picturing cancer survivorship

a collection of photographs from the ‘changing landscapes of survivorship’ study

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about

The changing landscapes of survivorship: a sociological study of cancer

Two out of every five Australians – almost half of us – will be diagnosed with cancer before we turn eighty-five. Whether cancer appears in our own body or the body of someone we love or care for, cancer will likely affect us all, in one way or another.

Even so, we generally don't fully understand what a cancer diagnosis, treatment and survivorship are like until we go through them ourselves. Before that, we hear about 'fighting the battle', see #fuckcancer hashtags and go-fund-me pages, and know – in general terms – how tough treatments like chemotherapy can be. But we typically only see a fairly narrow representation of cancer in the media and get only small glimpses into the experiences of people who are living (and sometimes dying) with it. These glimpses rarely show the full picture of what life with cancer is like away from the hospital and back in 'everyday' life.

How do people experience cancer, not only as a 'patient', but as a mother, father, daughter, son, husband, wife, or grandparent; as a person at home, or at work, as a friend, neighbour, or member of the community?

We wanted to build a better understanding of what people actually go through when they're living with cancer. This isn't easy to document. It takes place both within and well beyond the walls of the hospital or clinic, can be quite private and is sometimes difficult to talk about or explain.

So we gave some of the participants in our study a camera and asked them to show us, with photographs, what living with cancer was really like, for them.

The **Picturing Cancer Survivorship** study included volunteers from all walks of life, from young parents to elderly retirees, living with all sorts of different types of cancer – breast cancer, brain cancer, lung cancer, bowel cancer and more. Each of these everyday Australians had a unique story, which they generously shared with us through their photos and a subsequent in-depth interviews.

The result is this series of images, each accompanied by a caption or quote in the participants' own words. Together, they illustrate how cancer shapes people's lives – for better and for worse – in varied, complex and nuanced ways. These photos show something meaningful about the wide variety of experiences of living with cancer by capturing some of the ideas, experiences, emotions, difficulties, insights and empowering moments that cancer brings with it.

We are sincerely grateful to the participants in our study who have made this collection possible by sharing their photographs and stories with us. We hope that in some small way, it reflects the variety and profundity of their experiences and the experiences of those around them. We are also grateful to our clinical collaborators, who cared for the study participants, and their families, at The Royal Brisbane and Women's Hospital and Prince Charles Hospital.

Picturing Cancer Survivorship is part of 'The Changing Landscapes of Survivorship' - a multi-year research study supported by the Australian Research Council.

the team

Katherine Kenny is an Australian Research Council DECRA Senior Research Fellow and Deputy Director of the Sydney Centre for Healthy Societies at The University of Sydney. Her research draws on social theory and qualitative methods to better understand how health and illness are understood, treated, experienced and made meaningful both in healthcare setting and in daily life.

Alex Broom is a Professor of Sociology and Director of the Sydney Centre for Healthy Societies at The University of Sydney. He uses insights and methods from the social sciences to explore the lived experience of health and illness and the social structuring of healthcare delivery, and to help inform better healing and supportive practices.

Emma Kirby is an UNSW Scientia Associate Professor in the Centre for Social Research in Health, Faculty of Arts, Design and Architecture, UNSW Sydney. She studies advanced illness and end of life care, mapping its character and significance, with a particular focus on relationships in/and health care, health care practice, diversity and social justice.

Stefanie Plage is a Research Fellow with the Life Course Centre at the School of Social Science at The University of Queensland. Her research interests span the sociology of emotions, disadvantage and health and illness. Her PhD research used a mix of qualitative methods to explore the lived experience of people with cancer.

Zarnie Lwin is a Senior Staff Specialist in Medical Oncology, Cancer Care Services, Royal Brisbane and Women's Hospital and Associate Professor at the University of Queensland. She is past Vice-Chair and Treasurer of the Medical Oncology Group of Australia (MOGA), current Co-Chair for the Society of Neurooncology International Outreach Committee, and represents Australia on the Asian Society of Neurooncology Reform Working Group.

John Oliffe is Professor and Tier 1 Canada Research Chair in Men's Health Promotion at the School of Nursing, University of British Columbia. His work focuses on masculinities, men's health behaviours, and illness management, especially in the areas of psychosocial prostate cancer care, smoking cessation and male suicide prevention.

Rhiannon Parker is is a Research Fellow at the Centre for Social Impact at UNSW Sydney. She is a qualitative researcher whose work has focused on the intersections of social justice, health, and education. She is interested in improving lived experiences of education, health, illness and care. She has undertaken research on the social dynamics of cancer, end-of-life care, gender and educational attainment, and gender in medical education.

David Wyld is Director of Medical Oncology, Cancer Care Services, Royal Brisbane and Women's Hospital and Associate Professor at The University of Queensland. In addition to clinical interest in gastrointestinal and neuroendocrine tumours, he is also involved in qualitative patient-focused research and in medical education and training. He maintains active involvement in Cancer Services planning and development, including as a member of the State-wide Cancer Clinical Network executive committee.

Patsy Yates is is Distinguished Professor and Executive Dean of the Faculty of Health and Co-Director for the Centre for Healthcare Transformation at Queensland University of Technology. She leads a large competitively-funded research program focused on developing workforce capacity in cancer, palliative and aged care, treatment side effects, and strengthening the nexus between research, policy and practice. She is the current President of the International Society of Nurses in Cancer Care and a past-President of Palliative Care Australia.

when someone tells you you’ve got something
that is quite aggressive in you

you sit back and you think

“well whatever you’ve got,
give it to me

I don’t care what it is,
just give it to me”

my desk at work
like my old friend

even my mundane,
boring Monday to Friday
public servant life
is mine
and it’s worth defending
and it’s worth fighting for

you know?

my sister-in-law made me these
she knew that I would need them

so right at the very start she said,

“just put these away.
when you’re ready.”


it's just what happens
just the circle of life

life goes on
like the circle of life

he's just born, hasn't got a care in the world
he doesn't know what's going on...

just like, "don't worry about it"

it's just what happens

just the circle of life

a lot of people don’t know what a PICC line looks like

when they see that, it brings home that maybe I’m not as well as I look

a day in the life

walking the mile

sometimes it's just the little things that make you feel good

whether it's polishing your shoes or going to get a haircut... it just makes me feel better

might seem simple but they make you feel good

well most people would be amazed
by a woman driving that rig for a start,

but the fact that I’ve got cancer
and I’m driving that,

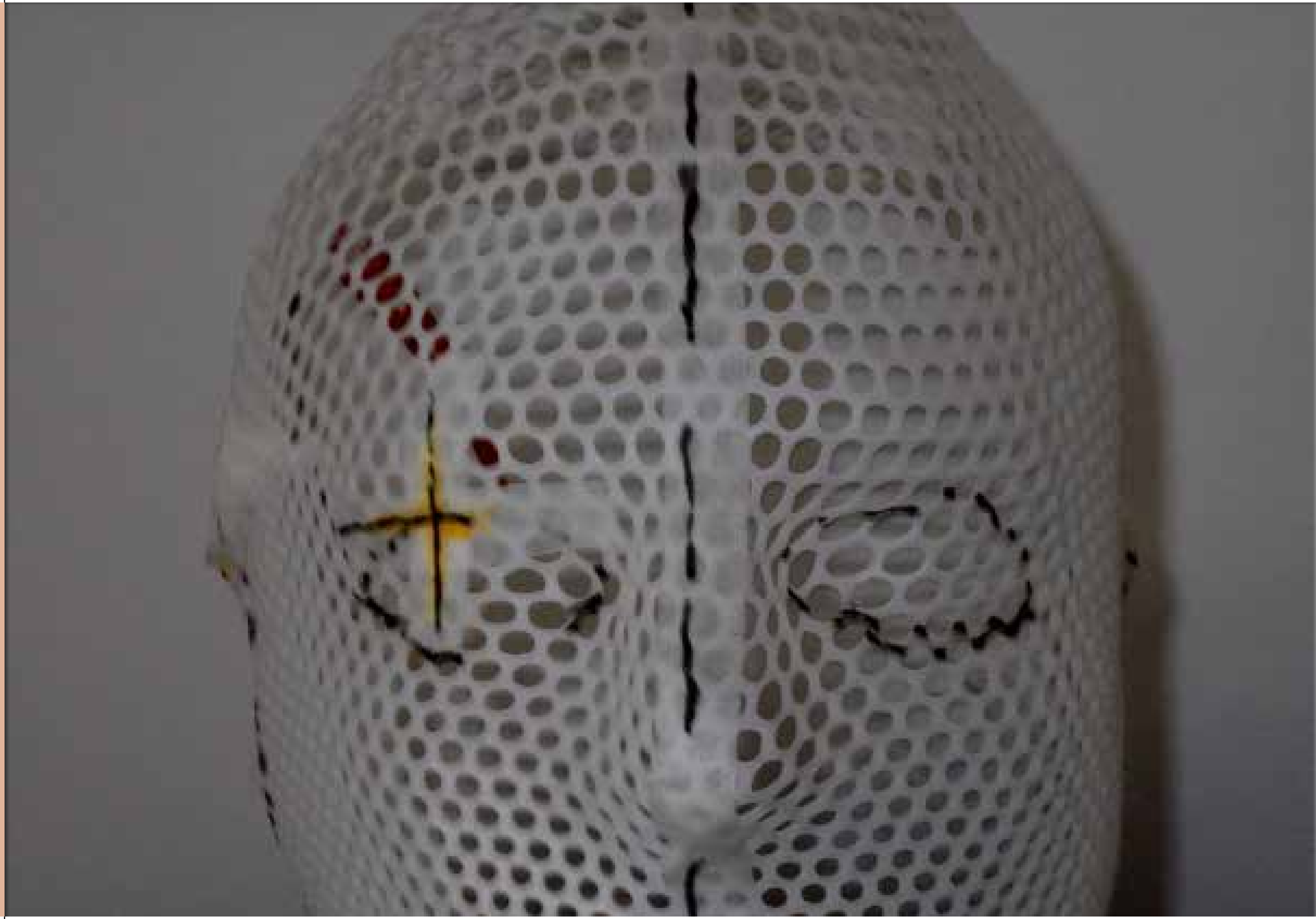
they’d be amazed

happiest place on earth

I will always be apprehensive
because, you know,
one day it might come back

I've been dealing with this for over ten years...

one day it might come back



#fightcancer

dressings had to be changed today

some things
one should keep to themselves,
I guess

scary scar

peace

asking for help is probably the hardest thing

I guess, reality hits
there's stuff I can do,
there's stuff I can't do

so you do a bit of work
stop
recover
a bit of work
recover

cancer is a bugger

two steps forward
one step backwards

fingers crossed

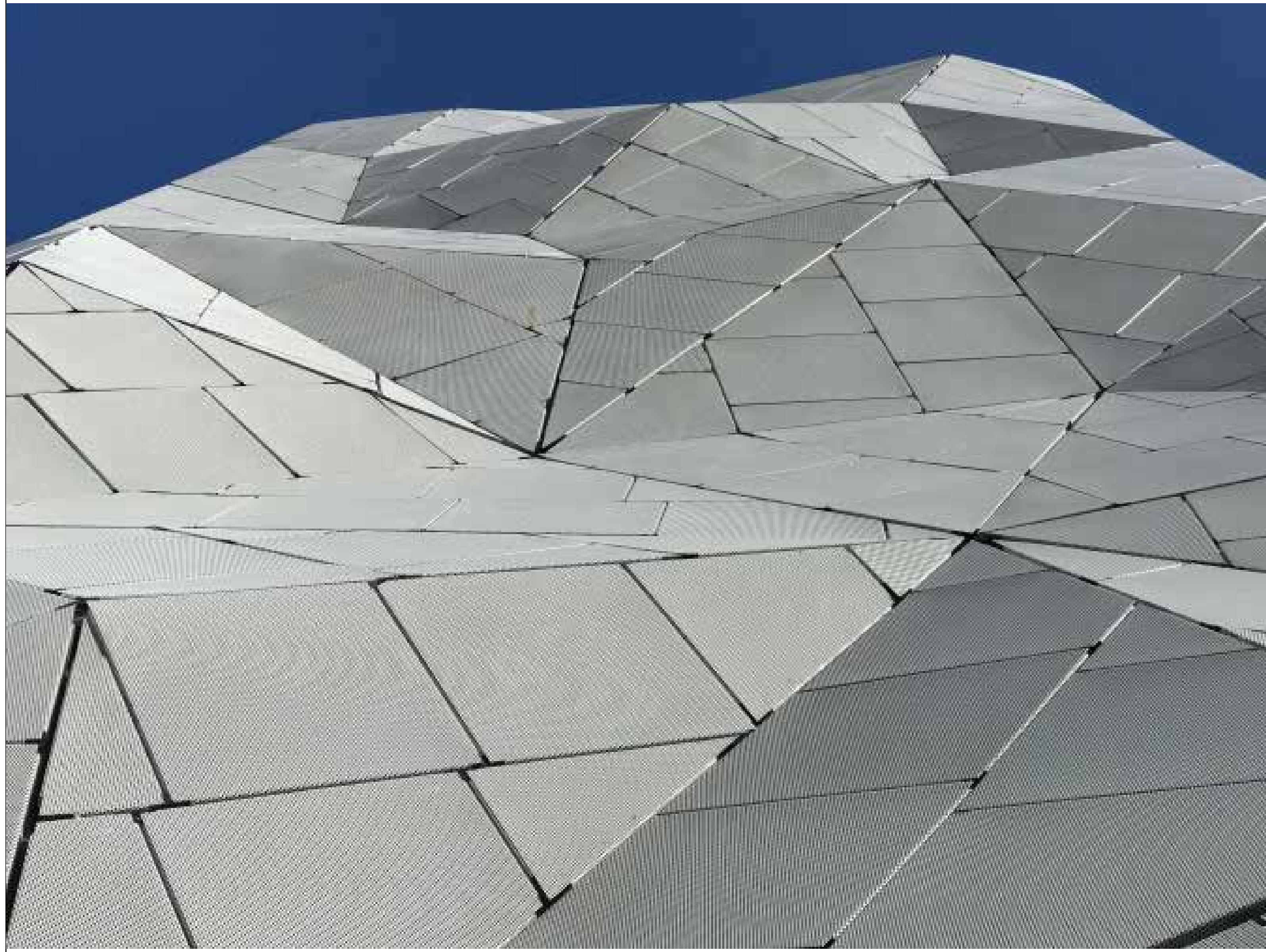
if you are sick and especially if
you’ve got a
terminal illness,
some people do not know
what to say or what to do

“what should I say? what should I do?”

I’ve spent a lot of time in one of those

the MRI machine is the one thing that tells the doctors what’s happening in my brain, otherwise they can’t tell

clear skies above



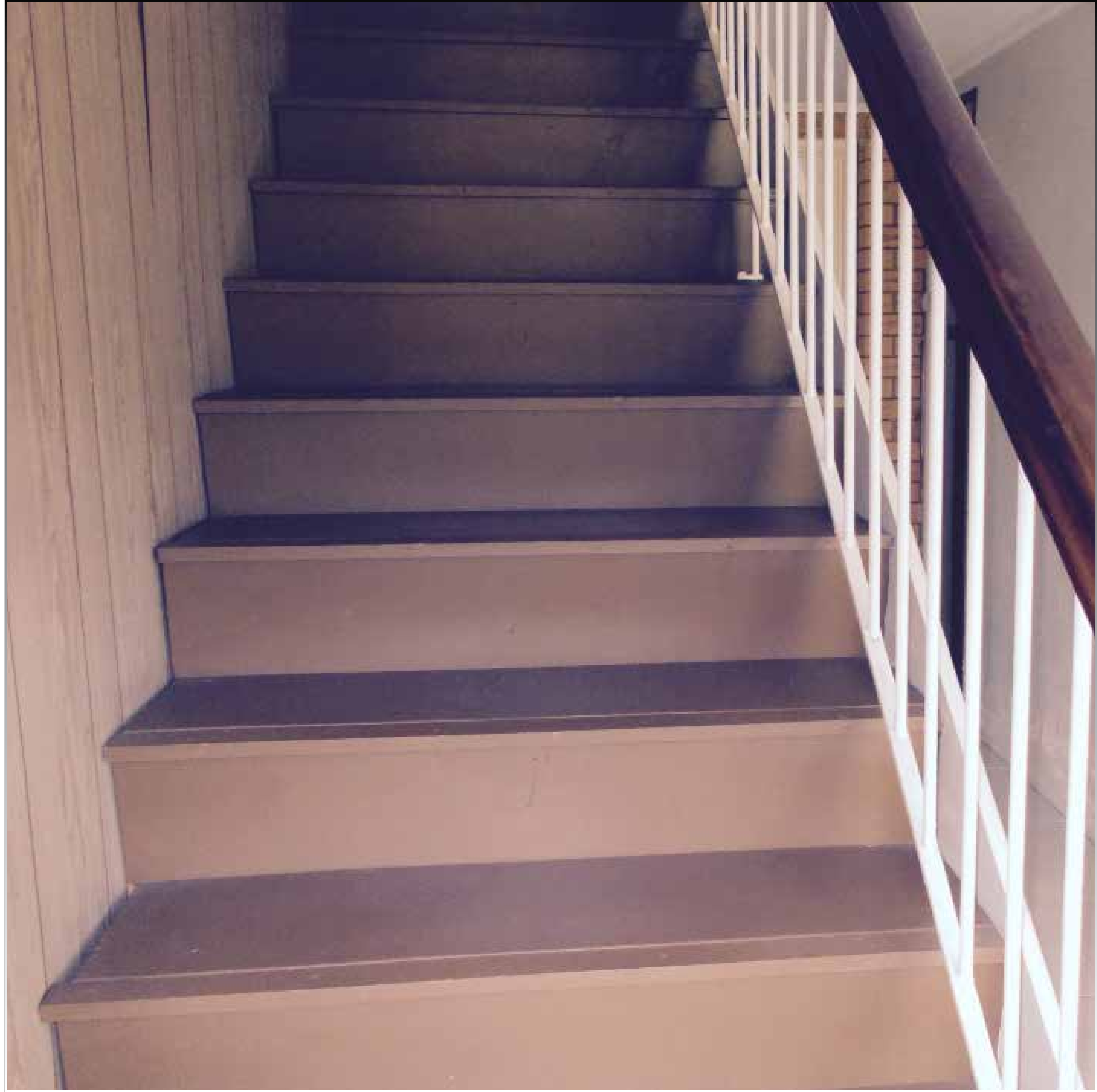
the fact that you managed to clean the house is
something…

that's where I find it hard
that I can't do
what I used to

left behind

it becomes one of the
obstacles in life

although it’s a small obstacle
it is one of them



another hospital tag

ever since I was diagnosed with cancer
I thought about it and thought about it

and thought,

“okay, if I die or when I die, he will have no one to talk to”

so in the end I said, “okay, look, you can have a dog...

so he is one of the things that help

#roadtorecovery

I have a priority
to live as long as I can

for my family

I think that it’s important,
in my situation,
just to keep enjoying life

just this simple little barbeque
shed and a bit of a fence,

you don’t need anything else

you’ve got that, you’ve got your friends
you sit around

just the food, the get together

you’ve got it made, haven’t you?

keep in contact with your mates

just because you're feeling crook or you might be
having a bad day, they might be having a worse day

keep in contact with them

go out and hang out
and see what they're doing,

it doesn’t matter
what’s wrong with you

whether you’re in a bad mood
or whatever

the old dog will still wag his tail

and love you

I don’t like the thing
when people say
everything happens for a reason

bad things happen
they do
there’s no reason for it

things just happen
and they’re not always good

and your resilience comes
from taking the good with the bad

I put my faith and trust
in God

for this journey

for myself
and future generations

things aren’t going right

this is not about me

cancer is just something

that happens

to have hit me

it’s nice to talk to other people

who understand
and have the same thing

and hear their stories as well

we’re all the same

getting up,
going to the hospital,
coming home
and going to bed

sometimes you just
want to
break that up

I love my roses
I have roses and lavender in the garden

the guy next door is a beekeeper
and so the bees are there every day

I love nature
if you’ve got animals around you,
no matter what they are,
birds and the environment,
you’re at peace because you’re with nature

that helps you get better as well

I went and saw my orthopaedic specialist
who was going to do a knee replacement
and had a chest x-ray in preparation

low and behold there was a nasty little surprise

I actually had lung cancer

that was a bit of a shock

I said to that doctor, “bloody hell. How am I
ever going to get these knees fixed now?”

he leant over and he said,
“you’ve got to thank your knees”

down the front there’s a few old trees
that are riddled with rot

that’s like a form of cancer too,
isn’t it?

this is the effect chemo had on me

all the skin on my fingers was peeling
the nails all cracked

it was a bit hard to take

that was the Thursday two weeks ago

he used that word “cured” very
pointedly

I think he was trying to really enforce to me,

“you’re better
take it”

the quiet

I don’t look like myself
I don’t think I look like that inside

I feel much fitter and healthier

this woman here looks tired, old, and sick
and I don’t really feel like that

I may look like it, but I don’t feel like it

aside from treatment side effects,
the only way I know I have cancer
is what I am told

I do not have any symptoms

probably the hardest aspect
of living with cancer
is actually accepting that I have cancer

I find it difficult to accept it

we are playing a waiting game

I’ve still got my health
and my ability to walk the dog
that’s what reminded me

how lucky I am still to have my health,

even though we’ve gone through this

how lucky I am

to still have my health

a great meeting place

we have, more or less, built all this
so when the family comes
they can all have fun

we have our barbecues and
we bond and
everybody always comes

cancer stays away from that

one of the many nurses

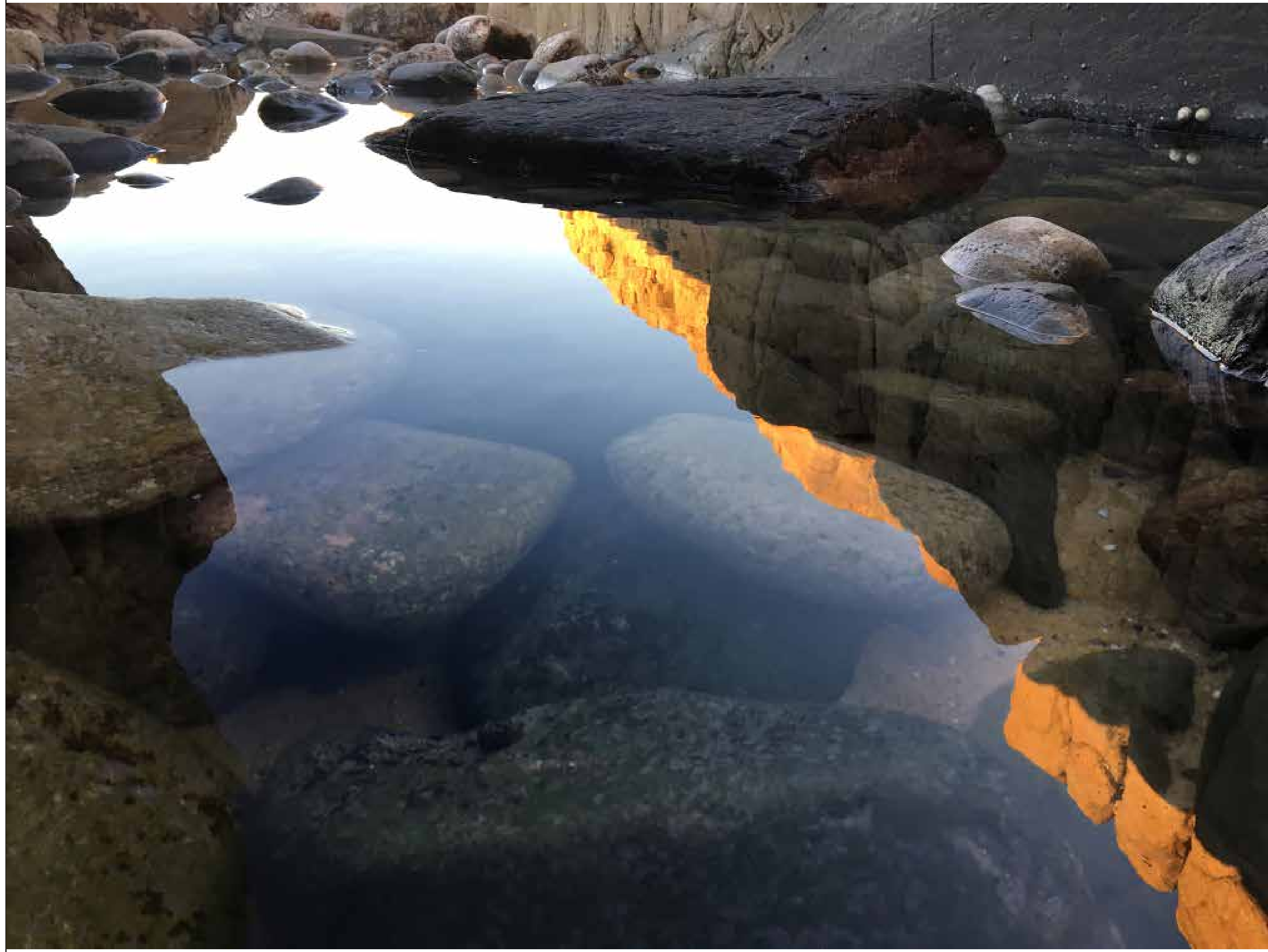
there they care for you 110%

it’s not unpleasant going to the hospital
because the staff are so pleasant

they make the horrible pleasant, you might say

in many ways not thinking about cancer
is half of my aim

trying to just feel normal again



We sincerely thank the volunteers in this study for allowing us to reproduce their images here. We would like to acknowledge the contributions of both those participants who chose to remain anonymous, and those who chose to be identified by the following names: Ashley (Instagram: @deadmanscrambling), Barbara Collyer, Frances, George, John, Judy, Lan, Leona, Lesley, Mark, Peter, Robert, Royce, Simon, Timothy Mark Coates, Trevor (Bull) Herrod, and Twincom.

To inquire about additional copies of this book, please email Dr Katherine Kenny
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