A Memorable Patient
3 aspects of care

'Super intelligent’, ‘very direct’, 'rare and unique' – some of the superlatives Victor evoked from professionals. The qualities that made him engaging also invoked the dilemma of the 'special patient' - one who consumes resources disproportionately and risks impacting the care of others.

Approaching death and a broken skin container are 2 powerful indicators that a patient may test our understanding of boundaries.

Working with people who are dying will always stir up painful emotions and anxiety. Unacknowledged, the unconscious aspects of palliative care transmitted between patients and professionals, compounded in severe EB by the team's likely function not just as 'medical family' but as 'second skin', may influence clinical practice in ways that we do not always have space sufficiently to consider.

In a spirit of legacy and an attempt to learn from experience, we will address some of the clinical, emotional and ethical challenges presented by a memorable young man in the last 6 months of his life.
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