

Supplementary material 1: Quotations from women with ovarian cancer receiving parenteral nutrition and their family caregivers

Theme: Subtheme
Theme 1 Competing priorities
“[its] just something else dripping into my system isn’t it?...here it’s just one more thing going through” (Michelle, 73) .
“in the whole scheme of things for me, there’s lots going on; it’s not been a massive big deal really.” (Hilary, 62)
I have been a bit (<i>downhearted</i>), but it’s.....it’s not through that (<i>HPN</i>), I think it’s just ...because I’ve not felt well...you’ve got this (<i>nasogastric tube</i>), and it’ll get hooked on everything...at night when you’re getting up for the loo, you’ve got that in one hand (<i>drainage bag</i>) and then you’ve got that (<i>HPN bag</i>) in the other...I’m not sleeping proper anyway, but I’ve had a few things, like I’ve got the results of my scan tomorrow so I’ve got that going round in my mind (Kirsten, 56)
Theme 2 Gains: Survival
“if I hadn’t have had it I would be dead by now “ (Laura, 57)
“Well, I mean, I don’t think I’d have survived eating anything...I was so sick when I first went into hospital, literally, vomiting quite a lot of the time. I wouldn’t have been able to take any feed other than something like that, so it’s been a massive advantage, massive.” (Hilary, 62)
Theme 2 Gains: Quality of life
“Obviously having it in your own home is even more of a plus point, isn’t it?” (Paul, husband)
“I have, yeah. I get dressed and when you’re in the hospital you’re in a nightdress all day and it’s just nice to get dressed...Yeah, it means a lot getting dressed, it’s normality, isn’t it? I like normality, yeah” (Penny, 72)

“Well, I have written letters. I’ve roughly written letters for my sons and my dad, so I want, like, to write those up properly. So, that has given me time that I can do that with as well.”
(Sylvia, 49)

Theme 3 Losses: Curtailment of activities of daily living

“I end up getting up in the middle of the night because there’s a lot of liquid to take in so normally I wake about three and then I have to go through to the [toilet]” (Stacey, 73)

Theme 3 Losses: Limiting bodily freedom

I stay downstairs until Scarlett (daughter) comes and then she brings it up and we just put it here at the side of the bed (Belinda, 70)

Theme 3 Losses: Imposed routines

it gets put on and then took off in morning; there’s nothing any different in that respect (Kirsten, 56).

“I think the biggest problem is the timing...They come too early in the afternoon” (Caroline, 60)

Theme 3 Losses: Changes in meaning of home

It was a bit of a shock when you see all the fridge and everything and all the equipment, but they did warn me. (Caroline, 60)

Theme 3 Losses: Changing relationships

But he’s been a diamond. He has been a husband in a million...I never thought that I would get that out of my husband...I’m his patient. Plus his wife (Sam, 63)

Theme 3 Losses: Family caregiver – Financial

Financially it’s not great. And you just want to keep on top of things, you know. It’s quite tough (John, husband)

Theme 3 Losses: Family caregiver – Time

It is a full day, there’s always something (John, husband)

Theme 3 Losses: Family caregiver – Cooking

“I’ve learnt how to cook...well it’s the beans on toast a la carte or I can do fish and

steamed vegetables, that's about it" (Phil, husband)

Theme 4 Balancing gains and losses: Stopping parenteral nutrition

Oh I don't stop it, no. If I stop that I'm dead. It is my lifeline isn't it? (Sam, 63)

Theme 4 Balancing gains and losses: Hope

"I want to go back to Egypt, but that's not going to happen is it?" (Sam, 63).

"I hope that they might find a way of doing something with this obstruction I've got. In the future they might be able to do something about it." (Laura, 57).

"Just to be pain free" (Penny, 72)