

**I could not
survive another
day**



Pregnancy
Sickness
Support



**Improving treatment and tackling stigma: lessons from
women's experience of abortion for severe pregnancy sickness**

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Introduction

Until someone experiences this level of illness it's almost impossible for them to judge your decision. When you are too ill to get out of bed to make your children's dinner or kiss them (the smell of my children made me vomit) you feel you need to save yourself to save them. (termination in 2014)

Only those who had seen me at my worst understood why I did it, the few others didn't really get it and assumed I was just weak or didn't try hard enough (terminations in 2012 and 2013)

I was vomiting blood...I can remember crying saying I couldn't cope much more to which a nurse replied "well you should count yourself lucky there's people who can't have babies at all". I wasn't feeling particularly lucky and yes I can conceive but being able to comfortably carry a baby to term dealing with [Hyperemesis Gravidarum] is a different matter (termination in 2014)

Hyperemesis Gravidarum (HG) is a severe complication of pregnancy characterised by extreme nausea and vomiting. The condition can present with a host of symptoms in addition to the nausea and vomiting such as ptyalism (excessive saliva production), headaches, heightened and warped sense of smell and extreme fatigue.¹ Poor management of HG can lead to complications

including but not limited to, dehydration and malnutrition, oesophageal tears, burst blood vessels, pressure sores, deep vein thrombosis and placental abruption.² In addition to the physical complications HG can lead to depression and social isolation as well as financial and relationship problems for those experiencing it and women feel they are less effective parents due to the condition.^{3 4} These complications in turn can lead to Post Traumatic Stress Disorder and the condition is known to limit family size.^{5 6}

Experience of pregnancy sickness is on a spectrum from mild nausea symptoms through to severe HG. HG can be diagnosed on the basis of clinical features such as losing more than 5% of pre-pregnancy body weight, signs of dehydration (including but not limited to ketosis), vomiting 5 or more times per day for more than 5 days, and near continuous nausea.⁷ It is important to note however that less clinically significant symptoms can still cause intense suffering for the woman experiencing them and that if a woman is presenting with symptoms which are affecting her ability to live normally and eat a normal diet then treatment may well be warranted.⁸ There are a wide range of anti-emetics now available. Early access to these treatments is likely to be more effective and may prevent symptoms developing into HG. However, as will be discussed in this report, women can struggle to access these.

Around 30% of women will require time off work to manage nausea and vomiting in pregnancy (NVP) and a further 1-1.5% will be diagnosed with HG.⁹ With nearly 1m pregnancies in the UK in 2013, we can estimate that around 10,000 women per year may suffer with HG and many thousands more with sickness that affects their ability to go about their daily lives. Given the levels of morbidity caused by severe NVP and HG, it is hardly surprising that recent research found around 10% of sufferers terminate otherwise wanted pregnancies for the condition.¹⁰ Some studies suggest the figure is much higher, with around 15-20% of women with HG ending their pregnancies.¹¹

The British Pregnancy Advisory Service (bpas) is a reproductive healthcare charity which sees nearly 70,000 women a year for advice about an unwanted pregnancy or a pregnancy they feel they cannot continue, at clinics across the UK. bpas regularly cares for women for whom severe pregnancy sickness is a factor, if not the main reason, behind their request for an abortion. bpas believes more could be done to support women earlier before symptoms become unmanageable and termination is the only treatment option in what is otherwise a wanted pregnancy.

Pregnancy Sickness Support (PSS) is a charity which provides information to women suffering all levels of pregnancy sickness and particularly those experiencing HG. It runs a helpline, forum and a national peer support network.

Together bpas and PSS have surveyed women who have experienced termination of pregnancy while suffering HG over the past 10 years. More than 70 women from the UK responded to the survey, which solicited responses from women who had been carrying otherwise wanted pregnancies. This report aims to reflect their experiences and examine what more can be done to improve care for women in this situation and better support their choices.

Underpinning this report is a firm commitment to straightforward access to compassionate, high quality abortion care to any woman suffering from pregnancy sickness affecting her quality of life. Sadly stigma and misapprehensions continue to shroud abortion for women generally, and abortion for HG is no exception. A number of women surveyed commented on the difficulty talking about their decision, fearing judgement for terminating a wanted pregnancy “just for morning sickness”. While the experience of the Duchess of Cambridge has dramatically raised awareness of HG, the coverage inevitably did not reflect that many sufferers unfortunately struggle to obtain comparable treatment.

Ultimately there is no silver bullet for HG,

and while we wish to see more women offered medication if they want it this should never be in place of abortion if she knows that ending the pregnancy is the right decision for her. Indeed, within our survey there are women who were offered a wide range of medications which did not prove effective. Termination of pregnancy services must be easily accessible, and we know many women find it extremely reassuring to know that abortion is there as a back-up if treatment fails.

However our research suggests that a significant proportion of women who have ended wanted HG pregnancies were not offered the full range of treatment options, but expected either to put up with the sickness or undergo an abortion. Possible reasons for the reservations about providing treatment will be explored in the course of this report, but it is the case that the Thalidomide tragedy continues to cast a long shadow over doctors’ willingness to provide medication. Doctors’ fears are understandable. But the care of pregnant women cannot be dictated by events of the mid-20th century in perpetuity. In 2015, a number of treatment options are available that should be discussed with women experiencing a level of pregnancy sickness that is affecting her ability to go about her normal life. Early treatment has been shown to limit the overall severity of the condition and may prevent deterioration. Regardless of whether a woman intends to continue or end the pregnancy, she deserves access to evidence-based information, care and treatment.

History of Hyperemesis

There were 6 deaths of pregnant women in the UK due to complications associated with HG between 2006 and 2012.^{12 13} While the condition is rarely fatal now, prior to the development of intravenous fluids in the early 1930's HG was the leading cause of death in early pregnancy. Doctors had no means of reversing the dehydration which can rapidly ensue when a woman cannot keep fluids down. Around this time, psychodynamic

theories became popular and symptoms were attributed to a subconscious rejection of the foetus or demonstrative of a problematic relationship with the father. No evidence has ever been forthcoming to support the hypothesis that HG is caused by psychological conflicts; all evidence which examines cause and effect indicates that any psychological problems associated with HG are caused by it, not the other way round. Although the precise mechanism of the condition is not yet fully understood, it is now widely understood to have a biological cause, probably related to the hormones of pregnancy. There is also a genetic element at play as women whose mother or sister suffered have an elevated risk, with around 30-35% suffering themselves.¹⁴

During the 1960's a number of anti-emetic treatments were developed, one of which, Thalidomide, had a devastating impact on the foetus when taken within the first trimester. At the time Thalidomide was being prescribed it was widely believed that substances consumed by mothers during pregnancy did not cross the placenta. Therefore as the effects of Thalidomide became apparent so did the mechanism of harm. Understandably this caused an intense fear for both pregnant woman and the medical professionals caring for them, but 55 years concerns about potential harms from medication are still preventing women being given safe and effective treatments for even very severe symptoms.

Most effective medications for nausea and vomiting are not licensed in pregnancy because pharmaceutical companies usually exclude pregnant women from drug trials. Doctors who prescribe medication for pregnant women do so off label, however they may do so when there is no suitably licensed medicine that will meet the patient's need and where there is sufficient evidence or experience of using the medicine to demonstrate its safety and efficacy. The National Institute for Health and Care Excellence Clinical Knowledge Summaries service, which provides primary care practitioners with a readily accessible

summary of the current evidence base and practical guidance on best practice, lays out the range of medications which can be offered and the safety data supporting them. Any risks of medication must in any event also be set within the larger picture of the risks both for mother and baby of not treating HG.

In PSS's experience, many women are under the illusion or advised by their healthcare professionals that there are no safe treatments that can be used in pregnancy. Women also confront attitudes which suggest they are putting their own wellbeing before their foetus.

*[The Doctor said] that the medication I was taking will harm my baby and my baby can't consent*¹⁵

It is also worth noting that treatments such as steroid therapy, which can be extremely effective for women with HG which does not respond to other anti-emetics, is commonly used in early pregnancy for a number of other conditions such as rheumatoid arthritis, Crohn's Disease, Ulcerative Colitis and recurrent miscarriage.

The impact of HG on pregnant women's lives

71 women from the UK who had ended pregnancies while suffering HG in the past 10 years completed the survey which was posted on Survey Monkey in February 2015, and promoted on social media, including the Spewing Mummy blog site. Nine women told us about more than one termination.

Just over a third of the pregnancies were planned (38%), a similar proportion unplanned (37%) and a quarter (25%) categorised as neither planned nor unplanned. It is important to recognise that while "unplanned" is often used interchangeably with "unwanted", this does not necessarily reflect women's feelings about their pregnancy. In our sample, the overwhelming majority of women (84%) said they would have wanted to continue with the pregnancy if they had not been suffering HG, and for most

HG was the only or the main reason for ending the pregnancy.

The overwhelming majority (95%) of the women, unsurprisingly described their symptoms as “intolerable”.

More than half already had one or more children, and for the majority of these women it was the impact that HG had on their ability to care for their existing children which was a key factor in their decision.

I soon felt negative about pregnancy due to feeling like I was dying. I could not look after my 2 children. Lack of support and understanding made me go from being excited to desperate to terminate (very wanted pregnancy) Had no idea there were treatment options available to me - just thought I had to GET ON WITH IT (termination in 2013)

I couldn't look after my six month old and the symptoms were utterly unbearable and unbelievable to me. My mum said I looked like a cancer patient (termination in 2011)

A third (32%) of women said they were either worried about losing their job, or that they could not afford to take time off from their job, or both.

“Being off work with no pay” was one of the key factors for one respondent who ended an HG pregnancy in 2011. In the absence of a company sick pay scheme, working women would be entitled to Statutory Sick Pay if they had earned more than £111 per week before they became ill, but this is paid at just £87.55 per week. It can also have a knock-on effect on how maternity pay is calculated. It is troubling that nearly a quarter of respondents were worried about losing their job. It constitutes automatic unfair dismissal and sex discrimination to dismiss a woman for a reason connected to her pregnancy. This applies from the start of employment, regardless of hours worked. Casual workers, agency workers, freelancers and self-employed women are protected by this legislation.¹⁶

Accessing treatment, obtaining support

Nearly half of women (47%) said they had either asked for medication and it had been refused, or that they did not ask for medication and that they were not offered any.

Of this group of women, 40% said they had asked for medication and it had been refused, and the remainder had not requested medication and were not offered any. Around 15% of respondents were worried about the impact of medication on their pregnancy.

Women who were prescribed first-line medications such as cyclizine, an antihistamine for which there is extensive safety data, then found themselves refused stronger treatments after initial prescriptions failed. Second-line treatments include ondansetron, an anti-sickness medication often used to treat nausea in patients undergoing chemotherapy, and metoclopramide, which moves food more quickly through the digestive system to prevent vomiting.

My doctor would only offer me cyclizine and they were no good for me, I needed stronger meds (ondansetron or something similar) this was my second HG pregnancy I knew how bad I was going to get” (termination in 2012)

My GP told me I could only take this one type of anti-sickness [medication] - this didn't work for me so I continued with pregnancy for further 2 weeks - in this time I couldn't eat or drink and became very unwell. Started calling clinic daily begging for an earlier date for termination (termination 2014)

I was prescribed anti emetics only I was not allowed zofran [ondansetron] (termination in 2011)

A third of women said they requested a particular medication, and of these most were refused (66%). In particular women commented that they were refused ondansetron and steroid treatment.

The doctor wouldn't prescribe anything stronger than cyclizine... When I went to the GP to beg for stronger drugs [respondent specifically requested ondansetron] I was shouted at and told to leave. (termination in 2014)

Ondansetron can be extremely effective for many women suffering from pregnancy sickness, although it should be prescribed alongside a laxative as it can cause intense constipation. However in our survey only around one in five women had been prescribed this medication.

Steroid therapy has been used for a number of decades, and should be an option for women with severe pregnancy sickness which is not responding to conventional anti-emetics.¹⁷ However fewer than one in 10 were offered this.

Reasons for refusal

I was told I couldn't have steroids because it would harm the foetus (termination in 2012)

Reluctance to prescribe based on concerns about the impact on the foetus appear prevalent. At least a quarter of women who were not prescribed medication said it was because the doctor felt it would “harm the foetus” or because the doctor said “there was no medication suitable for pregnancy”. Even women who were given medication were handed it with a such a severe health warning that clearly made using it the wrong choice.

The Dr prescribed the medication I asked for but told me it would harm the foetus so to use it sparingly (termination in 2012)

As previously discussed, the evidence base shows these medications can safely be used by women with continuing pregnancies, and that they should not be withheld from women with severe symptoms over fears for the foetus. It is curious therefore that these medicines are also being withheld from women who have made clear they do not wish

to continue the pregnancy.

My doctor refused to prescribe me anything because it would harm the baby despite me repeatedly saying I didn't want to continue with the pregnancy. (termination in 2005)

[my] doctor didn't think I should take before I was seriously sick and that I might change my mind about a termination and wouldn't want the medication to affect the baby (termination in 2012)

Cost appears to be an issue with ondansetron, which remains significantly more expensive than the other second line treatment, metoclopramide. However generic presentations of ondansetron are now available, and increased awareness of these should improve access.

The midwives in the hospital told me I was one of their worst patients but the consultants would not listen to me - I had terminated one pregnancy 10 years prior, managed to get through a pregnancy in 2007 and hoped they would learn from that and enable me to get through this one but they kept me in for two weeks so I deteriorated further. They tried every drug even though I told them they didn't work and needed Ondansetron and steroids but they said it was too expensive...I was only allowed Ondansetron for two days due to cost! (termination in 2009)

Some areas restrict the prescription of ondansetron to specialist approved use only, in some cases citing concerns about its unlicensed use in pregnant women, although cost is also likely to be a key factor. It makes absolute sense to prescribe short and therefore cheaper courses of the medication in case it is not effective, or no longer needed. However even a longer course of ondansetron will be more cost effective than a hospital admission for dehydration.

It was a twin pregnancy so my symptoms were a lot worse. I knew how well the steroids worked for me in my first pregnancy. I was so ill this time that I asked for them straight away at week six on my first hospital

admission when nothing was stopping my every 20 Mins sickness. I kept asking for them and it was written in my notes that I was negative and focusing on the steroids. What a total lack of understanding they had (termination in 2014)

If I hadn't been given such terrible facts about the use of steroid treatment...I would have asked for them. I am still very angry that I had to endure a termination and no alternatives were given. Regardless that the pregnancy was unplanned it would have been a very much loved addition to our family if I didn't have to endure severe hg for the majority of the pregnancy (termination 2014)

While other women were offered steroids, it was coupled with misleading advice or miscommunications about the abortion time limit, which is 24 weeks in the UK.

I terminated at 13 weeks - it was then I was offered steroids but was told if I took it and then still didn't want to/couldn't go ahead with the pregnancy I would be too far along and deeply regret the decision now (termination in 2013)

Impact of termination

As these women surveyed were predominantly ending wanted pregnancies, it is unsurprising to find reported levels of grief and sadness relatively high after abortion, and regret not necessarily for the abortion itself but for the circumstances that led to it. This is similar to the feelings expressed by women following a termination of pregnancy for foetal anomaly, where a wanted pregnancy cannot be carried to term because a serious problem has been found.

The terminations themselves were bittersweet as I was happy to feel alive again when symptoms went but at same time was so sad about losing the babies. Overall I think hyperemesis had a bigger impact on my mental health than the terminations themselves (termination in 2012)

For a long time I beat myself up for having a termination. It's still hard to accept and get other people to accept I had a termination "just" for sickness...I've since learnt to live with it with the help of my husband telling me I have to remember it was for health reasons. I was only a year over a previous severe hg pregnancy and I don't believe my body could have taken another one so soon (termination in 2013)

Yes [there was an impact on my mental health] when I allow myself to think about it. But things happen for a reason [and] we have to deal with it (termination in 2012)

I suffered real anxiety and have never felt so vulnerable in all my life. I don't think that the termination as such did this even though it was the worst and most horrific thing I had to do. I think it was how ill I was and how badly I had been treated that caused me my anxiety. My GP said when she saw me to consent to me having a termination, (this was the first time she had seen me) that she didn't think I would make it through if I didn't have the termination due to how ill the hospital had let me get. (termination in 2014)

I am comfortable about my actions but think about my lost baby everyday (termination in 2013)

Good practice

These cases provide an important insight into the picture of the care of some women with HG. These are pregnancies that end in termination, but we know there are also women who suffer while carrying their pregnancies to term without effective treatment. Indeed it is the experience of doing so which means termination can become the preferred option in subsequent pregnancies, particularly when sufferers have young children to care for.

The difference [with the first pregnancy] was I didn't already have a child to look after first time round. I only had myself to look after and didn't manage that very well (termination in

2011)

The trauma from previous hg pregnancy seriously affected this pregnancy to point that I was worried for my psychological health this time round so much that I made the decision to terminate again, even though the physical symptoms weren't as bad (terminations 2012 and 2013)

But it must be emphasised that there are indeed women who receive appropriate treatment for their sickness, and if their pregnancies are wanted, are able to carry these to term. It is notable that a significant proportion of the women in this survey were able to describe other pregnancies where they had received the care and support needed to continue their pregnancy.

More needs to be known about the use of steroid treatment in the first trimester for severe HG as this can make the difference between women having more children or not. I am currently 7 weeks pregnant again having had a pre-pregnancy plan put in place and have been on the steroids for almost a week. I feel amazing, wouldn't even know I was pregnant, eating lots, drinking, not been in hospital and looking after my daughter!! This is something I have never experienced in pregnancy before (termination in 2014)

Since the termination, I went for a consultant appointment to discuss HG and the birth of my first and to make a plan. This included ondansetron, fluids and steroids if needed, plus a birth plan to ensure I didn't lose that much blood again. This was 2 years after and could have been fluke with the consultant I saw, but he was very informed and sure that we could manage HG should we need to. I'm currently 25 weeks pregnant and am sure pre-emptive meds (inc ondanestron) is why I'm having such an easy pregnancy this time. I've been sick the whole pregnancy as much as I was in one day with my first/second pregnancy (termination in 2012)

This time my doctor knew what it was (different area) and the hospital assigned me a support midwife. I was also given medication

which reduced symptoms (but not completely) I also had perinatal support from a counselling group (termination in 2005)

The only thing I have found helps me carry on a normal/just nausea pregnancy is a mix of steroids and ondasetron. This is not always offered though. After termination [of] this pregnancy I wanted another child so badly in 2013 I had the support I needed and had a little boy It was just as I suffered before but with correct medication I was back in work within a month (termination in 2013)

[This time] I was given better treatment and hospitalised (termination in 2010)

It is noteworthy that nearly a quarter of women (24%) who described a pregnancy they had been able to carry to term referred to the supportiveness of employers and the fact they had not been worried about work.

It must also be recognised that even with the most supportive employers and the highest standards of care and support, treatment may not work, or not sufficiently alleviate symptoms to the point a woman can resume her normal activities, and termination of pregnancy will be the woman's preference.

Trusting women

It is crucial that healthcare providers of pregnant women are able to differentiate between nausea and vomiting in pregnancy which can successfully be managed with lifestyle and dietary changes and the more severe forms which warrant a much more tailored approach.

Most women with normal pregnancy sickness will not express concerns about it and are unlikely to present to a GP, as they experience it as a normal – and indeed reassuring – part of a wanted pregnancy. While it may be unpleasant, it is unlikely to interfere in any significant way with their ability to go to work or look after their household. Any woman who has made an appointment to discuss her symptoms should have her concerns taken seriously.

As discussed, there are a number of anti-emetics which are safe in pregnancy. As a 2011 article in the British Medical Journal noted, “women will be prescribed these liberally if admitted to hospital so there is no need to withhold them in primary care.”¹⁸ We believe anti-emetics should be offered to women in primary care in whom nausea and vomiting in pregnancy is significantly compromising their ability to press on with their normal daily lives while pregnant. Early treatment with an anti-emetic is likely to be more effective and is essential to improve a woman’s quality of life. Early treatment reduces the severity of symptoms, and without adequate intervention moderate NVP can become HG.

When asked whether healthcare professionals understood their condition and believed how ill they were, just over 85% of women said “no, none of them”, or “no, only a few of them”.

Every contact with a healthcare professional was difficult and exhausting due to lack of knowledge and understanding. (termination in 2011)

The midwife I had did not believe HG was real and thought I was being over dramatic (termination in 2010)

Consultant gynae at the hospital I was in said there was nothing wrong with me and that it was all in my mind. Midwife in same hospital shouted at me when I refused breakfast saying "You have a baby to think about! (termination in 2010)

I was treated like a child who should cope and just eat (termination in 2014)

If my doctors had listened to me I would have kept it. I was told on my previous pregnancy by my consultant that I would never have to suffer like that again but my current doctors at the time were no help. I knew I needed ondansetron (termination in 2012)

There was only one doctor who understood

my feelings after I asked for help before I did something stupid, she was supportive, made me feel hopeful again and asked me to come back to see her within two days if the medication they had given me was not working. I made a phone call to see her two days later and was told by the receptionist at the general practice that she was a locum doctor and was not there that day. So I was given another appointment to see another doctor, and I felt the other doctor did not understand how I was feeling, as with others. I was no longer hopeful (termination in 2014)

Women should not have to struggle to obtain swift care, and their experience in previous HG pregnancies of the difficulty securing medication influences their decision about whether to continue or end a subsequent pregnancy.

I did not go to my doctor as I already suffered with 2 hg pregnancies and I couldn't cope with having to fight for the right medication so I chose to terminate the pregnancy (termination in 2014)

Next steps

As I was quite young (20) I had never heard of HG and I assumed it was normal to be so sick and to be hospitalised because of it...I was totally unaware that there may be a possibility that I might get HG again with my next pregnancy, had I have been given information and advice then we definitely would have been able to prepare better (termination in 2006)

All women after experiencing an HG pregnancy, whether wanted or unwanted, and whether it ends in abortion or birth, should ideally receive information on how to prepare for subsequent pregnancies. Early treatment in the community, as discussed, may prevent deterioration.

Finally, we need to confront the stigma and guilt that surrounds abortion for hyperemesis. It is devastating to learn how women blame

themselves for the fact that they were unable to carry their pregnancy to term, or feel that they should have fought harder to get help.

I feel like a failure for not being able to do what women are suppose to naturally do (termination in 2014)

I feel like a failure, sad that I gave up on something I longed for (termination in 2014)

I've never forgiven myself for not being able to cope with this pregnancy (termination in 2008)

We were desperate to complete our family with the 3rd and final baby. Now I feel guilty and like a failure that I couldn't continue with the pregnancy (termination in 2014)

After having a child and getting through extreme hyperemesis with my son this time round (2010) I do feel guilty that I didn't seek out further help and pushed hospitals and doctors for that help (termination in 2005)

I actually wished the few people I told I'd lied and said there was something wrong with it or not said anything at all as people just don't get how bad it truly is (termination in 2014)

The stigma of hyperemesis needs to be discussed more, as people still think it's "just" morning sickness. As for terminations due to hyperemesis it definitely is taboo, and the fear of people's reaction is just terrible (termination in 2012)

Women should feel neither guilty nor stigmatised for their decision. Continuing to raise the profile of HG will hopefully go some way helping people understand the severe impact this condition has on pregnant women's lives. No woman should ever be judged, feel ashamed or a failure for deciding that abortion is the best course of action for her, or pressured into accepting medication when she believes ending the pregnancy is what she needs to do. But women with pregnancies they wish to keep deserve prompt access to treatments that may enable them to do just that.

One of the stand out moments prior to termination, was being told I should consider myself lucky to have one child already and that it was selfish to try for another, ie suffering and not being there for my child. I felt like the worse person ever, and was sure termination was the only option....I wish I knew then what I know now((termination in 2008)

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