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+ *Vivian* +

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• 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 Māori purākau

Yet how to persuade an audience of 3,000 comprised predominantly of clinicians that gender matters? We found our answer in Māori purākau. Purākau are a traditional form of Māori 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 Arai Palliative Care and End of Life research group – that individuals and their families/whānau 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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*I'm not one to complain
but those last four years with
my husband Jack were hard.*

One year before...

Is that appointment today?

Did I remember to give him his tablets?

This is taking too long...

Vivian!

He has to go into a home

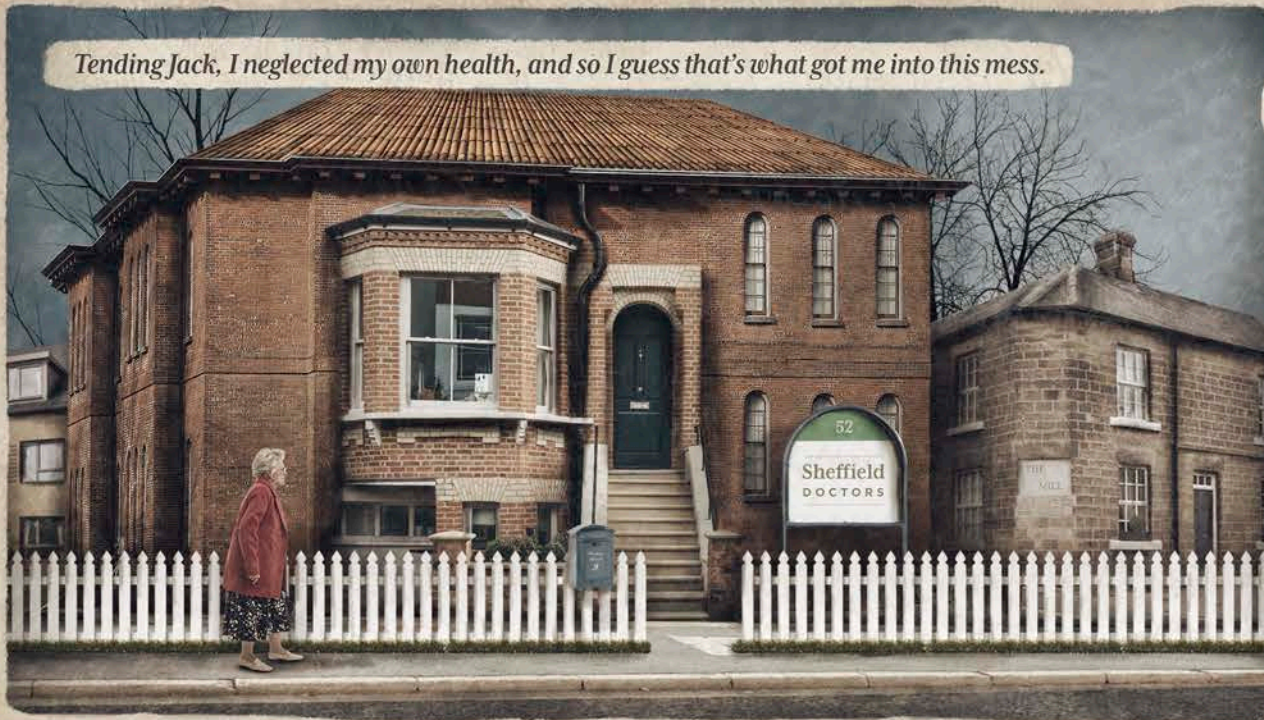
You can't cope anymore...

I'm fine.

I'm so exhausted. I can't do this anymore.

I promised him he'd die in his own bed. I failed him there. A wife looks after her husband.

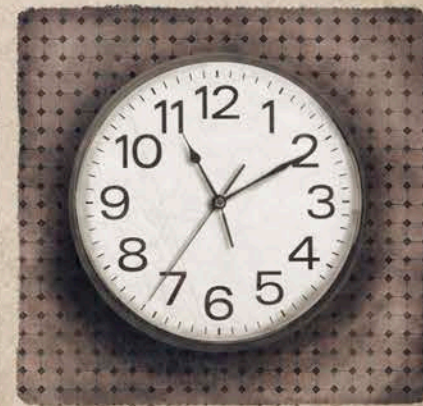
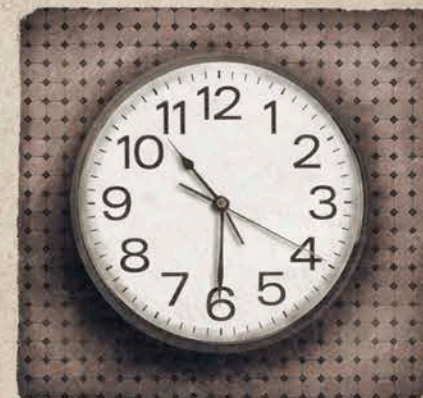
Tending Jack, I neglected my own health, and so I guess that's what got me into this mess.



Your GP,
Dr Wilson, retired.
You'll have to see
someone new,
dear

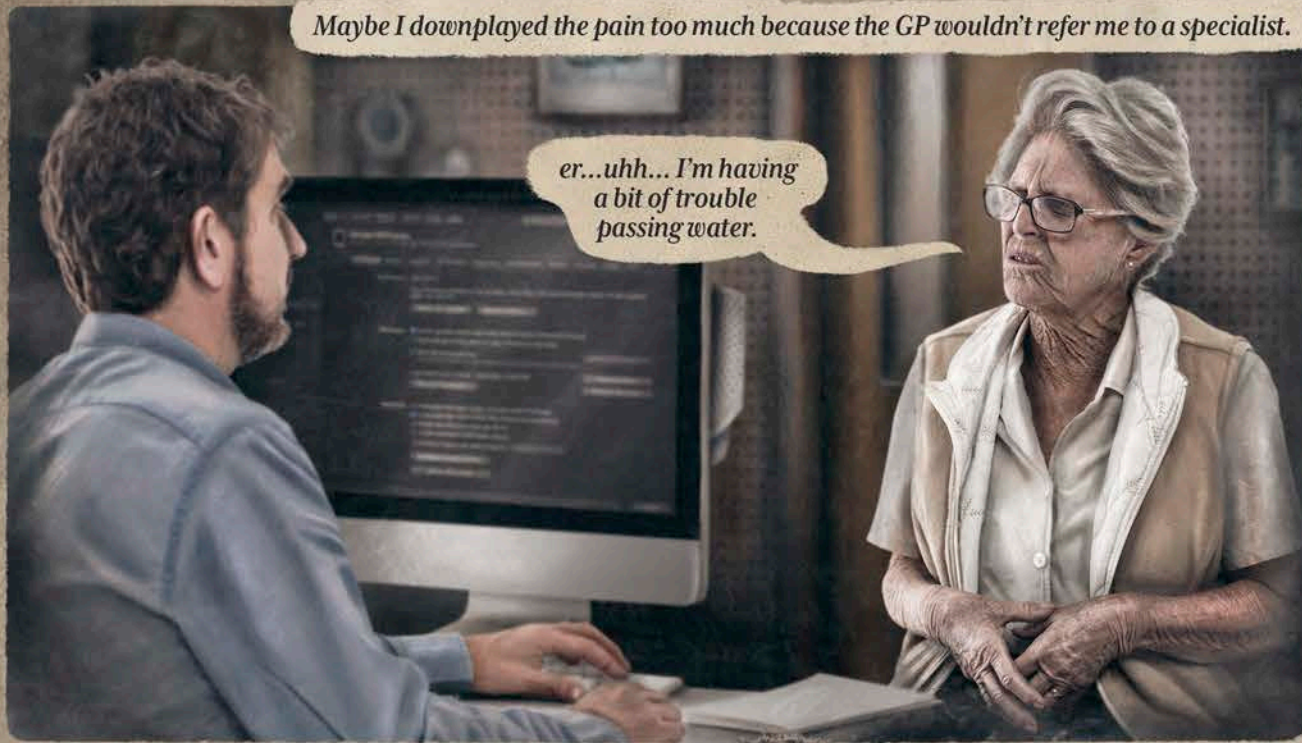


Don't call me dear.





Maybe I downplayed the pain too much because the GP wouldn't refer me to a specialist.



er...uhh... I'm having
a bit of trouble
passing water.



What?
Urinating?



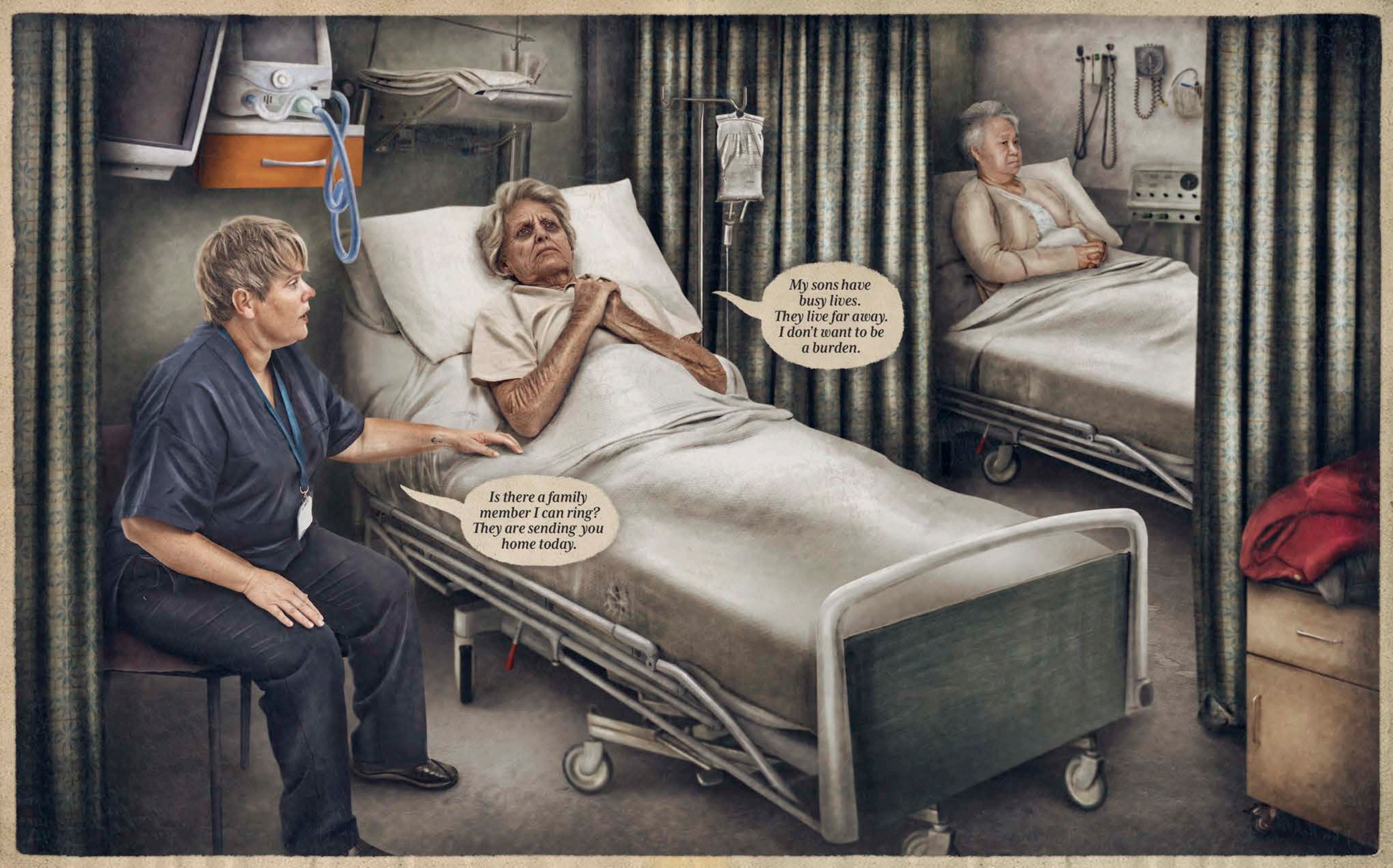
It'll just be your age.
There is no point
referring you. They won't
do anything about it.









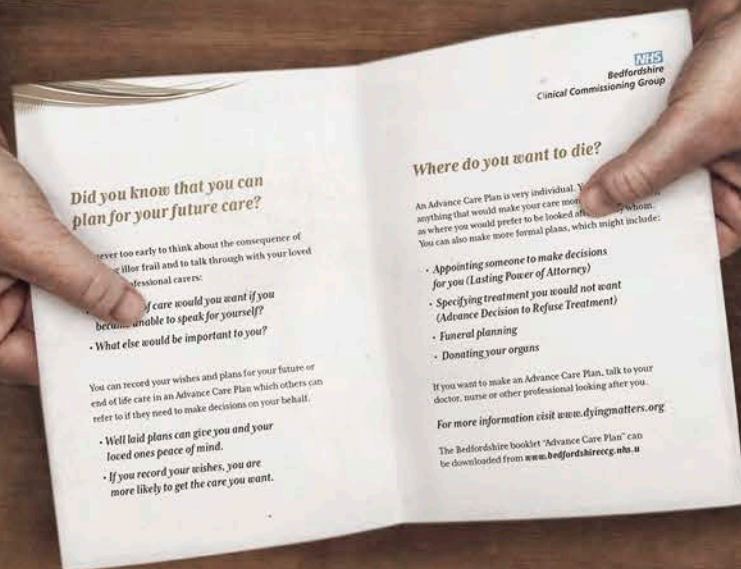


My sons have
busy lives.
They live far away.
I don't want to be
a burden.

Is there a family
member I can ring?
They are sending you
home today.



*I'm sorry the
biscuits are not
homemade.*



Here's everything you need to know about ACP.



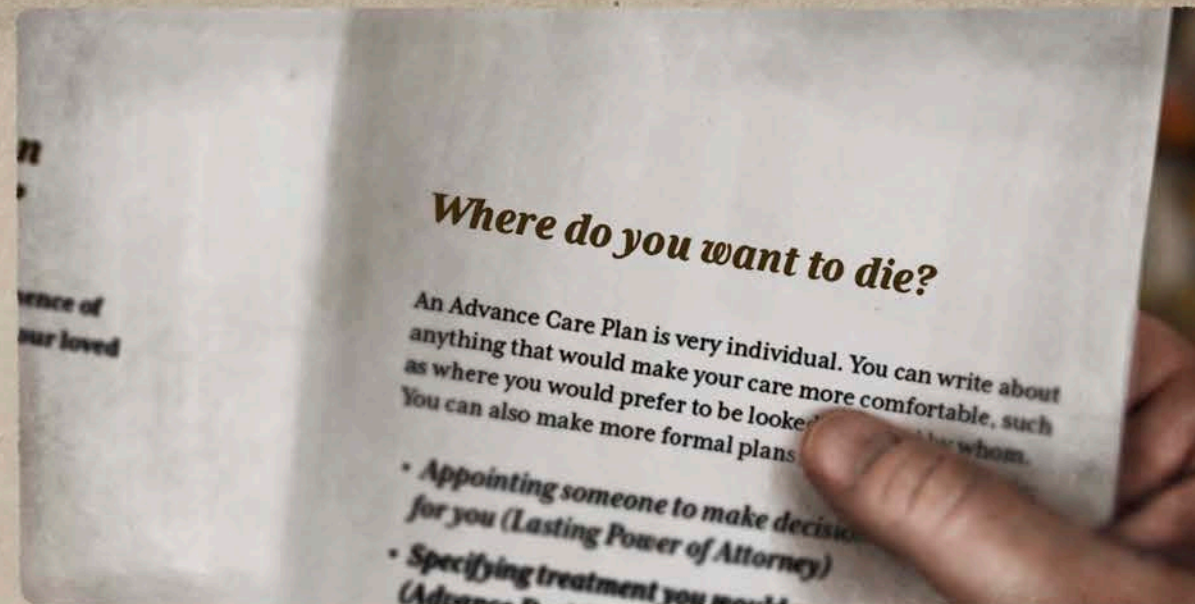
Now, let's start with what your main concern is at the moment. Pain?



I'm just tired all the time – even more than usual.



Actually, it's money... with winter coming on, how will I afford the heating bill? Can't say that.



At the retirement village...



