

See it, Say it, Sorted

To tell, or not to tell?

David Zigmond

© 2021

What do we want to know, and what not? This often seems 'irrational', even unnegotiable to others. Three vignettes from different decades portray our conundrums.

'Far more crucial than what we know or do not know is what we do not want to know'

– Eric Hoffer (1954), *The Passionate State of Mind*

1. October 1977

A crisp, bright autumn morning. It is only my third week in this poor, inner city practice: almost everyone is still a stranger. The phone rings in the brief handwriting-of-notes interlude between two patients. This is fortunately timed because the receptionist's voice explodes with urgency and without preamble: 'Doctor, Mrs O has just rung; she's really upset. She says there's something really wrong with her husband, Alf. She wants you to go there *now*... I really think you should, doctor. They live just fifty yards away, at the other end of this block... You can see your remaining patients when you come back...'

In 1977 such a request is not so unusual: the family-doctor is quite as likely to be called as an ambulance. In my haste I take the remarkably slim Lloyd George envelope of notes of this sixty-four-year-old man and slip them, unperused, into my well-checked medical bag. Speed and *now* is of the essence; history can wait.

Mrs O is waiting at her open front door. She is dabbing at her eyes with a handkerchief and then holding it to her chest, as if for comfort. She is clearly fearful yet coherent. She says, 'he suddenly sat up and started gasping and then he ... Doctor, it's terrible: you'll see...'

She leads me into a sparsely furnished yet meticulously cared-for bedroom: this couple may be poor, but they are proud. Alf is lying in a vast pool of blood, emitted from his mouth and now haloing his thorax. The blood has not dried and his emaciated body has the utter stillness and pallor of death, though still has the warmth of departed life. As I perform the confirming sign-checks of this I look toward Mrs O consolingly: she feared, now she knows.

'I'm so sorry,' I say, 'but I think he died quickly ... he would have lost consciousness very fast...' I look with puzzlement at Alf's clear emaciation and then back to Mrs O to venture an indirect question, 'but I sense he'd been unwell for some time...?'

'Oh yes, doctor, we both knew that', replies Mrs O with, I think, remarkable clarity, serenity, even relief. I am aware of my ignorance of what is being played out: I should have looked at his notes, however briefly, before my emergency-rushed exit from the surgery.

As I stand between Mrs O and her just-dead husband I reach into my medical bag to retrieve his meagre records. I quickly see, at the end of a few sparsely documented 'transient and trivial' complaints – listed over a period of thirty years – a two-lined fountain-penned entry from eighteen months ago. In his clear, unmistakable script, the senior partner Dr K has simply written:

'Yesterday 1st ever haemoptysis. Otherwise well. Smoker. For urgent chest X-ray and review.'

No subsequent entry. I am shocked with the disparity – the gulf of nothing – between this and the exsanguinated corpse beside me.

I feel in the record envelope for anything else: I retrieve a mechanically typed X-ray report signed in ink by the consultant radiologist. It describes a large mass in the right upper lobe, almost certainly a cancer of the bronchus. Almost needlessly it recommended urgent thoracic surgical referral.

Needless? It was not done. The void in the notes indicated no action or contact after the urgently requested X-ray result had been 'filed'. Possibly – probably – this report had never – until now – been seen by a doctor. How had this happened?

I plummet into a queasiness of shame and anxiety. I am certainly not the culprit, but I am surely the messenger. I decide to share all with candour and humility. I feel my heart racing and my mouth suddenly dry as I speak.

'Mrs O, this is obviously a very upsetting time, but I have just realised something, from looking at Alf's notes ... an important oversight was made with Alf, after the last time he saw the doctor, Dr K... I don't know how this happened, but it should not have... I think it's only right I share it with you...' I pause nervously, trying to gauge her response.

'Oh. What's that then?', her voice has more curiosity than alarm.

This reassures me a little but feel I am still sliding further from any understandable bearings. I steel myself. I describe the little I can deduce of this egregious failure of Alf's care, but cannot yet explain it. I will look into it, I say, I feel some strength returning, gathering beneath my profoundly sorrowful apology. I brace for a difficult exchange.

I do not know what to expect but it is not this: 'Oh, doctor, you shouldn't feel bad about it ... it's nobody's fault, really. In a way, I think it's all for the best...'. She smiles at me through welling tears, a sweet and peaceful melancholy.

'I don't understand... You see, Alf should have been properly followed-up after his X-ray but he wasn't and I...'

She cuts me off, but kindly. 'But I think Alf didn't want to know about bad news and neither did I. That's probably why he never went back to see Dr K. Neither of us could have shared it with the other, so if either of us had known, it would have been an unbearable secret... We always talked with hope about getting better even though, I suppose, we could both see that he wasn't ... but we lived with hope and he died with hope. That's what's most important.

We couldn't have borne it otherwise. I know doctors can do wonderful things, but sometimes they can't and then I think it's best not to know...'

I am moved and confused. How can there be such wisdom in such massive denial?

Mrs O leads me to her front door. As I offer my sorrowful farewell she gently touches my forearm.

'Thank you for coming so quickly, doctor. It means so much to me. I know it would for Alf, too...'

*

2. February 2021

Sandra is struggling for some peace – composure even – amidst forces tugging and conflicting inside her: courage, denial, defiance, retreat. Her spirit is sparky and disarmingly transparent; she speaks with candour and directness.

'The last dozen years were a catalogue of griefs and stresses for me: the decline and death of my two nearest and dearest – amidst this, ten years ago, the discovery of breast cancer, successfully treated, I thought – and then my inevitable retirement and relinquishing my marital home. In this refuge of my small flat I could lick my wounds and heal myself...

'And then, two years ago, I had a recurrence of my diverticulitis pain. The gastroenterologist, Dr G, said: "We haven't done an abdo CT scan until now: I think we should." So I had the scan, which showed nothing unexpected except some kind of ambiguity in the liver. So Dr G then said, "I don't know what this is, so I think we need a more focused scan, just to be sure."

'I saw Dr G again after this second scan. He was very serious and careful in his manner and said, "I've got mixed news. We don't need to worry about your liver: those lesions are just vascular and completely benign. But quite by chance the scan has shown some small lesions at the base of one lung. The radiologist thinks they look like secondary malignant deposits, possibly from your previous breast cancer... So I'm referring you to an oncologist."

'The oncologist, Dr O, seemed to me a can-do-must-do sort of doctor. She said to me, very quickly, "We need to arrange a needle-biopsy to confirm the diagnosis. Then we can start treatment without delay..."

'I tried to interrupt her: "I don't think I want any more treatment or investigation. Look, I'm seventy-five years old and right now I feel pretty well: I don't have any symptoms. It's now ten years since I had my breast cancer. If I've got small secondaries, maybe they've been there for some time and neither I nor any doctor would ever have known about them if I hadn't had that scan that was looking for something else... Actually, doctor, I'm happy just to go on with my prevention-maintenance dose of Letrozole..."

'Dr D clearly didn't like this. She stopped me and asked rather haughtily: "You've got grandchildren haven't you?". "Oh, yes...", I replied, rather bemused. "Well...", she said, with a kind of satisfied slyness, "you could have TB! You could give your grandchildren TB! You have to ask yourself how you'd feel then? I really think I should go ahead and arrange your needle-biopsy..."

'So I did what I was told ... I suppose I almost always do now what doctors tell me – I feel vulnerable, afraid of getting no support when I need it.

'Anyway, the tests confirmed the radiologist's view: it's secondary breast cancer. Obviously I didn't want to hear it, and all the oncologists since Dr O have often tried to persuade me to

have active treatment, though rather more kindly. I always resist that, but not the two-monthly scans they organise as a routine. Remarkably – and here’s the good news – in two years the lesions have not advanced at all. Not at all! And yet they say they’re sure of the diagnosis.

‘So, why do I continue to see the specialists when I decline their treatments? Well, it’s what I said earlier: fear – fear of what will happen if I go into a rapid decline – I’ll then want to be known to doctors who can quickly arrange the necessary. I wouldn’t want to be lost to the most direct system that can speedily provide palliative care, for example. I feel very vulnerable, so I hold tightly to the support that I have.

‘The strange thing is, despite all this I feel very well: I have no ominous symptoms. So I’m a ‘well’ person who’s been given a dread-and-death diagnosis.

‘Yes, I’m Sandra, but now I’m ‘cursed-Sandra’; like Cassandra, I have been granted the ‘gift’ of knowledge that makes me feel more powerless and more of an outsider. I know I’d be happier if I knew nothing of this sleeping-silent-killer-within and just took my chances – got on with the rest of my already-long life without this pall hanging over me.

‘The doctors are ‘just doing their job’, of course. *“Just one more test, to be sure”*; *“I must tell you the result of this recent test”*; *“We recommend this treatment – it’s often unpleasant but it might just help you. The decision is yours, of course...”* All this attention, watching, waiting and circling for bad news! I mirror that strange mixture: I am grateful and angry.

‘I often wish I were living in simpler, less technologically-determined times...’

*

3. May 2021

Now it is my turn.

For the last four years I have been getting paroxysmal atrial fibrillation. The episodes were initially rare, but they are becoming more frequent and lasting longer.

I am seeing a cardiologist, Dr C. He is busily friendly and well-briefed by good professional connections and long experience. His questions to me are almost entirely to those of my medical history; other aspects of my life seem, at least for now, irrelevant to him.

Because of this unprecedented (for me) condition, together with my previously insouciantly disregarded age and sense of entitlement to eternal health, I am feeling more vulnerable and afraid than I am used to. This is the first time I am seeing Dr C and he orders the usual screening and monitoring tests, but in my anxiety I am already asking him – prematurely – about catheter ablation procedures. Actually what I am wanting from Dr C is more a sense of protection and reassurance, but I find I am asking a technical question instead. He is eager to respond, in full, to this kind of query: he has comfortable command over his home territory. My head is full of anxieties and irrational fears: I cannot take in his courteously patient and lengthy account of the different ablation techniques. At the end of these, though, his speech speeds up as he engages a kind of autopilot. This is to convey the statutory warnings he must give me about the ‘possible significant adverse complications’ (ie serious risk). I think he mentioned ‘5%’, but it was his last words that I heard most clearly and remember still: they were: *‘thrombotic and embolic events, cardiac tamponade and death’*.

That evening, on my way home, I start fibrillating again.

I understood Alf, Mrs O and Sandra better than ever before.

*

Soon after, I am describing my fearful worries and my haunted reactions to F, a veteran friend and colleague. He seems especially interested in Dr C's rapid downloading to me of the grim catalogue of technical data, caveats, risks and prognosis.

F listens to this with a kind of amused weariness. He pauses with knowing familiarity.

'Look, we've now all got to do it: it's become a cultural imperative. I call it Brechtian Medicine – everyone's got to take part, and everything's got to be said, whether they like it or not...', his lament sounds tart.

'Yes,' I ponder, 'I sometimes envy the naïve faith and oblivion of Alf and Mrs O ... and I certainly sympathise with Sandra's wish to tolerate the ambiguous and the opaque. But I can't manage that now: I'm too knowledgeable.'

F sighs. 'Quite', he says, terse yet gently ironic.

-----0-----

'You can't depend on your judgement when your imagination is out of focus.'

– Mark Twain (1935), *Notebook*

Interested? Many articles exploring similar themes are available on David Zigmond's Home Page (<http://www.marco-learning-systems.com/pages/david-zigmond/david-zigmond.html>).