


.....
+ *Vivian* +
.....



*Jag är inte den som klagar
men de där sista fyra åren med
min make Jack var svåra.*

Ett år tidigare

Var det där
läkarbesöket
idag?

Kom jag ihåg att
ge honom hans
tabletter?

Det här tar för
lång tid.

Vivian!

Han måste
komma in på ett
äldreboende.

Du orkar inte
med det här.

Jag mår bra.

Jag är
helt slut.
Jag orkar inte
längre.

Jag lovade honom att
han skulle få dö hemma
i sin egen säng. Jag svek
honom. En hustru ska ta
hand om sin make.

När jag tog hand om Jack försummade jag min egen hälsa och jag antar att det var det som gjorde att jag hamnade i den här röran.



Din distriktsläkare Dr Wilson har pensionerat sig. Du måste träffa en annan läkare, vännen.



Kalla mig inte vännen.





Kanske jag bagatelliserade smärtan för mycket eftersom läkaren inte remitterade mig till en specialist?


eh ... uhh ... jag har lite besvär när jag kissar.

Vad?
När du urinerar?

Det är bara din ålder.
Det är ingen idé att remittera dig. De kommer inte att göra något åt det.

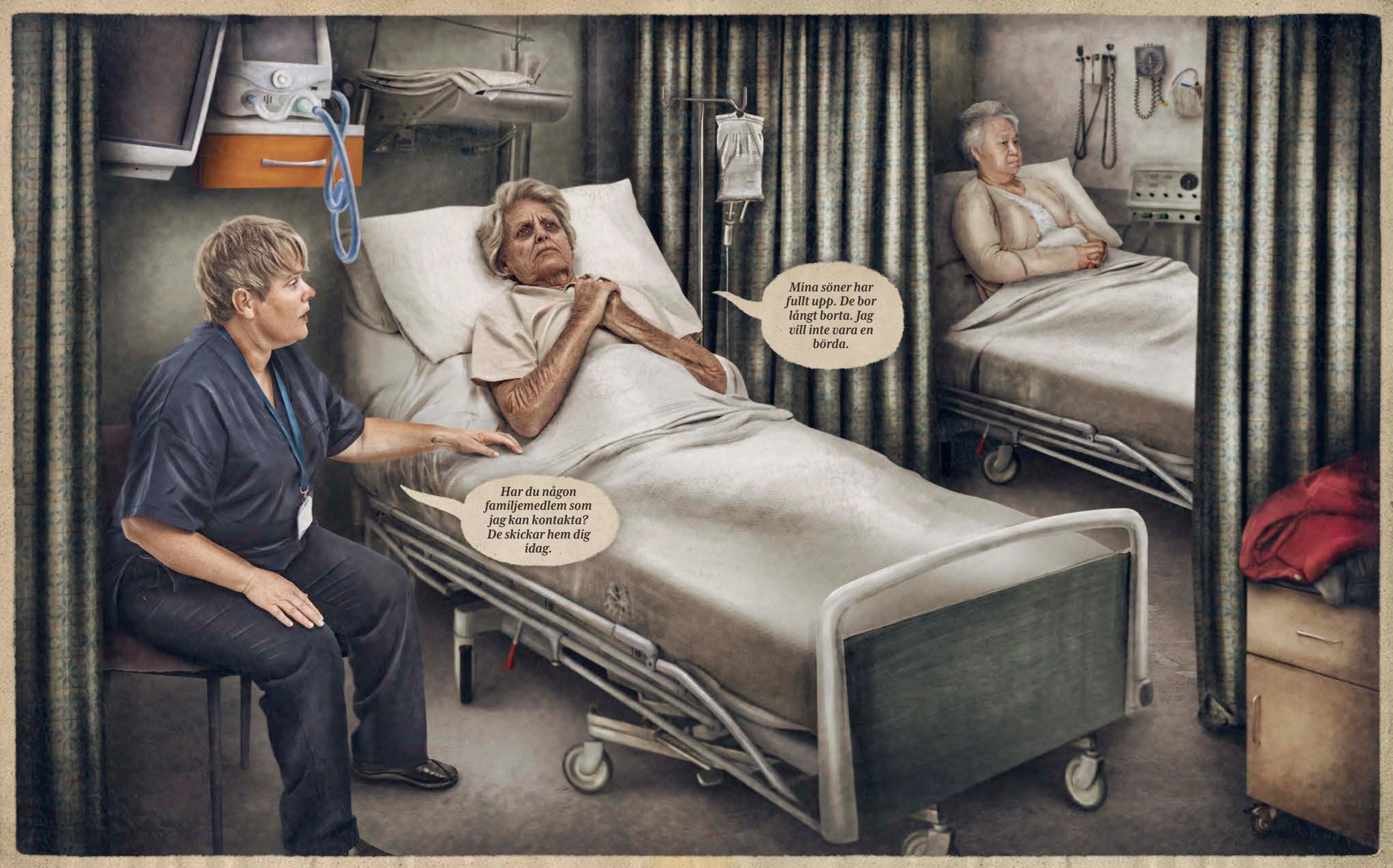






*Jag har precis
flyttat in i huset
bredvid. Jag hade inte
en aning om att hon
var så sjuk.*



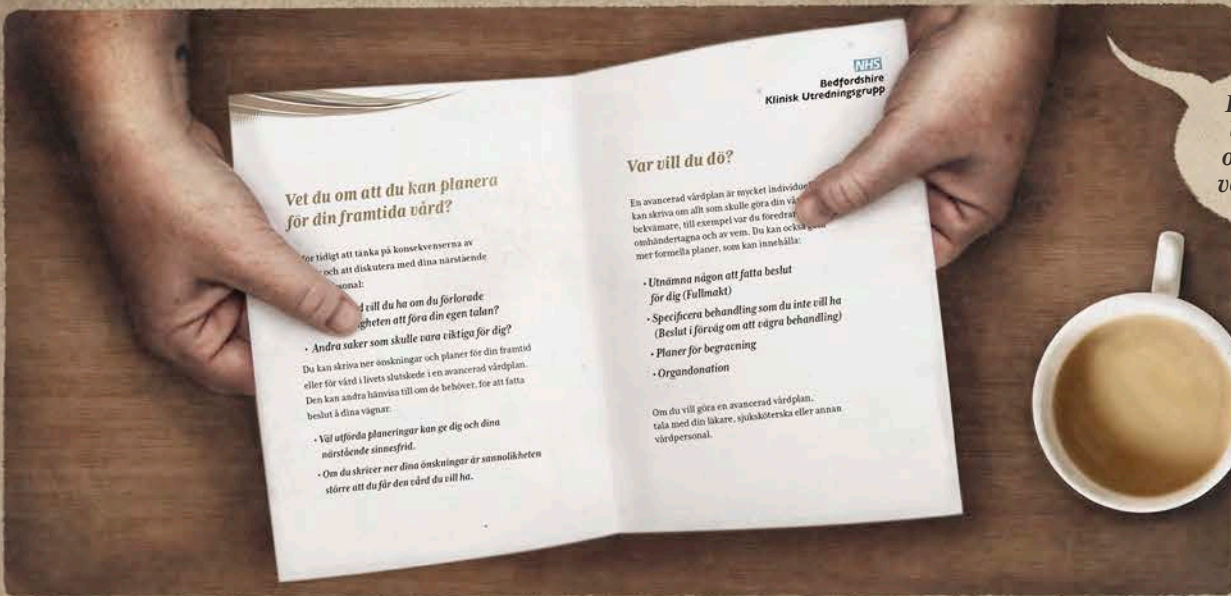


Mina söner har fullt upp. De bor långt borta. Jag vill inte vara en börda.

Har du någon familjemedlem som jag kan kontakta? De skickar hem dig idag.



Jag är ledsen att kakorna inte är hembakade.



Här är allt du behöver veta om avancerad vårdplanering.

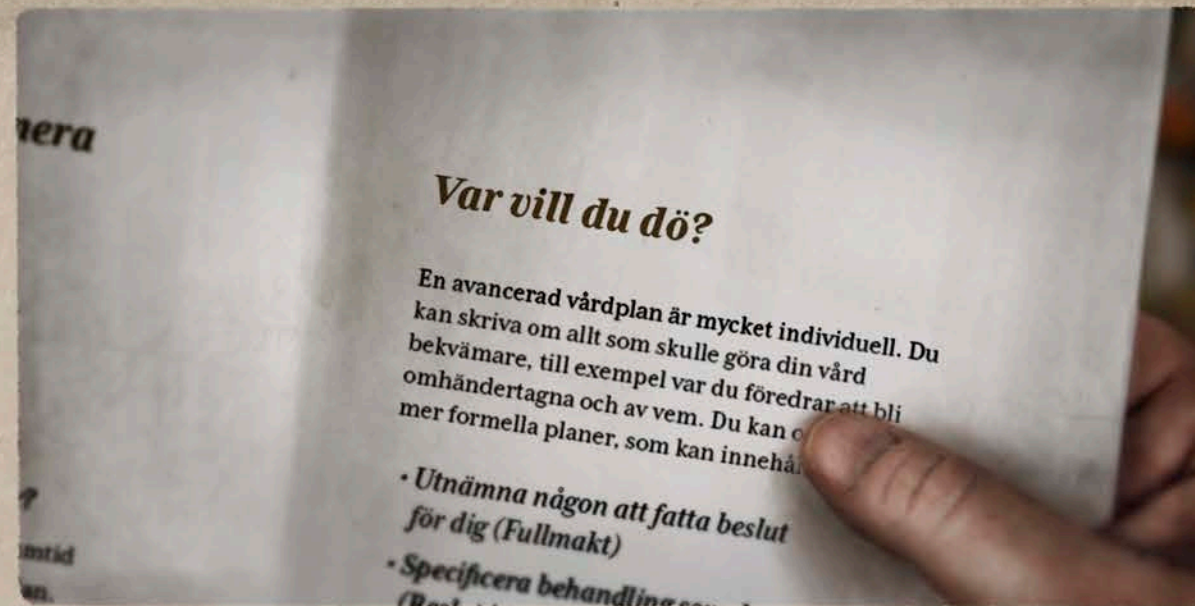


Jag är trött hela tiden – mer än vanligt.

Jag skulle vilja dö hemma. Men vem ska ta hand om mig?



Jag skulle vilja dö hemma. Men vem ska ta hand om mig?



Var vill du dö?

En avancerad vårdplan är mycket individuell. Du kan skriva om allt som skulle göra din vård bekvämare, till exempel var du föredrar att bli omhändertagna och av vem. Du kan också göra mer formella planer, som kan innehålla:

- Utnämna någon att fatta beslut för dig (Fullmakt)
- Specificera behandling...



Jag kommer åtminstone att ha det varmt på vårdhemmet. Jag behöver inte laga mat och mina söner behöver inte oroa sig.

På äldreboendet



Vivian

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INTRODUCTION

*Your assumptions are your windows on the world.
Scrub them off every once in a while, or the light won't come in.*

ISAAC ASIMOV

The impact of gender on palliative care

Vivian's origins stems from a plenary I gave at the European Association of Palliative Care Conference in Berlin in 2019. I was asked to speak to the topic: 'Is palliative care biased?' It was hard to know where to start. But I decided upon an issue that affects us all. Sex and gender are key determinants of end of life experience, but have been largely ignored within palliative care research, practice and policy to the detriment of both women and men. This bias is all the more powerful in being largely unconscious and almost wholly invisible.

The result of constructing research participants, and research concerns, as gender neutral is that a male worldview has been uncritically normalised and perpetuated. I was unaware of quite how pervasive this trend was until I started to scope the literature where I found evidence of male bias throughout the whole continuum of research from 'bench to bedside' with negative implications for us all, whatever our gender identity.

In my presentation I wanted to initiate a paradigm shift in how palliative care as a discipline thinks about gender. In particular I wanted to ensure greater critical attention to how societal expectations of femininity and masculinity determine end of life expectations and experiences. I wanted people who pick up a research paper to critique it from a gender perspective.

Ultimately I wanted us to talk about the fact that most work with animal models has been conducted with male animals because females are 'too troublesome' with implications for key medications in palliative care, that women are less likely to receive end of life intervention such as CPR or ICU admission than men, that women wait longer for pain relief than men, and that current evidence suggests early palliative care intervention improves quality of life only for men, not for women.

Whilst it is known that most family carers are women, it is less known that women carers experience greater physical and psychological impacts from caring than men and are more likely to be living in poverty. These are all conversations we need to be having if the goal of palliative care – to improve quality of life for all – is to ever be realised.

Inspired by M ori pur kau

Yet how to persuade an audience of 3,000 comprised predominantly of clinicians that gender matters? We found our answer in M ori pur kau. Pur kau are a traditional form of M ori narrative that serve as a vehicle for teaching and learning. More than mere myths or legends, they were (and are) vital for the transfer of knowledge, values and wisdom. In a similar vein, we created Vivian as a story that is imbued with knowledge gained from our research and the broader body of palliative care literature. While Vivian is no woman's particular story, she represents how gender can affect every woman. Vivian also foregrounds the values of the Te  rai Palliative Care and End of Life research group – that individuals and their families/wh anu are the true experts regarding palliative care and clinicians would do well to listen to them.

Thank you

It was Victoria Egli's brilliant idea to refashion Vivian as a graphic novel (for the EAPC conference the story was presented as a recorded monologue). Her creative insights, enthusiasm and remarkable op-shopping abilities for sourcing costumes fuelled the project. Lisa Williams provided editorial guidance and served as the project coordinator; as always, her ability to help turn our research findings into creative outputs was vital.

Tatiana Tavares took our text and transformed it into the amazing artwork you see in these pages. Like us, I'm sure you will be awestruck by her illustrations. Her work is supported by her colleague Marcos Mortensen Steagall's vibrant photography. Thank you Marcos for helping bring Vivian to life.

The characters in Vivian were portrayed by our friends and family who cheerfully gave up their time on a weekend during the summer holidays to pose for Marcos and Tatiana. Liz Hill played Vivian with grace, humour and vitality as did her husband, Ivan, our model for Vivian's husband, Jack.

As you read the story, you'll also find our School of Nursing colleagues, Julia Slark (community nurse); Michal Boyd (clinician at Jack's bedside); Victoria Egli (bystander with paramedic, medical student) Lisa Williams (medical student); Sarah Dayal (receptionist); Kim Ward (paramedic) and Michael Crossan (GP's waiting room). Kim's husband Paul and son Toby are featured at the bus stop with Vivian, as is Michal's partner, Fran Robertson (bystander worried about Vivian's health). My husband Jonathan Sudworth is the model for the grumpy GP and my son Owyn also plays a bored patient in the GP's waiting room. Julia's partner Jenny Parr is the nurse in Accident and Emergency, and Vivian's husband Tobi Egli is the A & E doctor.

While Vivian's story is not an easy one, it is an important one. I hope it will offer you food for thought about how gender influences palliative care and perhaps spur your thinking about how we can do better.

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