



This article was originally published in Essentially MIDIRS, a professional magazine aimed at midwives, students, maternity support workers, and all who work within maternal and infant health.

The journal is published eleven times a year, with a combined December/January edition.



You can find out more and subscribe at
www.midirs.org



A patient experience of **hyperemesis gravidarum** and how the midwife can support her care

Caitlin Dean

Nausea and vomiting in pregnancy (NVP) is very common, affecting 75% to 80% of pregnant women, and ranges from mild to severe. Hyperemesis gravidarum (HG) is at the extreme end of the spectrum affecting one in 100-150 women (Goodwin 1998). HG is a severe and potentially life-threatening condition which can have a profound effect on the sufferer's health and well-being. It can begin before a missed period and can last until delivery; therefore midwives will come into frequent contact with sufferers of this condition (Gadsby *et al* 1993). The care and treatment a midwife provides can have a significant impact on the experience of the sufferer.

HG can affect the psychological quality of women's lives by causing feelings of depression, difficulties between the sufferer and her partner, friends and family, feelings of being a less effective parent, and concern for the health of the unborn child (Mazzotta *et al* 1999). Further physiological complications in severe cases of HG that continue into the second trimester may include oesophageal tears, pre-eclampsia, placental dysfunction disorders (Bolin *et al* 2013) and the potentially fatal complication Wernick's encephalopathy (Gárdián *et al* 1999).

Clinical manifestations of HG include weight loss of 5% or more of pre-pregnancy weight, ketosis and/or a urine output of <500ml in 24 hours. Electrolyte imbalance can occur and if left untreated other complications can follow. A diagnosis of HG is considered appropriate when symptoms are severe and persistent enough that they prevent a woman from

eating and drinking, impact on her quality of life and prevent her from completing daily tasks (Dean & Gadsby 2013).

Many pregnant women have never heard of HG before they encounter it for themselves and struggle to make friends and family take their symptoms seriously. It is therefore vital that health care providers do not question the authenticity of women's symptoms (Sykes *et al* 2013). Power *et al* (2010) found that unhelpful attitudes from health care providers may prevent women accessing timely intervention.

A recent qualitative study of women's experience of HG in relation to health care professionals found that women were frequently offered '*folkloric*' remedies (O'Hara 2013). The study found that 96% of sufferers were aware of complementary and alternative therapies. Women from this study and also Swallow's research (2010) reported being told

inaccurate information, such as HG always being over at 12 weeks and ginger products being the cure for severe symptoms. This is worrying as research by Sykes *et al* (2013) found that inaccurate information by health care professionals may lead to mistrust and a breakdown of the doctor-patient relationship.

Sykes *et al* (2013) found that women suffering HG often struggle to advocate for themselves and may need help with this, particularly in accessing local services (NMC 2008); for example, in many areas of the UK, IV fluids may be administered at home and day units for IV rehydration are becoming available.

The Pregnancy Sickness Support (PSS) network is a peer-led system and national charity for women experiencing HG. Women who are currently suffering HG are matched with women who have suffered themselves, ideally in the local area, although this is not always possible. Women are supported via phone, text message or email and sometimes via face-to-face meetings at hospital or home. Volunteers are fully trained and provided with supervision and support. The network is run by an employed co-ordinator. See box 1 for further details.

The PSS website has a host of resources and leaflets which can be printed for sufferers and their families. Providing information about PSS may be enough to help to empower them. See box 2 for further PSS resources

Many women report feelings of confusion and guilt over their symptoms, often from not being able to care for other children and being off sick from work (Swallow 2010). It may be that these women had not heard of HG before diagnosis and had expected 'normal morning sickness'. By helping a woman to understand her condition better and self-manage it, in partnership with her midwife, she can regain some control over her life. PSS recommends discussing what does and doesn't work for her and talking to her about a treatment plan. Careful and thorough discharge planning can reduce hospital readmission rates (Kripalani *et al* 2014). Teaching a woman to monitor her own fluid balance intake/output at home is an effective way of giving a woman some control, as is monitoring her own ketones at home. Some women may not feel confident in doing these things and it should only be encouraged if she is keen to take control in this way. A care

Box 1

Features of the Pregnancy Sickness Support network

- Fully insured
- Supporters have first hand experience of HG or severe NVP
- Volunteers are interviewed and reference checked
- Full training is provided online
- Co-ordinator matches manually either geographically or case specifically to a suitable volunteer
- Ongoing supervision and training for supporters
- Full policies and guidelines in place

plan for self monitoring and knowing when to come back in for more fluids or for further medication could be devised. Calling or writing to the GP to ensure he/she is happy to facilitate the treatment plan is good practice.

Increasingly, women are reporting to PSS that hospitals are providing direct ward or early pregnancy unit (EPU) access and day case units for women to come in for rehydration before they deteriorate too much and require longer admissions. I am aware of women currently receiving IV at home in the south west of England and the Liverpool area and many more women are reporting to PSS that their hospitals are offering day case IV rehydration. Birmingham Women's Hospital is paving the way for day clinics and Sirona Care and Health in Bath is developing services for IV therapy at home, provided by Acute Care at Home nurses. Bath already has a protocol in place and is currently developing a hyperemesis pathway.

Sensory stimulation is a commonly reported trigger for sufferers (Swallow 2010). A woman suffering HG should ideally be in a side room, away from where food is served and

Box 2

Resources Pregnancy Sickness Support provide for midwives and nurses

- Treatment information on the website
- A pre-emptive care plan for subsequent HG pregnancies
- Reference list of research
- Tips and advice for supporting women
- An easy referral route for patient support
- Contacts for specialist
- Posters and leaflets for wards and booking in packs
- Printable information leaflets from the website



noisy areas. Odours reported to trigger symptoms include cigarette smoke, fatty foods, perfume and coffee (Gadsby *et al* 1993). The HG sufferer may be hard to cannulate due to dehydrated veins (Morales 2011) and extra care should be taken whilst undertaking this procedure. Some women experience windows of nausea free time (Gadsby *et al* 1993) and enabling them to eat at these times is key.

Contrary to historical theories, current understanding is that psychological factors are not the cause of HG, but a result of the condition; this is overwhelmingly supported by research (Munch 2002, Bozzo *et al* 2006). The woman experiences prolonged suffering from continuous, unrelenting nausea and vomiting; this can be violent, painful and unpredictable. She may be isolated for months and completely bedridden due to her condition. She may be unable to read, speak on the phone, watch television (Swallow 2010) or gain any respite from focusing on the crippling nausea, and the humiliation that comes when the vomiting results in episodes of incontinence or inability to maintain personal hygiene. A survey conducted via the PSS website in 2013 found that 51% of 769 women asked experienced episodes of incontinence induced by emetic episodes. Of the 51% who experienced it, we asked how distressing they found it on a scale of 0-10 (0 not distressing, 10 very distressing); 64% rated it 6-10 for distress caused and 31% rated it 10 out of 10 (unpublished report by PSS).

The suffocation sensation that comes with unrelenting retching or vomiting can be traumatic, almost tortuous. The fear and helplessness of HG may trigger traumatic symptoms, such as flashbacks, intrusive images, nightmares, numbness, depression, and a tendency to feel withdrawn. These symptoms can continue for some time after the baby is born. Women who experience HG are more likely to have depression and anxiety before birth and possibly an increased risk of poor mental health following birth, especially depression. Research has also found an increase risk of post-traumatic stress disorder (Christodoulou-Smith *et al* 2011).

HG can be a frustrating condition to manage for staff and sometimes the women may appear miserable and unwilling to help themselves. The sufferer may be exhausted, scared, depressed and feeling guilty, stressed, and constantly nauseous (Swallow *et al* 2004, Sykes *et al* 2013). Many midwives and nurses I've spoken to over the years express frustration at feeling as though they can't help, but actually, just being empathetic and supportive of a woman with HG

can make the most incredible difference to her miserable experience (Sykes *et al* 2013). Swallow (2010) found women who felt well supported rated their physical and mental health more positively.

If you are concerned a patient is depressed, then referring her for counselling or to the perinatal mental health team in your area is important. If these resources are limited then providing information about where else to seek help and support is useful.

In conclusion, advocacy is a key part of the midwife's role and women who are too sick to advocate for themselves may need their midwife to embrace this. Taking basic steps to ensure the ward environment is as accommodating as possible can reduce symptoms and aid recovery. Making referrals to appropriate support services for both the NVP symptoms and the mental impact of the condition can reduce the long-term psychological impact. Careful and thorough discharge planning can reduce readmission rates.

I speak from personal experience as I have suffered from HG three times, and my story is very similar to many of the stories we hear at the charity. Qualitative research by colleagues at PSS has found similar experiences from many women with the condition (Swallow 2010, Sykes *et al* 2013).

My story

My husband and I desperately wanted our baby. We had suffered a miscarriage seven months earlier so when, at six weeks, I was sick early in the morning we both laughed and were pleased to have the reassuring sign of 'morning sickness'. I felt like I was part of the club and was pleased to have experienced pregnancy sickness. Over the next few days the vomiting did not stop and had escalated to the point of 20-30 emetic episodes every day. Tiny sips of water would be violently ejected from my stomach the moment they went down and by eight weeks I was admitted to hospital.

I had planned to be as healthy as possible in my pregnancy. I didn't smoke or drink, had a healthy diet and had been taking pregnancy vitamins whilst trying to conceive. So when the doctor suggested I take medication for the pregnancy sickness I was terrified. There is a strong emphasis in society and in pregnancy literature that we should avoid medication in pregnancy (Koren & Levichek 2002). Yet I was too sick to do any research of my own despite having access to medical literature through my work as a nurse. Health care

professionals I came in to contact with, such as other GPs at the practice and the community midwife, would add to the anxiety by suggesting the medication wasn't safe. This was overwhelming and scary. As a result I would try to go without it for days, which caused frequent deteriorations. A study by Sykes *et al* (2013) found that many women were encountered 'scare-mongering' by doctors who were themselves scared to prescribe medication.

Long before this point I had tried various self-help strategies. I wore acupressure bands, took ginger in every form available, took homoeopathy pills, and tried to eat little and often but nothing would stay down. And I was resting. I was barely moving. Sensory stimulation, such as light, sound, smell and touch would exacerbate symptoms, so the room needed to be dark, and I couldn't tolerate much sound or movement, which led to extreme isolation. My husband and friends all worked long hours and I was off sick from work.

Isolation and constant symptoms led to depression and with little else to think about it was hard not to focus on wanting the pregnancy to end. I would fantasise about miscarrying

and was seriously considering termination, and yet I was constantly reminded about how grateful I should be for being pregnant at all and was told it would be better by 12 weeks. Twelve weeks came and went, as did 16 weeks, 20 weeks and so on, and I was still vomiting. Although I did improve a little at around 16 weeks, by 24 weeks I was signed off again and I was sick 2-3 times every day until my baby was born.

I went into my second pregnancy armed with information and mentally prepared for what was to come. However, the dismissive attitude from my GP was utterly disheartening and the pregnancy was worse than the first, both physically and mentally. I lost 20% of my body weight in the first few

“Long before this point I had tried various self-help strategies. I wore acupressure bands, took ginger in every form available, took homoeopathy pills, and tried to eat little and often but nothing would stay down”





weeks, but this was not taken seriously by my GP and I was told not to bother weighing myself. The feelings of guilt in this pregnancy were profound as even the smell of my first child could exacerbate symptoms: this is a commonly reported source of feelings of guilt amongst sufferers (Swallow 2010).

The decision to have a third child was tough and not taken lightly. I got in touch with PSS and learned about pre-emptive treatment (Maltepe & Koren 2013). I went to my GP at the time and was met with a dismissive attitude and a suggestion that I adopt a child instead. I changed GP and found a wonderful doctor in a nearby town. Together we made a treatment plan with criteria for moving on to the next level of medication. She took base line observations, such as weight and bloods and she documented the plan on my notes and discussed my case with the other doctors at the practice to ensure everyone knew the plan was in place to refer to in her absence. This care plan is now available via the PSS website.

This pregnancy was, in comparison with the first two, wonderful. I was still largely housebound but I made it downstairs most days. Despite constant nausea I was not sick very often, around 50 times in total throughout the pregnancy. By now I had made contact with lots of women via Facebook and other websites, which was the start of the support network we have today. This massively reduced the psychological impact of the condition as I was not so isolated, and I did not have to rely so much on friends who hadn't experienced HG and therefore had no idea what it was like. Instead, I was in regular contact via text and the internet with women who knew exactly what it was like having had similar experiences themselves, and they supported me every step of the way. For me, having the support of other sufferers prevented the perinatal depression that I experienced in my first two pregnancies as a direct result of HG.

References

- Bolin M, Akerud H, Cnattingius S *et al* (2013). Hyperemesis gravidarum and risks of placental dysfunction disorders: a population-based cohort study. *BJOG* 120(5):541-7.
- Bozzo P, Koren G, Nava-Ocampo A *et al* (2006). The incidence of nausea and vomiting of pregnancy (NVP): a comparison between depressed women treated with antidepressants and non-depressed women. *Clinical and Investigative Medicine* 29(6):347-50.
- Dean C, Gadsby R (2013). Severe nausea and vomiting in pregnancy. *Nursing in Practice* 7(1):45-6.
- Christodoulou-Smith J, Gold JI, Romero R *et al* (2011). Posttraumatic stress symptoms following pregnancy complicated by hyperemesis gravidarum. *Journal of Maternal-Fetal and Neonatal Medicine* 24(11):1307-11.
- Gadsby R, Barnie-Adsheed AM, Jagger C (1993). A prospective study of nausea and vomiting during pregnancy. *British Journal of General Practice* 43(271):245-8.
- Gárdián G, Vörös E, Járdánházy T *et al* (1999). Wernicke's encephalopathy induced by hyperemesis gravidarum. *Acta Neurologica Scandinavica* 99(3):196-8.
- Goodwin TA (1998). Hyperemesis gravidarum. *Clinical Obstetrics and Gynecology* 41(3):597-605.
- Koren G, Levichek Z (2002). The teratogenicity of drugs for nausea and vomiting of pregnancy: perceived risk verses true risk. *American Journal of Obstetrics and Gynecology* 186(5 Suppl):248-52.
- Kripalani S, Theobald CN, Anctil B *et al* (2014). Reducing hospital readmission rates: current strategies and future directions. *Annual Review of Medicine* 65:471-85.
- Maltepe C, Koren G (2013). Preemptive treatment of nausea and vomiting of pregnancy: results of a randomized controlled trial. *Obstetrics and Gynecology International* 2013:8 pages.
- Mazzotta P, Magee LA, Maltepe C *et al* (1999). The perception of teratogenic risk by women with nausea and vomiting of pregnancy. *Reproductive Toxicology* 13(4):313-9.
- Morales JB (2011). Introduction to IV therapy. 3rd ed. *Rutgers School of Nursing* <http://tinyurl.com/pyh7hjm> [Accessed 20 Jan 2014].
- Munch S (2002). Chicken or the egg? The biological-psychological controversy surrounding hyperemesis gravidarum. *Social Science & Medicine* 55(7):1267-78.
- Nursing and Midwifery Council (2008). *The Code: standards of conduct, performance and ethics for nurses and midwives*. London: NMC.
- O'Hara M (2013). *Women's experience of hyperemesis gravidarum: results of self reported online surveys*. *Biopsychosocial Understandings of Hyperemesis Gravidarum, 2nd National Pregnancy Sickness Support Conference*, London. <http://tinyurl.com/qexxrho> [Accessed 24 January 2014].
- Power Z, Thomson AM, Waterman H (2010). Understanding the stigma of hyperemesis gravidarum: qualitative findings from an action research study. *Birth* 37(3):237-44.
- Swallow BL, Lindow SW, Masson EA *et al* (2004). Psychological health in early pregnancy: relationship with nausea and vomiting. *Journal of Obstetrics and Gynecology* 24(1):28-32.
- Swallow BL (2010). Nausea and vomiting in pregnancy. *The Psychologist* 23(3):206-9.
- Sykes C, Swallow B, Gadsby R *et al* (2013). Seeking medical help for nausea and vomiting in pregnancy and hyperemesis gravidarum in primary care. *MIDIRS Midwifery Digest* 23(3):321-6.



Caitlin Dean

is a Registered General Nurse and writer. She has suffered three times with hyperemesis gravidarum. As a trustee for *Pregnancy Sickness Support* she set up the *National Support Network* for sufferers and is involved in research, raising awareness and education amongst medical professionals and via the media. Her *Spewing Mummy* blog about HG provides information and support for sufferers and she is writing a book about hyperemesis. Caitlin is currently travelling around the world with her husband and three children aged 6, 4 and 2.