

Amsterdam Reproduction & Development

What do our service users want?

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Conflict of interest

- ICHG organising committee
- No financial conflict of interest







1) Care-giver attitude

“I couldn’t even keep a mouthful of water down. If a GP then still says: ‘most pregnant women feel sick, with nausea and vomiting’. I thought: ‘yes, 3 times in the morning or 30 times, the whole day long vomiting, and not being able to leave the toilet, because you can’t even get on your feet any more, I think that’s quite different’.”

>> Refrain from using your own experience as a reference





1) Care-giver attitude

“In hospital they said ‘you have to eat’, ‘you have to get that food inside you’, ‘here, this is what you get, and you have to eat it’.” But if I can’t eat it because I immediately need to throw up, then I really can’t eat it. If I take two bites, three come out. It’s easier said than done. It isn’t easy to deal with being pressured like that.”



>>How do we do better?



1) Care-giver attitude

“Maybe by being kinder, like ‘try to eat, but if it doesn’t work, it’s no problem.’ There was so much pressure.”





1) Care-giver attitude

“The lack of knowledge on HG surprised me. Among professionals too, they think it’s all over after 12 weeks.”





2) Medical treatment

“At one point I called and said ‘I can’t manage any more, I can’t even walk to the toilet without fainting’. They said ‘alright, then I want you to come to our practice’. So I said ‘how will I get there?’ (...) Driving by car with HG is a nightmare. I was vomiting all the way to the practice, and in the waiting room too, with people all around me.”

>> Consider how can you deliver care- so you keep your patient most comfortable





2) Medical treatment

“But if I wasn’t dehydrated, they sent me home, although I knew I would be back within a few days, because it wasn’t a solution. (...) They let me go for so long, that I lost so much weight and was dehydrated in such way, that it went too far. (...) Waiting till I was dehydrated, only then they were willing to take action.”

>>Patients often know when they will benefit from fluids, listen to them.



>>If your patient has good access to your service, they will not feel ‘sent home’



2) Medical treatment

“The nasogastric tube feeding provided an 80 ml drip 24 hours a day, which provided a constant base intake(...) So my stomach stayed quite calm, (...). But in my first pregnancy I lived all those months on just two white rolls; (...)I was so extremely weak after giving birth, because I hadn’t taken and absorbed any nutrients. Because I received nasogastric tube feeding during my second pregnancy, I just noticed that it went so much better.”



>>In making a plan for the next time, use her experience



2) Medical treatment

“What I missed is that they didn’t tell me the therapeutic options; let’s say they didn’t even mention the words ‘nasogastric tube feeding’. Only because I started searching for something myself, because I thought: ‘Can I do something or is it just over? I mean, you don’t make the choice to remove the baby just like that.’”

>> discuss the options early, all of them, also if they are not (yet) relevant





2) Medical treatment

“I noticed that light really causes an extremely intense impulse to vomit. On the other side of the room a girl was admitted, and she had the television on during half the night. (...) how intense those impulses are, like noise, like food, like smells, like...that really is... that’s impossible to explain.”

>> Try to get her a single room





2) Medical treatment

“In one hospital Ondansetron is prescribed, and in another only Emesafene (=similar to Diclectin). In one hospital you can get Metoclopramide and in another you can't have it because of the harmful side-effects. Then I thought there needs to be a consistent policy.”

>> We need guidelines! Make a local guideline/ protocol if you don't have a national one



Royal College of
Obstetricians and Gynaecologists

Bringing to life the best in women's health care

■ The Management of Nausea and Vomiting of
Pregnancy and Hyperemesis Gravidarum (Green-top
Guideline No.69)

This guideline summarises the evidence and how to manage
women with hyperemesis gravidarum (HG)





3) Psychological Support

I felt guilty... (...) about work, (...) towards my child, (...) towards my husband... and I felt angry with myself: ‘why can’t I do this?’ (...) Yes, it would have been very nice if I could have spoken to someone other than my direct family. It doesn’t have to be solved, but it helps to talk about how you can deal with it.”



>> Offer a sympathetic ear, if necessary offer a counselor



3) Psychological Support

“Each time I saw the baby on the display, I thought ‘this is what I’m doing it for, for you’. ‘You’re still alive, and I need to do this for you; that’s what I owe you’. ‘I’m your mum, even though you’re still so small; that’s what I’m fighting for’.”



>> Do offer a ‘TLC’ ultrasound



4) Aftercare

“I pulled out my nasogastric tube during birth. (...) and after that it was finished. I think that’s wrong, that there is no aftercare. I wasn’t able to eat normally for the first 3-4 months, so I had serious weight loss. (...) My stomach and digestive system weren’t used to anything anymore, (...).”



>>20% have PTSS, offer a postpartum check up, ask after recovery from HG



5) Provision of information

“If I had known earlier about foundation ZEHG... I found a lot of information there, and I shared that with my boyfriend, my parents and his parents, who all didn’t understand... These were the people from whom I hoped to receive help, and from whom I eventually did, but only after all the information, because they just didn’t understand it at first, they just couldn’t imagine it.”

>> What is your local patient organisation?
How can your patient get in touch with them?



Stichting ZEHG

Je bent niet alleen



Pregnancy
Sickness
Support

