

## Andy's DC Speech #2

Good morning. My name is Andrea Taylor. I administrate the HER Foundation's discussion forums, and represent 1,000s of women who have suffered from hyperemesis gravidarum, which I shall paraphrase as HG. I would like to share my experience of HG and also read quotes from women who suffered as I did.

I was six weeks pregnant, and a newlywed of three months when I was diagnosed. We were so excited about the pregnancy, but two weeks later when I was unable to keep even water down, I was terrified. I called a Dr. and was told to go to the hospital where the midwife said, "we have a very sick little girl here, and she needs an IV". I had never been so sick in my entire life.

Many women with HG experience this reality as well. Meg from " " wrote in September 2005, "[I] was first hospitalized for HG at 5 weeks ... I really thought I was going to die. Any food or drink that touched my stomach came straight back up and my husband found me on the floor one night having convulsions and rushed me to [the ER]. I was hospitalized [twice] for 2 weeks [each]. I have never felt so useless and out of control in my life." End quote.

[Alternate quote: I am a nurse. My first pregnancy, I had HG the entire pregnancy, barely treated resulting in IUGR. My last pregnancy was severe. No food for about 3 months. I lost about lbs in 2.5 weeks. The only thing that kept me going was knowing each minute I stayed pregnant, was one step further ahead than if I aborted and started over. It is a never ending battle of wills between my desire for more children and my medical knowledge that another pregnancy could be catastrophic to my health." Yvette K., RN, Colorado Springs, CO]

During my pregnancy, everyone told me I'd be okay by 12 weeks. I was not. My symptoms continued, and despite treatment, I was hospitalized repeatedly, even beyond the first trimester.

Most women are assured they will get better by the end of their first trimester. When they don't, they fear how long it will last. Some are sick until delivery. Amber from Georgia wrote in July, 2005, "I guess it just comes down to the fact that somewhere deep in the mind we have this belief that it goes away at 12 weeks, and when it doesn't you really come to understand you are really, really sick." End quote.

[One additional quote could be: "[She] has been bedridden in darkness - with no TV, no ability to read, barely able to talk, for the last 7 weeks. A steady and heartbreaking moan can be heard coming from her room. she hangs on, because she knows if she terminates, she will never have the courage/strength to try again." Gail, NJ [mother of a HG survivor]

Unlike many, I was lucky. By 20 weeks I was feeling pretty normal and had gained weight. I ran out of medicine at 23 weeks and decided I didn't need more. Within three days I was back in the hospital on an IV, with HG out of control. I wasn't warned about relapse. From then on, I took my medication religiously until delivery. Other women relapse because their doctors tell them to stop their medication too early, while others seem to relapse for no reason at all.

Kelly from " " expressed this frustration in August, 2005, at 31 weeks pregnant, "It is so unfair. I am back to [lying] in bed all day, begging my kids to understand and canceling appointments because I can't drive again... I feel like crying, but [crying just leads to] throwing up." End quote.

Another mom, Amy from " " described what it was like to be sick for nine months. In June, 2005, she wrote "During ... weeks 6 to 16 I honestly felt like I knew what it was like to be in a torture camp. Then, from weeks 16 to 25, it was just hell on earth. Then, from weeks 25 to 37 it was just plain misery." End quote.

As you have heard, these women suffer greatly and the recovery can take a long time. Preparing for another pregnancy can take even longer. Eighteen months after my first delivery, I was in another doctor's office. This time we weren't going to take any chances and we weren't even pregnant yet. We heard, "Every pregnancy is different" and "there's no way you could possibly be that sick again". I was cautious, and began medication before we conceived. They thought I was overly cautious but they were wrong, my next bout with hyperemesis was worse. I soon found myself uncontrollably sick and being bounced in and out of the ER. My caution had only delayed the onset of HG. I had allergic reactions to two of the drugs they tried, and finally had to insist on being hospitalized, I knew how ill I was. They thought I would go home in the morning, but I had to stay for five days because I couldn't eat anything at all. I was nine weeks pregnant. I missed Easter with my family and watching my son hunt Easter eggs. Finally, I was given Zofran, and almost immediately I was able to eat a full meal. I went home on multiple medications but still couldn't care for my son for the next six weeks while I recovered.

"I was bounced from doctor to doctor who made me feel like I was actually making myself sick. They gave me oral medication (which of course never stayed down) and I had 13 [hospitalizations]. I felt like I was a nuisance to them and that they quite frankly didn't know what to do with me." Danielle O., Knoxville, TN

Sadly, I'm not the only one who had to insist on adequate care. Many women are denied the care they need due to the cost, or the lack of belief by doctors that they are really sick. As Emma from " " wrote, "I am currently 8 weeks pregnant and have just been through hell and high water to get treatment... After I finally persuaded them all that I am not attention-seeking or paranoid, I was put on a drip and given IV [medications for] 3 days [then] sent home... the nausea kept me confined to my bed... The hospital initially wouldn't admit me unless my ketones were over 3+. However, my [dr]... didn't even bother testing, saying it was probably all my "state of mind". [Even] the hospital didn't test [for ketones]... until I had been sitting in a waiting room for 3 hours, continually vomiting ... [Now] the thought of having to go back into [the] hospital fills me full of dread... I felt scared, belittled and hopeless." End quote.

"I was constantly worried about the baby. Why wasn't my doctor prescribing IV fluids. I hadn't gained a pound. the resentment of my ob/gyn fueled me to change doctors, throw away the useless prescriptions and aggressively take my health and my baby's health into my own hands. However, it was too late. I suffered a 20 week loss of my son. I think we desperately need to expose this issue, so that sufferers aren't misdiagnosed and mistreated by family and friends, doctors are more informed and more remedies are developed to help the women who endure this illness.." Cynthia T., Baltimore, MD

Emma is a great example of the lack of knowledge health professionals have about HG. Training for the medical community must be addressed immediately for the sake of these women. They fear enduring HG again along with potentially life-threatening complications. Thus these women must face the decision of whether or not to bear more children. Ann Marie from "Texas " wrote in May, 2004, "My HG was horrific, feeding tubes, staph infection, numerous allergic reactions to meds ... My husband and I have decided not to have anymore biological children, but adopt. However, this is so hard, because I just know how badly I want another biological child, but I am afraid of the consequences and decisions I would have to make if my HG was worse the second time around." End quote.

For many, each HG pregnancy gets worse. We were unwilling to take that risk and also decided to adopt. It difficult at 22 years of age to decide I was never going to bear a child again, and for my husband at age 29 to have a vasectomy. All but three months of our marriage have been affected by HG, which has burdened each of our children's passage into our lives. We will never allow HG to take another day from our family. HG touches everything with a loss that scars the souls of all who truly understand its reality.

We adopted our second son in Utah after a year-long adoption process that was harder on me emotionally than HG was on me physically, but I wasn't sick for a minute, and for that I am very grateful. His adoption coincided with my discovery of an online discussion forum for Hyperemesis Gravidarum Sufferers. I was appalled that medication combinations were uncommon, that women were literally waiting for HG to hit so their doctors would offer medication. Many doctors would not act until the HG was out of control and terminating wanted pregnancies seemed the only alternative. Yet, persistent women and a few compassionate doctors soon learned that controlling HG before women were in dire need lessened suffering, and saved lives.

"One girl. was admitted to the inpatient psychiatric unit during her 6th month because of HG. [HG] can be managed and treated if recognized. Providers continue to treat it as a psychiatric condition or, worse, do not even acknowledge that it exists. If people understood how to recognize it early, perhaps women would not be faced with decisions such as whether or not to terminate their pregnancies, or whether or not to ever have more children." Tristin C., RN, Mobile, AL

My frustration with the excessive suffering of these women grew. Soon, I volunteered to manage the forums because women needed concrete information in order to survive. Through my own experiences and by corresponding with hundreds of women, I learned many ways to cope with HG – strategies many needed to know, but few did. Women had new hope that they could survive HG again. Even my husband and I decided to conceive a third time. An unplanned pregnancy was too big a risk to reverse my husband's vasectomy when I was facing 20 more years of fertility. We prepared for two years but all that planning ended in the tragedy of an ectopic pregnancy. It's been two years, and that loss still hurts so much I cannot bear to conceive again. We are currently applying to adopt again.

"I speak with my husband and think about having another child everyday... Others say often, "it's only 9 ½ months" but if they could have seen me, or what those surrounding me went through then, maybe just maybe they would understand. The experience is so raw and scary and yes the outcome is glorious but the journey almost killed me." CR - Mill Valley, CA]

After 4 1/2 years on the forum, I am mostly immune to the emotional impact of the stories I read. The ones that have touched me the most are Aimee, who was kept alive by TPN, the joy of two women who survived HG after four terminations, as well as the tears of women who find treatment info on our site just after they abort ... but there isn't enough time to tell these stories, so I have told my own.

I sincerely hope that these words have motivated you to support us in easing the suffering and loss of these families. In a day and age when doctors diagnose, explain a cause and treat some illness in a few minutes; it is difficult to understand why HG has no known cause, why women must write their own treatment protocols, and why so few obstetricians know how to manage this potentially life-threatening disease. Too many women terminate purposely conceived pregnancies because they are not offered effective treatment options, and often their suffering is dismissed. It is difficult to accept that there may never be a cure for such a devastating disease. The hyperemesis journey continues, and we are left with little choice but to pick up the pieces of our lives, wrap our arms around our precious children, and help others who are trying to survive. Please, help us learn more about hyperemesis gravidarum so these women find the help and hope they need to survive.

Thank You