# AIMS JOURNAL

## Making Decisions

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# AIMS

## The Association for Improvements in the Maternity Services

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Editorial

# Making Decisions

*Emma Ashworth considers the challenges of making decisions in pregnancy and birth, and their consequences.*

A huge welcome to readers old and new! The AIMS Journal, the backbone of our work for nearly 60 years, is now entirely available online, to all. The decision to make the Journal 'open access' and remove all paywalls was made for two main reasons.

Firstly, we wanted to ensure that everyone was able to access these important articles, looking at issues in maternity services, and that the insights and wise words of those writing for the Journal could be shared widely, to help influence improved maternity care for all. We wanted everyone to have access irrespective of their ability to pay. We hope that more people will want to write for the AIMS Journal and website, knowing that their efforts will now be seen by a much wider audience. We know that some readers will miss the printed Journal, but the new website does have PDF versions of articles and information for download and print, for those who prefer to read that way.

Secondly, many of our members were shocked to hear that the costs of printing and posting the Journal used all of their membership subscription. This meant that money for campaigning, the website, and other activities had to be found from other sources. Publishing the Journal directly to the website will mean that membership fees will now also be able to help support other essential work in providing information, running the helpline, and campaigning for improvements to the maternity services.

AIMS is, and has always been, its members. The charity is completely volunteer-run and we hope that the changes we are making to how we work will enable more members to be actively involved with our activities. We will have groups working on the Journal, Website, Helpline, Campaigning, as well as other essential groups managing finances, and membership, in order to keep things running smoothly. So, if you would like to join any part of the team we would love to hear from you, and if you're not already a member, then please consider joining and supporting the work of the charity at *www.aims.org.uk/join-us.*

This edition of the journal considers some of the decisions that we make, and their consequences. Those pregnant for the first time have to start learning to navigate the system fast, and when there's often a wait of a few weeks from that first pink line to even meeting the midwife, it can feel overwhelming. All maternity care is offered and we can choose to engage with all, some or none of it – so, if we decide to meet the midwife at this point, during that first booking-in appointment we are asked pages of questions, weighed, measured and told to pee in a bottle. I can be absolutely sure that for almost all such appointments, not once will we be asked whether or not we wish to be poked, prodded or dipped and what the pros and cons of any tests and measurements are from our point of view.

**The first, and most important point to remember, is that the only person who can make decisions about pregnancy and birth is the owner of the body.**

Our pregnancy tends to continue in the same vein with phrases like "I'll book you in for your scan" and "just hop up on the bed and I'll feel your tummy", "so I'll do a sweep now and then we'll book your induction". The language used sets us up for compliance. There is no expectation of us questioning why, or whether or not we wish to do this, and often it's only when a test throws up an issue that we might start to wonder whether we really wanted it all in the first place. Do I want to know if the baby has Down's Syndrome? Do we really have to be tested for gestational diabetes? Is it really necessary to be induced? Can we just slow down a minute and remember whose body it is anyway?

The first, and most important point to remember, is that the only person who can make decisions about pregnancy and birth is the owner of the body. We cannot be "allowed" or "not allowed"; we are adults with legal rights to make our own decisions. No one else can make them for us. While many health care providers may forget to phrase their

suggestions in this way, the first way to reclaim control is to rephrase what appear to be instructions as suggestions or offerings. For example, if your midwife says "I'm just going to take your bloods now", you can choose to hear, "I'm offering to take blood for a test. Would you like me to? Do you understand why I'm offering this and what benefits or risks it might have?" You can then choose to give or decline your permission or if you prefer, ask for more information. For instance, "I'm not sure what the blood tests are for. Before I make a decision about whether to have them, could you talk me through what they're for, please?" It is important to note that you have the right to take as much time as you need to make a decision, and you can change your mind at any time.

Making decisions in labour can be really challenging, not least because physiological changes in our bodies mean that to labour well, parts of our neocortex, the 'thinking' area of our brain, needs to shut down. That's why questions and conversations can be so intrusive – it's our body telling us that we need to stop trying to talk or think, and just be. Ideally, before labour, we will all have the opportunity to plan for a variety of scenarios and consider what options we may or may not be happy with. We may rely on our birth partner to be our advocate at this time.

One such decision is the type of monitoring that we might be comfortable accepting. In this journal Gemma McKenzie has reviewed the INFANT trial which looked at whether a computer system to look at readouts of continuous fetal monitoring (CTG/CFM) gave better results than humans interpreting the data. What this trial doesn't look at is whether continuous monitoring itself is actually beneficial. Touted as an important way to check on the baby's well-being, and effectively forced upon people whose labours do not follow statistical perfection, in fact the evidence for it being of value to most women and their babies is either scanty or non-existent and, chances are, it is causing more harm than good. Our information page on monitoring gives more information on this topic and is well worth a read before giving birth, and always remember that the only person who can decide whether or not you want to be monitored, and how, is you.

Decisions still come thick and fast after our babies are born. Do we want to have the heel prick test? There are many more conditions that our babies can have which are not tested for, because there isn't a cheap and easy test for them. The heel prick test does look at some very serious conditions, which if picked up early usually lead to much better outcomes, but it is an invasive and painful test. Do we want our babies to have vitamin K, and if so, by injection or orally? Do we agree to all of the vaccinations offered, or do we choose some, or none at all? Where do we get the information to make these decisions? NHS information is not always unbiased, as can be seen on the 'invitation to vaccinate' letters with the owl image and "Be wise… Immunise". In this journal, twenty years after having her first baby, Alex Smith is still unsure about whether she made the right decision about vaccination. What she does know is that the decision was hers and she had the time to make the decision, and to change her mind at any time.

Ann Roberts has written to us to tell us her experience of giving birth in the 1970s and 80s, and how it led to her becoming a birth campaigner. She was told, "although we think it right to explain to women why we do the things we do, you should not expect to make management decisions about your pregnancy in an independent way". Bio-ethics states otherwise, and now in 2018 even our NICE guidelines state, "People have the right to be involved in discussions and make informed decisions about their care" and the NHS has an entire page on consent, *https://www.nhs.uk/conditions/consent-to-treatment/*.

Times have changed, and the law is clear. Our decisions are our own and ours alone, and no matter how we are spoken to, when any health care is offered, it is up to us whether or not we accept it. This is the first principle of making our decisions – knowing that we can make them ourselves, and understanding that we can hear what we're told to do as being an offer, because, in law it can be nothing else (*http://www.birthrights.org.uk/resources/factsheets/consenting-to-treatment-2/*).

**"People have the right to be involved in discussions and make informed decisions about their care"** - *NICE guidelines*

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Click on the "download pdf" option, which is last of the options to the left of the article.

Article

# To Vaccinate Or Not to Vaccinate?

## My Research on The Question

*Alex Smith considers the decisions that she made for her children over two decades ago, and she's still undecided*

My youngest child is twenty two and a half years old, and I am still undecided about whether or not he should be vaccinated. Vaccination is considered to be the wonderful advance in modern medicine. Like the Emperor's new clothes, it is spun from pure gold; appreciated unquestioningly by anyone of any standing and intelligence. Such is the prevailing hegemony, accepting vaccination is simply common sense[1]. We are reassured that vaccination is safe and effective. Those who express concern are generally dismissed as irresponsible, misinformed or subversive… effectively silencing anyone who wishes to retain personal or professional credibility.

As a mother, I resent the assumption that I have not looked beyond the newspaper headlines; as an educator, it is the sense of being silenced that I find most disturbing. It is not my role to maintain the status quo nor is it to act as an agent for the state. My role as an educator is to enable critical thinking in individuals so that they can decide… or remain undecided…for themselves. This paper traces my personal journey from conditional acceptance to thoughtful indecision, as a vehicle for raising legitimate questions about vaccination.

*"By hegemony, Gramsci meant the permeation throughout society of an entire system of values, attitudes, beliefs and morality that has the effect of supporting the status quo in power relations. Hegemony in this sense might be defined as an 'organising principle' that is diffused by the process of socialisation into every area of daily life. To the extent that this prevailing consciousness is internalised by the population it becomes part of what is generally called 'common sense' so that the philosophy, culture and morality of the ruling elite comes to appear as the natural order of things." (*Boggs 1976 p39)

When I had my first baby in 1975, I chose not to have her immunised against whooping cough or measles. My reasoning at the time was that in the healthy child these two diseases generally ran their course, whereas diphtheria, tetanus and polio were harder to nurse. My philosophy was that if harm were to befall my child I would rather it was by an act of nature than by one of my own hand. Rumours rife at the time about the safety of the whooping cough vaccine later proved true when GlaxoSmithKline admitted in 2002 that thousands of babies in Ireland and the UK were inoculated with a batch of toxic whooping cough vaccines in the 1970s[2]. Putting profit motives and corruption aside, the good intention of the vaccination programme was no safeguard against human error.

The immunisation programme started much later than it does today…for reasons which I will return to later. During this time, I heard stories about vaccine damage, and vaccine damage denial. I was pointed towards a child who had been a beautiful, bright and happy baby until he received the measles vaccine…and told how the doctor had said that the worrying changes were simply co-incidental. I learned that the parent's perception was not to be trusted, that it was only anecdotal. Even at the age of twenty, I understood that while one story may not constitute evidence, the denial of many stories was disturbing.

I attended a talk by a consultant paediatrician who explained that deaths from the childhood diseases were declining at the same rate before the introduction of vaccination as they continued to afterwards[3]. As with Marjorie Tew's later analysis of declining perinatal mortality[4], the central factor in these declines was improved living conditions. This stirred my sense of political wariness, a wariness reinforced a few years later when I met a man who had worked in the pharmaceutical industry manufacturing vaccines. This man explained that he was very against having his child vaccinated because he knew what went into the vaccines. In his time at least, money had sometimes come before safety. I stored these insights without judgement…and my next three babies received

the tailored, reduced menu of vaccinations decided for my first…combined diphtheria and tetanus, and polio drops on a sugar lump…Done.

Then in 1995 I had my fifth baby and was very surprised to find that the women in the antenatal course I was running towards the end of my pregnancy were all anti-vaccine. "How interesting", I said. "Why?" This is what they explained…told in a way that I could understand.

The immune system is like a store cupboard. When infection enters the body through the usual way there is an incubation period during which messages are sent through a chain of immunoglobulins, from IgA in the mucus membranes through to IgG in the 'store cupboard'. This gives IgG time to replicate itself, not only increasing in number but also shape-shifting a little to create antibodies that are perfectly suited to the specific visiting pathogen. However, when a vaccine is injected into the body, this chain is bypassed. It is like having unexpected visitors. Antibodies are produced from 'the cupboard' but there has been no time for replication or specification. The immune system becomes depleted and the antibody response is inferior and not as long lasting. For a fuller explanation of this read the papers below [5,6]. This vaccine induced immune response has (at least) three implications:

* Immunity from vaccination wears off after a while resulting in outbreaks of disease in adults when it can be more serious.
* The differently shaped antibodies are less able to cross the placenta or are not there to cross the placenta, so that newborns may not be protected by the same degree of passive immunity as they once were; hence the bringing forward of the immunisation programme and the untested vaccination of pregnant women.
* The depleted store cupboard may leave the body vulnerable to other infections and be associated with the steep rise in autoimmune diseases like asthma and type 1 diabetes…both of which contribute to morbidity and mortality in the UK.

In summary, vaccination may be making new born babies more vulnerable and replacing the childhood illnesses with serious chronic diseases for which there are no cures. Vaccination was introduced as a widespread well-intentioned measure at a time when we knew even less than we do now about the way that the immune system works and the impact that vaccination has on it[7].

## Vaccine Safety

Better informed but still undecided I read a book that one of the mothers on my course had passed to me. Conscious that the author was not impartial, I was nevertheless moved by accounts from parents whose children had become ill or had died following vaccination. In many instances, science cannot prove that morbidity or mortality following vaccination is caused by vaccination, but the UK government absolutely recognises that vaccination can do harm. In philosophy and ethics there is the doctrine of double effect where harm to some is accepted as a side effect of promoting the good end. People who have been very disabled by vaccination can make a claim for a one off government payment of £120,000 and apply for additional compensation[8]. Between 1979 and 2014 the fund paid out 73 million pounds to 931 people, following 6,026 claims; however, the government is unable to attribute causation to particular vaccines as so many vaccines are combined[9].

Vaccines are tested for safety both individually and to some extent in combination. For many reasons it is not possible to use the prospective randomly controlled trial with a saline placebo control group…the gold standard of testing. It is considered to be unethical to leave a control group of children 'unprotected', so many trials test one vaccine against another[10] and combined vaccines against a cohort being given non-combined rather than against a true placebo. Vaccines routinely given to pregnant women are untested on pregnant women for the same reason[11]. A new vaccine is considered safe if the harm from it is no greater than from the 'placebo' vaccine…or if no excessive harms are seen in real use. Trials controlled with a true placebo, looking for long-term harms, or comparing with non-vaccinated people are very rare…or rarely published.

One concerns the Pandemrix flu vaccine used in the 2009/10 swine flu outbreak. This is recognised as having caused narcolepsy in over 100 people in the UK[12]. The government appealed against the court's award of compensation to one of the children seriously disabled by the vaccine, but this was overturned in February this year…and in June, the European Court of Justice[13] decided

in a case of a man who had developed multiple sclerosis following vaccination and later died, that:

> *"If the development of a disease is timely to the person's receiving a vaccine, if the person was previously healthy with a lack of history of the disease in their family and if a significant number of disease cases are reported among people receiving a certain vaccine, this may serve as enough proof."*

Clearly, the answer to the question 'is vaccination safe?' is 'not always', and hopefully those damaged by vaccination will find it easier to claim compensation in the future.

## Reporting Bias

A recent review of data from the Vaccine Adverse Event Reporting System (VAERS) showed a dose-dependent association between the number of vaccines administered simultaneously and the likelihood of hospitalization or death from an adverse reaction, the association increasing with younger age at the time of the adverse reaction[14]. Wondering at the lack of media coverage about these findings, the author draws our attention to the degree of advertising revenue that comes from drug companies. Bias is a factor at every level of the vaccine enquiry. Indeed, a Cochrane review[15] found widespread bias in the publishing of studies related to influenza vaccination:

*"...industry-funded studies were published in more prestigious journals and cited more than other studies, independent of methodological quality and size. Studies funded from public sources were significantly less likely to report conclusions favourable to [influenza] vaccines... reliable evidence on influenza vaccines is thin but there is evidence of widespread manipulation of conclusions and spurious notoriety of the studies."*

Reporting bias is compounded by the pharmaceutical industry's well-documented history of concealing unfavourable findings[16, 17] making it impossible for anyone, including policy-makers, to really establish the reliability of the evidence that is available.

## Efficacy, honesty and coercion

For many parents, the chance of harm is outweighed by the reassurance gained that their child is now protected from these diseases…that vaccines are safe and effective. Tests of vaccines for efficacy (the ability of the vaccine to induce an antibody response in ideal circumstances), do not tell us about the degree to which they are effective, i.e. whether they reduce the occurrence or severity of the disease in real life. Finding reliable data about the level of protection conferred by a vaccine is difficult as information is often contradictory. This is best illustrated with some examples.

- The Welsh Government circular briefing health boards and medical practitioners said that influenza vaccine effectiveness was 52.4%, broadly in line with a typical flu season[18]. Meanwhile, Public Health Wales on their website say that the vaccine generally gives good protection with 70-80% reliability in healthy adults against all strains of flu included in the vaccination[19].
- A 2014 Cochrane review[20] concluded that the preventive effect of parenteral inactivated influenza vaccine on healthy adults is small with 71 people needing vaccination to prevent one case of influenza. Vaccination showed no appreciable effect on working days lost or hospitalisation. Meanwhile, more and more people each year are urged to accept influenza vaccination, targeting the elderly in whom the vaccine in the years 2016-2017 was 0% effective[21].
- The Cochrane review also found that the protection afforded pregnant women from influenza vaccination is uncertain or at least very limited with the effect on their newborns not statistically significant. Yet in the same year, the MBRRACE enquiry into maternal deaths[22] stressed that increasing immunisation rates in pregnancy against seasonal influenza must remain a public health priority…an uncertain policy that will leave many thousands of women experiencing flu-like side-effects[23].
- A report published this month about influenza vaccination for healthcare workers in the UK[24] concluded that the evidence for safety benefits was not straightforward and had been interpreted differently by different systematic review authors. Cochrane[25], whose job is to make sense of the complexity, also recognised the poor quality evidence but concluded that offering influenza vaccination to healthcare workers who care for the elderly may have little or no effect on

laboratory-proven influenza. Meanwhile, the NHS 'Flu Fighter Campaign'[26] aims for 100% compliance from health care staff with the offer of incentives to staff such as a 'flu fighter sticker'.

- And, plans to vaccinate children in the UK this autumn (2017) with the nasal flu spray Fluenz Tetra seem to be going ahead even though the CDC (Centers for Disease Control and Prevention) in the US has prohibited its use this year because no protective benefit could be measured.

**The (2014) Cochrane review also found that the protection afforded pregnant women from influenza vaccination is uncertain or at least very limited with the effect on their newborns not statistically significant.**

With such conflicting information, I feel I can be forgiven for my indecision. The good intention of vaccination does not remove the need for honesty, knowledge and respect in those giving advice about vaccination. Very few women are aware that the 'whooping cough' vaccine offered in pregnancy (Boostrix[27]) is in fact four vaccines in one. When I asked an immunisation nurse at a GP surgery I was visiting if she informed pregnant women of the four-in-one nature of the vaccine and of the fact that it had not been tested on pregnant women, I was told to 'move along'. When I asked again, I was told to move along more forcibly. I suspect that she didn't know. Then earlier this year, older members of my family received letters, purportedly from our GP surgery but actually from the health board. These letters strongly advised take up of the influenza vaccine stressing that flu could be fatal and saying that they must attend the surgery urgently. I was shocked by the alarmist and coercive use of language and wrote to the health board expressing my concern that this approach was unethical and breached the principles of informed consent…but received very short shrift.

If the uncertainty and complexity of the risk-benefit analysis was explained to people beforehand, vaccination take-up could well decline, but informed consent is still the law. The modern concept of herd immunity requires a large majority of the population to be vaccinated in order to protect the vulnerable, but the ethics of mass medication are complex. If the UK government adopted a policy of mandatory vaccination, believing the end would justify the means, they could equally argue the case for mandatory contraception for the poor, poverty being a major risk factor for increased morbidity and mortality from all causes. The original concept of herd immunity refers to the way that a healthy community becomes more resistant to a disease that is in frequent circulation. The cold virus for example, might wipe out a South American tribe exposed to it for the first time, but in the West it is regarded as a minor illness, even though it can lead to serious complications in the vulnerable. If a vaccine against the common cold was ever available we would quickly be educated about this 'deadly disease' and if the cold became less 'common', our herd resistance might dwindle making us all more vulnerable when outbreaks occurred. Building resistance to common diseases by improving living conditions and by maximising the incidence of breastfeeding is absolutely safe and effective, and without risk of debilitating side-effects. With the scale of economic inequality in the UK being one of the worst in the developed world[28], genuine intentions to reduce morbidity and mortality should perhaps address this first; that would indeed be spun gold.

My children, now grown up, make their own decisions about vaccination, while I remain undecided, but as a family we are all agreed that while the Emperor may not be naked, he is perhaps only partly clothed. With the number and combination of vaccines increasing yearly, it is time we all started to ask questions.

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*https://www.aims.org.uk/journal/item/vaccinate*
Click on the "download pdf" option - the last option in the list to the left of the article.

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AIMS

# Handling threats of Social Services

*Andrea Daniel was threatened with Social Services by her midwife. This is a great example of a Trust handling the situation well.*

It is not uncommon for AIMS to receive helpline calls from women who are being coerced into accepting interventions or antenatal tests by being threatened with Children's Services (formerly known as Social Services) if they do not comply. However, the law is clear: in the absence of a court order, pregnant women have the absolute right to decide to accept or decline interventions or care offered to them, from scans to vaccinations. Using the threat of Children's Services to scare a woman into compliance is coercion, and it is illegal to coerce a person into an intervention[1].

In Stephanie's case, after persistently declining an offer to attend a routine ultrasound examination, the midwife stated that in that case she would be referring her to Social Services (as it was then known). This tactic is not uncommon and, on AIMS' advice, Stephanie wrote to the Chief Executive at her local Trust. The Chief Executive passed the letter to the Head of Midwifery who responded immediately and positively. Stephanie is not her real name although she has given AIMS her permission to publish this article under a pseudonym, and all other names have been removed.

*Dear [Chief Executive], I am 20 weeks pregnant with my 5th baby and I have had the first meeting with the midwife. I am larger than expected and suspect that I may be expecting twins. The midwife wanted to refer me for an ultrasound examination, I declined her offer as I am not prepared to expose my babies to the risk of ultrasound. I home educate and also declined vaccinations. The midwife didn't inform me of any concern at my appointment and I thought all was well. The following week I received a copy of my case notes.*

1 http://www.birthrights.org.uk/resources/factsheets/consenting-to-treatment-2/

*I was asked if I took drugs and informed her that I had taken Ecstasy once in my teens and ended up in hospital. I have not taken drugs since and no other midwife or health visitor attending my previous pregnancies has found a problem. I found in the notes that midwife S of [the] medical practice intends referring me to Social Services as she considers me 'high risk'. When I called to find out why she had not discussed anything with me at my appointment she was rude and said I could still be taking drugs because of that incident as it shows I have a tendency for erratic behaviour. And also because I home school and she said she doesn't know if I am doing what I should and because I wanted midwifery led care and home birth as I did with my last 2 pregnancies where I had no problems. I am in regular contact with the local authority for my homeschooling and neither they nor my health visitor has any concerns.*

*Those are not grounds for an SS referral and should I be referred I will be making a report to the Nursing and Midwifery Council on the grounds that this midwife has used bullying tactics to force me to comply with her advice. Furthermore, bullying a woman into consenting does not comply with the requirements of informed consent.*

*I do not intend to see midwife [A] again and I would be grateful if you would appoint another midwife to attend me, as she is causing me unnecessary stress which is not good for me or my unborn baby/babies. Should I subsequently have my suspicions confirmed, that I am expecting twins, I trust that your staff will be making the necessary arrangements to ensure that I am attended by midwives who are experienced in attending twin births.*

*I look forward to your response.*

*Regards,*
*Stephanie*

The Trust responded positively, as follows:

*Dear Stephanie,*

*The Chief Executive] has shared with me your email, received yesterday. I am sorry that your experience of our midwifery care and communication has not been as we intend and appreciate you contacting us so that we can address this immediately and ensure your on-going care is more positive.*
*I have tried to phone you a short while ago to discuss how we can best proceed however appreciate Sunday mornings are not always the best time to make contact.*

*I have spoken to the community midwifery team's manager [B] and she has identified a different midwife to be your named midwife. Your lead and buddy midwives will be [C] and [D]. The intention is that we will be able to afford continuity of care to you through the antenatal and postnatal period, through the allocation of a lead and a buddy midwife.*

*[B] will aim to contact either tomorrow morning so that they can make contact and arrange to meet you.*

*I have reviewed your records and cannot see that any social services referral has been made however will explore this further with Midwife [A] before confirming this to you later in the week.*

*In relation to your choice to birth your baby or babies at home, this is far better chatted through in person so your midwives will ensure this takes place.*

*I will try to call you again during Monday / Tuesday and look forward to speaking to you then when I can explain how I would like to use your experience to improve the midwife's care for future women.*
*Kind regards,*
*Director of Midwifery*

It is important to note that not all Trusts respond in this way, and in some situations women have reported midwives continuing with the referral, and some women have alleged that midwives have made up reasons for referrals. In some of these situations we have been given clear proof that the reasons were indeed fabricated. However, it was good to hear that in this situation, the Trust did respond appropriately. Families who are being coerced by medical staff in this way might find the Birthrights' sheet "Social Services and Maternity Care" to be helpful (*http://www.birthrights.org.uk/resources/factsheets/*), and also the charity "Family Rights Group" may be able to offer free help and advice from solicitors who specialise in supporting this type of issue (*https://www.frg.org.uk/*).

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# Act now to keep the Better Births vision alive - a call to action

*Jo Dagustun calls to campaigners to make Better Births a reality*

In 2016, the National Maternity Review team, in their Better Births report, recommended a transformational change in the way in which maternity services in England are designed and delivered, with a vision:

> *'...for maternity services across England […] to become safer, more personalised, kinder, professional and more family friendly; where every woman has access to information to enable her to make decisions about her care; and where she and her baby can access support that is centred around their individual needs and circumstances. And for all staff to be supported to deliver care which is women centred, working in high performing teams, in organisations which are well led and in cultures which promote innovation, continuous learning, and break down organisational and professional boundaries.' (NHS England, 2016, p8)*

No-one seriously underestimates the challenges that will be involved in bringing about such transformation. But women and families in every area of England deserve no less. In that context, it is highly worrying that some commissioning areas are seemingly reluctant to sign up in full to the Better Births vision and recommendations. Instead, ongoing discussions suggest that the feasibility, affordability and even the desirability of the Better Births vision and its clear recommendations are up for debate. In this context, I would like to pose the following question: is there any reason why every local area should not adopt the Better Births vision and all its recommendations IN FULL as a minimum to drive local implementation work?

We know that the HOW will be affected by the local context, and in some very specific situations it is possible that agreement might be reached that some limited modifications might be acceptable. But I would like to suggest that it would be a big mistake for us to confuse the need for specific local action plans with moves to undermine local commitment to the Better Births recommendations more generally. If we don't commission for women to receive meaningful continuity or carer (based on a relational model of care over the antenatal, intrapartum and post-natal period), for example, what chance do we have of providers stepping up with plans to deliver this?

We need to stand firm. We have always known that the agenda for change set out in Better Births would be highly challenging for existing service providers. It is meant to be. It represents an ambitious demand for a shift in the power relations of maternity services, one which has been fully evidenced both by the best available scientific research as well as by a careful exercise in which the voices of a huge number of women and families around the country were heard. But we also need to be clear about one more thing: it does not represent an agenda that is infeasible or unaffordable, and it is important for us to avoid being dragged (or even seduced) into debates which seek to suggest any different. It is important that the vision and recommendations of Better Births is properly reflected in local visions and strategies. Without this, the likelihood of Better-Birth-compatible services being commissioned is extremely low.

I would urge AIMS activists across England to play a key role in ensuring that the Better Births vision, and its recommendations, are accepted in full. In full is important, because the Better Births recommendations are designed to work together as a package: each is necessary for the successful delivery of the others.

Now is the time – as each of the 44 sustainability and transformation partnerships (STPs) across England develop their 5-year maternity strategies and action plans – for the united voices of birth activists in every area of the country to be heard loud and clear. Local AIMS activists – in partnership with other service user representatives, doulas, antenatal educators, midwives, and indeed everyone else with a keen interest in improving maternity services – must

decide now whether or not they are willing to become the 'guardians' of the Better Birth vision and recommendations. For without our ongoing support, the promise of Better Births is bound to fail.

## Implementing Better Births: key actions for AIMS activists now

Find out which STP you come under. Link up with service user representatives already working with your STP. There are now 44 Sustainability and Transformation Partnerships (STPs) across England, bringing together the NHS and local councils to improve health and care. Each one should now be developing a strategy to implement Better Births. Service users should be involved in (or be co-producing) this work: it is probable that representatives of your local Maternity Voices Partnerships are leading on this work, and they will need support from all birth activists in the local area to ensure that Better Births remains central to the local strategy.

Get involved in scrutinising the activities of your local STP. Is the Better Births vision for maternity services at the core of local vision statements? Each of the Better Birth recommendations aimed at providers and CCGs should be replicated in local strategy documents and local action plans. Service user representatives can play a key role in ensuring that this is the case.

Keep AIMS in touch with how this work is going in your local area, and ask for help if you need it. AIMS is involved in work at the national level overseeing the implementation of Better Births and AIMS relies on its members across the country (you!) to understand how this work is progressing at the local level and to pinpoint emerging areas of concern. In turn, AIMS stands ready to support your efforts at the local level.

## Reference

NHS England (2016) National Maternity Review: Better Births – Improving outcomes of maternity services in England – A Five Year Forward View for maternity care Available at: https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-reviewreport.pdf



# Debate: Women and babies need protection from the dangers of normal birth ideology

*Beverley Beech sumarises the debate between Professor Dietz and Professor Lesley Page*

*BJOG Debate: International Journal of Obstetrics and Gynecology, Vol 124, Issue 9, August 2017, p 1384 and 1385.*

In August 2017 the International Journal of Obstetrics and Gynecology invited two Professors to discuss the claim that 'women and babies need protection from the dangers of normal birth ideology'. The first article was written by Professor Hans Peter Dietz, a professor of Obstetrics and Gynaecology who specialises in urogynaecology at the University of Sydney.

### FOR: The recent maternity review risks making the situation even worse

*http://onlinelibrary.wiley.com/doi/10.1111/1471-0528.14666/full*

In the first paragraph Professor Dietz referred to the Morecambe Bay Report, which he claimed caused 'concern over an ideology of vaginal birth at all cost' and that 'forced …. a nationwide review'. He argued that 'Many clinicians saw this as an opportunity to set things right...'

He considers the Better Births' report to be a whitewash and Julia Cumberlege to be 'one of the most prominent advocates of the ideology that led to the problems chronicled in the Morecambe Bay Report'.

According to Professor Dietz the issue is always the same: 'a culture of midwives [and sometimes obstetricians] promoting normal childbirth "at any cost"—which means late intervention, or none at all.' He claims that morbidity and mortality have been modern medicine's top priorities and that the Cumberlege Report wants to reduce interventions further in order to reduce the cost of medical interventions.

He argues that 'women are asking for more home birth, more midwifery autonomy, less intervention' because they are given biased information, which keeps them in the dark about the risks 'because that might frighten them' and that this is not acceptable and this will have to change.

In his view the Cumberlege Report will offer a poor defence when judgements will be based on the 2015 Supreme Court decision in Montgomery v Lanarkshire, (which requires doctors properly to inform women of the risks) and 'is likely to make matters worse' suggesting that the introduction of privatised, independent midwifery, similar to that in New Zealand will also make matters worse, leading to unintended negative consequences and an increase in both morbidity and mortality.

Finally, he claims that 'Natural childbirth ideology is not just dangerous to women and babies, it is becoming dangerous to its adherents.'

The counter-argument was presented by Professor Lesley Page.

## AGAINST: Support for normal birth is crucial to safe high-quality maternity care

*http://onlinelibrary.wiley.com/doi/10.1111/1471-0528.14668/full*

Professor Lesley Page, President of the Royal College of Midwives and the first Professor of Midwifery in the UK argues against the proposal, stating 'that support for normal birth as a dangerous ideology is to ignore the dangers of accepting birth as primarily a medical event that is prone to overuse of interventions'. The argument flies in the face of evidence-based policy and guidelines …. [and] ignores evidence of the risks of over-medicalisation of health care'.

In challenging the medicalised view of threats to maternal and perinatal health, which can be described as "too little, too late" Professor Page suggests that the threats of over-medicalisation of normal pregnancy and birth can be described as 'too much too soon' and highlights examples which include 'unnecessary caesarean section, the overuse of induced or augmented labour, continuous electronic monitoring, episiotomy and antibiotics postpartum. These, if overused, do not improve safety but increase risk of harm.'

In describing approaches to support normal birth, Professor Page points out the importance of respectful, compassionate and skilled care which aims to optimise the health of the mother and baby, taking account of physiological and psychological health and weighing up the risks and benefits of interventions and the long-term effects.

Finally, in pointing out that 'Normal birth' is in a minority, and the rates are falling.' Professor Page states that 'The argument that women and babies need protection from the dangers of normal ideology ignores the strong evidence base for supporting more women and babies to have a straightforward normal birth, and a positive experience of care. Support for 'normal birth' is a crucial part of safe high-quality maternity care.'

### *AIMS Comment*

Professor Dietz's argument appears to be based on the perception that women choose home birth and 'vaginal birth at all costs' because they are not informed of the risks and they need to be. He perceives the Morecambe Bay tragedy as exemplifying this, rather than an example of a dysfunctional obstetric unit.

He perceives the damage that many women and babies suffer is caused by a 'normal birth' ideology, and a reduction in intervention will lead to an increase in morbidity and mortality. It appears from his article that he is unaware of the growing evidence of the benefits of continuity of midwifery care and normal physiological birth, and the risks that he lists are precisely those that women face when they are required to book into an obstetric unit.

In contrast, Professor Page's justification of the 'normal birth ideology' is cogently argued and supported by frequently quoted research. Her paper also provides good explanations for the need to avoid 'too much, too soon' when intervention is really not required, but it happens anyway, causing as much or more harm in terms of numbers

of injured babies and mothers as the 'too little, too late' scenario.

The two original papers should be read by everyone involved in maternity care as they expose the blinkered thinking employed by those who seek to justify over-medicalised care, blaming it on what they perceive to be a 'normal birth ideology' rather than examining the adverse effects of over-medicalised, fear-based, care.

***Note:*** *Very few women achieve a straightforward normal birth in our obstetric units. A prospective cross-sectional prevalence survey of five consultant units in one region (Downe et al, 2001) found that only one in 6 first time mothers and only one in 3 subsequent births could be considered a straightforward normal birth. The 'normal delivery' statistics collected by the national Information Centre includes: augmentation of labour, ARM, electronic fetal monitoring and a managed third stage, an explanation perhaps for many over-inflated hospital claims of 40%, or more, normal births.*

## Reference

Downe S, McCormick, Beech BAL (2001). Labour interventions associated with normal birth, British Journal of Midwifery, Vol 9, No 10, p602-6.

To print this article directly from AIMS, please go to *https://www.aims.org.uk/journal/item/dietz-page-debate-normal-birth* Click on the "download pdf" option - the last option in the list to the left of the article.

# A normal birth story - at last

*Michelle Quashie shares the story of her postive birth*

After two previous traumatic Caesarean sections, followed by a hospital VBA2C (vaginal birth after 2 caesareans), my home birth was everything I have learnt that birth can be.

It's truly wonderful to end my birthing days with the most beautiful, empowering birth.

It was instinctive, intimate, undisturbed, empowering, peaceful and I was in control at every moment.

I didn't have anyone tell me what position to be in.

I decided when it was time to get in the pool.

No one told me when I could push or not push.

No one knew the dilation of my cervix at any point.

My movements weren't limited or hindered by machines or technology.

Time did not dictate my fate...

I had chosen not to have any vaginal examinations because I didn't need someone to tell me what my body and my baby were doing. There was no medical indication to do so. Instinctively I knew that everything was OK and my body was working just fine.

In the early hours of the morning I felt my membranes rupture. I lay in bed making the most of the rest as I felt the familiar feeling of contractions waving through my abdomen every so often.

As the dawn broke I decided that we should get the pool inflated as I knew that today I would give birth to my baby. Around 9am my midwife had arrived and was sitting across the room quietly drinking her tea.

I danced and swayed through each contraction and found my body wanting to lunge lower to the ground as labour progressed.

I wanted to be upright at all times. I couldn't imagine lying down and I wasn't expected to.

When my legs felt tired from dancing and the contractions felt too intense to dance through, I knew it was time to take comfort by the warm water that was ready to take the weight of my body. I got in and floated star shaped for a while before finding comfort leaning on the edge of the pool.

I was not distracted or disturbed at any point. I remained focussed, using all my concentration and will to feel my baby inside my body moving down into my birth canal. I didn't need pain relief, I just needed peace and tranquility around me to focus solely on my breathing and my baby. The more intense the contractions were the more I found myself panting.

I felt a sense of panic for a moment but reminded myself this meant that it was highly likely that my baby was soon to enter the world. This thought kept my mind on track.

After just over an hour of being in the water, I felt my body pushing my baby out so went with it and the head was born. I rested with the head between my legs for a few minutes. My midwife asked if I was having contractions. I was but they were restful contractions and my body did not bare down with them, so I remained restful. Seven minutes later I felt my body bearing down with the contraction so I went with it. My baby was born, I did not tear, I didn't need stitches.

My midwife gently pushed my baby through my legs. I scooped my baby from the bottom of the pool into my arms to see the cord wrapped around her neck. With the help of my midwife we looped the cord twice from around the neck.

With all of my children peering over the rim of the pool I discovered our new family member was a girl. I cried with happiness saying "this is amazing".

There I sat cradling my baby and feeding her for nearly an hour. I took in her beauty, I studied her face and observed her body from head to toe, in awe of the miracle my body had grown. I knew I was flipping amazing! I knew women were flipping amazing!

Protected by the water and the safety of the surrounding inflatable pool it was just her and I. Nobody took her, nobody tried.

Eventually I felt ready to share her with the rest of our family. My husband then tied her cord and my eldest son cut the cord so she could be cuddled by her brothers whilst I watched on in euphoria.

Eventually I left the pool for more skin to skin and a sausage sandwich. I gave birth to the placenta just under 3 hours later. My labour and birth was everything I had dreamed of. My sons had witnessed first hand that birth can be beautiful. In my children's own words they describe my birth to be exciting and astonishing. I hope this positive image stays with them and prepares them for adulthood, for the time they support their partners and welcome their own children into the world.

I knew this was going to be my last pregnancy and birth. I had spent the last three years since my previous hospital VBA2C, researching and gaining as much knowledge about physiological birth as I could. I didn't fear birth but I did fear surgery.

I knew that this time I didn't want to be observed and have numerous strangers entering my birth space.

I knew that everyone in my birth space needed to be free from fear and have my very best interests at heart.

I knew that I didn't want routine examinations and various fingers inside me to check that my labour was conforming to expectations.

I knew that I needed to feel safe in the hands of those caring for me.

I knew that I needed to move, eat and drink freely.

I wanted to be certain that my individual needs were at the heart of the care I was receiving.

I put my trust in those who were caring for me, despite the warning signs and red flags, until I reached 37 weeks. It was then that the reality hit me that those responsible for my care did not trust my ability to make informed decisions regarding my birth. They were so caught up in ticking boxes, outlining risks and providing care that met the needs of the system that they failed to see or listen to the woman that was stood before them. A women whom they knew, a women who had worked alongside them to improve maternity care for all women. Yet, they failed to provide the individualised care I needed to support my birth plans and make me feel safe which in turn led to them failing me.

Once again at nearly 37 weeks pregnant, I found myself feeling vulnerable, fearing for my safety and reduced to tears.

I knew that the lasting effects of this birth had the ability to heal me, shape me or break me. I knew this birth had the power to determine who I was as a mother, as a wife and as a woman in society.

I didn't want to battle again at this stage in my pregnancy. I knew I needed to remain calm during the last weeks of my pregnancy. It was then that I knew I had no choice but to privately hire the care I needed to support my plans for birth.

When I interviewed my midwife and heard her say, "Michelle, I don't intend to treat you any differently than any other woman I have cared for." I could have cried; from that moment I knew Kay was the midwife for me. At last I would be cared for as woman and not as the risk labels that were part of my history.

Giving birth to my daughter has made me more determined to join all those striving to improve maternity services for women.

I want all women to not just to be heard but be listened to.

I want women to feel safe and supported during pregnancy and birth.

I want women to have real choices in pregnancy and birth and be fully aware of their options.

I want women to have continuity of carer throughout pregnancy and birth.

I want women to receive care governed by their individual needs and not care that is determined by a system.

I want women to receive care that caters for their physical and emotional needs.

I want women to feel in control and make the decisions through their pregnancy and birth.

I want women to be given the knowledge to understand pregnancy and birth and to be encouraged to use their voice and ask questions.

I want women to feel that birth is a positive experience even if it didn't go as planned.

I want women to be treated with dignity and respect.

I want women to enter the post natal period feeling whole and emotionally well-knowing how to access on-going support should they need it.

# What AIMS did for me

*Ann Roberts shares her story of how AIMS helped her back in 1983*

I first contacted AIMS 34 years ago (1983), when I was pregnant with my second baby, having had a typical conveyor belt 1970s induction with my first baby eight years previously. My first baby's birth was a "natural" one, but not a fun experience. Routine care included: induction close to my due date, shave, enema, ARM (artificial rupture of membranes), syntocinon drip, episiotomy.

We survived all that and, having declined pethidine, managed to breastfeed twice that evening for the allowed two minutes each side; but then my precious baby was taken away to a nursery for the first two nights – I was devastated and couldn't understand how this could happen. I wandered the corridor waiting for her to wake and feed, terrified someone would give her a bottle. Miraculously we survived our five day stay and came home fully breastfeeding.

Eight years later, pregnant with my second baby, my eyes had been opened by the Pithiviers (Odent) documentary. At 11 weeks I decided to decline an ultrasound, knowing nothing about it, I just reacted to the authoritative tone of the "Attend this appointment with a full bladder" instruction. It brought back memories of the way I had been treated when I had my first baby – I felt inexplicably anxious and helpless as I made my way to the hospital.

On arrival I was greeted by a young Senior House Officer with a letter from "my" consultant explaining why I should agree to this ultrasound – "you are unlikely to know when you conceived" was among other unconvincing reasons to undergo this new procedure and it finished with "although we think it right to explain to women why we do the things we do, you should not expect to make management decisions about your pregnancy in an independent way". WOW.

I was left alone in a small room to digest this, cried, left the hospital distressed but unscanned. I contacted AIMS at once having spoken to a friend who had recently organised a home birth with their help. Beverley Beech herself offered support, by letter and phone call. I declined any further appointments with the hospital and organised a home birth. That baby was born at home, as were my subsequent two babies, with all my antenatal care at home or via the GP surgery; none of them had an ultrasound. I never entered a hospital when pregnant again.

I wrote about these experiences for the AIMS journal at the time, and later wrote articles about the home birth service offered by community NHS midwives which was fantastic. I have been a member of AIMS ever since, spending time with midwives at meetings, at conferences and of course reading the wonderful journal. I have also continued to campaign for homebirth, and against routine (and overuse of) ultrasound.

My third baby sat on Caroline Flint's lap at lunch when she did a day with the midwives for the Association of Radical Midwives. When my fourth baby reached a year old I trained with NCT and became an antenatal teacher – 26 years and counting! My mission has always been to empower women and their partners to understand that they have choices and can make informed decisions about their care.

My four children are all grown up now – and I have two grand daughters – I don't think things have got any easier for women and the devastating news from IMUK about the NMC decision over their indemnity makes me fear for my daughters' birth experiences in the future.

# Computerised interpretation of fetal heart rate during labour (INFANT): a randomised controlled trial, The INFANT Collaborative Group

*http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)30568-8/abstract*

*Gemma McKenzie summarises the INFANT trial, 21st March 2017*

## Background

Continuous electronic fetal heart rate monitoring (EFM) of the unborn baby is widely used throughout the UK during labour and birth. However recent research suggests that EFM does not lead to better outcomes for babies; in fact when EFM is used instead of intermittent auscultation (midwife listening to baby's heartbeat with a doppler), women are more likely to have caesarean sections and instrumental deliveries.

The researchers in the present study suggested that one reason why this could be the case is because health carers may have difficulty interpreting the baby's heart trace correctly during labour. They proposed using a computer, linked to the EFM, to objectively detect abnormalities in fetal heart rate patterns. Any abnormality would then be brought to the attention of health carers, who could respond accordingly.

## Aims

The aims of the study were to test the hypotheses that:

i a substantial proportion of substandard care results from failure to correctly identify abnormal fetal heart rate patterns;

ii improved recognition of abnormality would reduce substandard care and poor outcomes;

iii improved recognition of normality would decrease unnecessary intervention.

## Method

The researchers recruited 47,062 women from 24 maternity units around the UK and Ireland. All of the women had been clinically recognised as requiring continuous EFM during labour and birth (although the reasons as to why they needed EFM were not given or explored). All of the hospitals used a particular EFM system called Guardian. Women were randomly allocated to one of two groups: they would either have 'decision support', i.e. additional software called INFANT linked to the EFM equipment that would assess the baby's heart rate and if necessary produce a colour coded alert, or they would have 'no decision support,' i.e. the health carer supporting the mother would interpret the EFM results and respond according to his/her own interpretation.

The researchers then looked at the outcomes of the births including, for example, any stillbirths, admissions to the neonatal unit, caesarean and instrumental births, and duration of labour. In addition, a questionnaire was sent out to parents two years after the birth to assess the child's health, development and wellbeing. Finally, the case notes of any babies who had had an adverse outcome potentially associated with asphyxia during birth, or who had died during birth, or were stillborn, were reviewed by a panel comprised of a midwife, neonatologist and senior obstetrician, to see if the baby's care was suboptimal, i.e. 'if it was possible or probable that different management would have prevented the adverse outcome.'

## Results

The researchers concluded the following:

* There was no difference in adverse outcomes for the babies between the two groups. For example, in both groups 0.7% of the babies were considered to have had a 'poor outcome.'

* With regards to the cases that went to the expert panel for review, there were no differences between the two groups in the number of babies who had received 'suboptimal care'. Further, this preventable substandard care appeared to 'involve failure to take appropriate management decisions once a cardiotocographic abnormality had been recognised', as opposed to health care providers failing to identify a pathological fetal heart rate.
* From the results of the questionnaire, no significant differences in health, wellbeing and development of the children were noted between the two groups.
* Unnecessary medical intervention was not reduced by the use of INFANT, and intervention rates were similar between both groups.

### *AIMS Discussion*

It is interesting that the researchers decided to explore the problems of poor outcomes for newborns and unnecessary intervention for mothers by taking a very technological approach, i.e. by adding one technology to another technology, to interpret the wellbeing of the baby. Indeed, even though the INFANT decision support software was seen as having no benefit, the researchers concluded that 'further development of decision-support software could improve the quality of feedback that the system provides to clinicians to make a difference to outcomes'. It appears therefore, that the researchers may continue to pursue this very technological approach, even though EFM and now INFANT have been proven to not lead to better outcomes for babies or mothers.

If the context in which the research takes place is considered, it can be seen that almost 60% of women had their labour induced, around 24% of the births resulted in caesarean sections, 22% in instrumental deliveries and just over 29% of the women had episiotomies. Arguably these high intervention rates are symptomatic of a technocratic maternity system obsessed with a technological 'quick fix' and a highly medicalised approach to women's birthing bodies. The curious – and very worrying – aspect to this study is the continual insistence on more technology as the answer to poor infant and maternal outcomes, instead of perhaps an increase in midwife numbers combined with better training and support, or the reintroduction of continuity of care. A study that challenged the overreliance on technology at the expense of more traditional midwifery, may highlight that the maternity system is looking for answers in the wrong place, and that the continual quest for a technological solution may in fact prove a red herring.

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Beverley Beech was AIMS Chair for 40 years. She is a legendary campaigner for women's rights in pregnancy and birth, a skilled international orator, and a writer. Am I Allowed? is a must for any pregnant woman who wants to exercise informed consent and be more in control of her pregnancy and labour. It gives you the information to make YOUR informed decision.

**Am I Allowed?** is published by AIMS and is available from our shop, *www.aims.org.uk/shop/item/am-i-allowed*.

It is also availble as an e-book, please see *www.aims.org.uk/general/aims-kindle-publications* for further details.

# Monitoring babies during labour: what are the issues for pregnant women and their health professionals? A study day report

*Jo Dagustun reports on the INFANT trial study day in October 2017*

This national (central Birmingham based) free-to-attend study day on the 17th October 2017 was organised by the NCT. I wasn't sure what to expect, but I was keen to go along and listen (and to catch up with fellow birth activists). I know from my own doctoral research that this is a really important topic in the context of women's accounts of their maternity-service experiences and that it also plays a key role in debates about service improvement.

A key focus of the morning was a briefing on the INFANT trial[1], a study that the NCT had collaborated on (a review of the trial is available on page 20 in this journal). Commencing the day's presentations, the lead academic on the project, Professor Peter Brocklehurst (University of Birmingham), presented the background to this research, its key findings, the team's conclusions and an interesting perspective on the politics of publication (all a little too quickly for me, I will admit, but Peter's presentation was certainly engaging and his main points clear enough). The burning research question, in particular, was clearly communicated: does CEFM (Continuous Electronic Fetal heart rate Monitoring) have the potential to improve outcomes if traces are interpreted more accurately and consistently, and if more effective action is taken based on those interpretations (or, in other words, if human error is significantly reduced). The hope was that complementary technology might help to better identify which babies might benefit from an early c-section as well as reduce intervention where CEFM interpretation has previously been over-cautious. Key to Peter's presentation was the finding that the '*…use of computerised interpretation of cardiotocographs in women who have continuous electronic fetal monitoring (CEFM) in labour does not improve clinical outcomes for mothers or babies*'. As such, the results of the INFANT trial laid the ground for one of Peter's key challenges: perhaps it is our belief in the power of the technology of CEFM (which is, at its core, simply a sophisticated machine to measure pulse) that is deficient, and perhaps therefore we need, as a community of researchers, practitioners and service-users, to be far more creative in how we seek to reduce adverse maternity outcomes. It was also suggested that we still know very little about whether changes in pulse in labour (as measured by CEFM) represent impending or existing damage: this is surely key to how we approach service development in this area.

A wide variety of speakers had been invited to talk after Peter's keynote presentation. First up was Rhona Hughes (NHS Lothian), representing the NICE guideline development team tasked with taking such research into account in updating the relevant guidance. It was interesting to hear Rhona discuss the process of drafting guidelines on the usage of CEFM, reflecting the scientific evidence at the same time as seeking to respect the principle of choice: to what extent should birthing women's choices be facilitated when these choices are not supported by the evidence on what makes for effective care? Rhona also discussed the technique of fetal scalp stimulation[2], which is now recommended as an interim step before fetal blood is taken from the scalp in certain circumstances. Next we heard from Louise Robertson (RCOG), who focussed on the need to improve teamwork and situational awareness in emergency obstetric situations, as identified in the Each Baby Counts initiative. The last of the morning's speakers was Milli Hill (Positive Birth Movement), who offered an important service-user informed perspective on the role of monitoring

in labour. Milli highlighted, for example, how women's experiences of monitoring in labour were so often associated with major restrictions on their mobilisation and choice of positions, whilst the seemingly mythical technology of telemetry – which could presumably lessen this impact - lurked in the shadows of women's accounts.

In the afternoon, there were further presentations (from an antenatal teacher, obstetrician, midwife and neonatologist), each shifting the focus to practice implications. During this session, the issue of labour ward understaffing was highlighted, and it was claimed - rather worryingly given their key responsibility for safety - that the vast majority of labour ward co-ordinators were not allocated specific times to carry out their role. From an AIMS perspective, I would hope that this staffing issue will be scrutinised carefully by the CQC during provider inspections going forward. There was also an interesting, but inconclusive, discussion about the role of specialist monitoring midwives, and a call for the improvement of intermittent monitoring skills.

**It was also suggested that we still know very little about whether changes in pulse in labour (as measured by CEFM) represent impending or existing damage ...**

But the day was so much more than a series of presentations. For the last session of the day, all participants were invited to contribute to the proceedings, with each table discussing a series of questions related to the topic of the day. For me, this was perhaps the most fascinating part of the day, as the tables of obstetricians, midwives, service-users and others started to talk, with participants often coming from very different perspectives on any given issue. I was particularly pleased to witness the robust discussions going on around me, not least to try and shift the discussion away from work designed to simply improve our utilisation of existing electronic foetal monitoring techniques to many broader questions, including the wider impact of CEFM on the social practice of birth.

So was it worth travelling from Manchester to Birmingham to attend this event? For me it certainly was, and I would recommend that all AIMS activists look out for similar events to attend. (Birth activists, just as much as practitioners, benefit from continuous professional development opportunities!) For me, the main benefit of the day was the way the organisers had thoughtfully created an important discursive space in which service-user representatives, academic researchers and healthcare professionals could come together to start to explore the many issues surrounding foetal monitoring for women, babies and families. Although I came away from the day convinced that EFM was perhaps even more of a problem than I had previously thought, I was also inspired by the meeting. In particular, I felt that it was a really good example of researchers engaging well with service-users, in the presence of healthcare professionals, in a respectful way. Breaking down barriers between academic researcher, practitioners and service-users can only be a good thing, for therein lies a future in which the research agenda is truly informed by the research priorities of women. Many thanks to the NCT for organising the day, and - via the very experienced birth activist Mary Newburn - for providing a thought-provoking last word: *in 2017, a maternity service that assigns labouring women to a bed for lengthy periods, because of the constraints of outdated CEFM technology, is simply not good enough.*

References

1 The INFANT trial http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)30568-8/abstract

2 Fetal Scalp Stimulation https://medical-dictionary.thefreedictionary.com/fetal+scalp+stimulation

## Information on booking a Home Birth

The decision whether or not to have a home birth rests with the mother, and no-one else. The decision is hers alone.

For more information from AIMS, see:

*www.aims.org.uk/information/item/booking-a-home-birth*

# A message from the new AIMS Book Review Editor, Jo Dagustun

Over the years, AIMS has provided a trusted book review service to its members and others, publishing reviews in its Journal and on the AIMS website. As the new Book Review Editor, I have committed to support this element of AIMS' work. And as I take on this role, I would like to acknowledge the work of my predecessor, Gill Boden, who I found to be a wonderfully thoughtful and kind Book Review Editor.

AIMS is often sent newly-published books for review, whether direct from authors or from the publishers. We also receive information about books about to be published, which we follow up by requesting a review copy as appropriate. We also take a proactive role in seeking out new books that look relevant: if you think you've found a book that we might usefully review, please let me know. I would also like to start a series of 'classic' book reviews, looking back at some old favourites that might be worth bringing to the attention of a new audience. Do you have an old favourite that might fit the bill?

If you fancy getting involved in reviewing books for AIMS, I would be delighted to hear from you. I will then add you to my email list, so that you are included in emailed updates from me; this is how I share the list of books awaiting review and other book news. Please email me at jo.dagustun@aims.org.uk

# Little Daisy-Mae: The Girl Who Couldn't Wait

*Wayne and Jennie Little*
*Published by The Solopreneur Publishing Company, 2014*
*ISBN Number: 0992784077*


Through this book, the Little family offers a rare glimpse into the secret world of premature baby care; care that goes on twenty-four hours a day, seven days a week, behind the closed doors of wards and units offering care for premature, small and sick babies across the UK. This is a hugely important space of care within the NHS, as Wayne's story testifies, and this book makes excellent reading for anyone who hasn't personally experienced that space (as well, I'm sure, as bringing back bitter-sweet memories for those who have).

Through the collected facebook updates and personal diary entries of Wayne, an ordinary fire-fighter facing an extraordinary challenge when his second daughter is born at just 25 weeks gestation, there is much to be learnt in this book about the ups and downs of being, and being a parent of, an extremely premature baby. Daisy-Mae Little was born unexpectedly at just 25 weeks. As Wayne puts it, she was just two-thirds constructed. The story of how she manages to complete her construction over the following 108 days, until she is eventually discharged, is a detailed one, and offers important insights into the many challenges and diverse medical needs of one extremely premature baby.

Charting almost every day of that period, this is not a short book, but it is a page-turner. As such, it is tempting to read it quickly, not least to escape from the precarious situations in which Daisy-Mae finds herself, in the hope of finding better news in the next entry. But that is perhaps to lose the sheer sense of time that must inevitably elapse before Daisy-Mae is ready to

forego the various life-support lines she makes good use of whilst in hospital. But the innovative structure of the book is useful in forcing the reader to pay attention to this sense of time unfolding, by drawing us back to each day's events up to three times before we can move forward: after Wayne's facebook entry, there is his diary entry to be read, and sometimes too a further perspective offered by Daisy-Mae's mum, Jen. Whilst the double (and sometimes triple) daily entries may prove too much for some readers, I believe that this is a key strength of the book. By being forced to read again, from a different perspective, the same day's events, the reader is offered a tiny flavour of how it might feel to be living through, in real-time, this hugely powerful experience.

Through publishing their writing, Wayne and Jen have offered an important insight into the experiences that they faced with the challenge of an extremely premature baby. It is far from an academic treatise on the issues surrounding the care of premature babies - indeed some may be put off by the informal style of the writing - but it is none the less for that: indeed, it is perhaps even stronger for its divergence from the usual texts. As a highly-articulate narrative from the parents of an extremely premature baby, this book has the potential to teach many people a great deal about the experience of extreme prematurity. Wayne and Jen's voices not only deserve to be heard, but they do a great service in offering us their voices through this book.

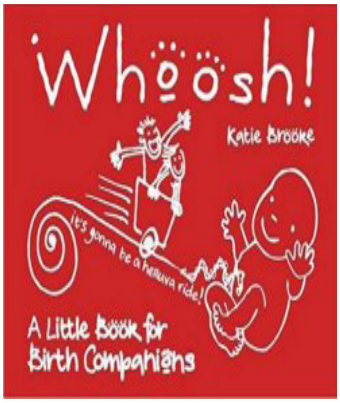
But this book is not just about Wayne, Jen and Daisy-Mae. Wayne also generously devotes space to the many people who support them in these first 108 days, friends, family, facebook followers and professionals alike. Although we do not get to hear their voices, for example, this book provides an excellent insight into importance of the professionalism, dedication and love offered by each member of the multi-disciplinary team caring for Daisy-Mae and her family.

With Wayne as the main author, dads finding themselves in a similar situation might find this book particularly accessible, and the Little family have pledged to ensure that a copy finds its way into every neonatal ward and unit in the country, so that it reaches those who might be most helped by it. But I would suggest that the benefits of reading this book go far wider. It represents an important and educational read for anyone interested in the development of babies and the well-being of babies and their families. And once you've read this book, I can guarantee that you will hear the words 'my baby was premature' in a completely different way. This is a simple book which has great potential to build important understanding and empathy. It is a privilege to be guided by Wayne and Jen through their experience of being parents to an extremely premature baby.

*Jo Dagustun*

## WHOOSH! A Little Book for Birth Companions

*Written and illustrated by Katie Brooke*
*Published by Pinter and Martin, 2015*
*ISBN: 9781780661858 , £9.99*




If you think that you might struggle to get your partner clued up about physiological labour and birth, and suspect that a full explanation of the physiology of birth won't be appreciated, then this very short and quirky book might be just the thing. With lots of cartoon illustrations and minimal text, this book sets out to offer birth partners a good mini-introduction to physiological birth and the important role that they might play in supporting its achievement.

After a lovely positive introduction, the book is split into three main sections: what you might want to include in the hospital bag and why ('birth supplies'), the physiology of birth ('the science bit') and strategies that might be useful in avoiding induction ('if things are moving too slowly'). The book also ends on a really positive note, including some space for noting down possible baby names, reinforcing a key message of the book: let's enjoy this together.

When first reading this book, I worried that it seemed to infantilise the prospective male birth partner, and that its style might be better suited to a book intended for siblings.

According to one father I consulted, however, 'it strikes just the right tone'.

Where I found this book to be really strong was in the way it introduces birth partners to 'the science bit': it presents the role of oxytocin and endogenous endorphins in labour and birth in a really straightforward manner, accompanied by lots of practical tips. The section on induction is also good, but I was expecting the perils of unwanted augmentation during labour to be discussed in this section, so this was a little confusing.

Do also be aware that this book isn't necessarily suitable 'as a loving gift for any birth partner', as the blurb claims. There are many assumptions embedded in this small book which may or may not suit your own circumstances and preferences, and a bit of tinkering might have given this book wider appeal. For example, the current edition assumes that the birth partner will be your intimate male partner and that the birth will take place in hospital, possibly in a birth pool. The list of birth supplies is a good starting point, but is not exhaustive and might be read as rather prescriptive (not everyone thinks a TENS machine is an essential technology, for example, and not everyone eats honey). Nevertheless, the book is sure to appeal to many birthing women and their partners, and it is encouraging to see an expanding range of resources available to support those aiming for a successful physiological birth.

*Jo Dagustun*

# Obituaries

## Prunella Mary Briance

(31 January 1926 - 14 July 2017)

Prunella Mary Briance founded the Natural Childbirth Trust in 1958; it became the National Childbirth Trust three years later. Like many birth activists she was provoked into action by her own birth experiences, the loss of her second baby, and a desire to ensure that no other woman suffered as she did. "Curious minds may wonder why I was prompted to start something as important as NCT. It was due to a horribly mismanaged birth and the loss of my precious baby girl."

Throughout her life she promoted a more natural way of giving birth where women would feel confident and in control. In a letter to The Times in 2013, she wrote: '97 per cent of mothers, accurately instructed, attended and encouraged, can give birth without any interference or medication whatsoever'.

Tens of thousands of women, babies and families throughout the years have benefited from her initiative and life-long dedication to improving maternity care.

Her husband, John, died before her, in 1989, and our thoughts are with her two surviving children, Richard and Alison.