

Ethereal and material gain: unanticipated opportunity with illness or disability

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ABSTRACT

When caregivers address the positive aspects of illness or disability, there is a risk of patronising the sufferer. It is equally problematic when secondary gain is judged in a negative light and impedes an effective doctor–patient relationship. Changing attitudes, and particularly the negative perception of a patient's gain from illness, are reflected in biographies of artists, philosophers and other creative individuals. In contrast, some memoirs about illness feature a retrospective discussion of the positive features of the experience – from one who is now free from the ordeal. The experience of continual sufferers may be more instructive. We examine contemporary examples of unanticipated advantage or gain arising from ongoing disability or illness. The contribution of disability/illness to remarkable achievement promotes enhanced self-appreciation for patients and may foster in others a better understanding of what it means to suffer and live with disability.

KEYWORDS: Arts, disability, dyslexia, illness, medical humanities, secondary gain

For all you lose, you have an opportunity to gain . . . you are embarking on a dangerous opportunity. Do not curse your fate; count your possibilities.

Arthur Frank, *At the will of the body*¹

It is difficult for a caregiver to address the positive aspects of illness or a disability without sounding patronising. To borrow from Philip Larkin,² it is difficult to find 'words at once true and kind/or not untrue and not unkind'. For the sufferer, the concept of a disability advantage may, at first, seem contrived, an irritating distraction. Yet many sufferers and survivors of chronic illness have come to acknowledge various forms of gain from their ordeal. With characteristic enigmatic style, Emily Dickinson alluded to this in her poem 'My first well day – since many ill':³

*My loss, by sickness – Was it Loss?
Or that Ethereal Gain
One earns by measuring the Grave –
Then – measuring the Sun –*

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When clinicians refer to gain associated with illness, it usually has a negative connotation, associating the patient with blame. In the mind of many clinicians, secondary gain from illness (defined below) is often confused with malingering, compensation seeking or other medico-legal motivation. In this setting, the patient's behaviour and motivation in relation to their illness are seen as obstacles. In fact, secondary gain for many patients is seldom a true gain, and the usefulness of the term has been challenged.⁴ Even when substantial compensation is at stake the long-term gain is dubious, as succinctly stated by Hadler, 'if you have to prove you are ill, you can't get well'.⁵ Understanding of terminology for the types of gain associated with illness has changed over time.^{6–8} First introduced by Freud, the term *primary* gain referred to unconscious benefits or relief of emotions arising from expressing physical symptoms, such as a sense of peace or atonement, whereas *secondary* gain referred to a conscious benefit – social, occupational or otherwise – from other people. More recently, *tertiary* gain has been used to refer to a gain sought or attained from a patient's illness by someone other than the patient, including the caregiver.

Changing attitudes, and particularly the negative perception of the gain from illness, are reflected in biographies of artists, philosophers and other creative individuals. In exploring the notion that illness, including psychological illness, might occasionally be advantageous and not always an unmitigated disaster, Sir George Pickering's book on illness in the lives and minds of several celebrities was a landmark.⁹ For example, Charles Darwin, who complained of great debilitation from illness, was also open about his gain from the condition. He was afflicted by illness throughout most of his productive years, detailing his complaints in a daily health diary, but he conceded that although his ill health 'annihilated several years of my life', it also 'saved me from . . . distractions of society'. Illness granted Darwin the solitude required for his work, including formulation of his theory of evolution by natural selection. However, in a subsequent commentary on the same illnesses experienced by Darwin and others that Pickering had analysed, Dilon dismissed the gain from illness as hypochondria.¹⁰

Increasing interest in illness narratives and memoirs reflects a cultural shift in consciousness about the position of illness and disability in human life. There have been striking examples of artists whose work has been shaped by illness. The impact of sensory impairment, loss of manual dexterity or other dysfunction on the output of great writers, musicians and artists is ripe for academic speculation and intellectual

intrigue. However, contemporary examples of unintended or unanticipated advantage or gain arising from ongoing disability or illness are instructive. The contribution of disability/illness to remarkable achievement promotes enhanced self-appreciation for victims, but, paradoxically and more importantly, it may foster in others a better understanding of what it means to suffer and live with disadvantage.

Philip Schultz, a winner of the Pulitzer Prize for Poetry, was unaware that his difficulty with words and reading was due to dyslexia until he was 58 years old.¹¹ The late discovery was made when his son was diagnosed with the condition. Schultz describes the ‘pain’ of dyslexia as an ‘assault on self-esteem’ and explores the differences in his self-perception before and after the diagnosis. This is no triumphalist survival story told from the safety of recovery after an ordeal. Schultz still struggles with the ‘alphabet of woe’ and still has occasional problems reading even his own poems in public. His panic on trying to pronounce the word ‘arthritis’ while publicly reading lines from his poem ‘The magic kingdom’, is palpable. ‘I love everything about books’, he says, ‘except actually reading them’. Although he has found ways to circumnavigate many problems, he still has trouble transforming words into sounds and needs to memorise and rehearse before reading aloud. From great shame, embarrassment and frustration in his struggle with words grew a deep appreciation of language and its music.

As instructive as his account is of the hidden difficulties suffered by those with dyslexia, his technique for circumventing the problem by thinking in a ‘compensatory roundabout’ Byzantine manner is particularly insightful. In contrast to speech, which is acquired subconsciously, reading must be acquired by learning at a conscious level. Schultz describes how he would ‘imagine’ that he could read and would look at his mother reading words from a comic book while pretending to be reading them himself. ‘I didn’t know it at the time but I was inventing a boy who didn’t suffer from dyslexia, who was “normal”’. He imagined the words and now applies this as a method for teaching others with the same problem. ‘My dyslexia has played . . . an important role in my development, both as a poet and a teacher of writing.’ The irony of mastering that which once mastered him and the fact that words that once failed him ultimately saved him is clearly acknowledged by Schultz, ‘The very things I couldn’t do have helped provide me with a profession and a means of knowing myself . . .’

Others who have struggled with processing words and language have turned disability to advantage. Richard Branson, entrepreneur and business tycoon, identified his dyslexia as a secret to his success.¹² The challenge was not only a driving force for success but also guided how his company communicated with customers and prompted him to learn how to delegate tasks with which he was uncomfortable or inefficient, such as reading and writing, to others. The Irish author, drama critic and newspaper columnist Fintan O’Toole has attributed much of his success to his stammer, which helped expand his vocabulary and enhanced his appreciation of the written word.¹³

Melody Gardot is a Grammy Award-nominated singer/songwriter who traces her accomplishments in music to when, as a 19-year-old fashion student, she was the victim of a motorist who collided with her bicycle after driving through a red light. She sustained severe injuries to her head, pelvis and spine and required hospital care for more than a year. Prior to this, she had supported her studentship by playing piano in various bars in

her native Philadelphia. Her recovery from injury was arduous. She had to learn to walk again with intensive therapy and had a significant speech deficit, with mild persistent expressive dysphasia. When her recovery stalled, her physician suggested she use music as a therapy. Gardot wrote:

Music . . . helps to reconnect neural pathways in our brain: listening, performing, singing, making a verbal attempt to sing along or hum. In my case this was why it was pointed out to me. First because I had some experience as a young person playing piano bars and so it was an innate ability but furthermore because of its ability to really help me progress when no other progress could be made.¹⁴

Gardot’s disabilities – in addition to residual dysphasia, she has hypersensitivity to sound and light – dictated the kind of music she could listen to or play herself:

What I was seeking was a sound that was soothing and to me a trumpet was much more soothing than a guitar. Too much sound was just too much noise. Sticks on the drums were aggravating to my ears so we used brushes; I didn’t like the sound of the steel strings on electric bass so we used an upright. It was very logical in that sense.

Unable to sit at the piano, she learned to play guitar lying flat in bed. She began to write songs about her slow and painful rehabilitation, including ‘Some lessons’:

*. . . to think I could have fallen a centimetre to the left
I would not be here to see the sunset or have myself a time.*

She writes in the sleeve notes of her first album *Worrisome heart*:

One evening held particular significance for me when I realized the date: November 11th. Two years prior I was lying in a street, unable to move after being slammed into by the front end of a Jeep. I thought back to the cold hospital and the insensitive doctors, the many months spent lying in a hospital bed wanting nothing more than to be able to get up and run, the harsh reality of realizing I was disabled and the eventual grace and understanding that came with time. Never, could I have planned this. I would have been called crazy to even suggest it. And yet two years later, to date, I was sitting in the cutting room surrounded by incredible musicians with the opportunity of a lifetime. Part of me still doesn’t believe it.¹⁵

Gardot has since released two additional platinum-selling albums, toured the world and been nominated for a Grammy Award. Today, she still uses a walking stick and always wears dark glasses. Her quiet voice has a striking quality, as does her vocal phrasing. Her songs are about pain, loss and love. Had she not had her accident, it is unlikely that she would have progressed beyond the piano bars of Philadelphia. Her music and unusual performing persona are largely a result of her severe injuries. She has visited several hospitals and medical schools in the USA to talk about music as therapy and is understood to be collaborating with the hospital that treated her on a programme for treatment of traumatic brain injury.

What are we to make of stories like those of Schultz, Gardot and others? These people are special not despite their disabilities but because of them. What set them apart in early life contributed to their later achievements. Their frustration and the stigma they perceive arise partly from within, but mainly from the reactions of others. Acute sufferers with illness or disability have little need of pity or patronising platitudes. In the case of Schultz, the disability was undiagnosed, whereas Gardot was stricken in her late teens. In both cases, their disability was a factor involved in their later artistic success. We know of

these cases because of their remarkable capacity for clarity and engaging expression. Whether others, perhaps less creative or artistic, can convert some of their loss to gain, or can be helped in this respect, is uncertain. There is a gulf in knowledge and understanding about how this can be achieved. There is also risk – for example, if inexperienced caregivers misinterpret the concept of gain as a signal for patients to somehow 'pull themselves together'. However, gain from illness and disability should not be viewed as a barrier to an effective doctor–patient relationship. As part of the story of illness, patients should be encouraged to reflect upon and discuss gain, so that others can understand and perhaps use the information to advantage when coaching, teaching or caring for other sufferers.

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