

# Making the Best of Hard Times

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# Speaking Up or Acting Out? On Advocacy, Marginalisation and Ethical Practice

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# Prologue

# Act 1, Scene 1: Ways of Knowing

# On Theatre and Medicine

- The clinical and the theatrical depend on implicit agreement about a shared endeavour.
- Each party will bring both themselves and a commitment to playing their part.
- There are conventions, assumptions, norms and rules about the interaction, many of which are assumed, unarticulated and unacknowledged.
- The encounter is inherently interpretive and infused with questions of identity, emotion and meaning.



“Theatre has tended to be a place that accepts people in their brokenness, in their states of rebellion and pain. It is the place for accidents of connection between interior worlds and external realities.”

(Mark Fearnow in ‘Theatre for Good’)

# Ways of Knowing in Clinical Practice

- ❖ Population or cohort
- ❖ Objective
- ❖ Expert
- ❖ Specialist (patient and professional)
- ❖ Quantitative
- ❖ Empirical
- ❖ Deductive
- ❖ Prospective and predictive
- ❖ Public
- ❖ Medical e.g. model of disability
- ❖ Rational
- ❖ Generalisable
- ❖ Individual
- ❖ Subjective
- ❖ Experiential
- ❖ Family narrative
- ❖ Qualitative
- ❖ Phenomenological
- ❖ Inductive
- ❖ Retrospective
- ❖ Private
- ❖ Social e.g. model of disability
- ❖ Emotional
- ❖ Particular (cf: the likeness and 'this-ness')

# On Ways of Knowing and Advocacy

- In clinical work, as in theatre, a question, choice or problem is likely to be nuanced, contestable and more complex than it first appears.
- Framing the dilemma(s) or questions are integral to effective clinical ethical decision-making (and being a theatre-maker).
- Put simply, one might ask: what is this problem, issue, speech or play about?
- Perhaps more significantly, who decides and how?
- Our responses will shape whether we discern marginalisation, if we consider 'advocacy', what we advocate *for*, how efforts are received and what happens next.
- Fricker's work on epistemic injustice in healthcare demonstrates why these questions (and our answers) matter.



# Marginalisation and Meaning

“Every glimmer of residual light is extinguished and the effect is devastating. There is nothing between us and ourselves. No distracting or reassuring visual clues that we have a place in the world. All that remains is the blackness. We wait until our eyes adapt – for surely they will adapt – isn’t that what eyes do? Isn’t adaptation the essence of humankind? But they don’t. We don’t. It is inescapable: our altered state.

And then, looming above us in a beam of light, is the mouth. We cannot help but focus. It commands our focus. This disembodied mouth. All that there is in the room is the darkness, the mouth and our thoughts. And so it begins. Words, sounds, glimpses of sentences tumble out of those bright red lips – a life pouring forth, demanding to be heard. At first we can’t make out the words. Some are familiar, but some a nonsense. Is it the speed? Is it the accent? We are concentrating so hard; why can’t we understand? And still the words cascade into the darkness and still we search for meaning. We revert to the comfort of clinical categorisation: this is logorrhea. But how pointless that seems – what is the value of naming but never knowing?

And still the mouth moves and the waves of sound wash over the auditorium. We sense damage. We intuit harm. We no longer need the details – we can feel it. In our altered state, all communication convention is overthrown and we discover it doesn’t matter. If we persist in attending to another, then we will make a connection.” (Bowman 2014)

“Then on your blue bike you come breakily up the drive.”

“Listen in to doctor chat. We done the best we could. There really wasn't much. It's all through his brain like the roots of trees.”

“I do not want. I do not want to hear this. But suddenly it's clawing all over me. Like flesh. Terror. Vast and alive. I think I know it. Something terrible is. The world's about to. The world's about to. Tip. No it isn't. Ha. Don't be silly. Stupid. Fine. Fine. Everything will be. Fine. Chew it lurks me. See and smell. In the corner of my eye. What. Something not so good.”

# Act 1, Scene 2: The Seeing Place

# Sight Lines, Seeing, Marginalisation and Advocacy

- Multiple stories, experiences and perspectives co-exist.
- An audience reflects on, and contributes to, multiple perspectives, meanings and interpretations of a shared experience.
- Sight lines will shape what is seen and attended to. They may be literal or metaphorical.
- Searching for, tolerating and exploring, the divergence of experience, perception and preference is integral to clinical practice.
- Advocacy (or not) is about seeing (or not) and being seen (or not).

# Act 2, Scene 1: Emotion and Imagination

# Emotion, Theatre and Advocacy

- Aristotle conceptualised theatre as a source of pity and terror in its audiences.
- Following the enlightenment, modern theatre evolved and sought to evoke compassion in its audiences.
- Compassion, sympathy, sensitivity and a facility for making a connection with others, especially those who are different or may be difficult, are as integral to clinical ethics as moral reasoning, theoretical frameworks and biomedical knowledge.
- Marginalisation can be discerned by rationality and emotion, advocacy likewise
- So too, is 'not seeing', 'preferring not to notice' and 'not acting'.

“Empathy means realising no trauma has discrete edges. Trauma bleeds. Out of wounds and across boundaries”

“Empathy isn’t just listening, it’s asking the questions whose answers need to be listened to. Empathy requires inquiry as much as imagination. Empathy requires knowing you know nothing. Empathy means acknowledging a horizon of context that extends perpetually beyond what you can see.”



# Act 2, Scene 2: Narrative and the Construction of Advocacy

# Narrative and Stories

- Narrative and stories are the essence of human life, interactions and activities.
- From the outset, clinicians are trained to sift, restructure and ‘tidy’ narratives and systems reinforce, even demand, that ‘tidying’.
- Being open to, and working with, the truth(s) of narrative, which is unlikely to be neat or constant, broadens moral vision, deepens understanding, shapes sensibilities and develops trust.
- What are the narratives that influence, and are constructed, when you respond to an individual, a group, a question or an issue?
- How do you resist ‘neat’ and manage complexity?

# Act 2, Scene 3: Bea

# Ms B: Patient Summary

- 27 year old woman with paralysis of unknown origin.
- Bed-ridden, doubly incontinent, requires 24 hour professional nursing care.
- Three admissions for respiratory infection in previous 18 months.
- PEG has become infected twice in last 6 months.
- Depression treated with Citalopram, 20 mg.
- Wishes to discuss future care plan.

# Bea's Story

I've thought about this for the last 8 years. For the last 7, every single day. I've looked at it from all angles. The full 360 degrees, one tiny segment at a time.

What I am asking, no, not asking, demanding. What I am demanding will cause the most unbearable upheaval within you. I do know this. But we have to face this fact: I am not going to get better. I am not going to have a boyfriend. I'm not going to have children. I'm not going to have any friends. I'm trapped. Now, I want to be free. And I want my mum to be free too. I know this from a place so deep that for the first time in my life I can understand why people believe in God. I can't. The only thing I can believe in is release. There are worse things than death. We all know that.

# Bea on Empathy

There was a girl in college. Her name was Joanne. Funny, I can't remember her surname, even though I've been trying for 8 years. She had M.E. *allegedly* – That's what we always said. Allegedly. M.E. Me. Me. I just thought that, well, I didn't just think did I, and she was so pretty, really, she was, very, very pretty, petite, all the boys, you know, and I wonder now is it because I couldn't or just because I didn't actually give a damn. But when we talked about her, not with her, obviously, with her it was serious faces and gentle nods, but behind her back it was - oh come on! Pull yourself together and get on with it! Get the fuck on and stop all this attention-seeking! We're all chronically fatigued.

Yeah, maybe empathy has a limit. A geography. Maybe empathy has a boundary. Or maybe I wasn't able to understand. My mind protected me, or knew, so wouldn't let me engage, even imagine. Maybe Ray's right. We're all a little mind-blind. And if we are or our mind rejects – repels – refuses, quietly but certainly, to put itself in another's place, do we even notice, is it even conscious? Or was it just that I didn't believe her. And thought she was pathetic?

# Act 3, Scene 1: Role, Character and Boundaries

# Roles and Characters

- In medicine, patterns, typologies and categorisation abounds. Situations are repeated and classified.
- Clinicians and patients are playing roles with ethical expectations attached.
- In theatre, plays are performed and characters are represented on stage, repeatedly.
- Yet, each presentation, situation, interpretation, performance or encounter is unique.
- What is the role of an 'advocate'?
- How and when do you play that role?



“Actors create the amazing double reality of being themselves in this performance space at this moment and simultaneously being other people in another place at another time; being both here now and there then.”

“Presence reveals an encounter that is true to that moment and that performance and that performer.”

“This duality is what makes theatre theatre. It reminds us of our inexhaustible potential as human beings. We all have something of everyone else within us.” (Alfreds 2007)

'I' and  
'They'  
became  
part of 'We'  
and 'Us'.

EMILY: I know! But its . . .all these bloody decisions all the time. I can feel them still.

JAMES: Feel them?

Beat

EMILY: On my back . . . Do you think the job makes us sick?

Beat

JAMES: This bit's the worst, Em. I drank a lot in my first A&E job. You last this, you'll be okay.

EMILY: When we were trying to resuscitate her, I looked up and I saw her. Up in the corner of the room. Just before she completely flat-lined. The anaesthetist said there was no rhythm, that it was just interference.

JAMES: You're tired and freaked out.

EMILY: All through the rest of the night shift my shoulders were stiff and aching. I couldn't think why then I realised. It was the CPR I'd given that girl. I felt....dirty. She'd got into me. That dead girl. I thought I could do this job...I can't.

JAMES: Why have you got your arms like that?

EMILY: To keep myself sterile. This place is making me sick. It stinks of death. It's making you sick too James...You go into this job because you care. To stay in it, you have to stop...

Something's broken....like a tiny cog inside a clock that's jammed...and I can't mend it. . .

“Love as action, not passion. In love, we break through our feelings of isolation and separateness, yet retain our integrity. The conception of love as an activity and not as a passive state is essential. Loving relations for Fromm are characterised by four elements: care, responsibility, respect, and knowledge. Of these, respect is the most complicated. *Respicere*, which means *to look at*. The word emphasises seeing the person as he or she is and not as I need him or her to be.” (Mark Fearnow on Fromm at pp. 52 ff)

“He carries a billion pictures of life that have no consequence to him and a few pictures which will always haunt or please him. He’s made from purpose and mistake and controlled by the movement of this planet around a star – yet in the second he’s led by some great need or some little urgency. Only occasionally he’s conscious that around him life is beginning and ending to the beat of time – that millions of others are walking in the exact same moment that he is – are travelling with the same purpose but with singular histories – but travelling nonetheless with the same basic need – to keep on living. How unremarkable and how faintly unique to wake and walk in this way – with doors pushing open into a sky bizarrely blue and giving to us systems of weather, shaping us with forever-movable seasons. And too hard it is to think how rain is made – how the sun can push light through darkness – and what it is that holds us up here imperceptibly in space –

And to stand there in the magnificence of this world with all these animals and plants and trees too many to ever imagine clearly – and standing with the you as was made – in a life that is so chaotically structured by nature – to continue living – to remain upright and to be able to carry on searching for something other than what you have – anything at all – something which makes you continue without the mindfulness of it all ending at any moment – for everything is here and we are here to lay down legacy – to give life purpose by reaching its edge.”

(Ballyturk by Enda Walsh)

# Curtain Down

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