusions.

Fitness to Practise is ineffective. Complaints go through a screening process where care quality or the impact of abusive practices on women are often dismissed as insufficiently serious. The NMC's definition of "seriousness" is vague and

subject to their own biases. In a complaint investigation report from May 2019 that was shared with me, the NMC Case Midwife defended the hospital practices and dismissed the woman's concerns even though there was repeated evidence of violation of human rights in the hospital midwives' conduct. For example, coercion for vaginal examination, withdrawal of pain relief, verbal abuse, physical assault – a midwife carried out a dangerous, controlling and damaging manoeuvre (to restrain the woman) that was not in the midwifery curriculum. It is horrifying to see, in writing, the NMC's support for midwives who abused and assaulted women – the violence and the severe injuries caused.

Failure to Protect Women

The problem with 'Fitness to Practise' is that it focuses on the future practice of the midwife, i.e. how they will practise AFTER the incident that led to the complaint. The underlying assumption that the NMC makes is that if the offender appears remorseful, they will not abuse women again. They even said the NMC "is not about punishing people for past events". It is like saying if a rapist says they are sorry and will not rape again, they are set free.

Where does this leave women who have been abused? It means no acknowledgement for the abuse carried out by the midwives against the woman and a continued culture of no accountability. In the investigation report, I could see the Trust knew how this worked and provided scripts to keep the NMC satisfied without being called into further investigation or requests for policy changes.

Lack of Respect for Women's Rights

Another thing that stood out in the NMC investigation report that I read was the lack of respect for a woman's right to decide her place of birth, to decline tests, assessments and interventions. They also did not recognise and acknowledge coercion which was carried out by midwives in violation of human rights. This is troubling because when a regulator fails to defend women's rights, it is not doing its job in holding its registered midwives accountable to their professional requirements: advocating for women's rights and supporting them in their maternity journeys with kindness and compassion.

Lack of Independence and Oversight

The Professional Standards Authority (PSA, <https://www.professionalstandards.org.uk>) is meant to be an independent organisation overseeing the NMC. It conducts performance reviews of the NMC but cannot intervene in the NMC's decisions about individual cases. There is no external body that can intervene in the NMC's case work. In other words, there is no mechanism in place to ensure informed consent and respectful care is being practised. Consequently, there is no real culture of accountability in the maternity system.

In fact, the NMC's own fitness as an organisation and regulator has been called into question time and time again^{2,3,4}. Sadly, it appears little has changed in practice since the PSA's Morecombe Bay report was published in May 2018. When a regulator minimises and dismisses women's experience of abuse by midwives, defends the abusers and the abuses, it is not just victimising and mentally abusing the victims but also enabling abuses. Fish rots from the head.

When a regulator minimises and dismisses women's experience of abuse by midwives, defends the abusers and the abuses, it is not just victimising and mentally abusing the victims but also enabling abuses. Fish rots from the head.

The Public Health Services Ombudsman (PHSO, the Ombudsman) is supposed to be an independent complaints investigator, but it will only take cases after women have gone through the complaints process with the hospitals. This not only gives the maternity units the opportunity to deny the woman's experience and defend their actions, but also alert them to close the ranks, cover up evidence of abuse. The Ombudsman also applies a strict time limit of one year from the incident – so the date of birth of the baby – for women to file complaints. Many women who have been abused by hospital staff find this timeline difficult to meet. This is because they are often still traumatised, riddled with anxiety in dealing with the health system or their abusers, struggling with caring for their babies, self-recovery or mental health issues caused by the birth abuses.

What about the police? I reported the birth rapes and assaults I experienced to the police but they dismissed my complaints and defended the hospital staff despite the extent of the violence and human rights violations. This was not from lack of evidence or seriousness of the offence, but because they believed that what a healthcare provider does must be necessary, and because they did not recognise that women's rights to their own body do not cease when they are pregnant or go into labour. The law must evolve to recognise obstetric violence as a punishable offence in order for practices and healthcare culture to improve. This is happening, but too slowly.

What Needs to be Done

Our government needs to be serious about protecting women's safety and our rights when accessing the maternity system. What is clear is that what happened to us – the abuses and failures by healthcare providers, regulators and police – were not just isolated incidents but consistent systemic failure. What we need is an urgent parliamentary investigation into the effectiveness, usefulness and independence of regulatory organisations, especially the NMC, which are failing women and families, and enabling abuses to carry on. Failure of the regulator is failure of a maternity system. It needs fixing.

Despite its current ineffectiveness, I urge everyone who has experienced violence of any form and degree, verbal, physical, mental, emotional or psychological, at the hands of midwives, when feeling able to, to continue to report to the NMC. If we do not report, we do not have evidence of abuses and the regulators' failure. We should not be silenced or gaslighted, for the way to stop abuses is by speaking up, comparing notes and uncovering systemic failure.

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The Sun newspaper article on Obstetric Violence: <https://www.thesun.co.uk/fabulous/8778305/birth-rape-obstetric-violence-investigation-childbirth/>

The PSA's Morecombe Bay report and recommendations for the NMC: <https://www.professionalstandards.org.uk/publications/detail/nmc—lessons-learned-review-may-2018>

AIMS' review of the PSA's report <https://www.aims.org.uk/journal/item/psa-review>

Example of the failure of the NMC: <http://www.fosteringchange.co.uk/unfit-to-practice/>

Article

Therapies for Birth Trauma

by Emma Svanberg



[Photograph by Phil Taylor]

There can still be some confusion around what birth trauma means, and as a result also some confusion about the best available therapies and treatments to resolve symptoms of trauma. Birth trauma in essence refers to symptoms which relate to the experiences of birth and around birth. So this may be the birth itself, or there may be symptoms of trauma related to the pregnancy journey, the postnatal period, feeding experiences. The key link is that, at some point in these experiences, an individual felt that they or a loved one were fundamentally unsafe. This is why not only women and birthing people may experience symptoms of trauma, but birth partners, health care professionals and wider family members. One can also experience symptoms of trauma through hearing about traumatic events, leaving ripples that can span through a whole family, group of friends or team of healthcare providers. What's key here is that the experience of trauma is entirely subjective, and can't be defined by anyone else¹. If a person feels that they have been negatively affected by a traumatic event around their birth, even if on

paper it may look like a straightforward experience, then listening with an open heart and lack of judgement to their experiences can be a significant first step on the road to recovery.

For some, their symptoms may meet the criteria for a diagnosis of Post Traumatic Stress Disorder (PTSD). Currently around 4% of women who give birth are being diagnosed with, or thought to be suffering from, PTSD². Or, as is the case for about a third³ of women, there may be some symptoms of trauma but not the cluster of symptoms that defines a diagnosis of PTSD. Whether or not a diagnosis exists, such symptoms can have a far reaching impact on daily life, on relationships with our babies, partners, family, friends, and health care services, on our sense of confidence, our mental and physical health.

When we feel traumatised, our brains get 'stuck' in fight or flight mode. It's as if our bodies haven't quite registered that we are now safe. Many of the symptoms therefore revolve around reminders of the traumatic event, avoiding such reminders, feeling vigilant to threat and inevitable mood changes that result from this.

So what can we do about traumatic symptoms? At Make Birth Better⁴ we are working as a collaboration of parents and professionals to examine the systemic causes of birth trauma and campaign, alongside our colleagues at AIMS, for wider cultural change. But until that happens, what can help those women, birthing people, partners, family members and healthcare professionals who are affected by trauma?

There are a range of different therapeutic options available for those who have symptoms of PTSD, many of which will also be suitable for those with sub clinical (below diagnosis) symptoms. All of them target the continued feeling of being unsafe – particularly in changing the ways that traumatic memories are stored in our brain. The feeling of continued threat experienced after trauma is due to the traumatic memory being stored in a part of the brain called the amygdala, which is our 'alarm system'. Treatments tend to focus on exploring the traumatic memory and allowing it to be processed, so that it can be stored in the hippocampus alongside our other long-term memories.

The National Institute for Clinical Excellence (NICE) guidelines, which are research based guidelines for health practitioners, suggest Trauma Focused Cognitive

Behavioural Therapy (TF-CBT) and Eye Movement Desensitisation and Reprocessing (EMDR). The majority of people in the UK who are offered treatment are offered TF-CBT. Other treatments have also been evaluated but not recommended by NICE, however psychiatrist and trauma specialist Bessel van der Kolk suggests in his book *'The Body Keeps the Score'* that many people will benefit from a range of different approaches, and that these may change over time.

TF-CBT and EMDR are both manualised approaches (approaches which follow a defined protocol), which therapists are encouraged to adhere to strictly. Both begin with a lengthy process of teaching the client 'grounding' techniques. These are techniques which 'ground' a person in the here and now, reminding them that they are safe. These might be focusing on breath to bring a person back to the present (particularly when they might be experiencing flashbacks), looking at all of the blue objects in a room, counting the number of circles you can see, asking questions about the day, date, what is happening in the news and so on.

These treatments directly combat the trauma memory by enabling someone to quickly return to a sense of safety. It is useful to note that, in brief therapy of 6-12 sessions—which is what most people are offered from local NHS psychological therapies services – this grounding part of therapy may be the only technique used to ensure that someone is left feeling safe. In brief therapy, moving too quickly to exploring and resolving the traumatic memories themselves can feel very destabilising.

Trauma expert Babette Rothschild emphasises the need for clients to feel able to 'put on the brakes' before tackling any memories of trauma. She says "...I never help clients call forth traumatic memories unless I and my clients are confident that the flow of their anxiety, emotion, memories and body sensations can be contained at will. I never teach a client to hit the accelerator, in other words, before I know that he can find the brake."⁵

This can be frustratingly slow when you are desperate to free yourself of trauma symptoms, but it is imperative that, when accessing traumatic memories, a person is able to feel deeply relaxed so that a feeling of safety can be held on to. The risk of going too quickly is that you can re-traumatise a person, and leave them with more distressing symptoms. This may mean that therapy may be accessed a number of

times before symptoms are resolved, or that a request for therapy from another source is made. Within the NHS, services follow a 'stepped care' model so that if symptoms are not resolved by the first therapeutic option offered, further support should be requested. However, in reality many people find it hard to access support and knowing the recommended treatments of choice can be helpful when requesting help. These can be found by looking at the NICE guidelines on Post Traumatic Stress Disorder⁶ and Antenatal and Postnatal Mental Health (section 1.9.4)⁷.

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Cognitive Behaviour Therapy (CBT)

During Trauma Focused CBT, once the client and therapist both feel that it is safe to do so, they will begin to explore the traumatic memory together focusing specifically on the meanings that were made at the time and the parts of the memory that feel particularly emotionally raw (called 'hotspots'). They will then work together to create new meanings, and go through the memory together (called 'reliving') introducing some of these new meanings to the traumatic memory. In this way, the old traumatic memory is updated with new information that affirms the person's safety and begins to make the memory feel less powerful. TF-CBT may also include exposure, such as taking small steps to visit the hospital in which the trauma occurred. This can be particularly useful when any avoidance symptoms are stopping the person from living their daily life. With birth trauma, some people feel that the baby themselves can be a reminder of the traumatic memory, and put strategies in place to create a buffer between them and the baby (such as feeling unable to be left alone with the baby), so exposure may also involve gradually building up confidence in this way too. Other CBT models, including mindfulness and shame-focused interventions are sometimes used in addition to this model.

Eye Movement Desensitisation and Reprocessing (EMDR)

While EMDR looks quite different, it works in a similar way in processing the traumatic memory. EMDR follows a protocol of eight phases. The first three phases overlap somewhat with TF-CBT; a thorough assessment is carried out to learn about the traumatic event and also any current difficulties, grounding techniques are practised and the process of therapy is discussed, and a particular traumatic memory is described alongside the symptoms it brings up. Where EMDR then diverges is that the therapist will use a particular tool, such as a finger movement, using tones or tapping, to create a dual awareness. This means that the traumatic memory can be processed while attending to something else, removing the intensity of the memory. A more positive or hopeful belief or meaning is then added to the memory. The body is also attended to, and any feelings of tension are targeted as trauma can so often be held in the body. During every session, progress will be reviewed, and each session will end with using techniques so that the client leaves feeling calm and grounded.

The body is also attended to, and any feelings of tension are targeted as trauma can so often be held in the body.

Alongside these therapies, some people also choose to take medication (according to the NICE guidelines, medication should not be offered unless one of these therapeutic interventions has been declined, but in the realities of the NHS this is not always the case). Many are offered Birth Afterthoughts or Birth Reflections sessions – these are different according to each Trust and most are not grounded in evidence based practice (see the article in the AIMS Journal Vol 30 No 4). It is useful to note that one-off debriefs are advised against for PTSD in the NICE guidance as this may also heighten symptoms of trauma if the traumatic memories are left unresolved. NICE also recommends that therapists should be flexible about the

treatments that are offered, and acknowledge that symptoms of trauma may themselves make it challenging to attend appointments. What we hear from women who contact us at Make Birth Better is that they also find other strategies helpful – such as breathing exercises, yoga and massage. Peer support can also be beneficial, and groups such as the Birth Trauma Association's peer support Facebook group or local face to face peer support groups can normalise the often distressing experience of birth trauma. However, some people find that hearing others' stories can add to their distress so it is useful to access such groups with additional support (this may be from a friend or family member, or a health professional).

What's key is that you find something that works for you, with someone you trust and who has the appropriate skills and experience to work with you. It can be frightening to take that first step towards seeking help, but the effectiveness of these treatments means that birth trauma is something you absolutely can recover from. Many people do find it difficult to find the most appropriate help. For this reason, we have created a number of free-to-download crib sheets⁸ on the Make Birth Better website, including information about birth trauma, possible treatments and therapeutic techniques, which you are welcome to print off and share with any healthcare providers. There is also a crowd-sourced map of local services⁹ on the website, including both NHS and independent services. Many people find that a range of different techniques is what helps them to recover and – like birth trauma itself – what can help is as individual as you are.

Many people find that a range of different techniques is what helps them to recover and – like birth trauma itself – what can help is as individual as you are.

If you would like to access support for a traumatic birth, or would like to support a client, friend or family member, the first option is always to speak to your GP or another healthcare provider. There is still misunderstanding around

birth trauma so taking a crib sheet from the Make Birth Better website to explain your symptoms and what you are entitled to can be helpful. Depending on your symptoms and the age of your baby, you may be offered access to a brief psychological therapies service, to a Perinatal Mental Health Team or to a Trauma service. Sometimes there are long waiting lists, or you may have to see a number of people before you find the right support. Do take a look at the Make Birth Better website and Why Birth Trauma Matters for ideas about supporting yourself as you wait. You are always welcome to contact us at Make Birth Better if you have any questions about this process.

Emma Svanberg

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9. www.makebirthbetter.org/services-map

Article

Against the odds: Breastfeeding twins despite NHS errors, and how I found the support I needed

by Nija Dalal-Small



Photo by Michele Selway for the *Hidden Mothers Project*

My breastfeeding experience was unusual, because I breastfed twins, which is less common than singletons. But, even for a mother of twins, my experience was unique. Due partly to poor advice from the NHS, and partly just bad luck, I had a really hard start to breastfeeding, which led to challenges that took a whole team of people to support me to overcome.

I had a doula, a fantastic doula, who told me a lot about breastfeeding before the babies were born because I wanted to exclusively breastfeed. I was advised to express colostrum before the birth, but I was never able to get anything. I think now that I didn't really have any kind of knowledge of how to do it. I looked online and tried a few times but it just didn't happen. So I wasn't able to express anything antenatally, and then the babies were born by a planned caesarean, because of the position of the babies and various other issues.

**We fought very hard for donor milk
but the staff kept refusing and
refusing and refusing and so we had
to use formula.**

I was exclusively breastfeeding them in the hospital and for the first few days when we got home. On the day they were born the hospital said that they both had a mild tongue tie, so we were slightly concerned, but our doula watched them feed and said they were doing well. By day five, however, the babies had lost too much weight. We went to hospital and they were put on formula top-ups. We fought very hard for donor milk but the staff kept refusing and refusing and refusing and so we had to use formula. The hospital brought me a pump but no one really advised how exactly to make sure that my supply didn't drop, even though I was breastfeeding every three hours. When we were readmitted to hospital on day five they said that the ENT could come and cut the tongue tie. They did it, and it helped a little bit with the latch, but it still wasn't great.

Then, a number of other things happened.

I had severe anaemia and I got very ill. The hospital thought it might be sepsis, and took it very seriously - but luckily, it wasn't that. I got Bell's Palsy on day six, so I was just very, very sick in the postpartum period. In the first few weeks on top of recovering from the caesarean birth, I was feeding the twins through it all. I was so ill, we ended up asking my mother to come to the UK from Atlanta, USA, and move in with us for 6 months. Far from looking after twins by myself after my husband's 6 weeks paternity leave, as I had expected before the birth, we needed an absolute deluge of support.

Our health visitor who came to our home after we got out of the hospital said, "Oh you know, yeah, just let them feed all the time. Just lay back, you rest and let them feed. You won't need to pump because you've got two of them." She also told us to "give them a top-up whenever it seemed like they needed it", which is honestly the most pointless advice to give to two exhausted parents of twin newborns who have just come out of hospital for infant weight loss. How do we know when they need a top-up versus just more breastfeeding? What on earth did she mean? We could not get more information out of her, so we sometimes gave a top-up just to allow me a chance to get half an hour's sleep.

**Every time they let go and fell
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for more feeding. I was exhausted.**

I spent about a week with them like this, just feeding and feeding and feeding and feeding. The feeding situation was that I was on the couch 24 hours a day. Every time they let go and fell asleep, or every time I pulled them off to use the bathroom, they would immediately wake, screaming and wailing until I came back downstairs for more feeding. I was exhausted. We asked the health visitor - who was also on the Infant Feeding Team - to come back and check it was going ok. She said she couldn't come visit us again. And when we described how the babies were feeding, never letting go, even when they fell asleep, she said it was normal and what they expected.

The health visitor and the many midwives who saw us just looked at the babies' latch and said it was fine, none of them noticed that the babies weren't feeding effectively. When I asked if their latch seemed a bit small, one of the midwives said, "Well, they've only got small mouths." Around when the babies were a month old, our doula suggested getting a second opinion, because she finally noticed the babies weren't feeding effectively. She told us about a private tongue tie clinic, Milk Matters in Huddersfield. They told us that their tongue ties had

reattached and needed cutting again. The hospital had said that reattachment never happened, not to worry about it at all.

After that appointment, Charlotte, the lactation consultant at Milk Matters, said to me, “Are you pumping after every feed?” Well, no, I wasn’t. I mean, who has the time or energy for that? I’m feeding them all the time! When I fed one and they fell asleep, the other woke. One of our babies was feeding, falling asleep, and waking every half hour.

Charlotte put us on a feeding and pumping plan and it was clear. It was inhuman, but super clear. We had told her that our goal was still to exclusively breastfeed the babies. We wanted to get off the top ups. We didn’t want to do combi-feeding. Exclusive breastfeeding was the goal. So, she was very clear, this is what we needed to do. She gave us a plan that would eventually get us there - but it was going to be tough. I didn’t realise how tough it would be, or how long it would take – or how much help we’d need to be able to do it.

Charlotte advised, essentially, that I feed them both once every three hours for 20 to 30 minutes and the whole time I was feeding them, I should be doing compressions making sure that they’re getting let downs and trying to feel how much milk they were getting. At the beginning, I found this very tricky, I remember just really not being able to tell, I could not feel it. I had no sense of it. I couldn’t feel let downs.

I very rarely saw a let-down. Some women may see their other breast leak when a let-down happens, but I could never see that, because I was tandem feeding. So I really struggled with having a sense of knowing how much milk they were getting. Charlotte understood, I think, and therefore gave us a plan that didn’t rely too much on my sense of a ‘great feed’ or a ‘bad feed’ and my doula, Nikki, also helped me to understand how to look at their suck and swallow patterns as a sign of let down and milk transfer.

...the babies had to be fed every three hours. Eight times in 24 hours. And I needed to pump every three hours; eight times in 24 hours.

So the plan was, first breastfeed for 20-30 minutes. Then I (or my husband, mother, mother-in-law, sister-in-law, father-in-law, sister or a doula - so much support!) would give a formula top up. Eventually we moved to informal donor milk top ups, as the babies handled breastmilk better than formula and gained more weight on it. We went with informal donors because we were denied milk from the hospital’s milk bank. After the top up, I would wait 40 minutes to an hour and then pump for 20 to 30 minutes. At that point I would get an hour or an hour and a half of sleep. Then, I’d have to get up and feed the babies again because the babies had to be fed every three hours. Eight times in 24 hours. And I needed to pump every three hours; eight times in 24 hours. And one of those pumping sessions had to be a power pump, where you spend an hour pumping – so that was a whole session where I got no sleep at all. I watched many series on Netflix and Amazon Prime and BBC iPlayer. Many, many series. I can recommend *The Americans* and *Parks and Recreation*!

We were using all the milk that I pumped to feed back to them as the first part of their top-up and then using formula or donor milk. My boy (I had a boy and a girl) was on insanely big top-ups at first, like a full feed on top of his breastfeed, which was intended to overfeed him, so he’d gain weight quickly and be able to come off top-ups sooner. This carried on, feed, top-up, pump, feed, top-up, pump, eight times every 24 hours, from when we started Charlotte’s plan at about six weeks after they were born until they were about four and a half months old.

So, I had a number of months of only getting sleep in one hour, or even just 40 minutes chunks. I pumped at 2am, 3am, whenever the schedule dictated. Bleary-eyed, staring at the weak blue light emitted by my pump, watching the minutes slowly tick by until I could stop pumping and go back to sleep, always tense in case one of the babies woke crying before I got to sleep in the first place. I remember being so tired, by the time the 6am pumping session came around, I often couldn’t face it, and felt horribly guilty for skipping it, even as I fell asleep.

And we had to record everything every day, every feed, as Charlotte tweaked the plan daily, weekly, sometimes on a feed-to-feed basis, based on how well the babies were doing and how my supply was. When did they wake from the last

nap? How long did they feed for? How long did we have them on the breast? Was it a decent feed? What time did it start? And how much of their top up did they take? And we just had to keep these charts every day, all day. And there was excruciating anxiety every time we had them weighed, we would pore over their charts, hoping for a sign of success, for a jump in centiles, for something.

We went back to Milk Matters several times over the next few months, to check on how their tongues were healing. Strands kept reattaching and both babies needed quite a lot of cranial osteopathy, which we found helped them to latch and feed in more comfortable positions. I remember wondering if their tongues would ever, ever be ok, if breastfeeding would ever work properly. I asked our doula if we would ever get there, it all seemed so relentless. She reassured me - if she wasn't sure we could get there she would not have encouraged us to keep trying. Through the months of hellish pumping, in the dim light of my heart, I held tight to those words.

The survival through these months is, in hindsight, unbelievable. My 70 year old mum was staying up until midnight or 1am every night, doing the last feed with me, so my husband could get a chunk of sleep. We were sterilising my pump & all the bottles every day. My mother cooked and cooked and looked after the babies, in the mornings when my husband and I were getting some sleep, and throughout the day as I grabbed my 40-minute snatches of sleep.

I felt guilty for not being able to take the babies to baby sensory classes, baby swimming lessons, baby music class. ...[My mum] said, breastfeeding is important to you and it's good for the babies. That's what they need to have, get that sorted out and then worry about all this stuff...

My mum helped me with my pumping, bringing me food and water, and she helped me through the really quite treacherous emotional side of it. I felt like I'd failed my children, because I wasn't able to feed them exclusively. I felt that it was all my fault for making bad decisions, for not

working harder to express antenatally. For not doing things right. I remember feeling chained to the pump, trapped in my house. I felt guilty for not being able to take the babies to baby sensory classes, baby swimming lessons, baby music class. She told me that in India, mothers and new babies stay home for months while they get ready for the world. She said, breastfeeding is important to you and it's good for the babies. That's what they need to have, get that sorted out and then worry about all this stuff that didn't even exist when you were born. She helped me see that it was about deciding what was important, what we would need most. She took care of us all, in a lot of ways. We also had postnatal doulas come to help out with the feeds or with laundry or just looking after the babies. Sometimes my mom would have one asleep in a sling, a doula would have the other asleep in a sling, so that I could go get some sleep myself.

When I think back, we did top ups in a billion different ways. My boy took to a bottle very quickly in hospital, but my girl wouldn't take a bottle and so sometimes it would take an hour to finger feed her top-ups using an NG tube¹. Eventually she started taking her top-up well through a bottle. We had to try a few different bottles to get her there, but she started taking it well, and then we worked out how to use an NG tube like a supplementary nursing system. It was an endless headache figuring out how to get the NG tube exactly right, so they were actually suckling and not just sitting there with the tube in their mouths.

It was an endless headache figuring out how to do get the NG tube exactly right, so they were actually suckling and not just sitting there with the tube in their mouths.

When they were around four and a half months old, Charlotte got us onto a much easier pumping routine where I would do a feed for them and then just pump for 15 or 20 minutes straight after. And then I could just go to bed. I didn't have to wait, pump and then go to bed. It was around when the babies were about five months old, I think, when they were being fed exclusively my breastmilk, although I was still expressing and feeding back what I'd pumped. So we had a few days in there where I was actually pumping enough to top up only with my milk. It was about another ten days of pumping to get them to be just breastfeeding, which was so exciting and such a huge freedom, it was amazing.

Then of course, they started eating food at just about six months. We did baby led weaning, so they weren't exclusively breastfed for all that long but we did get to exclusive breastfeeding. I'm proud of that. We're still breastfeeding today and they're over two years old. I'm proud of that, too. Every morning and at various times during the day, they have milk and it helps them through illnesses, and it helps us stay connected. It helps them when they're just feeling a bit grumpy. It's really been beneficial to us but it was definitely super hard going.

We ended up needing so much support. It was really, really tough. I don't know, but if someone had said at the beginning, before I got pregnant, this is what it will be like when you're breastfeeding, I feel like I might have decided right then and there that I wouldn't even try, because it was so hard.

But I guess it's just that thing that happens. You have the kids. And then they teach you who you are. And they teach you what you can do, and what you will do. For them.

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A guide to finger feeding: <https://www.ouh.nhs.uk/patient-guide/leaflets/files/11016Pfingerfeeding.pdf>

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## Article

# Consent to treatment post Montgomery – Plus ça change?

by Stuart Bramley



The law governing consent to treatment, and refusal to consent which is often more important to birthing women, stood essentially unchanged since a 1985 legal case<sup>1</sup>. Those principles were well summarised by a Department of Health guidance issued shortly afterwards –

*“Patients are entitled to receive sufficient information in a way they can understand about the proposed treatments, the possible alternatives, and any substantial risks so that they can make a balanced judgement. Patients must be allowed to decide whether they will agree to the treatment, and they may refused treatment or withdraw consent at any time”.*

Thirty years later, in 2015, came the Supreme Court case of *Montgomery v Lanarkshire Health Board*. Arguments still run as to whether Montgomery established new principles or simply confirmed and clarified the old ones. It is worth considering the facts.

It is generally accepted that when pregnant in 1999, Nadine Montgomery and her unborn child faced enhanced risks. She was diabetic, 5 foot tall and of slim build, a



combination of which the medical experts on both sides in the claim agreed would create a 9-10% possibility of shoulder dystocia. Mrs Montgomery had raised her own worries with her obstetrician that she may not be able to give birth vaginally but did not ask for the precise risks in her case. Her obstetrician was aware of the higher chance of dystocia but felt that if Mrs. Montgomery was told she could ask for an elective caesarean she would choose to have one, which the doctor felt would not be in Mrs Montgomery's best interests.

Shoulder dystocia did occur, but led not solely to Erb's palsy, but also to hypoxia and cerebral palsy due to the length of time the baby was impacted before being freed. Mrs. Montgomery brought a legal claim in negligence based on obstetrician's failure to warn of the risks.

At the Supreme Court she succeeded. Whilst recognising that a doctor, or any other health care provider, is not obliged to discuss risks with someone who specifically asks not to know these, the judgment held that in normal practice the patient (or, in the case of maternity, pregnant or birthing woman) is entitled to be told.

This was a lengthy judgment and it is tempting to quote here numerous comments of relevance by the Law Lords. Much of the verdict seems to simply reflect the old principles –

*“An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment interfering with her bodily integrity is undertaken.”*

However, the Montgomery case is significant because of the way the court defined what is a “material risk”. Before this, the test had been a purely objective one, and to an extent Montgomery still retains aspects of that –

*“Whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk ...” but the Law Lords then added a subjective test as well – “... or the doctor is or should be aware that the particular patient would be likely to attach significance to it”.*

Arguably this is not the end of the consent story but just the end of the beginning. Opposing lawyers for patients and hospitals will still press for their preferred definitions

of “*should be*”, “*likely to*” and precisely what constitutes “*significance*”. However, a lack of precision has never meant that those affected by poor medical care cannot seek and win legal remedy. Civil claims still revolve around exactly what comprises negligent treatment even though the case which set the test of negligence was heard over 60 years ago (Bolam -v- Friern Hospital Management Committee (1957) 2 All ER 118).

### **Women must be informed of what they want to know, not what someone treating them thinks they ought to know.**

What the Montgomery case has allowed, which can be much more important to people than the chance to bring a legal claim for compensation, is a recognition of the right of birthing people and patients to make and enforce their own decisions regardless of what a “*reasonable patient*” in their position might favour. Women must be informed of what **they** want to know, not what someone treating them thinks they ought to know. Some have argued that this was happening well before Nadine Montgomery attended her antenatal appointments, so it may be argued that the decision comprised the obituary rather than the death knell of medical paternalism. But even if that were true, many AIMS members and supporters will have heard of, or experienced, the ‘doctor/midwife knows best’ stance, regardless of what the particular hospital's guidelines may have trumpeted about patient autonomy and rights.

This development may be of real interest to women who, for instance, are told that they **must** submit to an induction even where that is not clinically essential. That alone would be a breach of their rights; if as a result of the induction the woman or baby is injured such as by forceps, if the injury is serious enough there may also be grounds for a civil claim for compensation even if the use of the forceps was not itself substandard. Mrs. Montgomery won her claim not because the steps taken to overcome shoulder dystocia were themselves brought to the court as part of the case of negligence, but because she should never have been in that situation in the first place. The failure to offer a Caesarean **was** the negligence, regardless of the adequacy or otherwise of what happened during the birth itself.

**Hopefully the old paternalist attitudes will wither away from a combination of a more compassionate and respectful approach to women's rights, and the rights of patients in other areas of health care...**

Hopefully the old paternalist attitudes will wither away from a combination of a more compassionate and respectful approach to women's rights, and the rights of patients in other areas of health care, and a bedding-down of the Montgomery repercussions. My fear is that if the situation before the Montgomery decision was to recur in real life, it will instead do so where unexpected, often emergency steps are needed. A mum-to-be may well decline a particular intervention if the pregnancy and intrapartum period are going as planned, but the challenges of birthing can change very swiftly, preventing a full and detailed consent discussion even where the obstetrician or midwife would normally support and want that. The situation is not helped by a widespread misconception about the rights of the unborn child trumping those of the mother (they don't: in summary, women cannot be forced to undergo care just because that is thought to be in the interest of the fetus).

What is likely to remain a grey, and hence dangerous, area is where the treatment is given to a woman without her consent, not because her own views can be overridden but because she temporarily cannot give consent – for instance where an *unexpected* decision not previously outlined in, say, a birth plan has to be made whilst she is under general anaesthetic. Here, Montgomery has changed little. Treatment must be given in the woman's best interests but, if no discussion with her was previously held, best interests defined by whom? The views of family members should be taken into account but ultimately the decision is for the treating doctor – family members, including the baby's father, cannot give or withhold consent on behalf of a patient who temporarily cannot.

It is also worth considering at this point that where a woman has received Continuity of Care from a known midwife or doctor through her pregnancy, who is then also present at her birth, this gives the health care provider the

opportunity to understand that specific woman's wishes and needs far better than when she is giving birth with attendants who have never met her. This is safer for women and for the health care provider even though they cannot make consent decisions on the woman's behalf.

But away from the situation of a patient unable to give consent, what Nadine Montgomery has done for pregnant women is a real advance in patient autonomy. How much of an advance? In 1972 the Chinese premier Zhou Enlai was asked about the effect of the French Revolution\* and famously replied "*It is too early to say*". I hope the effect of the Montgomery judgment will be clear much sooner than in 200 years' time. Although this is only anecdotal my experience is it is possible that because it was reported much more widely than most legal judgments we are already seeing a greater awareness of the legal requirement to provide information to support informed decision making, and more respect for the decisions of women and other patients who wish to enforce their own choices in health.

**Stuart Bramley, Partner, Tozers LLP**

(\*It was subsequently reported that Zhou was referring not to the events of 1789 but to the student revolt in Paris in 1968. Probably true, but it spoils a great quip.)

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**AIMS Comment**

It is not clear in the legal documents upon what evidence the medical experts in Montgomery used to obtain the risk of shoulder dystocia (SD) being as high as "9-10%". As a mother with Type 1 diabetes Nadine Montgomery's risk of shoulder dystocia was probably higher than that of a non-diabetic mother with a similar predicted birth weight.<sup>2</sup> This assertion requires more discussion:



The Royal College of Obstetricians and Gynaecologists<sup>3</sup> has stated that shoulder dystocia affects between 6 and 7 out of every 1000 women who give birth vaginally (0.6-0.7%) and that “There is a relationship between fetal size and shoulder dystocia, but it is not a good predictor: partly because fetal size is difficult to determine accurately, but also because the large majority of infants with a birth weight of  $\geq 4500\text{g}$  do not develop shoulder dystocia. Equally important, 48% of births complicated by shoulder dystocia occur with infants who weigh less than 4000g.”

In other words, it's very hard to tell with any accuracy how big a baby is going to be at birth, most large babies – even if over 4500g (9lb 15oz) - are born without any difficulty, and almost half of all cases of shoulder dystocia occur in babies that weigh less than 4000g. Note that these figures refer to ALL women, and the figures for women with diabetes will be different.

One significant issue is the definition of SD. It has been variably defined as:

More than 60 seconds after the birth of the head<sup>4</sup>

Birth requiring manoeuvres to release the shoulders<sup>4</sup>

Body not being born after the shoulders when the mother

continues to push and there is traction (by a birth

attendant) on the head<sup>5</sup>

All of these definitions have serious flaws, explained here, which means that being able to quantify the chance of a SD is even harder because there is no clear definition of what one actually is.

Perhaps more helpful is to consider the outcomes for mothers and babies who do experience SD. A Cochrane Review<sup>6</sup> looking at whether induction reduces the chance of an adverse outcome for babies expected to be macrosomic (over 4000g) tells us that of women who had expectant management, 6.8% experienced shoulder dystocia, 3 babies in 1000 suffered nerve damage, and 20 in 1000 had a broken collar-bone (which usually heals quickly). Where labour was induced early, 4.1% had shoulder dystocia, and 4 babies in 1000 had a fracture, but there was no significant difference in any other outcomes. This Cochrane Review does not look at how diabetes might affect the outcomes, however, nor whether well controlled diabetes may make a difference compared to less well controlled diabetes. It also doesn't examine how planned caesarean birth might change outcomes. The huge

challenge here is working out the risk profile for individual women and babies – and then working out the best way to deal with those risks. AIMS looks at these issues in its new book, “The AIMS Guide to Induction”. In this book we show that:

- It is known that predictions of birthweight in late pregnancy have limited accuracy.
- There is some evidence that early induction when a baby has a predicted birthweight of over 4000g (8lb 13oz) might reduce, though not remove, the risk of shoulder dystocia, but the evidence isn't conclusive.
- Mothers with diabetes have a higher chance of experiencing shoulder dystocia, especially if they have one or more other risk factors. In particular, the risk seems to be much higher if the predicted birthweight is over 4500g (9lb 14oz).
- For mothers with gestational diabetes good blood glucose control in pregnancy should help to reduce this risk. It is less clear whether it has the same benefit for mothers with pre-existing diabetes. Even so, we do know that even with well-controlled diabetes the fat distribution on a baby can be altered.

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# Interview with a Birth Activist: Verina Henchy

*Interview by Rachel Boldero*



*Verina is a birth doula and homeopath. She volunteers on the AIMS helpline and has just been welcomed to the AIMS Trustee team.*

**When did you get involved in birth issues, and why?**

I had my first baby when I was 21, in 1981 (39 years ago). I was always quite rebellious and loads of people were saying that I was too young to have a baby... so I went out of my way to be as informed as possible. I read a lot of books like 'Childbirth without Fear', 'Magical Child' etc. My heroes at the time were Michel Odent, Frederick Leboyer, Sheila Kitzinger and Grantly Dick-Reid. I got really excited about the physiology of birth and how this could be a transformational experience for me. I loved the idea that I would be stepping from maiden to mother. It really was the making of me and that is what switched me into birth.

I have two children and I made the decision at the age of 26 that I wouldn't have any more. That was quite liberating for me - I was strong and firm in that decision. It allowed me to really enjoy other children without my own ovaries screaming out! I guess that I became a 'baby whisperer' early on in life, but I didn't recognise myself as such. But when I look back at how I interacted with young children, I always connected with them and their mothers with ease.

My journey from young mother to birth activist has been a long one. Initially I trained to be a youth worker. I was drawn to helping young people and quickly became the person they came to talk to about their drug misuse. I became an 'expert' in the field of drug misuse and have had some interesting roles and responsibilities over the years. When I was in the position of having influence over commissioning decisions, one of the services that we commissioned involved a midwife who was specifically attached to people who misused drugs. So when I look back at my career, I've always had interaction with women and mothers - e.g. pregnant women experiencing struggles with alcohol and/or drug misuse. It is amazing how when you are at a certain point in your journey you can actually see that the road has been pretty straight, even though I didn't see it at the time.

In 2004 I was coming to the end of my career in the world of drug and alcohol misuse. I felt in conflict with the policy at the time as this had moved from being health focused to becoming more criminal justice focused. Whilst I could see why this was happening, it wasn't me. I therefore decided to do something very different that would bring me back to working with individuals, working with their own agenda. I undertook a 3 year degree course in homeopathy. So in some ways, I moved from social care and mental health policy work and got back into my comfort zone, 1:1 care of individuals. In my role as homeopath, I was asked to accompany another homeopath through her first birth. I supported her and her partner from the onset of labour through to the birth of their baby. When I reflected afterwards with another homeopath, I felt that my presence alone had given her comfort. My colleague said to me, "you were being a doula"...and I said "what's a doula"? That was the start of my journey into becoming a birth worker. I completed a course and became a doula very quickly

afterwards. That was the next stage of my journey, which was about 10 years ago.

### Did your personal experience of maternity care affect your birth activism?

I certainly didn't come away from my own births thinking I had a bad or traumatic experience. I went to NCT classes, however, and felt cheated as I was left with the impression that birth could be a really pain free and comfortable experience and for me, it was not. I was given an enema which was not pain free at all. I was managing very well until that point but then lost control and the pain was something that I cannot describe... I never really got back in control. This ancient tradition was shown to be ineffective in speeding labour in a 1981 British Study yet the practice continued for many years after this. So, I had an early awareness that policy doesn't always reflect evidence.

I do remember having a really strong sense that I was an 'expert' breastfeeder and this was quite amazing because I'd not really been a 'high achiever' before this but I don't think I really reflected back upon my births until I became a doula (you are encouraged to do so as part of the training). Even though I was involved with pregnant women, I don't think I was a birth activist before this point.

### How did you get involved with AIMS?

There were two stages. Firstly, when I trained as a doula I was introduced to AIMS as an organisation and they became a source of reference for me. E.g. if someone wanted to know about the physiological third stage, I would pull out the relevant AIMS book. Then, I arrived quite by accident at one of their meetings! I thought I was going to an ARM (Association of Radical Midwives) meeting and I was confused because the Debbie I thought that I had been liaising with (Deb Hughes) wasn't there. Half an hour into the meeting the penny dropped and I realised where I was. I thought, "I'm in a room with the great and the good!" They were discussing work streams and talking about the need for AIMS volunteers on the helpline and I thought "I could do that, I do that all the time". As a doula, I was giving people information over the phone already and was sure I could offer AIMS some time to do that. I offered my services and haven't looked back.

### Can you tell me about some of your achievements?

I hate to reinvent wheels and think I'm a natural plagiarist. If someone has already put something into writing, why reinvent that? I asked AIMS if they had a Helpline FAQ crib sheet, and they said "no not really, would you like to do us one? I said "I would love to!" and I spent the first 6 months listing responses that others (more experienced than me) were making in email replies and putting these under headings. We now have a really extensive database of issues raised, e.g. home birth, induction, complaints etc. you name it! All the issues that people phone us up about now have a captured response so any one of us can access the responses at any time. That makes it easier to do the job well. If someone comes in with a new question, I hang back until the question is answered and then we have a new response for our database. I'm proud of how effective and efficient this has been - it makes it easier for new volunteers to pick up the task of responding to queries.

A few years ago I also initiated a pilot project in Peterborough to try and address the needs of vulnerable women who were struggling to navigate the maternity system. We buddied these women up with local doulas who gave their time voluntarily and we journeyed alongside these women from early pregnancy through to early parenting weeks and months. We worked with women who were suffering from e.g. mental health issues, learning disabilities, physical disabilities, women who have been 'looked after' by children's services and women from the local prison. In spite of the proven success of the project, we were unable to secure funding after the pilot phase. A similar project has now been set up in Cambridge ([BAM4Change](#)), and funding has been secured, enabling us to build on lessons learnt from Peterborough and create something unique and life changing for the women who are referred into the service. As a doula, I have personally supported more than 50 women and their partners to achieve the right birth on the day for themselves and their babies, knowing that all decisions taken were their own.

### What changes have you seen in maternity care - for the better or worse?

I'm honestly not sure if the scene has changed or if I have changed but I do have a sense that women are beginning to reclaim their power in what has become a very medicalised and often male dominated environment.

Another huge change I have observed, or am observing in action, is an increasing focus on technology that is definitely at the expense of investment in low tech, relationship based care. If we look at all that is coming through, e.g. the 'Saving Babies' Lives' care bundle and the increased number of scans, inductions and, for many people, a subsequent increase in interventions, this has a huge associated cost. On the other side of the coin, 'Better Births' is trying to bring back Continuity of Carer but in many areas they simply don't have the resources to deliver this. Not enough midwives to deliver continuity of carer is not always down to funding. I'm referring to resources in every sense, e.g. giving midwives support and empowering them.... not undermining their confidence; that takes resources. Not giving them ridiculous shift patterns. For instance, in some Trusts, if midwives are out all night at a birth then they are expected to run their clinic the next day. This lack of resources impacts on the service user. The culture of being so risk averse really is not helpful either.

### What is the biggest challenge for UK birth activists and AIMS going forward?

Change can be painfully slow, which is always a frustration, and an activist will see what needs to be changed with such clarity and yet it is difficult to share this with others because everyone has their own focus. I think we are working in an environment where the politics of health are financially and commercially driven. We therefore end up in a place where dogma often competes with evidence. We know that so much of what is being done is not evidence based. If we present evidence (or highlight a lack of evidence), we can still be told "clinical experience tells me x, y, and z" and that is harder to challenge as it is the entrenched belief (dogma). Some of this becomes a self-fulfilling prophecy which is a frustration. Those who are most disenfranchised (and we know who they are - women from BAME groups are one example, as the risk of a woman of colour losing her life during the childbearing year is five times higher than white British women) are often the groups with the least-heard voices. Those that need changes within the system are probably the last to receive it.

### What do you hope for the future?

Trauma in childbirth has to end. Protecting human rights in pregnancy and birth should be the guiding principles of all interventions. *I hope that I can work with AIMS to Support all service users to navigate the system as it is and to campaign for a system that truly meets the needs of all.*

~ ~ ~



## Article

# Want to get moving?

*by Dr. Rehana Jawadwala*

When we're pregnant, one of the easiest ways to put us off doing something is to tell us how our actions may have a negative impact on our unborn child. It's the classic rabbit in the headlights. Fear, anxiety and lack of clear information can quickly elicit inaction.

When it comes to physical activity, moving more and generally enjoying our bodies whilst being pregnant, many women are terrified of placing a wrong foot forward... literally!

**How helpful are official guidelines?**

Reading the official guidelines, it's not a surprise that some people are concerned. Some of the official guidelines are vague and unhelpful. They have more cautionary tones than encouragement. Keeping active throughout our pregnancies means we enjoy higher cardiorespiratory fitness, less chance of urinary incontinence (with low impact exercise) and less lower back pain.

Physical activity also helps to lift depression. Fewer women who are diagnosed with gestational diabetes require insulin to manage their conditions when they are more active in pregnancy<sup>1</sup>. Compared to being sedentary, light to moderate activity is all that is required to reduce the incidence of preeclampsia by 24% (95% CI, 0.48 to 1.20)<sup>2</sup>.

But the benefits are not all for us, our unborn children have better protection against chronic non-communicable diseases such as obesity, diabetes and cardiovascular diseases when we exercise whilst being pregnant with them<sup>3</sup>.

And yet, this slow trickle of information and positive outcomes is not yet fully embraced by many midwives or consultants.

The National Institute for Clinical Excellence (NICE), for example has a rather vague statement on exercise during pregnancy. "*Pregnant women should be informed that beginning or continuing a moderate course of exercise during pregnancy is not associated with adverse outcomes.*"<sup>4</sup> This statement unfortunately does not encourage proactive action on trying to get more active and the benefits of doing so during pregnancy. In fact, the statement only points towards the lack of adverse outcomes. By simply mentioning that a particular activity will not have adverse outcomes does not encourage people into doing that activity, it may only increase anxiety about adverse outcomes. What adverse outcomes might there be? If you have not thought about adverse outcomes in relation to physical activity now you have a reason to worry. Stating that there will not be adverse outcomes also implies that women who like to do physical activity for themselves will not *harm* her baby - whereas instead we might be encouraged to consider all the *benefits* the baby will receive if we stay active during our pregnancy. This kind of advice gives very little incentive to women to start or continue exercising during pregnancy despite the benefits to them and their baby.

Not only does NICE give us this very vague and unhelpful statement, they actually go on to induce fear by mentioning all the things that may go wrong.

*"Pregnant women should be informed of the potential dangers of certain activities during pregnancy, for example, contact sports, high-impact sports and vigorous racquet sports that may involve the risk of abdominal trauma, falls or excessive joint stress, and scuba diving, which may result in fetal birth defects and fetal decompression disease."*<sup>4</sup>

Just the long list of potential issues is enough to put off any responsible mother to be!

The information is not technically incorrect, but, like so many health warnings, such guidance suggests extraordinary levels of caution which can actually lead to women not wanting to do anything, just in case. It's simply a matter of vocabulary. Using positive, empowering, clear and specific guidance is the way to encourage women to benefit from more physical exercise.

Simpler messages about reducing sedentary behaviour may be far more beneficial than talking about specific activities and their risks. These risks can be conveyed on a case by case basis or as caveats. The proportion of the pregnant population who may have a prior interest in contact sport or scuba diving is rather small! Why talk about these specific risks for extremely rare cases alongside the big and important message of staying active and reducing sedentary behaviour?

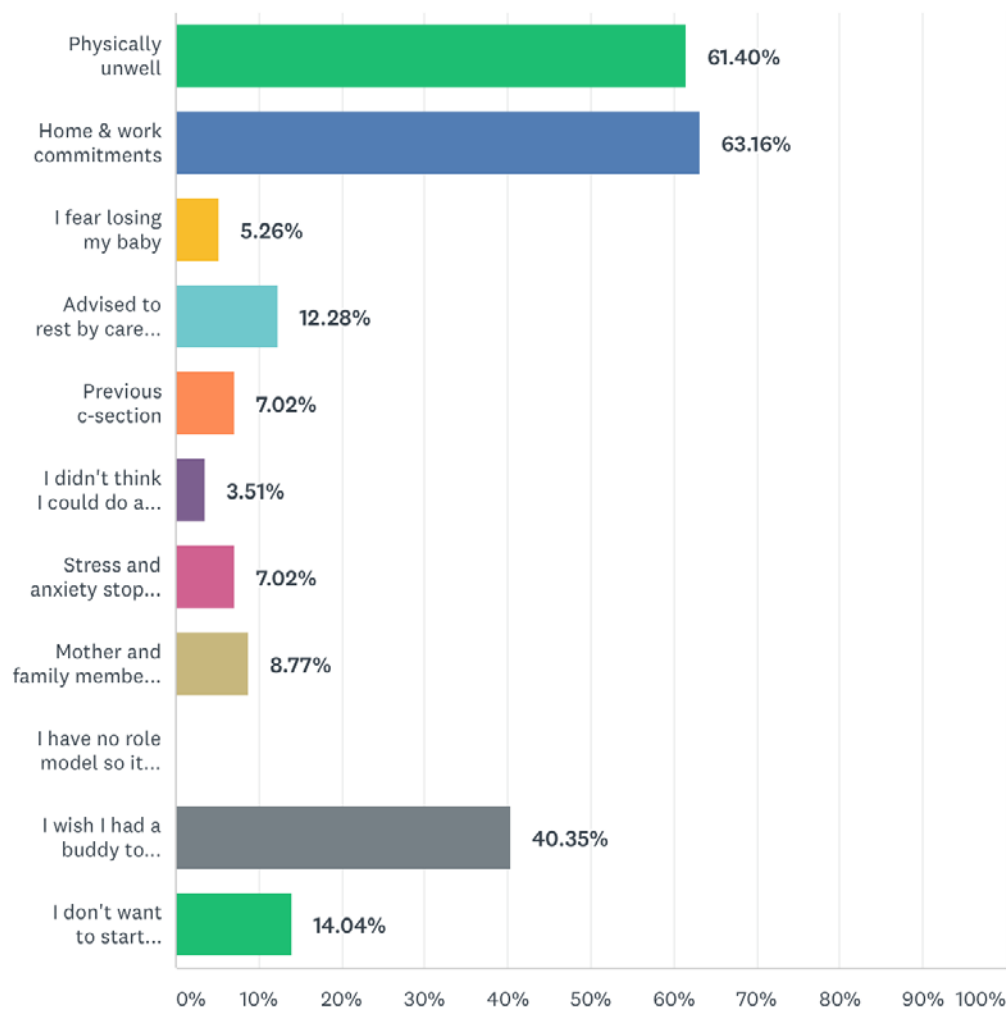
No time for exercise:

In preparation for this article, I put out a short survey within my network of mothers on social media. The survey asked several questions on barriers women faced during pregnancy towards getting and staying more active.

Out of this small snapshot of 57 respondents, 63% (n = 36) of them felt that their work and home commitments meant they gave less priority to physical activity. Could it be that without guidance from our midwife clearly stating the benefits of moving more during pregnancy (light to moderate physical activity) we don't prioritise our valuable time to make sure we include it?

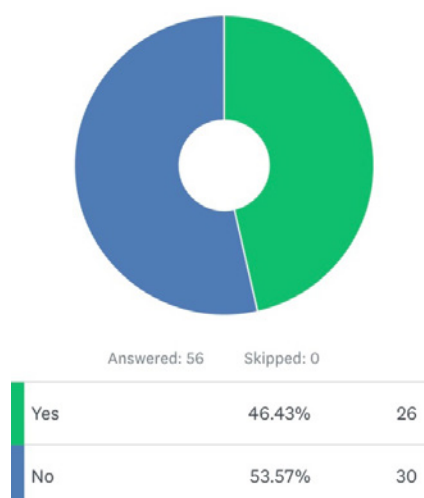
If you answered yes to the above question, what has created barriers for you? Tick all that apply.

Answered: 57    Skipped: 6





8. My midwife/consultant actively talks about the benefits of physical activity during pregnancy



A recent study<sup>5</sup> conducted as semi-structured interviews with midwives, have identified lack of resources specifically designed to encourage women to take up exercise during pregnancy. One midwife responded, “...I can’t think of any Trust or NHS leaflets specifically about exercise where there is on diet, there is on drinking, there’s on smoking”

Other factors play a role in discussions on physical activity during pregnancy too. In the same study the midwives who were interviewed identified a lack of specific knowledge and training on giving advice and guidance to the people in their care. They also said that physical activity is only a tick box for the booking appointment and there are no recurring prompts to discuss the agenda throughout antenatal care. Some of the more insidious reasons the midwives stated for not talking about an active pregnancy included fear of litigation, high workload and their own personal beliefs.

For example, one of the interviewees said, “I don’t think a pregnant woman is going to start exercising because she is pregnant necessarily”. This sort of personal bias belief will only serve to further alienate the topic and not help women to feel confident about starting or continuing to be active during her pregnancy months.

### Health related barriers:

Of 57 responses to this question, more than 61% (n=35) of our respondents stated health related issues such as lack of energy, back ache and general nausea as their reason for reduced physical activity. Ironically these are all known to be helped by physical activity<sup>6</sup>. A larger survey<sup>7</sup> agrees that health related barriers are a major determinant in lower participation of physical activity among pregnant women. Among the 1535 pregnant women participating in the survey, 85% reported barriers such as feeling judged for having a high BMI, health conditions such as diabetes or other restrictions such as childcare issues and lack of motivation were all important aspects in reducing physical activity.

The question, then, is how to facilitate an increase in physical activity if we suffer from physical discomfort during exercise? When a study<sup>8</sup> looking at increasing physical activity levels among overweight and obese pregnant women examined ways of encouraging the participants to increase their levels of physical activity, they found using mind-maps and identifying individual barriers and enablers (things the women considered helpful in doing physical activity) were an important aspect of making changes to our behaviour and practices. But even more importantly, what are barriers to some of us are actually enablers to others. For example, a high BMI or gestational diabetes can be a major barrier to exercise for many and yet it can become a source of motivation for some.

Despite there being various reasons people cite for not being able to do more physical activity, it is important to understand reasons that are specific to each individual. For some, the lack of affordable childcare means we cannot engage in certain activities despite having the motivation and desire to do so. For others, it’s the intrinsic motivation that needs addressing. So, each one of us will have valid reasons which reduces our ability and participation in physical activity. Thus, the solution has

Article contd.

to be one that considers individual circumstances rather than a “package” that is rolled out without nuanced understanding of why we struggle to keep active during pregnancy. Hopefully, this individualised need, driven by us, will encourage guidelines to be more positive, encouraging and appropriate. This in turn will empower midwives, who will be at the forefront of supporting women to seek the training to help to provide this individualised care.

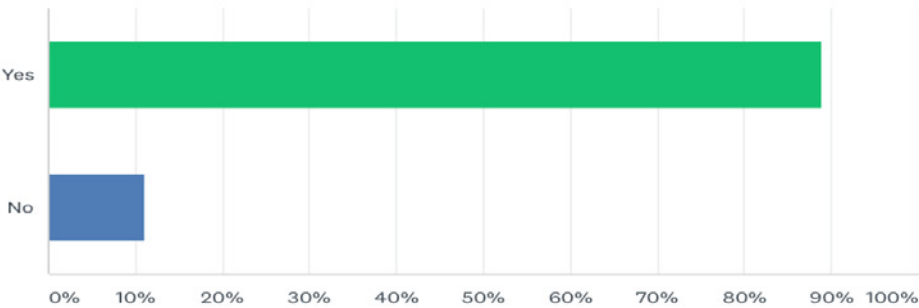
But with the current vague official guidelines, extra cautionary tones and lack of care providers’ engagement with building evidence of the benefits of physical activity during pregnancy, it is an uphill battle to increase the sense of priority to exercise during pregnancy.

**Women’s desire to move more:**

Despite setting lower priority to physical activity during pregnancy, a staggering 89% (n=56) of the respondents in our survey said they would like to do more exercise.

Would you have liked to move more, do more physical activity?

Answered: 63    Skipped: 0



| ANSWER CHOICES | RESPONSES |    |
|----------------|-----------|----|
| Yes            | 88.89%    | 56 |
| No             | 11.11%    | 7  |
| TOTAL          | 63        |    |

The barriers to physical activity are a real and important part of this conversation. The physical discomfort of moving, the lack of access to other pregnant women within our community, social pressures to “take it easy”, childcare and other financial burdens all contribute towards lower physical activity.

**Make it social:**

In my survey of 57 responses just over 40% (n=23) highlighted the need to find a likeminded “buddy” to exercise. This social aspect of physical activity has been shown in research<sup>9</sup> as an important benefit for not only increased commitment to physical activities but it also improves our mental health. Further research<sup>10</sup> indicates that inactivity during pregnancy worsened mood amongst pregnant women. Part of the mood enhancing effects of having an exercising buddy are the social connections we build.

Creating a culture of shared physical activity amongst pregnant women helps us in creating deep bonds. The natural law of coupled oscillators holds that when two or more rhythms meet, they will become coordinated—a phenomenon seen across the natural world, from fireflies matching their flashes to groups falling into step. There is some evidence beginning to gather that bodily movement, such as communal dancing, allows for heart rates to synchronise and thus increase empathy and bonding between members of the same group<sup>11</sup>. The bonding that doing physical activity together creates, allowing us to be in a positive mental space during pregnancy, can help create strong networks of new mothers within our community.

**What can we do?**

As a first step we need to have more robust ways to document the current levels of physical activity of pregnant women, so we have a good idea of what the current situation is. There is very little research on profiling the physical activity levels of women

during pregnancy. We have no idea what the picture is nationally and if there are any pockets of good practice in the country where we can call upon the success of those ideas to inform a good, structured and coherent strategy on getting the message of physical activity louder.

We need a strategy where we see physical activity conversations between pregnant women and care providers to be more than a tick-box exercise. There needs to be an increased awareness of this from our midwives and as we demand more meaningful conversations, resources and guidance we can hope that this will translate to better training for the care providers too. Better training will mean that the midwives and other carers in pregnancy will not feel intimidated by our requests but will be sufficiently equipped to answer our questions.

The language that is used is key. We must consider the impact of vocabulary. A positive approach rather than the cautionary words about sports that most of us will never do are more likely to create engagement with physical activity across our entire pregnancy journey.

Midwives and other care providers need more training and support in talking to women about the health aspects of exercise. We have strategies for smoking reduction, healthier eating and other positive health messages. We don't say that eating more vegetables won't have a negative impact on ourselves and our baby! Why are we saying the same thing with exercise?

We definitely need a clear and loud message. We don't expect to complete physically challenging activities like running marathons without any physical and mental training. We as a society have even started to grasp the importance of preparing mentally and building emotional resilience to encounter the event of birthing our babies. And yet, we are reluctant to talk about the need to physically keep strong, active and prepare for birth which is one the most physically demanding activities we as women will ever do. But we know that an active pregnancy is not only about birth, it's about the resilience of the next generation<sup>3</sup>, it is about combating lifestyle generated diseases in our future generations, it is about changing our epigenetic profile during pregnancy to improve the quality of life for not only our children but our grand and great grandchildren!

**Let's talk about moving more during pregnancy... all of us; pregnant women, our care providers and society at large.**

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# First Baby at Cossham Birth Centre

by Emma Mason



At the time we discovered we were having a baby we were pretty clueless about pregnancy, labour and birth. I imagine this is the same for most people about to embark on the journey towards their first child.

Early pregnancy was tough to say the least with horrific abdominal pain just a few weeks in, necessitating a very early scan to investigate the problem. The cause was unclear as there were two things seen on the scan, either or both of which may have been a fertilised egg. One was in my fallopian tube and the other in my womb. A few days were needed in order to check my blood hormone levels and rescan after further growth. Luckily, the mass in the fallopian tube turned out to be a cyst from which fluid was draining, causing me the intense abdominal pain, but no further treatment was needed as it was resolving itself. The other scan finding, situated in the womb, was an established pregnancy.

We didn't have much time to celebrate though, as it was at this time that hyperemesis gravidarum (a form of very severe and debilitating morning sickness) set in<sup>1</sup>. My symptoms worsened and worsened, with various advice of eating ginger, snacking frequently, staying hydrated etc

making no difference at best, and often exacerbating the problem. I rapidly lost weight and at my worst had occasions where I couldn't stop being sick for long enough to leave the bathroom, let alone the house.

Through this time I couldn't figure out why other pregnant women were coping so much better than me and concluded that I was weak and had a lower tolerance. Feeling sick became the norm and I was uncharacteristically unreliable for weeks, cancelling whole evenings of classes with little notice, my full time job being a dance and performing arts teacher. I finally spoke to a GP who prescribed me prochlorperazine but explained that it could not be guaranteed to have no effect on my unborn baby. The tablets stayed in the packet for a few days until after a particularly bad morning my brother-in-law, a paediatric registrar at the time, told me to take them. Within an hour of taking my first tablet I felt hungry (a sensation that took me a while to identify, having not experienced it in such a long time!) and ate some toast, the best toast I have ever tasted! Although I still felt sick it was a lot more manageable and the symptoms began to ease up at around 18 weeks so I could cope without the tablets.

The rest of the pregnancy went very smoothly, and from fairly early on I decided that I wanted to give birth in the midwife led suite at Southmead Hospital in Bristol. I wanted the option of a water birth with the security of consultants just down the corridor. The choice for me at the time was a home birth, a stand-alone midwife unit at Cossham Hospital, or midwife led units at St Michaels or Southmead hospitals. However, at no point were these various options discussed with me, nor was I offered research data to illustrate the actual risks of each. As a result I felt a home birth was completely out of the question, and the midwife-led unit at Cossham was also an enormous risk to mine and baby's safety.

It was through friends and family that I heard about hypnobirthing, and after an internet search, felt it was worth

investigating further. The course wasn't cheap, at £200 for 5 sessions of 2.5 hours each but I convinced my highly cynical husband that we should book in. After just one session I had done a complete U-turn, declared that I would not set foot in any hospital and had my heart set on Cossham. As the course progressed I became increasingly astonished at the skewed view of birth, doubtlessly absorbed from the media, the portrayal of birth on-screen, and horror stories from other women who ironically had perhaps suffered due to an over medicalised birth rather than been saved by it.

My husband, Rich, was also completely convinced by the hypnobirthing ethos and dutifully did all the homework required of him, vowing to be the perfect birthing partner. The physiological approach of the course really spoke to us both, giving a clear explanation of what happens to the body during labour and how the sympathetic and parasympathetic nervous system have a major effect on birthing outcome. Rich felt he had a real, defined purpose during labour and birth which was undoubtedly helpful for us both.

### **The physiological approach of the [hypnobirthing] course really spoke to us both, giving a clear explanation of what happens to the body during labour...**

People we spoke to were generally not very supportive of our choice to plan for a hypnobirth. Attitudes ranged from doubtful to purely scornful, and common responses were "Just wait until you're screaming to get the baby out, you'll be asking for all the drugs they've got" and "There's no point in making a birth plan, it'll all be out the window once you go into labour". Luckily for my wonderful family, I am a very stubborn person and had absolute faith in what our hypnobirthing teachers were telling us, so I was able to smile serenely and thank people for their unsolicited opinions.

My 36 week midwife appointment was at Cossham with one of the midwives there. I had a private tour of the facility and was able to ask any questions I had. I left that appointment even more convinced that Cossham was where I wanted to give birth. The midwife had made me feel confident of my own strength and my body's capability to give birth. At 40 weeks I had an appointment with the midwife back in Portishead where I live.

Despite my protestations she booked me in for my induction, at 40+12. I requested a sweep, as in my view I would rather start things artificially in that way and still be able to go to Cossham than have to go to hospital and be induced. When I asked for a further one if necessary, I was told that the resources weren't available. On hearing this I called Cossham, who had told me to ring if I needed any further help. They immediately booked me in for two more sweeps and also explained that I had the right to refuse the induction at 12 days 'overdue'. They informed me of the procedure I should follow in order to maintain the safety of myself and my baby and I finished the call feeling empowered once more and still hopeful for the birth I wanted.

I went into labour at 40+7 in the morning. Rich had already left for work so I had a shower, figured out that this was the real event and gave him a call to come home. We spent most of the day walking, breathing and eating, with contractions (or surges, as we called them in hypnobirthing) mounting towards 5pm. I called Cossham who recommended I stay at home a little longer, so I settled down with my birthing ball, rocking and breathing. I was becoming concerned about the potential traffic as it was rush hour and then my waters broke, so the Birth Centre said to make our way in. The journey was fairly uneventful and the traffic not too bad, so after about 40 minutes we were walking into our private room at Cossham Birth Centre.

The atmosphere was incredibly relaxing and we'd arrived just before the midwives' shift change so we were left on our own to settle in and wait for the new midwife to start her shift and come to look after us. I was still able to breathe effectively through surges and was feeling fairly calm. Our midwife plus a student came in and introduced themselves. I got straight into the water which provided immediate relief and relaxation. Rich provided solid support, cooling my forehead with a flannel, offering a cold sports drink and coaching me through the breathing and relaxation that was necessary to maintain my focus.

I had one shock when suddenly a huge pressure built from within and something shot out with what felt like the force of a cannon firing! It turned out that in fact only my hind waters had broken at home and this was the rest. It did shake me for a while but with reassurance from the midwife I soon regained my composure!



During my time in the pool I'd been on my knees, resting my arms and head on the edge of the tub. All of a sudden I felt the most excruciating pain in my hamstring and screamed out loudly. It was interesting that this was the first pain I'd actually felt and I completely lost focus. I had bad cramp from fighting the water to stay on my knees. Rich immediately massaged the area to relieve it, but not in time for the next surge, which was significantly more intense and did hurt. Having got rid of the cramp, Rich brought me back into the necessary relaxation and the next surges were far more manageable. Even at the time I found this interesting, that my loss of focus made such a noticeable difference to the sensations I was experiencing.

Up to this point, the midwife and student had been very much in the background as I had requested, leaving me and Rich to go through our relaxation processes. They came over occasionally from their place at the other side of the room, and gently performed checks before withdrawing again. I was starting to feel as though the strength of the surges was reaching my limit and called over to ask for some gas and air. They responded with a smile and a nod and unhurriedly made their way over, at which point my baby arrived! I felt the head appear, where it stayed for one more surge and then fully emerged, at which point I remember looking straight at Rich and saying "Next one and it's coming out". I breathed down as hard as I could, working with my body, and my baby was out in one rush.

I sat in the water, cuddling my new bundle for at least a minute before it occurred to me to ask what we'd had. The news we'd had a girl, my most secret and private wish, was the perfect end to an amazing birth. I had a physiological third stage with little drama, on a birthing stool in the drained pool. Baby Girl was taken for checks after a while and then given to Rich for skin to skin while I had my stitches, having had a second degree tear. It was at this point I had my first pain relief; I instinctively refused when offered, but then the midwife gently congratulated me on a super birth and suggested I give myself a rest!

She recommended that gas and air would help me at this stage and I took her advice. I was glad I hadn't had any during the birth, as although it was a definite help through the stitches (not to mention being helpless with laughter

for most of the procedure) I'm not convinced I could have maintained the necessary focus while taking gas and air.

By the time everything was done (including a hot meal brought to us!) it was about 2am. The midwives offered to take Baby Girl so we could have our last uninterrupted sleep before taking her home. We accepted and settled down together, feeling so grateful for our double bed and private bathroom. At 6am we went to find our little girl who was safely with the midwives, and spent the rest of the day relaxing in our room and getting to know our daughter. I was struggling to get her to latch to breastfeed and received plenty of help from the staff who finally hit on the right position for us, at which point she had a lovely long feed. We went home later that afternoon.

**My birth experience was such a positive, empowering one. I strongly feel this is mostly due to the hypnobirthing classes we took.**

The birth of our second little girl was very similar in every way and just as wonderful. Interestingly, we had an extra birthing partner who was a friend of mine training as a midwife. She said she hadn't covered anything about hypnobirthing or similar as part of her degree and despite many different placements had never before witnessed a birth like ours.

I do find it difficult sometimes to share my story as there are so many women who did not have the labour and birth they wanted; however, I do think that more of us need to share our positive experiences.

*Emma Mason*

Further reading:

Hyperemesis Gravidarum support group:  
<https://www.pregnancysicknesssupport.org.uk/>



## Obituary

# Frances Oldham Kelsey, 1914-2015

by Marein Schmitthenner



*Frances Oldham Kelsey was a Canadian-American pharmacologist and physician.*

*As a reviewer for the U.S. Food and Drug Administration (FDA), she saved thousands of babies from thalidomide by refusing to authorise the drug for the U.S. market due to safety concerns.*

*Her stance led to much tougher drug testing and new laws regulating pharmaceuticals.*

Frances Oldham was born on Vancouver Island in British Columbia on 24 July 1914, the daughter of Frank and Katherine Stuart Oldham. She had an unusual career for a woman at the time – she earned a master's degree in science in 1935 and a PhD in pharmacology in 1938. By 1942, she was studying possible cures for malaria at the University of Chicago. This led her to become increasingly interested in drugs that pass from mother to fetus through the placenta.

She got married in 1943 and she and her husband had two daughters. She continued her studies and received a medical degree from the University of Chicago in 1950.

After working as an editorial associate for the American Medical Association Journal, teaching pharmacology and practicing general medicine, in 1960 she accepted a job with the FDA, evaluating applications for licenses to market new drugs.

The pharmaceutical company Merrell's application to licence thalidomide, a sedative that had been developed in Europe and was widely sold there since 1957, was one of the first cases Frances dealt with in her new job. Although the company claimed the drug was safely giving people deep, natural sleep and doctors had already been prescribing it to pregnant women in other parts of the world to suppress nausea, Frances found the safety evidence to be insufficient. She withheld approval and asked for more data on toxicity from controlled studies. A battle lasting months with Merrell ensued, during which time Frances was called 'stubborn' and 'unreasonable', but, luckily for thousands of American babies, she did not give in. About a year later, reports started to flood in from Europe and Africa about horrendous side effects and babies born with terrible malformations of their limbs. Merrell withdrew its application and the drug never made it onto the American market.

Dr. Kelsey's strength of character and courage are all the more amazing considering the laws on the safety of pharmaceuticals were not rigorously enforced at the time. She could have done what everyone else at the FDA was doing, with approval often being routine, but Dr. Kelsey was a very intelligent woman and not easily fooled. She acted according to strict scientific and ethical principles and according to her own strong morals, and she was not afraid to speak up for what she believed in.

The Kennedy administration used the Thalidomide tragedy to pass stronger drug regulations, and the 1962 law required tighter proof of safety and effectiveness of new drugs, disclosure of side effects and the swift removal of unsafe drugs from the market.

Dr. Kelsey moved on to head up the Division of Scientific Investigations of the FDA, which ensured the scientific integrity of the data on which the agency's decisions on drugs were based.

Her contributions have been widely recognized through Presidential and other awards. In 2000, she was inducted into the National Women's Hall of Fame.

Francis Oldham Kelsey died on 7 August 2015 in her daughter's home in London, Ontario, Canada.