
The body as a microcosm

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When I as a theologian write about health, it is for a very specific reason. I have become seriously ill. In my encounters with various aspects of the health services I have had some thoughts – reflections that are relevant not only to me.

My diagnosis is motor neuron disease, which is expected to gradually develop into amyotrophic lateral sclerosis (ALS). A small leaflet that the hospital sent me describes the clinical picture. The main content is linked to the description of the bodily, biological processes that have become upset: motor neurons die and fail to relay the information necessary for the muscles to function. This is seen as an irreversible process that cannot be affected by external stimuli. In other words, this means that the disease is progressive, and no form of treatment is available.

The crucial question for me, having lived through the course of this disease for nearly six years, concerns how to live with such a diagnosis. When I arrived for the check-up four months after my assessment, I was frustrated by my life situation. I was at a loss. I has no idea of how I should relate to all the uncertainty associated with my future.

My meeting with the neurologists was dispiriting. I was left with the main impression that nothing would help: physical activity makes no difference. Even when the deterioration seemed to slow down, I was assured that sooner or later it would catch up with me. I had the clear impression that I was a collection of dead motor neurons that were caught in a kind of ill-fated no man's land: before me lay a world that would gradually be bereft of any form of activity.

Needless to say, this made me despondent.

Nothing can be done

The best I can say in hindsight is that this demonstrated a medical approach with certain distinctive characteristics. The professional approach that I encountered isolated the clinical picture from the rest of my person. This is not to say that focus was placed only on the purely biological processes. Focus was placed exclusively on the diseased biological processes. This meant that the doctors related to me only as someone who was ill. This was not the worst of it, however. The worst of it was that this approach was transferred to all the other parts of the health services that were mobilised with regard to my illness. Everybody had the same idea: nothing can be done. Therefore, we do only one thing: we provide the necessary support on the way down. And what are needed on the way down are primarily various forms of technical aids.

I have gradually come to realise that even though the diagnostics should prove correct, the perspective underlying the diagnostic process is extremely problematic: it isolates the illness from everything else, in a way that has a paralysing effect far beyond the paralyses that are already there.

Intensive training

However, in my encounter with dead motor neurons I have chosen a strategy different from the one I was recommended by the health services. Immediately after my diagnosis a friend who is a physiotherapist said to me: ask for twice-weekly physiotherapy sessions and start a programme of hard and intensive exercise. This advice was not in accordance with the guidelines applied by the ALS team. I nevertheless followed my friend's advice. Now I have a training programme which is even more intensive, as I have changed to daily training sessions. Along the way I have learned that I need to listen better to my body than I did in the beginning. At the same time, however, I have experienced that the body adapts and gradually becomes more resilient when put under pressure.

What is crucial in this context, however, is not the extent to which diseased muscles can be exercised or not, although this is also important. The key issue is that physical exercise is very good for me. It is good to have a regular schedule for attending a physically stimulating environment. Moreover, it is good to feel that I still have muscles that respond when I use them. I like to use them, I feel the endorphins flowing when I engage in activity, and I feel happy and content afterwards.

I have always enjoyed swimming. Since I fell ill, we have spent large parts of the winter on the Costa Blanca, which has had a surprising effect. Not least because the ALS team told me that travels to a warm climate have no effect on the group of patients to which I belong.

My experience has been quite different. Staying in Spain has made the winter season tolerable in a very different way than at home. The sun and the heat benefit me, like everybody else. Moreover, I can go out for hours every day, at times when staying outdoors in a wheelchair is impossible back home. The main thing, however, is the opportunity for daily trips to the swimming pool. My body makes progress when I am in the pool. This progress is not overwhelming, but it is tangible. My body becomes more supple. I spend all day in my wheelchair, on the couch or in bed, with only minimal movement in my lower extremities. I can move my toes a little, but everything else appears lifeless. I am thus astonished each time I enter the pool. There I can move, almost normally. I raise my legs and move them forwards, I cycle, I can stand up when holding on to the edge of the pool, and I push myself upwards by the muscle strength in my thighs and buttocks.

The impossible is made possible

It will hardly be difficult to understand the importance of experiencing all this. That I, who cannot move, have found an arena where the impossible is made possible. I derive boundless joy from having my lost opportunities restored to me.

One year ago I received a phone call. An acquaintance of mine had told my story to a Norwegian-Thai masseur who found my case interesting. She asked if she could see me. Since then, I have had twice-weekly massage sessions. The masseur has an unrivalled eye for the body as a coherent organism, and the results are there. Stiffened muscles have become supple again, and the blood flow in my legs has improved significantly. The muscles have also expanded, so that I no longer sit on bones. My mobility has also improved. This painstaking work with my diseased flesh is borne by a fundamental care for my entire being. This should not be confused with a pleasant interaction with my diseased body; the massage is occasionally quite painful. Nevertheless it is a form of care for what has been destroyed, and it gives me zest for as well as enjoyment of life. It makes me less estranged from everything in me that is diseased. Through the massage that I am part of, I can more easily accept all aspects of myself.

Coping strategies

It goes without saying that the illness affects my mind. I need not attempt to describe what life is like with the future prospects that follow from my diagnosis. What has been clear from day one, however, is that I should not dwell on this. This is easier said than done.

When things fall apart, all I can do is wait. Wait for the coping strategies to regain themselves. In this respect I have been fortunate in having a professional activity to turn to. Immersing oneself in something outside of oneself is a source of energy.

I might also have listed all the positive aspects of daily life. These may somehow be summarised in two fundamental experiences, both of which can be linked to specific events. The first concerns a death. During our last stay in Spain, a close colleague of mine died. In the days around the death and the funeral I pondered on the life we had shared. One day I sat listening to quiet, classical music that suited the occasion well. I was composed, but sad. Then something strange happened. As I had put the headphones down and was getting ready to go out, I had a completely new experience: I opened the front door, and at that moment the world out there struck me with a force that I had never felt before. It was as though everything that unfolded before my eyes, in its totality, breathed, radiated, moved and lived more intensely than before. And in my mind I thought: I am part of this, and I want to remain a part of it. It meant: I am not merely a collection of dead motor neurons, I am infinitely much more that is still alive.

Such was my first experience. The second is linked to the progress that actually takes place day by day. The steps are small, and they make only modest changes to my opportunities to be mobile. But they are there, and they confirm that being active is worth the effort. I believe that what is most important about these experiences is that they lead me from a closed to a more open universe. This is not a matter of false hopes. What has become important to remind myself, however, is that nobody knows what my future will look like.

Professional discourse

I have gradually realised that my experiences also belong within a professional discourse. I have few qualifications to participate actively in the ongoing debate, but it is encouraging to view personal experiences in light of a professional discussion that in fact applies to me directly.

In the book *Descartes' Error* by Antonio Damasio from 1994, *the body* constitutes the fundamental reference for understanding the human. This body interacts with its environment as an ensemble, and the physiological operations that we call the mind are derived from this structural and functional ensemble, not only from the brain, Damasio claims (1). This may immediately sound quite self-evident, but it is not. Damasio points out that the brain's most valuable product, the mind, has never played a leading role in the study of brain diseases, i.e. neurology.

My small forays into this matter have been important to me on a personal level. They underpin the certainty that much remains unexplored in the interaction between the environment, brain activity and the rest of the body that may have a bearing also on the manifestations of my own disease. Now, I believe that my ailing nerve cells are not only diseased. They are part of a dialogue with the entire body and the life conditions to which I am subjected. And even though this dialogue will not restore my health, a dialogue of sorts nevertheless continues inside me between my nerve cells, those that are healthy as well as ailing, and other forces in my body, in both my brain and my muscles. All these nerve cells are in direct contact with my mind as well as my surroundings.

This perspective differs from the one I have encountered in the health services, where all the attention was directed to the dead motor neurons.

My life is not exactly dead and empty. In many ways, I can say that during these last years I have lived a richer and deeper life than ever before. Obviously, this does not imply that I am happy about my fate, far from it. However, deep, deep within me there is a glimmer of hope that someday, my fate will take a different turn in a direction other than what the prophecies indicate. Until then, I struggle on and wrestle with the challenges that constantly turn up in new guises. All told, however, these endeavours create an existence which is bearable. This is quite different from sitting there waiting for what lies ahead to catch up with me, which is just intolerable.

LITERATURE

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