Funding the Future

Medicine, autonomy, urgency and the politics of care

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My recent hopes that my kidney stone had gone away have turned out to be misplaced. My latest tests show that I do, in fact, still have a stone, and it is in a position where action will, in some way or other, be required. What I do not know is what will happen as yet, even though the NHS assures me that I am on the waiting list for an urgent appointment to decide what should be done, after which I will be put on an urgent waiting list for urgent action.

The thing about all this, which I am sure that others know all too well, but which I am now experiencing on a personal basis for the first time, rather than as an observer, is that *urgent* does, in the case of the NHS, have a very different meaning to that which it has in any other context. It implies a need for speed and conveys a sense of stress, neither of which is reflected in the actions taken.

What I am also discovering is that the NHS is excellent at sending information without explanation, whilst providing no opportunity to ask the most basic questions to secure understanding. It is a good job that I am married to a retired GP, or some of the gobbledegook that I have been sent of late would have required a GP visit to secure interpretation.

I suppose it could be said that I should have known all this, and in principle I did, not least precisely because I have had relatives who have had intimate relationships with the NHS where I have provided support. The difference on this occasion is that I am the subject of the supposed care, which is apparently urgently required, for which no timescale is being provided, whilst the risk that I might return to a situation where I suffer intense pain and require urgent attention, as I did in late June, is actually stated to be a real possibility.

The consequence of that is that I feel utterly depersonalised by what is happening. I am no longer a person, but have become an object, subject to a process. In that transition, I have lost my autonomy and had my agency removed.

The experience that I had over a month ago was, to put it nicely, exceedingly painful,

and I have been left with the open-ended possibility that it might recur, with the risk that damage to a kidney might arise as a consequence, which feels less than desirable. That now creates an aura of uncertainty around my plans and expectations, with the possibility that I might have to become an emergency admission again, and all for the sake, at this moment, of a telephone call described as urgently required but apparently not possible.

It would be all too possible in this circumstance to blame the NHS and state care, but I am not persuaded that that is appropriate. I think the depersonalisation of what is described as care, but which should properly be described as process, is deliberate and is a consequence of the medical-industrial complex.

Within that complex, the creation of which was a deliberate choice that originated in the USA with the *Flexner Report*, *written at the behest of the Rockefeller Foundation before the First World War, the person is deliberately removed from their autonomy within the medical process and becomes a cog in the medical machine, whose existence is intended to create people fit to work within the capitalist industrial complex, but not to consider their wellbeing during their engagement in this process, whether during their illness or afterwards.*

The approach the Flexner Report prescribed, which did require the removal of agency from patients within the system, who ceased to be considered autonomous individuals with human needs, and instead became inputs into a production process requiring that remedies be applied, is the foundation of modern medicine, and, in turn, of the treatment that I am receiving from the NHS at present. I am not blaming any individual, and I am certainly not holding any of them responsible. The failing is systemic, but it appears almost complete. It is not that the NHS, or those within it, are failing; the failure lies in the medical system and in how it is organised, irrespective of whether profit is a factor.

The problem is that medicine is taught as if doctors, and everyone else in the medical hierarchy, treat symptoms and not people, and the consequence is that the whole person is ignored, and siloed specialities are emphasised. In my case, that means the only apparent issue of concern is the state of my passageways between my kidney and the outside world, and the risk of blockage within them, rather than whether I might have any relationship to the issue involved.

The consequence is that I do now appear as a statistic, or at least on one urgent waiting list, and maybe more than that, when a simple conversation could resolve a great many issues, because I could, for example, decide that it was in my best interest to take no action at present and wait and see what happens. I could take that decision, and accept the risk that pain might provide the indicator that this turned out to be an inappropriate course of action, but in the meantime I will be on the waiting list. Granting me the right to make that decision would also restore my autonomy. But that possibility is not reflected in any of the correspondence I have received, or in the discussions I have had.

Everything is about what might be done to me, but not what I might want.

As I have noted, the result is that I feel my autonomy has been removed. Thomas, in the meantime, felt exactly the same when being treated for the broken metatarsals in his foot, which have now thankfully healed. His foot was treated as an object that existed almost independently of him, and discussion on treatment became about something that felt like a third party, independent of both the doctors and him, which was then the subject of the medical process undertaken. None of that felt any more logical, or reassuring, than the process I am engaged in.

My point, then, is a very simple one. If we create a world in which people are denied their autonomy, and so their right to be engaged in processes that impact them, what outcomes do we really expect?

Move this one stage away from medicine, and look at why so many young people are disengaged with the economy. Is that any surprise when they are discussed by politicians, and so many involved in the education and early employment processes, as if they are units of production, and not real people with aspirations, desires, fears and sentiments all of their very own? I am sure that they feel as alienated and subjugated to a process of which they have little control as I do with regard to my kidney stone. Is it any surprise, then, that their treatment might increase the problems of finding them employment, rather than aiding them?

If we are to have a politics of care, that word needs to have meaning. Above all else, it means we have to respect the individual, whoever they are, wherever they are, and however they view themselves. And to achieve that, we have to level the playing field when it comes to power.

My loss of autonomy enhances the power of those in the medical system. That is inevitable. I am now subject to their control, and I think that is exactly what the system was designed to achieve, and succeeded in doing. The idea that there might be cooperation and even co-creation in the healing process seems alien in this system, and yet it should not be. That we have something very wrong is apparent as a result. There is much to rethink here.