

**Off-piste:
only fresh tracks lead to fraternalism in healthcare**

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Care Pathways – executively designed systems for all – can easily displace the nourishment of our healthcare from *fraternalism*. What is that? Two intimate vignettes illustrate.

True kindness presupposes the faculty of imagining as one's own the sufferings and joys of others.

– Andre Gide, *Pretexts* (1903)

When we now talk of 'advances in healthcare' we usually assume a processing of our afflictions into clearly managed and monitored care-pathways: systems and procedures that pay little attention to individual variation and meaning. Our comfort in using the terms 'diagnosis' and 'treatment' anchors and expresses such expedience.

We have much to be grateful for here: in the last century such pathways have been the mainstays of near-miraculous public health programmes and the neutralisation of many previously lethal diseases. Currently they can assure certain safe standards, too.

Yet elsewhere our success within such management and packaging is far less assured. Good examples come with our frequent encounters in the vast territory of functional dis-ease – especially our disorders of behaviour, appetitive, mood and impulse: 'BAMI'. Here our diagnoses and treatments often struggle to make sense or have effect. For such disorders – our dis-eases – require additional and very different approaches: those that can evoke our capacities for personal immunity, growth and repair.

All these can take root only from the establishment of certain kinds of imaginative personal bonds: those in which the other feels a sense of being recognised, understood, accompanied and held. These bonds are subtle and paradoxical: powerful but delicate, crucial but unorganisable. Often such bonds constitute a major essence of personal meaning-making and then healing.

But even when this is not possible, such encounters offer powerful comfort and palliation. We can call this kind of care 'fraternalism': we seek and see ourselves in one another, and vice versa. It is through pursuing this kind of imaginative resonance that we may find a commonality of fears, dilemmas,

and eventual fate – simultaneously recognising the infinite variety of each person’s struggle and settlement: we are all unique, just like everyone else.

Beneath the innumerable ways we manifest our conundrums – and the ways we both cleave to, and flee from, others – lie four primal anxieties, and then our bulwarks against them:

- *mortality* – the inevitability of our transience, decline and death: our need to identify with things that may survive us.
- *personal insignificance* – in our evanescence we need to feel significant to others.
- *meaninglessness* – we must each confer and create our own meaning: there is none otherwise (though there are plenty of offers to provide this for us).
- *aloneness* – our unique consciousness is also our inescapable aloneness. We mitigate this by creating bridges and resonance with others.

Clearly, such existential notions seem very different to our dominant medically-modelled diagnoses, treatments, and care-pathways. How can they be relevant to a busy, frontline doctor? Here, to illustrate, are two consecutive home visits from General Practice. Such encounters have become increasingly rare – our efficiency-seeking systems drive them out. Yet as our lives and eventual declines lengthen, our need for such contacts can only increase.

We need to awake to what we are jettisoning.

1. Monday: Florence

The Nursing Home faxes me: ‘Florence has been aggressive and violent with us when we try to change her pads, hitting us on several occasions ... Can the doctor please advise? ...’

I have visited this Home many times. Today I am again reassured: the staff are direct and friendly, and their care seems unaffectedly warm. I see this in the faces of their vulnerable residents and the environment in which they must eke out the pathos of their last days.

Florence is sitting with well-kempt and calm stillness at a table. Her greeting is friendly and trusting and she is soon nodding and laughing at everything that is said to her. I am quietly aware that her conviviality has little occupancy: her intact appearance masks a vast cognitive deficit – she has long lost almost all memory and recognition. That her persona is so intact already speaks highly of her quality of care.

I try to engage the little attention I can find in Florence. With the clarity and economy that she might just understand, I convey to her how the staff are doing their best to keep her safe, clean and well; that sometimes this is very difficult, but they are always her friends. She nods, as if understanding. I am unsure.

I look toward the two Carers whose broad African faces smile with attentive appreciation for my support of their often frustrating and unpleasant work. I suddenly realise a remarkable cultural fact about this institution: that these frail elderly Caucasian Londoners are being tended with such tender diligence by staff that are almost all black African and Afro-Caribbean. Yet there is a touching convergence in this discrepancy: the shared loss of homes and roots. Certainly the protected old people have lost their homes, most evidence of their roots and primary family. Florence has lost even memory of all these. But the Carers, too, have similar losses, though not through age and involution. They tell me deeply affecting tales of migrations to escape civil wars, primitive intolerances, famines or penury. They come to start safer lives and families; from this 'advantage' they are often sending money home to destitute relatives. All are now surrounded by terrains, language and people far from their source. Often, when they can, they will cluster with their compatriots to retrieve a little of what they have lost.

I am thinking of this noble and heartening paradox: how the unrooted are caring so assiduously – with such generous patience – for the dispossessed. For all my experience and training, I am doubtful I could sustain such benign fortitude.

My 'intervention' with Florence seems, to me, meagre by comparison.

Yet not to her two Carers. I turn to leave with an apology: I am sorry I cannot do more to ease their burdens. But they move toward me, wanting to shake my hand. One Carer grasps me warmly between both of hers. 'Oh, no, doctor ... Don't say that. Your support is so important for us. Thank you so much for coming.' Her eyes glow.

I walk away humbled, swelled by a soft wave of warm sadness. The little I had done had great personal meaning for others, yet would leave almost no trace in official data, figures or informatics. My interactions have not been guided by any kind of diagnosis, care pathway or expert directive.

Off-piste.

2. Tuesday: Ivan

Maria, the Community Matron, phones. Her voice is tinged with the forlorn: 'Ivan is terribly low. He says he's not interested in anything any more and can't see the point in his life: that everything worthwhile has gone. I suggested psychiatric referral or, at least, an antidepressant, but he says he has had all that and it never helps. But then he told me that you've known him and his family for years and said he would like you to visit ... I know you're very busy, but I said I'd ask you...

Maria's timbre and request captures much of Ivan and our problem. I have witnessed some of Ivan's grievous and successive losses: with each he has less life energy and time to retrieve, recover or restart. He has little left.

I had first met Ivan thirty-five years ago: I now remember a handsome, courteously dapper middle-aged man. He had – even then – an aura of abject irony: ill-fortune would not surprise him. This seemed embodied, too, by a struggling limp. My enquiry revealed an anciently, but massively disfigured foot that was partially amputated. I asked more: he told me of his family fleeing the terrors of an Eastern Front in World War Two. He had stepped on a landmine. He was aged ten. Ever since his walking had been painfully

limited and vulnerably unstable. I never knew the story of his family's wartime migration: I assumed further horrors.

Further recollections come now. His marriage to Siobhan and their two children: she was a fiery Gaelic woman whose sharp tongue often deflected from her warm heart. I witnessed how she both attacked and defended his vulnerability, her flashing eyes settling to a loving gaze. His look was doleful and his defence feebly ritualistic: he survived stoically, a rock in tempestuous seas. The bickering was surface melodrama: their loving devotion was less evident but much deeper. Over many years I was reminded recurrently of the often tangled illusoriness of our most important attachments.

Their twin sons – deemed biologically identical – were developmentally certainly not. Stephen, twenty minutes older, was always focused, contained and meticulous. I saw his trajectory from watchful toddler to professional young adult. The younger, Duncan, was an affectionate but distractible little boy, easily upset yet readily comforted. This, too, had an equivalent trajectory.

When Stephen anchored, Duncan drifted. Before securing adulthood Duncan had 'got in with the wrong crowd'. Drugs and alcohol were the media, an ineluctable unravelling the result. Over several years the nature of my contact with him was diagnostic and predictive: his warmth engaged me, but I could never reach or mobilise in him any sense of agency, curiosity or commitment. My suggestions, interest and initiatives all rapidly dispersed into his alcoholic haze. I remember my growing and sad foreboding. He drifted away. I failed; we all failed.

Duncan was found dead in his bed, in a hostel. Siobhan came to tell me, flanked by Ivan. Siobhan sat gasping, gulping, weeping and choking. She told me her shocking news from a vortex of bewildered disbelief laced with intolerably pained realisation. Ivan stood as a sentinel, with a hand on her shoulder. He hardly moved and his tears were silent.

Siobhan – always a force of nature – then turned that force against herself. Her defiant animated spirit remained, but to console (or punish?) herself she unleashed her own undertow: she became a chain smoker.

‘You’ll kill yourself ... You should stop.’ I had enjoined, probably clumsily.

‘Well, I won’t be the first, will I?’ her eyes lanced with a kind of retributive guilt: an acid rejoinder.

We were both right. Siobhan declined slowly with her self-wrecked lungs. She would come to see me oxygenated by a mobile cylinder, shepherded tenderly by her stalwart, limping husband. Even through her laboured and rattling breathing she sparkled with fatalistic wit and affectionate defiance. Ivan waited with patient devotion; she died at home.

Ivan retreated from my view.

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I have not seen Ivan for two years. He answers the door with weary deliberation. He is looking smaller, frailer and greyer. His decline is evident, yet his greeting has great warmth: I feel lapped by a brief and welcome tide.

Soon the current takes us out to deeper waters, we are talking of his growing loneliness and his vaster sorrows, known to me but now to few others. And what of his earlier sorrows, far over the horizon? I ask gently about his childhood, before his crippling.

His narrated answer makes sense of so much of the stoic melancholy I have witnessed over three decades. He tells me of two toddler siblings dying of Diphtheria, of his tender and loving mother dying in childbirth shortly after. At the age of eight he was left alone with his father to cope with their shared losses, and then the horrific warring maelstrom destroying Eastern Europe. They shared survival but not consolation.

'My father was a hard man, he had little kindness. He showed me how to survive, but not how to love.'

I am disarmed by the rawness of this. I now want some comfort: 'And Siobhan?' I ask, hopefully.

'Siobhan had the toughness of my father but the tenderness of my mother. We maddened one another, but there was always love ...'

'Like mother ...'

'Yes ... First my mother, then, much later Siobhan ... they both kept me going. I know I won't have that kind of love again.'

'No. But there are things we can arrange ...'

'Ah. I think I know what you mean. But I don't want to be seeing a specialist or social worker who I don't know but asks lots of questions and then gives me tablets or a recovery plan ...'

'What would you like me to do, then?'

'Nothing else, doctor. You've known me a long time ... you're the one who understands me now ...'

'But I can't give you enough time. Though I could ...'

'No. Just having you know about me as you do, and me knowing that you think about me sometimes ... that's better than tablets. It's more important than most people realise ...'

It is time for my afternoon surgery. I stand to leave.

'Call me in two weeks. I shall want to know how you are' I say.

Ivan tilts himself toward me and I extend my hand. He grasps it with a hand that is now anciently gnarled and veined, enfeebled but warm. I notice his silent reticent tears: I last saw them when he tried to palliate Siobhan, for their loss of Duncan.

As I walk back through Ivan's front door I have a similar sorrow to my departure from Florence, yesterday: I could witness but I could not relieve; I could provide some sense of comfort and meaning, but it would rarely be enough. It is insufficient but invaluable.

Fraternalism.

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I don't ask for your pity, but just your understanding ... not even that, no ... just your recognition of me in you, and the enemy, time, in us all.

Tennessee Williams, *Sweet Bird of Youth* (1959)

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