

# Opening the word hoard

## Two stories and an ode

Literature can enable insight and understanding in both writer and reader.

A reader has issues explained in memorable ways. *I know* that icebergs make a terrible racket grinding against each other because Coleridge has told me so: “The ice was here, the ice was there, / The ice was all around; / It cracked, and growled, and roared and howled, / Like noises in a swound<sup>1</sup> (despite never knowing what a *swound* is). And I empathise with Roquentin and his struggle with connectedness.<sup>2</sup>

Significant health benefits from writing about stressful events have been reported from many randomised control trials—for example, Smyth<sup>3</sup> and Pennebaker *et al*<sup>4</sup>). The opinion in a JAMA editorial was: “Were the authors to have provided similar outcome evidence about a new drug, it likely would be in widespread use within a short time”.<sup>5</sup> Sadly creative writing is never likely to be promoted by a drugs company. Virginia Woolf commented about her own use of this “drug”:

I used to think of him  
[father] and mother daily;  
but writing *The Lighthouse*,  
laid them in my mind. And  
now he comes back  
sometimes, but differently.  
(I believe this to be  
true—that I was obsessed  
by them both, unhealthily; &  
writing of them was a  
necessary act.)<sup>6</sup>

Literature, medicine, and health care are all the study and care of the individual person. An understanding of the human condition, in all its aspects, must be central to medical and health care education, research, and individual study. This can only be undertaken by including the values, ideas, and images of individuals and culture, as well as the way the human body and mind function and dysfunction. The nature, importance, and role of the human *experience* of patients and practitioners, including their experience of the patient-practitioner relationship, are central.

Opening the word hoard is edited by Gillie Bolton. Ideas and items should be sent to her at the address on this page.

The medical humanities exist to facilitate and enable the recording and interpretation of the human experience of health, disease, illness, medicine, and health care. The study and writing of literature must be one of the best ways to do this.

Many of our great thinkers, such as Sartre and Lewis Carroll, embody their thinking in fiction. Novelists such as Woolf, Austen, and Eliot, poets such as Eliot, Coleridge, and Plath incorporate deep understandings of human nature and the human condition. Classical literature, for example written by Sophocles, Homer, and the anonymous author of *Beowulf*, offers deep insight into human dilemmas, and the underpinnings of our culture.

The *fictionality* of fiction does not devalue the events, characters, dilemmas depicted. Fiction is written from the deep experience of the author, and those close to them. Dostoyevsky, for example, explores his own personal experience of epilepsy in *The Idiot*. Fiction can be somehow even more *true* than case studies—because the writer is not restrained by having to stick to the actual events, which can hamper the reader’s understanding of the core issues. Poetry has, since the time of the first recorded poets, nearly three thousand years ago, offered unparalleled insight and expression.

The study of literature, and the practice of imaginative and reflective writing, offer the kind of well-rounded understanding of life necessary to medical and health care practitioners. Reading and writing literature can:

- develop essential critical, reflective and reflexive abilities and skills,
- contribute to the development of practitioners’ and students’ abilities to listen, interpret, communicate, and tune in to nuances and hidden meanings,
- encourage sensitive appreciation of the ethical and moral dimensions of practice,
- extend the development of insights into, and concern for, different aspects of the human condition,
- facilitate an ability to see connections and carry ideas from one area to another,
- widen perspectives, and
- improve self-awareness.

The writings which follow were written in very different ways, but all offer insight and understanding. Michele Petrone explains how the writing of his dream, and the essential reflection which the writing occasioned, helped

him in a situation which anyone would find almost unbearable. Written immediately after a dream, and while still in the struggle of an illness and hospital experience, it has not been redrafted. The writing is vivid, drawing the reader into the unreal experience, alongside the writer. Reading material such as this must support readers in relating closely and immediately to the experience of severe illness and hospitalisation.

Michele felt the image in the painting reproduced here was the visual counterpart to the one in the writing. Most of his image making is visual, so we wanted you, our readers, to “read” this one alongside the written ones.

Lindsay Buckell’s account was written after a period of time had offered a degree of perspective. It reflects upon the experience, helping her come more to terms with it, and to learn as much as possible from the gift her friend gave in asking her to stay close through dying and death. The piece was written with intensity at one sitting, but later redrafted to the satisfaction of both the person she calls A, and Lindsay herself. I can’t help but be certain that Lindsay’s work with the dying has benefited from this depth of reflection. She has clearly drawn comfort and wisdom from the writing, and in doing so offers these also to the reader.

Evelyn’s song was clearly created—cleverly and wittily—to enable the understanding of others. I feel certain that most of Evelyn’s students will have the central role of iodine in thyroid function burnt into their consciousness as a tragic melodrama. Happy, engaged students learn when a subject is brought alive for them. I only wish we could reproduce her singing at the harp in these pages, like we have Michele’s painting. Perhaps I’ll be able to travel to Texas to hear her.

Whether these three writings were redrafted or not, they all follow Pooh’s timeless philosophy of writing—in their energy, impetus, and impact: “‘It is the best way to write poetry, letting things come’, explained Pooh”.<sup>7</sup> As editor of *Opening the Word Hoard*, I am keen to receive contributions from writers who have “let things come”.

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## The tattooed intruder

“Shit!” Startled in my sleep. Towering above me, beside my bed, was this tattooed stranger. Menacing crude indigo tattoos on his scrawny-yellowed skin. Not pictorial, but almost as if self-inflicted, drunken inked scratchings, piercings, mainly on his neck. I remembered particularly this large square, amongst others, over his Adam’s apple, his voice box. Who was he? What was he doing standing over me? I don’t know him. He scares me.

I awake. It’s the middle of the night. It’s four am. I call for a urine bottle. I’m on a fluid chart so all my pee has to be measured and my last one is full. It gives me a chance to wake fully, pull out my notebook to not forget this nightmare and write it down. How could I forget it? But like a dream startled in the night, this was the one I wanted to have forgotten about in the morning.

I know who he is. He is my cancer. The tattooed intruder. He has no name. Only a description. Yet he is a part of me that I don’t recognise. That is what brings tears to my eyes. In the calm darkness. In the stillness of the night emerges death. I want to think it is only a shadow, a sign, a symbol, a possibility. Not a fact this time. But it is a possibility I am aware of. A possibility I want to deny. Another throat cracked, teeth clenched, sick stomach, body shuddering tear swells in my eyes. Blurring my vision.

I continue to write in this emotional haze, through this painful sea, that threatens to drown me. Yet I have this sleepwalking drive to ink the tattoo here on this paper. Unthought, uncorrected, just scrawled as it is, gripped in my tracks. Word for word, moment for moment, tear beat, heart shudder. This is no premonition. No dream to be forgotten in the morning. This is what is happening.

As my senses are fully taking in, I’m in the dimly lit corner of a four-bedded ward. The sound of the twenty-four hour constant fungal extractor is the measure of my silence. I remember I am tethered, to a LCD flashing chemo pump beside my bed by the triple alumen Hickman line that protrudes out from a gash in my chest, still only two days sore and the black dissolving stitches still visible. The red electronic display flashing in three descending lines, like those of a mobile phone on charge. Only it is a sign of me being charged day and night by the cisplatin chemotherapy drug and accompanying saline solution. Charging through my body. 0.50 mls per hour and 0.48 mls hour respectively. What is that 0.02 mls difference, flush? Who knows. 0.02 mls dash of healing.

I have nausea on the tip of my throat, standing at the entrance of my

gut. And a constant ache round my temples. It is not as bad as times before. But it is a sickness I did not feel three days ago, before my treatment started. This is not my bedroom of three days ago neither. I know it is now my home. Three different institution patterned curtains partition me from three other beds and the outside ward. Behind me on my left, someone else is also awake. He frightens me also. I know his name. But we haven’t spoken. His white patchy skin, scrawny skeleton, cowered bent forth stance from which hangs his pyjamas stalk me. Telltale signs of future possible side effect of my impending transplant. Graft versus host disease. Common enough here as people talk about it in the corridors, by the nurses in its abbreviated terms GVHD. One of the many an acronyms . . .HGL (Hodgkin’s Lymphoma—my disease), NHGL (Non-Hodgkin’s), AML (acute myeloid leukaemia).

GVHD. That haunts me. Because that is not real for me yet, and may not be. But it haunts me because of its possibility, because of my decision. Because of a frightening possible side effect of my decision. A decision to go ahead with this bone marrow transplant from my Italian cousin. She is a perfect match. But she is not my bone marrow. And so there is a chance that her bone marrow once transplanted into my body, through a now relatively simple procedure of a blood transfusion after enforced growth through injections, and harvesting through transfusion, may reject my body. They say it can be chemically, medically controlled. But I can see his skin has been rejected. He looks half ghost, the patches of pigment less, bloodless, lifeless, what do I call it, engulfing his body.

I didn’t realise until yesterday morning that the boy in the other window is also suffering this. Latex gloves cover his raw skinless hands. His girlfriend explained that he now has GVDH in his liver and is in

day-care receiving the drug to combat this. And he is still smiling. No let up since 1998 for him, except for one holiday, a cruise, to find out after he had relapsed again with NHGL. His bed is empty but is always here for him. His bag keeps watch beside it, a constant reminder, that a bed awaits for when he is more ill. Everyday he returns for five minutes, ten minutes, half an hour. A quick hello. “I’m going home,” he says cheerfully. “Just waiting for my blood test.” And off he goes with his girlfriend, who bears a t-shirt with “treat me like a princess” on it. She smiles too, disbelieving of his constant outward cheerful demeanor that hides a myriad of constant disappointments and hardships.

Here you can’t but be confronted by future side effects, sickness, decisions, enforced, unknown, unwanted, even agreed to. I’m still one of the well ones. I still have my hair, my short goatee stubble, my slight tan from my recent Italian holiday. I pass open doors with people, bald, ashen, gaunt, slumped in chairs, silent, alone, waiting for it all to be over. Room after room. Surrounded not by personally picked paraphernalia of homely delights. No individual swathes of taste, neither Habitat nor Ikea, neither Harrods nor World of Leather. But hospital property, polystyrene ceiling tiles, miles of tasteless curtain track, the obligatory visitor’s chair by every metal institutional bed. The fan, the blood pressure pump stand. The oxygen mask and the green tubes. The angle poise lamp. The bed number, the room number, the ward number, the floor number. The alarm switches, the fluorescent light switches. The sickness bowls. The definitely not bedroom carpeted lino floors. The alcohol wipes. The functional sinks. The weighing scales and the sharps only bins. The communal telly, the hospital clock. The smoke alarm and telltale security, safety indicators. Left, right, up, down and all around. And yet it feels safe.

I want to go to sleep now. I want to go to the loo but I remember that my



The author/artist felt this image was the visual counterpart to the one in the writing.

loo is the plastic bottle with its ml counters up its side. A fan swathes some cool-ish air on my face, a somewhat short relief from the constant freshless heated environment. I may need a cool drink too. It's a hassle. My tethered lead doesn't allow my free movement. A metre or two to the left or right of the bed. I could unplug for a moment or two, wheel my five un-oiled screeching castors around to waken my other room companion. The only one asleep, too sick to be awake. I'm reminded of an Antoine de Saint-Exupéry quote that the beauty of the desert is that it conceals a well. Oh where is that fucking well?

It was cathartic to write this down... I wrote it as if recalling a dream/nightmare literally on the ward at 4am, just after waking and it helped me gather my feelings and emotions, my fears and my concerns, where I was and how I was. It is really hard to be able to express your feelings in the hospital environment and even though the dream was startling, frightening, it helped me place myself, express myself to myself and that was such a release.

The truth is—it is frightening; and one does feel the impact of being in an institutionalised environment, not at home, with no privacy, control, and that is hard. Although it was also hard to write it up too... But it was the eye of the storm and I was able to take through issues on board, particularly the impact of the other patients—as they were suffering serious side effects of the transplant that is proposed for me. And then that became the basis of my questions, that I probably wouldn't have asked about, with my consultant, and that gave me in turn more answers that has given me more confidence about the treatment. Funny how these things work.

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## Remember me when I am gone away (Rossetti)<sup>8</sup>

It is Easter, the diagnosis breast cancer—an aggressive invasive tumour, such harsh words. You balked, you wept, you thought you'd be all right, you thought you'd die. The family wept, they thought you'd be all right, they thought you'd die. You set about finding out all you could to help yourself. A mastectomy, the choice for treatment—the nurse who ripped the dressing off too soon before you were ready to look. The news—the worst, it's in the lymph glands—"a long hard road" the surgeon said. You all set

about adjusting to this news. The next thing, a course of chemotherapy was advised. Perhaps a cure, or at least the staving off of that quite awful thought of death before you had a chance to see your children grown, to sit your grandchildren on your knee and tell them stories.

So six months of chemotherapy ensued. Each one worse than the last, so sick, so weak. Your sisters came to care for you, your friend, each by turns while you and A tried to keep a semblance of life for the children. They went on holiday; they went to school. They sat on your bed and teased and laughed.

Then the trial, a new drug, they didn't know if it would help or not. You thought you'd try, not just because it gave you hope but "to do your bit for those who would come after". Someone else might be helped by this knowledge they would gain.

Eventually they told you both that it was no good: death would happen. You wept, you sobbed, you wrote your diary: what a friend that became. You grieved for the future, for watching your children grow, for sharing it with A. You worried how they would manage without you, and you knitted them mementoes. You raged because it simply wasn't fair. You fretted for A and hoped he'd find another loving friend with whom to be. Eventually you took on dying like a project to be managed: to be lived to the full. You told the children: they howled, they wept, but how they gained from honesty. The four of you were in it together. The family joined in, your beloved sister came so often, took you on holiday, reminisced. A took time off, made too many cups of tea, reworked the house, you wanted it right. He took the barbs you threw, where else is safe to put them, but in the one who's best?

You wore your baldness like a badge—the wig too hot—your flattened breast a sign of courage. You chose not to disguise the truth. How much easier that made it for those of us who loved you. Direct and honest, always clear, no games to play, except the good ones, laughing at some silly joke. You went on trips, on holiday to well loved places and some quite new. Sometimes the depression would overwhelm but always you TRIED; you never just gave up, I don't think I would have that courage.

Macmillan nurses, district nurses, occupational therapists, social services came and went. The constant solid rock, your family doctor, who listened, supported, made decisions when you needed, backed off when all was well.

A commode arriving prematurely knocked you off your feet with what was coming. You wept for fear of what death may be like. You begged that I might help you die, an overdose at the right time—but it had to be the right

amount, you didn't want damage. I panicked at the request—how could I deny my friend, but how could I do it? The thing that helped, I learnt from an old teacher long ago, that staying where the person is makes helping easier than we often allow it to be.

So where were you? I felt you were in grief and fear, panicked by the thought of loss of dignity. I said that if you got to that point then we would talk some more, the only promise I could make in honesty and know that I could keep. I bought you flowers, poor inadequate blooms, a gesture of the hope, I believed, that dying might be easy for you.

The offer of some more chemotherapy—what did this offer mean? Another six months of sickness for another six months of life—a poor gift. With courage you declined.

I sat on your bed... "it's here, it's there, the sooner it all joins up and finishes me off the better". Your best friend and your sister had said you should tell the doctor. I said I thought you should, there would be things she could do to help. The rock-like GP came, she got the palliative care consultant to come to you. In days he turned you round. "He really listened," you said, "then he gave me the best examination I have ever had." Each symptom was listened to, evaluated, thought about. The effect was instant, swiftly followed by the dear good drugs that gave you back some life. The palliative care unit a constant source of help, you could call or go there anytime you needed, what a comfort. You went out again, though any distance in a wheelchair, you felt you could enjoy what was left to you. You spent time with your beloved A, your children and your precious sisters. You worried still about the children, about A, about what legacy you were leaving. Love was the answer.

The next decision was a hard one: radiotherapy to the tumour in the skull which otherwise might make you blind, or even worse—lose control. Yes, that you'd have; weak, ill again, loss of hair and sickness, but not blind.

Then another crueller blow, your spine was crumbling and would keep you in a wheelchair, incontinent if you didn't have surgery. You opted for the surgery. Pain past believing, you yelled, you called for help. The nurses kind but so busy: "no time to scratch their bums" as A so succinctly put it. By contrast convalescence in the palliative care unit where care was kind and time not at a premium.

Back at home you gradually became weaker, sicker, breathless, but so good to be there. Then the broken leg, crueler still—back to the busy hospital where no one had the time to make you comfortable. They hurried in and out, "call if you want anything". The family brought you food that you

could like. I shut the door, tried to make you comfortable, the little things, so important. I wept for my profession. Where was care and comfort now?

I found it still, in the hands of the district nurse. Eventually you made them let you go home. A promise made that you could die there. She came—the district nurse—she washed you gently daily. She listened; she knew just what was needed. A bed came via the Macmillan nurses—what a laugh to set it up, nebulisers, oxygen, a frame to stand, a cushion comfortable to sit on. Each thing as it was needed and always the calm assurance that she knew. The GP and the palliative care staff always there when they were needed.

Then the day came for you to die. The palliative care consultant came to oversee the drugs that took away your pain. That same nurse came again, a gentle wash and comfort making, a syringe driver for the pain, a catheter to stop the worry that you'd wet yourself again, a humiliation too hard to bear. She did what needed to be done, never getting in the way of those who loved you most. She said to call if more was needed. The GP said to call: "I'm at the football but my bleep is too. Don't call the emergency service, they don't know you".

The family came—a birthday celebration—you blew a candle out with painful breath. We sat as evening turned to night, your best loved A, sister, and your friends. We drank so many cups of tea and coffee, listened to Mozart, reminisced. We talked and laughed while you fought to breathe, a little nod or gesture showed you heard. And then it seemed that you were ready, your breathing came and went. They held your hands, that well loved sister and that friend. He held you close, that man who loved you, your best friend; a word of love, a look, a real farewell. A few more breaths, a sigh and peace... "perfect" was what he said. The children slept. You had your wish, a peaceful death, at home with those you loved. We laid you in the bed, we drank to you in wine, we laughed, we wept. The children in the morning saw your peace, no ghostly nightmares of fantasy corpses to make worse their grief. Some time later A told me that the only comfort in it all was the manner of your death.

I thought of those inadequate blooms I offered you a year ago and which kept their promise. One for you, one for A, one each for your beloved children, one for your sisters, constant carers, one for your family supportive to the end, one for all your friends, one for the palliative care consultant and his staff. One for your wonderful GP

and for the one who came in the night to say farewell, and one for that good nurse who stayed beside you through those last months.

And as for me, one of so many friends, what a privilege to share your journey.

This piece was written as part of a reflective writing session. It was therefore waiting to be written. It has been redrafted but is little changed from the original "splurge". It felt important to commit such powerful memories to paper and in many ways felt like a memorial to my friend and the way she and her family coped with her death. I also feel that my perspective as a friend has given me a view of the professional care she received (both good and bad), "as the mountain is clearer from the plain" which continues to affect the care I try to give my patients.

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## Ode to Iodide

I find that music and science form a satisfying blend. This song is one of several I have used to teach histology to upper-level undergraduate students in our biomedical science programme. All of the songs generally employ personification of either cells or other structures.

This song tells the tragic story of Iodide, a molecule trapped forever in the thyroid follicle and cycled again and again through the synthetic pathway for thyroid hormones. It is sung to the tune of "The Three Ravens," a poignant 17th century British ballad that tells of a slain knight whose body is protected from carrion birds by his faithful hounds, hawks, and "leman," or love. The leman is symbolised by a gravid fallow deer, who dies after the effort of bearing his body to safety.

I keep a small pedal harp in my office and cart it to the classroom to accompany myself when I sing this song to students. It opens with minor arpeggios solemnly played on the low and middle strings. The three stanzas then tell the story with rising melodrama. The song ends with the sound of plucked strings, slow and dying away. Naturally, one may read other levels of meaning into a song such as this, but its primary purpose is to entertain and help students remember the central role of iodide in thyroid function.

## Ode to Iodide

(Sung to the tune of "The Three Ravens")

In yon thyroid follicle cell,  
(Thyroid cell, O, thyroid cell!)  
An Iodide was forced to dwell.  
(Iodide!)  
Once a blood-borne carefree iodide,  
The basal membrane pumped it inside.  
(Iodide, trapped inside, iodide!)  
Along there came peroxidase  
(Peroxidase, peroxidase!)  
And left iodine in iodide's place.  
(Iodine!)  
Expelled into the colloid space,  
A thyroglobulin stuck to its face.  
(Iodine, colloid-bound iodine!)  
A thyroid cell engulfed the pair.  
(In a phagosome, a phagosome!)  
And fused them with a lysosome there.  
(Lysosome!)  
The proteases snipped them here and there  
To make thyroid hormones and parts to spare.  
(DIT, MIT, thyroxine, T<sub>3</sub>!)

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Michele Angelo Petrone is a painter who helps medical undergraduates, medical and nursing staff, and sick people to learn how to express themselves through painting. Lindsay Buckell is a nurse, currently employed in palliative care. Evelyn Tiffany-Castiglioni is Professor and Head of the Department of Veterinary Anatomy and Public Health, and Associate Dean for Undergraduate Education, College of Veterinary Medicine, Texas A&M University. Gillie Bolton, Editor of *Opening the Word Hoard*, is a writer and Research Fellow in Medical Humanities, University of Sheffield Institute of General Practice and Primary Care, Sheffield, UK. Authors' affiliations

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