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Divine defragmentation

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The article explores the author's experience of living with Parkinson's disease and engaging in theological reflection from that perspective. It is structured around meditations on three different passages of Scripture: Paul's metaphor of the Christian community as a body where no part can disclaim the need for any other, and how her experience of intermittent or disordered connections between brain and foot (dyskinesia) affects her reading of this passage; Isaiah's depiction of the suffering servant, and contemporary stereotypes the author and others experience, based on how they look or how they move; and the gospel passage about Martha and Mary, and the importance of presence rather than activity.

ACQUIRED DISABILITY • PARKINSON'S • BODY METAPHOR • INTERDEPENDENCE • DYSKINESIA • VISUAL STEREOTYPES • DISABLED GOD • SUFFERING SERVANT • MARTHA AND MARY • PRESENCE

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Introduction

This piece of writing is in several ways not what I intended to produce when I was first asked to contribute to *Holiness* in an edition on holiness and the body. It is, however, a reflection, theological and otherwise, of my present life experience in several ways. I am not able to access my library as my books are in store so there is not the more scholarly practice of citation and reference, or at least very little. It is also – at least partly intentionally – fragmented, in that I have tried to place alongside each other themes that are interrelated though initiated by reflecting on very diverse experiences. Marshalling thoughts and ideas under the influence of certain neurotrophic medication after some years can be more scattershot than one would ideally like and I thought I would not try to iron that out in editing. At least that is my excuse, though those who taught me years ago might well say that they do not really notice any difference …

The head cannot say to the feet …

Sooner or later, as a person with an acquired disability which results in a severe movement disorder who is involved in Christian theological thinking, one must make something of the Pauline body metaphor. Indeed in my case I feel I have revisited what significance it has for me more than once in the last 15 years. The second half of 1 Corinthians 12: 21 has: 'The head cannot say to the feet "I do not need you"', and reading this, or hearing it read aloud in recent times, I find I automatically stop before 'I do not need you'.

If the 'head' can stand in for the brain, then I can certainly say that in my case the head is frequently not on speaking terms with the foot. In fact it does not say anything at all to the foot, and in effect behaves as if the foot is not needed, since the required chemical signals to do foot-like things, like move up and down and stay balanced and cross thresholds, do not come. To push the image a little further, when medication intervenes and provides the required reaction, it is almost as if the offended brain exacts revenge, since then foot and knee and indeed the whole leg go into a crazy dyskinetic movement that is of no use in practical terms but makes for an exhausting few hours. Yet as in Paul's image these limbs, however wayward or recalcitrant, 'belong to the body nonetheless'.

It is in playing with, or meditating on, that passage about belonging to the body despite the efforts of part of the body to deny that belonging is its proper role that I find a way to understand what for me is one of the most strange aspects of my condition, which is a kind of fierce physical/mental dualism that it is hard to articulate. It happens this way: to go back to the Pauline body parts in mutinous revolt. When I am stalled in walking or 'freeze' on a threshold it is not that I do not know what to do to take another step or to cross a doorway and go into a room. Indeed I can stand there and cognitively assess and instruct myself, saying something like, 'Pick your right foot up and move it forward a little and put it down.' I can even say it aloud, but still nothing will happen for minutes, perhaps for longer still. In practice, of course, one does something to distract the brain such as starting a song. (For some reason the song that sometimes works to unstick me is the Toreador's song from *Carmen*, an opera I don't even like!) But the very physical reality of not being in control of the body makes me turn to this image of interdependence, both to assert my awareness of the wholeness of the body both in the very literal sense and to ponder further possible parallels in the body of the Church, the Body of Christ. Viewing Methodism as I now do more from the sidelines than used to be the case, I see the unpreparedness of the church culture in which I was raised for the vast and very threatening changes that the latter half of the twentieth century and onwards have brought. We have been afraid to walk further across new territory and we have had liminal anxiety over many and various thresholds which claimed to be places of potential.

In some important ways many are breaking new ground now and encouraging others to go forward, and maybe the hesitant will emerge singing – though I shall not tempt fate by suggesting what the song that reinvigorates may be, as whatever I choose will be anathema to some. I just repeat that the song that works for me is, after all, one I would not choose if left to myself!

This part of the reflection illustrates something that is a growing part of my experience – that reading the Bible and preaching the good news have become for me a much more connected experience physically and mentally. Living with the somewhat surreal 'conflict' between a brain which on the one hand knows exactly how to walk across a room, and open and step through a door, and on the other hand has no idea how to do that, is sometimes the most difficult challenge, and brings to mind Paul's outburst in Romans 7:21 and onwards, lamenting the two parts of himself engaged in a fight: 'In my inmost self I delight in the law of God, but I perceive a different law, fighting against the law that my mind approves and making me a prisoner' (REB).

While this has always been a text with all kinds of powerful resonance for me in personal life and as a preacher, it has come together with my bodily experience and inner reflection on that. It is at the point of honesty, which comes from not really having any other option – to deal with increasing physical decline, or to deal with the unforgiven and unforgotten, if often misremembered, wrongs we have committed or been party to – that there is, despite everything, a possible realisation about rescue.

'Who but God?'

'in the beauty of holiness …'

Two members of one of my former congregations once were describing a friend of theirs who lived in the USA and attended the church they also went to when over in the States. Their friend had been blind from birth and was well known in his local community for his thoughts and comments on living with blindness, one of which was that his condition meant that he had 'no definition of ugliness'.

It was an attractive comment, and it is clear why it was a saying worth sharing, but of course it begged any number of questions, such as can one not hear ugliness or feel it. Certainly, though, in a culture so dominated by visual imagery, to have no reason to judge someone by their looks or clothes or any other mere visual impression might well be considered a gift. Many people find, despite the best intentions, that their opinion of a stranger seems to have been formed before conversation or introductions have begun. I have had cause to consider this from both sides of the issue in recent times. I help in a voluntary capacity at several archives, and, together with a colleague, was staffing an information and bookstall at an open day, when we spotted what seemed to be some odd and potentially 'shifty' behaviour on the part of a young couple who were appearing and disappearing, and later reappearing in the cloakroom area where coats, bags and other potentially stealable items were stored. In Britain, archives are changing but still tend to be places of predominantly white, middle-class, middle-aged culture, and my reaction and my colleague's was to question each other about what we were seeing. Both of us started a sentence with something like, 'This is going to sound bad but …', and packed into the next three minutes was a whole run through our potential capacity for judging by deeply ingrained, childhood-acquired racist assumptions, overlaid by conscious adult training at racism awareness courses

and indeed simply living in a broader, richer world. Would we call security, or go over and greet the visitors and ask if we could help? Were we seeing what we thought we were seeing?

I am not going to continue the story beyond there on purpose – your thoughts on what happened next may well reflect your own inbuilt filters. It remains a telling incident to me in company with, in particular, other experiences which involved other people's visual impressions of me and the inference drawn from them. One of the features of medicating someone for Parkinson's is, in the medium to longer term, that a person develops a dyskinesia in arms or legs, which in my case means a quite severely over-active and twitching foot. Observing me with leg tapping not in time to the Christmas carols in Sainsbury's a fellow customer asked if I wanted to dance but reminded me to keep to the beat. On an unrelated day, when the lack of control of the leg was making me list (or 'weave', as my current consultant prefers) I gained a sympathetic word from one of our local drinkers out in the precinct: 'I know how it is, love.'

I am not so well adjusted by far as to be able to say I am able to absorb incidents of this kind with instant and equable composure, but reflection later does suggest that the 'emotion recollected in tranquillity' can be worked out alongside some of the familiar biblical texts which have as a focus physical appearance or disfigurement: 'He grew up … like a young plant whose roots are in parched ground; he had no beauty, no majesty to draw our eyes, no grace to attract us to him' (Isaiah 53:2, REB). This well-known biblical account, with its image of people turning away from the stricken figure of the Servant, invites exploration of what it is that causes people to find difficulty in dealing with certain forms of mental and physical disability. However, it is also one of the results of visible awkwardness and lack of control of the limbs that is the opposite of being one from whom people turn away. As in my encounters with the street sleeper and his cider and with the misled fellow Sainsbury's shopper, it can actually mean that more attention is paid rather than less, because as an object of curiosity and/or confusion or charity, you have become stare-worthy. In the scheme of things, being able to meet the street-dweller's 'understanding' with thanks, still more to give him attention as his own person, would be 'the more excellent way'. To have invited the shopper to dance slightly lopsided dances in the aisles of the supermarket seems similarly to have a 'kingdom' feel about it. There is nothing grand in this as a theology or a strategy, just the working out of some themes in life and ministry now as opposed to once upon a time. Theological theories of disability have been developing at quite a rate

since the 1990s, An early writer, Nancy Eiesland, still one of the best known, developed a liberation-based theology of the Disabled God, focusing on the figure of the wounded Christ, with pierced hands and feet. Her work is based on a social model where what matters is God's ability to be with the disabled, to be among them and in union with those who are oppressed. She is also responsible for applying the term 'temporarily able bodied', arguing that everyone will, sooner or later, have some problem which will render life more arduous and possibly amount to a 'disability'. For me, reflecting on her work some years ago and also again more recently, it is helpful when she describes how disabled people are more aware of their bodies, and goes on to argue that their contribution to reflection on embodiment is invaluable. For me, as I hope this article goes some way to show, the practical living out of the day-to-day is (yes, a challenge and all those synonyms as well) a slowly emerging vocation, or perhaps more accurately a discipline of waiting and trying to get right the small things.

> A liberatory theology sustains our difficult but ordinary lives, empowers and collaborates with individuals and groups of people with disabilities who struggle for justice in concrete situations … creates new ways of resisting the theological symbols that exclude and devalue us and reclaims our hidden history in the presence of God on earth.[1]

Choosing the better part?

The transmission of the story of the two sisters Martha and Mary has changed radically during my lifetime, and in a way that has been noticeable not just to preachers and biblical commentators but to those who have sat in churches and many times overheard children's and all-age talks and sermons on the subject of Mary, whose sitting listening to Jesus is (in)famously praised. Not so much driven by, as trailing somewhere in the wake of, feminism's effect on all disciplines and theoretical traditions and on everyday life, the general emphasis has leaned various ways.

One can quite legitimately choose to emphasise the defence of Mary as having the right to sit as a disciple, or one can take the view now more openly and critically of standing in Martha's shoes and feeling genuine irritation or anger. I like to imagine generations of, for instance, our Victorian and Edwardian

grandmothers in hundreds of chapels spending their morning listening to admonitions of what a privilege Mary had as a woman and how good it is to choose like her to sit and learn, and all of them with an inward wry smile because they well knew what would be the effect on the midday meal should they decide to immerse themselves in learning when everyone got home.

The image of the bustling Martha and the contemplative Mary has been another passage to come home to me differently in recent years, because of my gradual inability to do some of the tasks involved with the domestic running of a home, and because I not infrequently find myself invited to sit still or rest while my hosts rush about and prepare supper or come in from digging the garden and picking up fallen apples and much more. I have been an observer so often now that at least I have begun to see that there really is too sharp a dualism thrown up in many interpretations of the story, and for me there has to be something of a path between them. While there are tasks that I know are beyond me, there are a number of things I can still do as a gesture of thanks to the host. And there is a further element to this and that is presence. It has become a habit of mine in several friends' houses to find a stool to sit on and put it in the least obtrusive corner of the kitchen, and sometimes to chop onions or shell beans, but mostly just to accept that I can best contribute by 'being' – and that is again in several ways. One is by being able to offer the host a time for them to do the talking even while busy. Another is the sometimes pastorally important emphasis that I am alongside them – not taking advantage of my being let off cooking to be absorbed on laptop or with a book. Such times can become a gift and they are a way of committing time to God and one another which derives from the insights of disabled people in the most basic arena, around the table where the people of God are gathered in one place.

Note

1. Eiesland 1994, p. 86.

Bibliography

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