

# Living Well with Cancer



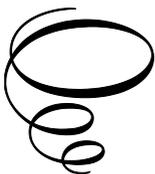
# Living Well with Cancer:

*A Solution-Focused Approach*

By

Dominic Bray

**Cambridge  
Scholars  
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Living Well with Cancer: A Solution-Focused Approach

By Dominic Bray

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## THE BOOK IN A PAGE

‘Courage is being scared to death... but saddling up anyway’<sup>1</sup>

This book is about that ‘both/and’ approach to, what may be for you, the hardest challenge you’ve ever had to face. It follows the pattern of many appointments I’ve been involved in over the years. Starting with a recognition of the lived experience of diagnosis and treatment, a crucial part of ‘being heard’, it then moves on to discuss how, by using *solution-focused* thinking, life may be lived well, whether it’s for a very short, or ultimately a very long, time.

Written in an informal style, as if the reader is taking part in a chatty-but-powerfully-effective appointment, it is for people of any age who have, or have previously had, cancer and their families and friends... and includes some bonus ‘clever bits’ for health professionals who seek to help them. It is also highly relevant to other profoundly life-changing conditions.

It may be especially useful if, for whatever reason, you don’t have access to someone who can offer this sort of appointment. It’s mercifully short (not only because it’s all I have to say), *but also* because you have a life to get on with; reading books like this may not be, and maybe *should* not be, your top priority. The *aim* is to validate and inspire. And, just possibly, entertain...

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<sup>1</sup> John Wayne (1907-1979)

## ACKNOWLEDGEMENTS

I'd like to thank everybody whom I've ever met.

But most of all my accountant.

## PREFACE

It's quite common to see books that have a long-winded, often tedious preface you feel you'd better read in case you miss something. This isn't one of them.

By the way, all views expressed in this manuscript are that of the author and do not reflect those of any other entity, including, but not limited to, the Publisher, the NHS and any other affiliated charities.



# CHAPTER ONE

## THE IMPORTANCE OF A *GOOD LISTENING TO*

*The single biggest problem in communication is the illusion that it has taken place<sup>2</sup>*

3

### **Chapter summary:**

It's key that you, the patient (and oftentimes your loved ones), have your 'day in court'. This means a chance for you to set out:

- What have you, the patient (and your loved ones), been through?
- How well have you been helped?
- Have you been *heard*?

Once upon a time, perhaps some time that feels long ago, you were getting on with your life.

In that life you were busy, meeting obligations, chasing lists of tasks, doing what needed to be done to make a home and/or earn money somewhere. Some things bothered you and you complained about the weather, the kids not getting ready for school, other people's kids, the price of petrol, call centres, bad driving...

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<sup>2</sup> George Bernard Shaw (1856 – 1950)

<sup>3</sup> I've included these summaries at the beginning of chapters for my colleagues with short concentration spans... like medics. Only joking... By the way, this is a good opportunity to insert a disclaimer to the effect that the views I express are my own and do not necessarily reflect those of my employer (the NHS), any particular charity or anyone else who knows me or who might not want to afterwards.

Ah... if only...

The past was a great place, as it turns out. Because the present is, frankly, a bit \*\*\*\*<sup>4</sup>

‘What?’ I hear the reader gasp. ‘Shouldn’t this weighty tome be all about solutions, living well, positive thinking and all that?’ Well, yes, it is. With the possible exception of the last—there’s a section later called ‘Positive Thinking Makes Me Sick’.

However, the lived reality I’ve heard, sitting in small rooms with disappointed people<sup>5</sup>, is that these worthy aims are not where the conversation starts.

### *Are you sitting comfortably?*

...then let’s begin. Chances are if you’re reading this, you’ve either had a cancer diagnosis yourself and are interested in exploring ‘what better might yet look like’ in your life ... or you know a family member/friend/patient<sup>7</sup> who has/had cancer themselves and you want to help them. If it’s the latter, please bear with me as I address my comments for now to the patient...

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<sup>4</sup> Insert your favourite expletive here

<sup>5</sup> I’ve stuck in lots of footnotes so as not to break up the flow of the story, and for people who like me generally don’t read them because they want to get on with it.

<sup>6</sup> One definition of a psychologist is *someone who sits down in a small room with disappointed people and tries to talk them out of it*. It’s not original to me; I heard it at a conference so can’t attribute it. Similarly, ‘what’s the difference between a psychologist and a psychiatrist? About fifty grand and a prescription pad’.

<sup>7</sup> I use the word ‘patient’ here as that’s what’s standard in hospitals and that designation seems to be generally acceptable to...er...patients. Other psychologists refer to ‘clients’ or ‘service users’. However, people on the end of helping services themselves don’t necessarily like these terms, which, as ever, shows ‘you can’t please everybody’! Now, if as a patient/client/service user you are disrespected, that IS a different story...

So how does the world, and, more to the point, life, look to you?

Most likely, *different*.

So, as you're gathering, I firmly believe that what people really need is a good listening to<sup>8</sup>. And, truth be told, this doesn't always happen in healthcare. This is often part of people's back-stories, often the first thing I hear in an appointment. So, I'm going to start with common experiences I've heard and the reasons, some excusable, some not, why they happen.

### *A question of the availability of time*

Frequently, health services<sup>9</sup> are stretched. As medical technology gets ever better at keeping people alive into old age, so professionals become ever busier, helping ever more people<sup>10</sup>. Well done, by the way, to my medical colleagues (and researchers etc.) for achieving that! Seriously.

But, and here's the rub, the perception amongst many of my colleagues is 'I wish I could do more listening, but I just don't have the time'. My come-back is 'you don't have the time *not* to listen', but that's another argument<sup>11</sup>. The point here is that many patients have not had sufficient time afforded to them, especially by people traditionally seen as being of high status like medical consultants. Patients have not had a chance to tell their story, which causes added anxiety as consultants are often the decision-makers, the very ones to whom they, the patients, need to get through. Ironically, it's the

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<sup>8</sup> Mary Lou Casey

<sup>9</sup> I'm writing this from the perspective of the British NHS but many of the same challenges apply elsewhere.

<sup>10</sup> More elegantly, 'delivering interventions'

<sup>11</sup> For an excellent book written by a medical doctor who's just about done it all, see Youngson, R (2012) *Time to Care*. Raglan (NZ): Rebelheart. He argues that investing time in listening can actually *save* time.

very same thing, anxiety (in this case, concerning caseloads and opening cans of worms), that is hamstringing these professionals<sup>12</sup>.

### *A question of 'fixing'*

Sometimes patients have the experience of remedies being offered to them that either don't fit or are premature, given before they've had a chance to be 'heard'. A bit like this<sup>13</sup>:



*Patient : I feel like my world's falling apart.  
Doctor : I can give you some antibiotics.*

This may be due to a perceived pressure of time on the part of the health professional who wants to 'cut to the chase', or may be because the health professional quite likes being the one with the

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<sup>12</sup> See an excellent paper: <https://www.health.org.uk/publications/when-doctors-and-patients-talk-making-sense-of-the-consultation> (Health Foundation, 2012, accessed 10/06/2022).

<sup>13</sup> The monochrome cartoons in this book are by Suparna B, who can be contacted via [illuminecreations01@gmail.com](mailto:illuminecreations01@gmail.com)

answers<sup>14</sup> (or feels a pressure to be, or indeed struggles with a ‘non-fixing model’<sup>15</sup>). This poem<sup>16</sup> illustrates the scenario nicely:

*PLEASE LISTEN*

*When I ask you to listen to me  
and you start to give me advice,  
you have not done what I asked.*

*When I ask you to listen to me  
and you begin to tell me why  
I shouldn't feel that way,  
you are trampling on my feelings.*

*When I ask you to listen to me  
and you feel you have to do something to solve my problems,  
you have failed me, strange as that may seem.*

*When you do something for me  
that I can and need to do for myself,  
you contribute to my fear and weakness.*

*So, please listen and just hear me, and  
if you want to talk, wait a minute,  
for your turn; and I will listen to you...*

***A question of unfair treatment***

It may also be that the ‘practical’ things haven’t gone well. Was there a delay in diagnosis with missed opportunities? Did someone fail to listen to crucial clinical information that could have made all the

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<sup>14</sup> For a fuller discussion on this and what might help health professionals to change their approach, see Bray, D. et al. (2020) *Unleashing the Solution-Focused Power of the Ormskirk Model by Minding Your Language* Diabetes Care for Children & Young People 10 (1) p.58.

(<https://diabetesonthenet.com/diabetes-care-children-young-people/unleashing-the-solution-focused-power-of-the-ormskirk-model-by-minding-your-language/>)

<sup>15</sup> For example, Fox, E. (1997) Predominance of the Curative Model of Medical Care: A Residual Problem. *JAMA*. 278(9) 761-763.

<sup>16</sup> Leo Buscaglia (1924-1998) *Please Listen* (abridged).

difference? Did the COVID pandemic get in the way (more on this later)?

Alternatively, was treatment delayed because a letter went missing, a phone-call left unanswered, a promise not kept? Were there traumatic experiences on a ward?

Where does that leave you? At best, wary. Can these people upon whom you depend, with ‘your life in their hands’, be trusted to get it right? Not that, necessarily, you have much choice. Will they tell you the truth? Can you cope with the truth? So how will you find a way of co-operating with professionals, when, really, you’re on a ‘once-bitten-twice-shy’ footing? Maybe it’s already too late because trust is broken, whether with professionals, or perhaps life itself. Maybe there’s no going back and you never will.

For various reasons then, it may be too late for a cure because a delay has resulted in the cancer only being able to be held at bay or slowed down. Where on earth do you go from there?

### *A question of compassion*

Sometimes patients I see can get past, and even forgive<sup>17</sup>, professionals in healthcare for being busy, trying to fix and not listen, and ‘dropping the ball’. After all, one frequently leads to another. And we’re all human.

But what if that professional, on whose words you hang so much, doesn’t even appear to *care*? Thankfully, this seems to me like a rarity and in my experience is something to do with being emotionally exhausted. But once is too often. Where do you go from *there*? For all you may be able to rationalise it, perhaps saying ‘they’re still a good person, they’re just burnt out’, that doesn’t necessarily help. It’s still you on the wrong end of the bad experience.

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<sup>17</sup> And I’m forever grateful for patients who forgive me. If you’re one of them, this footnote is for you!

And people remember what they experience in healthcare; it really matters<sup>18</sup>.

Before I go on any further, I would also say *all* professionals can be prone to any number of ways of *not* listening to patients.



*Have you tried telling yourself you're being irrational?*

Here is another passage<sup>19</sup> that captures common human experiences in situations of suffering:

*Let us not underestimate how hard it is to listen and be compassionate.*

*Compassion is hard because it requires the inner disposition to go with others where they are weak, vulnerable, lonely and broken. But this is not our spontaneous response to suffering.*

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<sup>18</sup> For an excellent read on this topic, and how we in healthcare can do better, have a look at Fred Lee's *If Disney Ran Your Hospital: 9 1/2 Things You Would Do Differently* (2005). Second River Healthcare Press: Bozeman.

<sup>19</sup> Nouwen, H.J.M., (1981) *The Way of the Heart: Desert Spirituality and Contemporary Ministry* p. 34. New York: Seabury Press.

*What we desire most is to do away with suffering by fleeing from it or finding a quick cure for it. As busy, active, relevant people, we want to earn our bread by making a real contribution. This means first and foremost doing something to show that our presence makes a difference.*

*And so we ignore our greatest gift, which is our ability to be there, to listen and to enter into solidarity with those who suffer.*

Unfortunately, the habit of *not listening* or *not being fully present* is not the exclusive preserve of healthcare settings. The truth is, sometimes the outside world's *not much cop* either. And sometimes this occurs in quite subtle ways....

### ***The wider world: out of the frying pan, into the frying pan...***

Not so long ago, people didn't talk publicly about cancer. I remember it; I was there.

Now, you can barely switch on your TV without seeing an appeal for Cancer Research UK, an advert for Macmillan or a storyline in a soap opera. But much as cancer is significantly more visible, our 'folk memory' persists. Cancer is still scary; it is linked to death. It reminds us of our mortality. And so, with the best will in the world, 'Jo(e) Public' doesn't always get it right; sometimes Jo(e) gets it spectacularly wrong. Because it's an emotive subject, people will say all sorts of things to try to (or appear to try to) make the situation better. Whether it's wholeheartedly for the benefit of the patient, or to make themselves feel better, is an interesting point. I suspect the latter in a number of cases. Here are some things I've heard that you, as patients, have heard:

'You look well'  
 'Why don't you just...?'  
 'If I were you...'  
 'There's lots of good treatments out there'  
 'Do you know cow's milk is full of hormones?'  
 'Have you heard about the broccoli diet?'  
 Etc. *ad nauseam*

This is called by various names, including the *Tyranny of Positive Thinking*<sup>20</sup>. This captures the sense of oppression that can be felt when there is an implied obligation to be positive, to try harder. As the respected BBC journalist Jenni Murray<sup>21</sup> once put it, ‘Positive thinking makes me sick!’. If one is not a hero (or at least a trainee-hero), battling away, then the implication is that one is not trying hard enough, or simply enjoying being ill. Or, perhaps, one has brought it on oneself. The underlying moral judgement is clear.

This in itself is not a new story. There’s a tale in the Bible about a man called Job, afflicted as he was on many fronts. Fair enough, his friends did sit with him for a number of days and kept their peace, but true to human nature, before long began to advise him of what he needed to do because he was clearly getting it wrong! Here’s a modern ‘take’ on Job:



And this story also nicely illustrates something that’s become apparent in many conversations I’ve had; telling the patients where they’re getting it wrong serves a psychological function for the teller.

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<sup>20</sup> For example, Coifman, K.G., Flynn, J.J. & Pinto, L.A. (2016) ‘When context matters: Negative emotions predict psychological health and adjustment’. *Motiv Emot* 40, 602–624.

<sup>21</sup> Positive thinking makes me sick: Jenni Murray on why she hates the self-help industry. <https://www.dailymail.co.uk/health/article-1247850/Positive-thinking-makes-sick-JENNI-MURRAY-hates-self-help-industry.html#ixzz4am4rCZac> (accessed July 2020)

‘It won’t happen to me because I have done it / would do it differently ... and he’s a sinner<sup>22</sup> anyway, not like me....’ No wonder the unfortunate Job felt so miserable.... as if his many afflictions weren’t bad enough, his ‘comforters’ made him feel worse!<sup>23</sup>

...‘*how are you?*’

As you’ll have gathered, I tend to get my best ideas from my patients. This is another one. I once met this lady<sup>24</sup> who had caught on quite quickly regarding how to field enquiries. She’d realised being asked ‘how are you?’ was often-times more of a polite enquiry rather than an invitation for an authentic answer<sup>25</sup>. It was, even at times, the very opposite; an indication that the enquirer was hoping for an up-beat response. *Her* response, she told me was generally:

Would you like the short or the long answer?

Having said that... *being positive, and encouraging others to be, isn’t (necessarily) a negative.*

In fact, the consensus increasingly states that positivity is good for your health. I won’t get into the ‘mind/body’ debate, the cul-de-sac about whether your mind ‘influences’ your body or the other way round... the very language we use betrays a certain ‘dualism’<sup>26</sup>, which

<sup>22</sup> Contemporary equivalents—‘unmotivated’, ‘loser’, ‘mood hoover’ etc.

<sup>23</sup> Spoiler alert: in the end they get shown up and he is vindicated. For people of faith, and maybe those who aren’t, the story has a helpful spiritual message, offering some thoughts around the ultimate question ‘why do bad things happen to good people?’

<sup>24</sup> She preferred the designation ‘lady’ to ‘woman’ in case that matters to you.

<sup>25</sup> You may have heard this one... Q: ‘What’s the biggest lie told in church?’ A: ‘I’m fine thanks’

<sup>26</sup> If you’ve got nothing better to do, look up Descartes (1596-1650) who wondered how we experience pain, given that it appears to be a physical stimulus (e.g., fire) that triggers a ‘mental’ experience (i.e., ‘ow!’). He wondered whether a little bell might be ringing in the brain.

would be alien to some traditional Asian philosophies. What seems to be clear enough is that a ‘positive’ mindset seems to be associated with a better immune system<sup>27</sup>. Even if you don’t happen to believe that the mind can directly influence the wellbeing of the body, it makes sense really; getting stuck in, as one<sup>28</sup> might call it, means doing things that are good for you, rather than by choice crawling into a safe but depressing shell. Conversely, being ‘stressed out’ with ruminations of negative thoughts like worries because one never breaks the pattern by going out, when done as a long-term habit, has been linked with higher cortisol<sup>29</sup>, which apparently is bad news for the health. So, the bottom line is that, yes, being positive is good, as much as you can be, but it needs to be *your* positivity and done when *you’re* ready—and that only tends to emerge when you feel well and truly listened to.

So far, we’ve devoted a bit of space to ‘listening’ to your experiences of professionals and the wider public; maybe it’s a good moment now to come closer to home...

### ***And what do you make of it all...what is your story?***

#### ***...‘bad luck’***

We all know it, don’t we? Stuff<sup>30</sup> happens. I began writing this about four months after the UK’s COVID lockdown began. The reality is that cancer diagnostics and treatment have been delayed, with a great deal of NHS resources poured into crisis-management. On top of this, many potential patients have been quite understandably reluctant to come forward to their GPs for fear of becoming COVID-infected or wasting the doctor’s time (assuming they could have secured an

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<sup>27</sup> A chance to use a long word here; the field of science is called.... deep breath....’Psychoneuroimmunology’. You may wish to visit <https://www.uq.edu.au/news/article/2014/09/positive-boost-immune-system> (accessed 10/06/2022)

<sup>28</sup> Alright, as *I* would call it

<sup>29</sup> For example, <https://www.nhs.uk/news/mental-health/stress-and-heart-attacks/> (accessed 10/06/2022, subsequently ‘retired’)

<sup>30</sup> Another chance to insert your favourite 4-letter word

appointment of course). In the UK, urgent cancer treatment was down by 60% in April 2020<sup>31</sup> and the media has plenty of stories about delayed tests/treatment<sup>32</sup>. Much of this is nobody's fault. But it has psychological consequences. What will it feel like to be told, 'I'm sorry, the cancer's too advanced, we're looking at keeping it under control not taking it away'? What will it be like for the professionals having to break this news for that matter?

What impact do these sorts of situations, which although nobody's fault, have on you? We may know 'stuff happens', but do we really *accept* it? Or did we at some level always think 'the bullet's got someone else's name on it'...it won't happen to me. But then, when it does, where do we go from there?

I've heard various versions of 'this should not have happened, it's not the life I had in mind'. You may have worked hard for many years and five minutes after you retire you get a diagnosis. Or you may have young children.

It's not unusual at that point to embark on a retrospective search for reasons, and sometimes we find out what we really believe; e.g. 'I've always been a good person ... not like ... [insert group of people who deserve bad things to happen to them]'. We tend to believe bad things happen to bad people, not good<sup>33</sup>, and 'you make your own luck'. After all, you've spent some serious time in the gym, or eaten lots of broccoli. You can't have lung cancer, you've never smoked (or gave up years ago).

There are undoubtedly whole books written about this stuff<sup>34</sup>; why people look for medical and moral causes when the diagnosis

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<sup>31</sup> Clover, B (2020) 'Urgent cancer treatment down 60 per cent in April'. Health Service Journal. 11/06/2020.

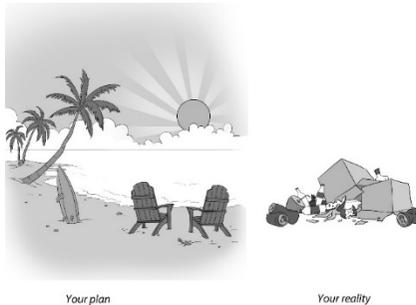
<sup>32</sup> For example, Sunday Times 05/04/2020.

<sup>33</sup> Known by academics as the 'Just World Hypothesis'.

<sup>34</sup> For the interested, you may wish to read Elisabeth Kubler-Ross' work on stages of coming to terms with a diagnosis: *On Death and Dying* (2008) Abingdon: Routledge.

happens to them<sup>35</sup>. My hunch is that there is a comfort in restoring a sense of order, in predictability, in ‘this-causes-that’ thinking because, however uncomfortable our conclusions may be as to why it has happened to us, it’s better than no conclusions, and gives us something we can work on. For these reasons, for most people, ‘bad luck’ just doesn’t cut it...

...‘*this wasn’t in the plan*’...



Your plan

Your reality

### ***Staying with the pain?***

Where do you go from there, if anywhere at all?

Do you stay with a ‘thanks, but no thanks’ stance to the life that turns out to be on offer, as opposed to the one you had in mind? I call this ‘*brassed off syndrome*’<sup>36</sup>. If that’s ‘where you’re at’, I would not judge you for it. That’s not my place; if I were to judge, I would

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<sup>35</sup> Interestingly, I’ve noticed on my travels that some cultures, such as in Ghana, do have a way of explaining misfortune along the lines of ‘someone’s got it in for me’. As I understand it, such beliefs persist, albeit more under the surface these days. My guess is that may serve a useful psychological function for the sufferer.

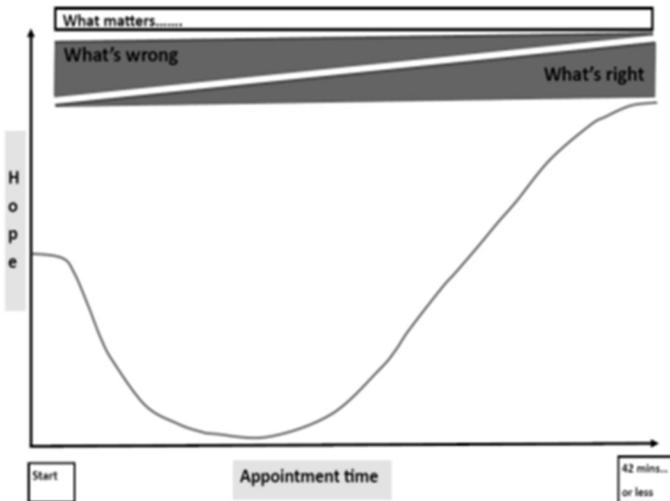
<sup>36</sup> Well, that’s the cleaned-up version. And, yes, a little bit pretentious of me, I’ll admit. Just shorthand really. Insoo Kim Berg, one of the founders of the solution-focused practice, might call this the ‘complainant’ position: Berg, I. K. (1989). ‘Of visitors, complainants, and customers: Is there really such a thing as “resistance?”’ *Family Therapy Networker*, 13(1): 21.

become part of the problem rather than the solution. In these situations, in this book, just as in an appointment, I would say... ‘maybe that’s enough for now’. Read on when you’re ready. In an appointment, I might say ‘is this as far as you want to go for the foreseeable; will it be enough to have vented today... or are you hoping for more? Would you be pleased to see signs of you even minimally dealing better with life? If so, let’s keep talking’.

Similarly, if you’re ready, read on. If not, that’s also OK. Maybe re-read this chapter. Just come back when ready...

### *Summing it up: timing is everything...*

Speaking of choosing the right moment to engage with change and the importance of being prepared to ‘sit with the sh\*t’ in the meantime, here is *something I prepared earlier* that encompasses the typical sequence of events in an appointment<sup>37</sup>:



<sup>37</sup> If you’re looking for a learned academic reference in this footnote, there isn’t one. I ‘drew’ this graph one day on my laptop to capture the typical choreography of a few thousand appointments I have been involved in during my work as a clinical psychologist.

Typically, during the early part of an appointment (which usually lasts 42 minutes), especially a first one, whilst listening out for what matters<sup>38</sup> to the patient, and what's right<sup>39</sup> in their world, I hear a lot about *what's wrong*, as represented by the top left of the blue area. Fair enough... it's their chance to be heard, especially if, in the manner described above, they haven't been particularly well listened to by professionals or wider society! Or, indeed, if they've had way more than their fair share of 'bad luck'. As you'll see, the red line goes down as, for a time, the sense of hope in the room (mine as much as theirs) drops. Actually, maybe it's largely mine... People at some level know another story about themselves, have some sense of their own resilience, even if the right moment in the appointment hasn't yet arrived when they're ready to share this alternative story. As you can also see, the curve *does* turn upwards, but more of that in later chapters. The most important point for now is that this is their 'day in court', and it does no harm for me to feel a little of what they feel<sup>40</sup>. And, for that matter, one should not 'signpost' to other services prematurely because of being busy or out of a need to 'do' something.

And the conversation will move on when it's ready...

### ***Stick or twist?***

So... have you felt listened to so far? Some sense of 'I (me, Dominic) get where you're at?' If so, when you've had a cup of tea<sup>41</sup>, you might want to read on. You may even want to jump to Chapter three if you want to get straight down to business, to get working on your future life. If you're *not* ready to read on, maybe reflect to yourself, 'maybe

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<sup>38</sup> Much more of this in Chapter 3.

<sup>39</sup> Much more of this in Chapter 4.

<sup>40</sup> After I'd written this, I heard Tony Hawks talk about 'Nonviolent Communication (NVC)', which has been described thus: "When we focus on clarifying what is being observed, felt and needed rather than on diagnosing and judging, we discover the depth of our own compassion"; Rosenberg, M.B. *Nonviolent Communication: A Language of Life*, 3<sup>rd</sup> edition (2015) Encinitas (USA): Puddledancer Press, p. 3

<sup>41</sup> Other beverages are available...

I just need to lick my wounds for a bit.... I'll come back to this book if/when ready'. Maybe you're already thinking of better uses for it, like a doorstep or a fire-lighter...

Or, if you do want to read on, but are wondering *why* you seem to be not quite yourself while the rest of the world carries on, have a look at Chapter two...

## CHAPTER TWO

### YOU ARE NOT ALONE; EXPERIENCES OF ‘BEING IN THE SAME BOAT’

#### **Chapter summary:**

‘Actually, no, you’re probably *not* losing the plot’

- Examples of typical lived experiences of cancer;
- A little bit of explanation for them;
- Some more long words.

More often than not, and sooner rather than later in an appointment, it becomes apparent that the patient has a sense of losing themselves; they’re not only noticing weird stuff happening, but they’re becoming concerned about it. Their lived experience<sup>42</sup>, frequently of anxiety regarding cancer recurrence, its effect on their family, etc, is compounded by an anxiety about the out-workings of their anxiety.

You may well ask: *What does all that mean?*

Well, it’s not unusual for people to tell me they’re losing their memory. They forget where they leave things, whatever they’ve just read<sup>43</sup>, even their train of thought. Alongside that, they lose their confidence; in going out and about, especially to busy or public

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<sup>42</sup> This is a chapter about the phenomenology of cancer. There’s no particular reason for this footnote other than to use a long word to impress any professionals who might still be reading by this point...

<sup>43</sup> This is one of my excuses for writing a briefer-than-averagebook.

places<sup>44</sup>. They lose their confidence in their ability to make decisions and frequently their confidence in the future. On top of all that, and maybe worst of all, they start noticing, really noticing, all sorts of aches, pains and other bodily sensations they wouldn't have given the time of day to in their pre-cancer life. Ah yes, that time long, long ago when things were so much better. This is not necessarily even an exhaustive list.

Let me expand on some of these things. I won't go on too long; there are other, inside-story autobiographies out there that speak eloquently, and I don't want to accentuate the negative or to lower the mood more than is necessary or get repetitive.

### *A question of remembering<sup>45</sup>*

If you're 'in the thick of it' as you read this, then you may be struggling to absorb the text, although that may be something to do with my writing style. Alternatively, and I would like to think this is more likely, it could be because you're finding everything difficult to 'process' at the moment. I've seen this many times with folks I've met. *War and Peace*<sup>46</sup>? No chance. A modern novel? Unlikely. *Chat* magazine? That's more like it. I once met a chap who would normally read *The Liverpool Echo*. His 'starting point', post-diagnosis, was just the headlines. On a good day<sup>47</sup>.

Basically, what psychologists tend to call your 'short-term memory' isn't working well. This is probably why you lose your thread in

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<sup>44</sup> The real definition of agoraphobia, by the way, which comes from *agora*, Greek for 'gathering space'. It's not to do with 'agriculture' so it's not really about fields or open spaces. I note this in case it's useful, hopefully not to show off. Too much...

<sup>45</sup> Some people attribute these signs/symptoms to 'chemobrain' but the truth is they also occur in people who haven't had it so the biomedical effects of chemotherapy cannot be the whole story.

<sup>46</sup> This gives me an opportunity to mention casually that I have read it. And *Lord of the Rings*. But not a lot else.

<sup>47</sup> Spoiler alert; he worked his way up from that and did OK. But he had to start very small.

conversation and forget where you put your keys (etc.). Because, most likely, your mind’s not quite on the job, for good reasons (see below). I know for myself if I have to retain something, I have to pay attention<sup>48</sup>, which often amounts to mulling on something, and making an effort to remember it<sup>49</sup>. One way of doing this consciously<sup>50</sup>, or sometimes unconsciously, is to associate whatever one is trying to remember with something that is already well remembered or noticed in the environment in some kind of ‘mental journey’<sup>51</sup>, like tying a knot in a later-to-be-retrieved hankie, but mentally<sup>52</sup>. However, if one isn’t fully concentrating, this is less likely to happen.

### *A question of confidence*

As I write this, many people are subject to the ‘lockdown’ part of the COVID-19 response. By the time you read it, all being well, this will be in the past. But you may yet remember, whether you have had cancer or not, what it was like suddenly to confront the world again; surprisingly daunting. Right now, I’m doing a fair few telephone appointments and a number of people who have or have had cancer have shared variations of ‘I suppose I shouldn’t be saying this... but I’m sort of glad that we’re all in the same boat, I don’t stand out now, other people know what it’s like’.

This sense of being daunted seems to be a common feature of post-diagnosis life, particularly when the initial treatments are done-and-dusted. There comes at a time when others expect the individual with cancer to come out of their particular ‘cocoon’; when their nearest-

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<sup>48</sup> I’m hoping my wife isn’t reading this.

<sup>49</sup> No, I’m *really* hoping my wife isn’t reading this.

<sup>50</sup> I’m using these terms colloquially here; no reference to psycho-analytic theory intended, mainly because I don’t understand it.

<sup>51</sup> The ancient Greeks thought of this first, like lots of psychological things; for example, in a legal trial remembering the sequence of an alleged murder by envisioning daggers growing on a tree. For a better explanation, see <https://www.britannica.com/topic/mnemonic> (accessed 10/06/2022)

<sup>52</sup> Another useful sort of mnemonic, in case useful, is rhyme; for example, ‘divorced, beheaded, died...divorced, beheaded, survived’ (which pertains to Henry VIII, if you haven’t heard it before)

and-dearest want to have a party and are expecting, or some could say prescribing, positivity (see the *Tyranny of Positive Thinking* section in Chapter 1).

But, of course, by its very nature, a cocoon, like the ‘lockdown’, is simultaneously constraining and *safe*. My ‘take’ on the phenomenology<sup>53</sup> of this is that there are three sets of reasons why people feel safe in their cocoon, and correspondingly unsafe when it’s time to leave it.

**Firstly**, modern treatment tends to follow diagnosis very quickly, thanks<sup>54</sup> to cancer targets. There is no time to ‘draw breath’, in modern parlance. Before you know it, you are getting prepped for an operation, tattooed and bombarded with information<sup>55</sup>. Swept off your feet and not for romantic reasons. You have a whole new career, or at least occupation: cancer patient. Welcome to your new life. You embark on ‘ticking treatments off the list’; ‘how many chemos to go?’ etc. People begin to rally round; the classic ‘if there’s anything I can do’ emerges and, often, your nearest-and-dearest may begin to cosset you.

If I may digress for a paragraph, this cossetting may yet be a two-edged sword. Yes, for many it’s lovely to be looked after. But then... at what cost? Does a person lose their very sense of self? The one who is the ‘go-to’ pillar of the family may become the person whom now nobody asks for advice. Or more practically, the one who runs

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<sup>53</sup> I felt it was time for a long word again as I was offering a theory. In this context, it means ‘lived experience’.

<sup>54</sup> I use the word ambiguously. For many, quick treatment is a good thing from a medical outcome point of view. But this isn’t always the case: I’ve seen situations where the target is the priority, where medical benefit of fast-tracking is marginal at best; the preference/overall wellbeing of the patient is not the deciding factor.

<sup>55</sup> By the by, I read many years ago that at an appointment when the diagnosis is given, patients can only remember one word. Cancer. For example, see M. van Osch et al. (2014) ‘Reducing patients’ anxiety and uncertainty, and improving recall in bad news consultations’. *Health Psychology*, 33(11), 1382–1390. <https://doi.org/10.1037/hea0000097> (accessed 10/06/2022)