With the support of:

MAGGIE'S
Everyone's home of cancer care

Marie
Curie

Dedicated to the memory of my darling wife and life partner, Melanie Dicks.

Your personal guide to being the carer for a cancer patient

15 THINGS

I wish I'd known from the start

By PAUL EVANS

INTRODUCTION

The day my wife was diagnosed with
pancreatic cancer was the worst day of my life.

It's something that happens to other people, not us.
Well now it has.

One day, fine.
The next? Nothing will ever be the same again.

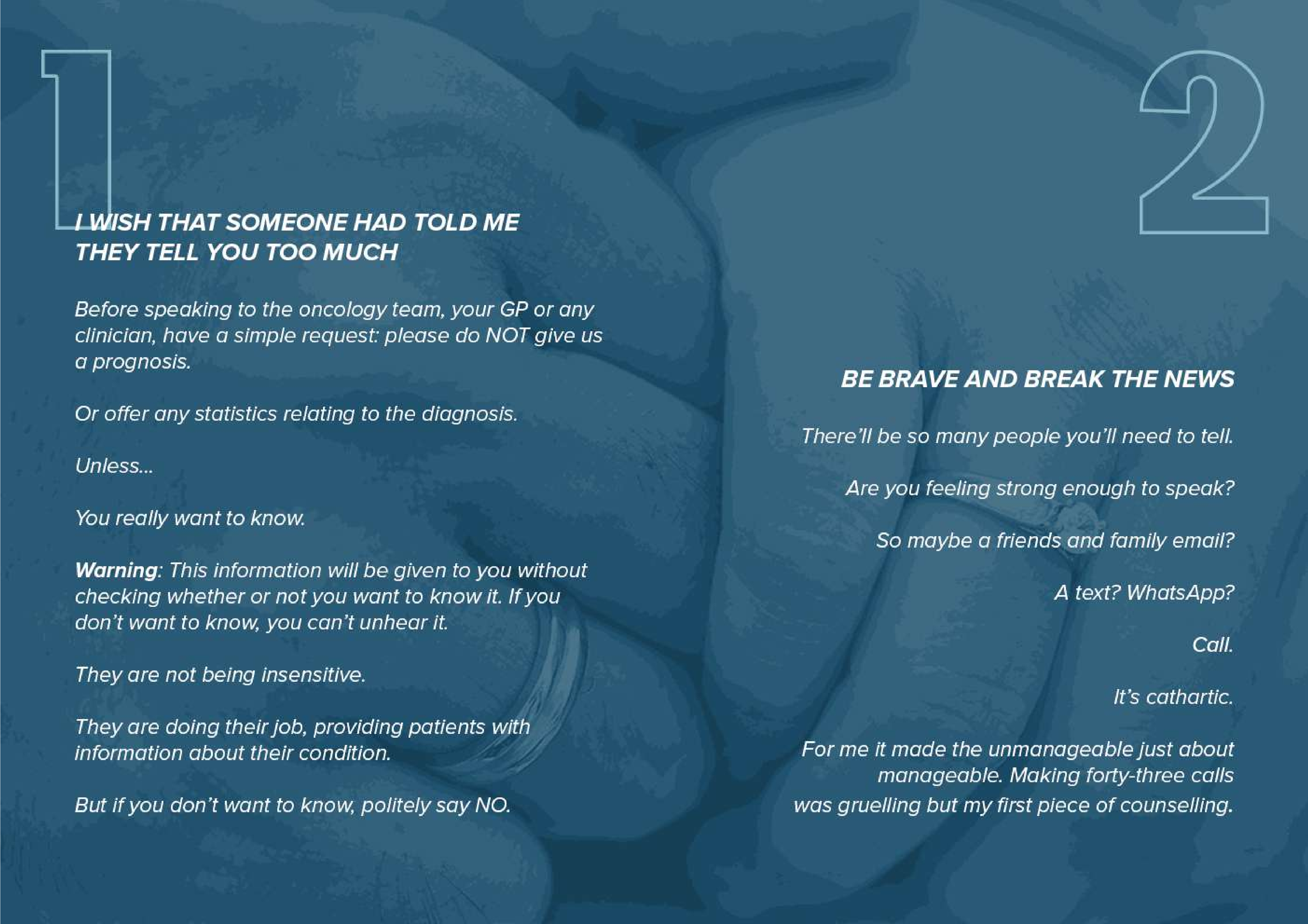
A journey has begun, one you have no idea how to navigate, where it will take you, what will happen on the way, or where it will end.

These fifteen things are what
I wish I'd known before it all began.

You may find some obvious or of no use,
but even if just one is of help,
then this will have been worth it.

I hope your journey ends well.

Paul



1

I WISH THAT SOMEONE HAD TOLD ME THEY TELL YOU TOO MUCH

Before speaking to the oncology team, your GP or any clinician, have a simple request: please do NOT give us a prognosis.

Or offer any statistics relating to the diagnosis.

Unless...

You really want to know.

***Warning**: This information will be given to you without checking whether or not you want to know it. If you don't want to know, you can't unhear it.*

They are not being insensitive.

They are doing their job, providing patients with information about their condition.

But if you don't want to know, politely say NO.

2

BE BRAVE AND BREAK THE NEWS

There'll be so many people you'll need to tell.

Are you feeling strong enough to speak?

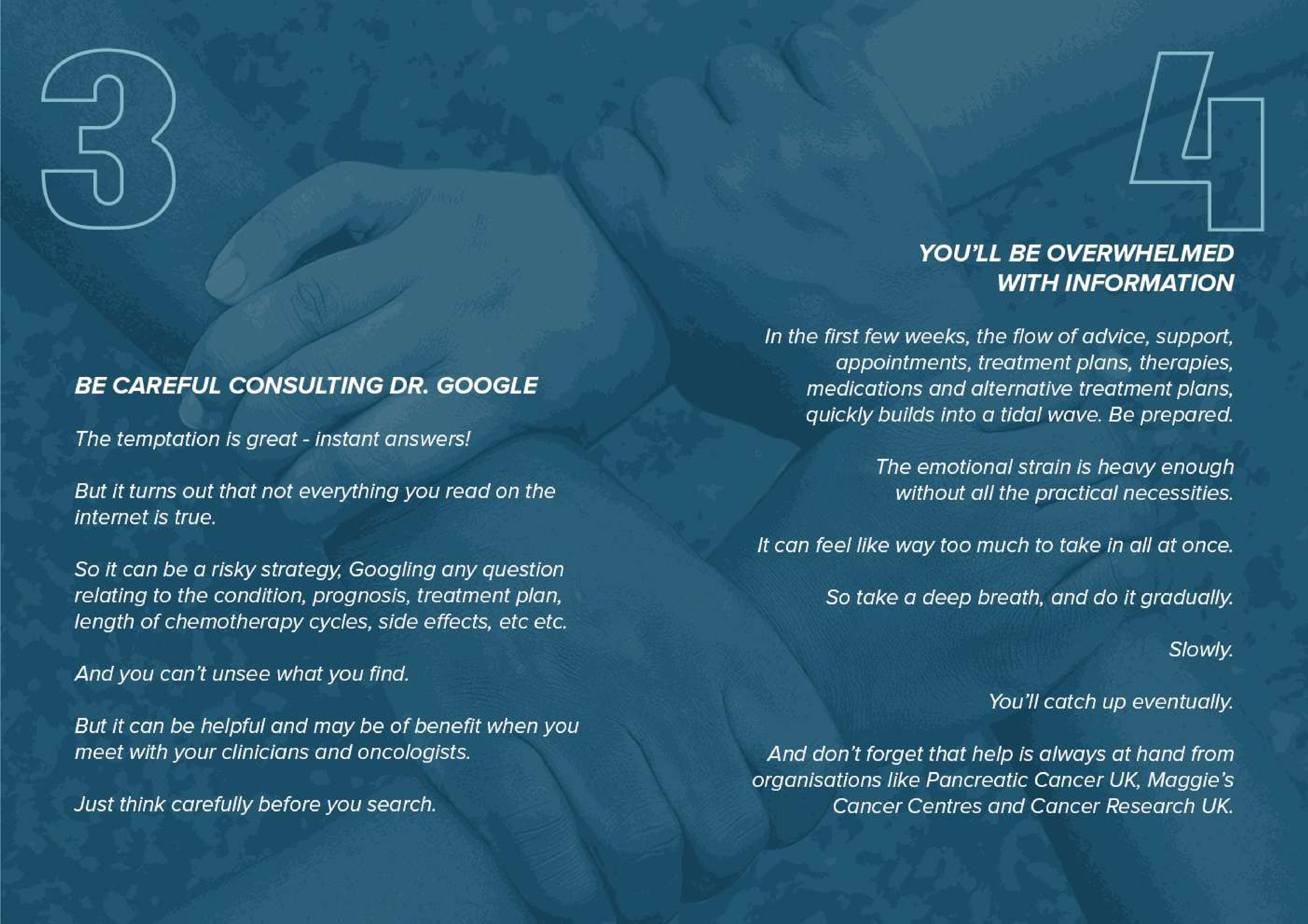
So maybe a friends and family email?

A text? WhatsApp?

Call.

It's cathartic.

For me it made the unmanageable just about manageable. Making forty-three calls was gruelling but my first piece of counselling.



3

BE CAREFUL CONSULTING DR. GOOGLE

The temptation is great - instant answers!

But it turns out that not everything you read on the internet is true.

So it can be a risky strategy, Googling any question relating to the condition, prognosis, treatment plan, length of chemotherapy cycles, side effects, etc etc.

And you can't unsee what you find.

But it can be helpful and may be of benefit when you meet with your clinicians and oncologists.

Just think carefully before you search.

4

YOU'LL BE OVERWHELMED WITH INFORMATION

In the first few weeks, the flow of advice, support, appointments, treatment plans, therapies, medications and alternative treatment plans, quickly builds into a tidal wave. Be prepared.

The emotional strain is heavy enough without all the practical necessities.

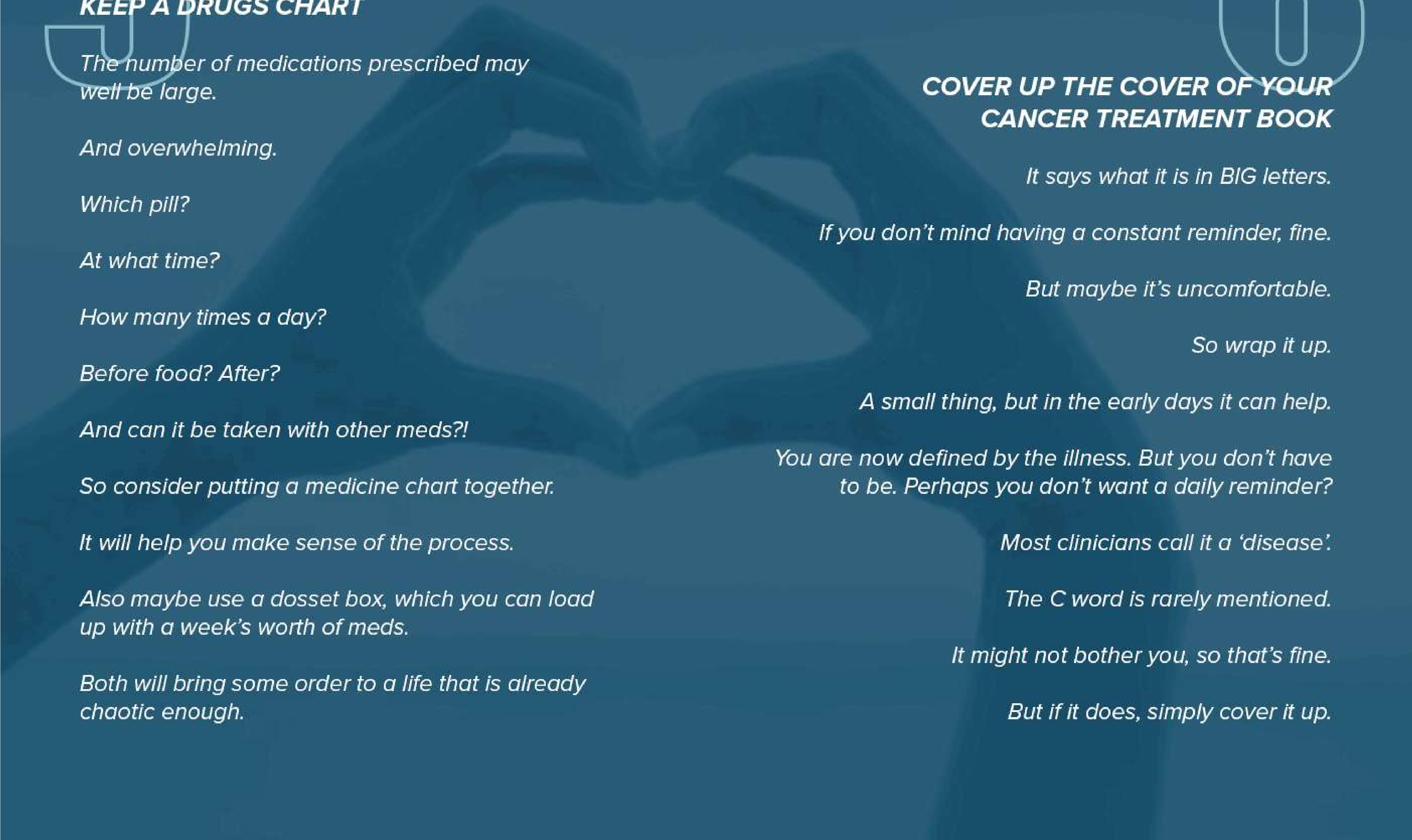
It can feel like way too much to take in all at once.

So take a deep breath, and do it gradually.

Slowly.

You'll catch up eventually.

And don't forget that help is always at hand from organisations like Pancreatic Cancer UK, Maggie's Cancer Centres and Cancer Research UK.



5

KEEP A DRUGS CHART

The number of medications prescribed may well be large.

And overwhelming.

Which pill?

At what time?

How many times a day?

Before food? After?

And can it be taken with other meds?!

So consider putting a medicine chart together.

It will help you make sense of the process.

Also maybe use a dosset box, which you can load up with a week’s worth of meds.

Both will bring some order to a life that is already chaotic enough.

6

COVER UP THE COVER OF YOUR CANCER TREATMENT BOOK

It says what it is in BIG letters.

If you don’t mind having a constant reminder, fine.

But maybe it’s uncomfortable.

So wrap it up.

A small thing, but in the early days it can help.

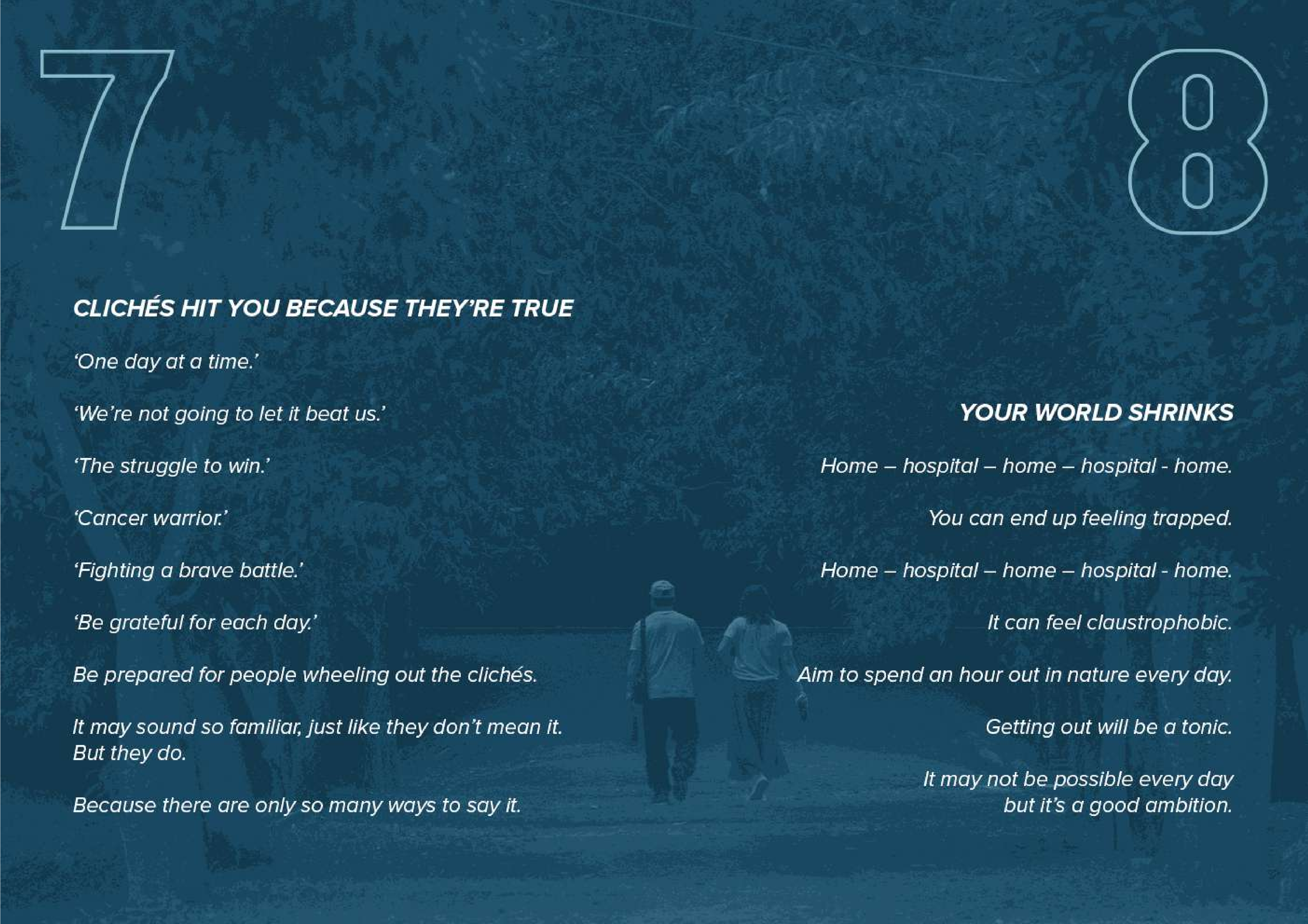
You are now defined by the illness. But you don’t have to be. Perhaps you don’t want a daily reminder?

Most clinicians call it a ‘disease’.

The C word is rarely mentioned.

It might not bother you, so that’s fine.

But if it does, simply cover it up.



7

CLICHÉS HIT YOU BECAUSE THEY’RE TRUE

‘One day at a time.’

‘We’re not going to let it beat us.’

‘The struggle to win.’

‘Cancer warrior.’

‘Fighting a brave battle.’

‘Be grateful for each day.’

Be prepared for people wheeling out the clichés.

*It may sound so familiar, just like they don’t mean it.
But they do.*

Because there are only so many ways to say it.

8

YOUR WORLD SHRINKS

Home – hospital – home – hospital - home.

You can end up feeling trapped.

Home – hospital – home – hospital - home.

It can feel claustrophobic.

Aim to spend an hour out in nature every day.

Getting out will be a tonic.

*It may not be possible every day
but it’s a good ambition.*

9

SUDDENLY, CANCER IS EVERYWHERE

All of a sudden, what was previously an occasional subject, rarely mentioned, something that happened to other people, other families, is everywhere.

Be prepared for overload.

News websites, local papers, radio shows, TV dramas, TV comedy, podcasts...

Watch or listen to any programme, seemingly unrelated, and more than likely there'll be a mention.

It feels like you're being targeted.

But it was always there.

You just didn't notice because you didn't need to.

It wasn't anything to do with you. But now it is.

10

IT'S LIKE BEING FORCED TO HAVE A BRAND NEW HOBBY YOU DIDN'T WANT

It will consume you. And your mind.

And your time. And your conversation. And your thoughts.

And your every waking moment.

And many of your sleeping moments. So try and find distractions.

Find someone to talk to.

Walk.

Play sport.

Exercise.

Read.

Anything to take you somewhere else.

11

IS IT THE BEST POSSIBLE TREATMENT FOR YOU?

The treatment your oncology team recommend is the best for your diagnosis.

Or is it?

It’s based on many factors, one of which is money.

Is it the best possible for you?

Or for the NHS finances?

Don’t be afraid to ask, “Is my treatment the best for me - or just the least expensive?”

Don’t let money potentially cost you a chance of having the best outcome.

12

HAVE YOU PROCESSED IT?

The cliché is: ‘You need time to process it’.

Maybe.

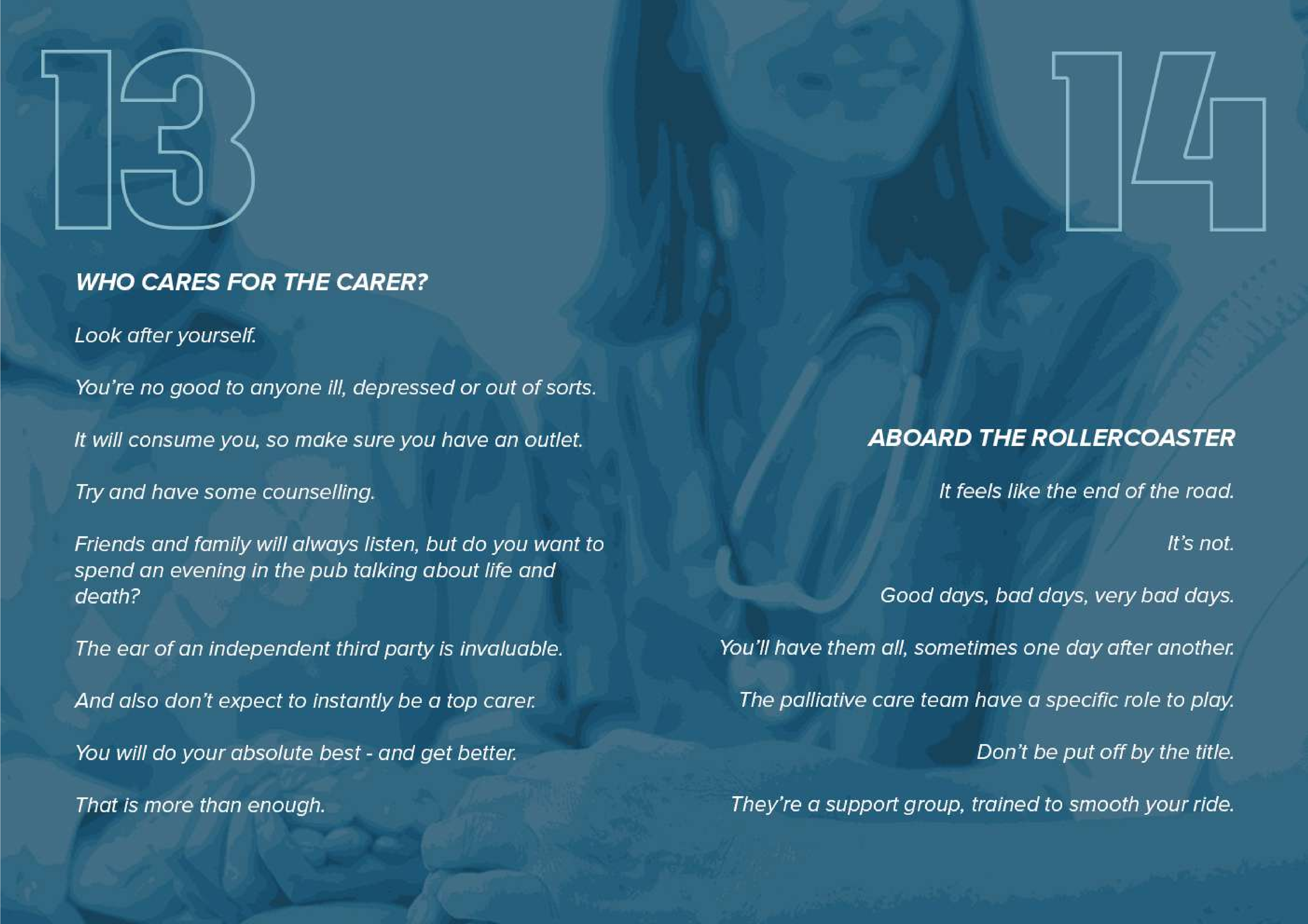
Or maybe it won’t be so simple.

The word is processing.

It’s an ongoing process.
Potentially lengthy, maybe never-ending.

Don’t expect too much of yourself.

‘Life changing news’ is called that for a reason.



13

WHO CARES FOR THE CARER?

Look after yourself.

You're no good to anyone ill, depressed or out of sorts.

It will consume you, so make sure you have an outlet.

Try and have some counselling.

Friends and family will always listen, but do you want to spend an evening in the pub talking about life and death?

The ear of an independent third party is invaluable.

And also don't expect to instantly be a top carer.

You will do your absolute best - and get better.

That is more than enough.

14

ABOARD THE ROLLERCOASTER

It feels like the end of the road.

It's not.

Good days, bad days, very bad days.

You'll have them all, sometimes one day after another.

The palliative care team have a specific role to play.

Don't be put off by the title.

They're a support group, trained to smooth your ride.

15

THERE IS ALWAYS HOPE

The study and development of effective cancer treatments is a global, non-stop quest. While your treatment is going on, progress is being made.

It means there is always hope.

Hold onto this.

NOTES

This guide is provided as general guidance for information purposes only.
It is a personal reflection by the author.
Please visit Marie Curie or Maggie's to find further Information and support.

It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.