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Restoring the balance: Living well with pain

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Stories about time shifted, folded and shared, the extraordinary ordinary, and keeping separate and being a-part.

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Restoring the balance: Living well with pain (<http://somatosphere.net/2019/restoring-the-balance-living-well-with-pain.html/>)

By Else Vogel (<http://somatosphere.net/author/elsevogel/>)

Like dementia, persistent pain comes with irreparable losses: physical restrictions, strained relationships, financial problems, perished dreams and ambitions. Both conditions require ethnographers and care professionals to shift focus from cure to care, from treating illnesses to learning how to live with restrictions. The question thus emerges: how *do* we learn to live with such 'diseases that do not go away' (Pols, 2013 (<https://sciencetechnologystudies.journal.fi/article/view/55300>))? What may constitute living *well* with disease?

In her research, Annelieke Driessen (2018) (<https://www.berghahnjournals.com/view/journals/cja/36/1/cja360103.xml>) challenges a dominant story in which dementia becomes associated with loss – of personhood, of meaning, of sociality. Drawing on her detailed ethnographic fieldwork in residential care homes, Driessen shows us the transformative power of care in living with dementia. She unearths the painstaking efforts of care workers to elicit pleasure in the residents – through organizing a dancing event, in offering a luxurious bath, and through mundane practices of feeding and cleaning. If they accept their caregivers' invitation, residents may be enacted as, and enact themselves as, appreciating subjects – if only for a moment.

While doing ethnographic research in a rehabilitation clinic for people with persistent pain, I saw similar attempts at enacting appreciative subjects, albeit through very different means. In the treatment sessions with psychologists and physiotherapists, good care often hinged on explicit reflections on what people find meaningful. These moments were actively created in the clinic. For instance, I participated in an exercise called the 'life compass', where patients 'rate' several domains in their lives; such as family, work, sports, friends and spirituality, in a scheme echoing the Dutch school system. First, they assess how important this is for them. In the group where I am participating, many patients award 'friends' and 'hobbies' with an 8 or 9 out of 10; 'very important'. The little time they have lately been able to dedicate to these domains, however, prompts most of them to put down a 1 or 0 in response to the second question: how much of their time have they been able

to spend on it in the last three weeks? The psychologist introducing the exercise explains that a difference between these grades reveals a ‘disbalance’, meaning their activities no longer reflect their values. The ‘compass’, then, serves to re-direct and offer a renewed sense of purpose. Often, this exercise was an eye-opener for the patients as they realize how their lives had started to revolve around their restrictions.

This was the case for Rudy, a successful journalist with crippling back pain. When I meet him in his home for an interview, he has been on sick leave for over a year. An energetic man in his fifties, he seems happy to talk – as much interested in telling me about his past travels as in sharing his experiences with the rehabilitation trajectory. Pain management currently structures most of his day. Before I came in, he lay flat on his electric blanket for an hour; after I leave, he plans to take his daily walk, the only thing that still gives him relief. In the afternoon, he has another four hours of sessions at the clinic. I sit at the kitchen table and he stands against the sink as he explains what happened to him after filling in the ‘life compass’ with one of the psychologists:

“The other day I noticed my 4 guitars. I used to play guitar every day, just to relax. But because of this hernia I am uncomfortable sitting, so I stopped doing that. But then I also realized, hey, I have not seen a whole bunch of my friends for a long time, family... I noticed... I kind of hospitalized myself a little. [...] so under the heading of ‘restoring the balance’ I invited a friend the other day I have known since university. But then I said, I need to limit this because I cannot sit for this long. She came at 5, left at 6.30pm. Well, this is really... we used to dine for hours, you know. But when I am in pain, after a while I also get annoyed, you know, irritated, and that is not much fun either.”

Since Rudy is rehabilitating, he is taking up the challenge of restoring the balance. But orienting towards one’s passions, values and appreciations is not easy; it requires energy, motivation, planning and consideration around one’s restrictions. As Rudy’s negotiations around dinner with his friend exemplify, it can lead to more pain, and deciding to do something often means something else is no longer possible.

The example shows how unlike the practices Driessen describes in dementia care, where care givers take the lead in orchestrating pleasure for residents, living well with persistent pain is very much staged as a task of the self. In thinking pain *with* care for dementia, however, my attention is drawn to the support that is necessary for such considerations to emerge. Next to the ingenuity of a simple exercise, it helps to highlight clinicians’ work in orienting towards a meaningful life. It is not just during our interview that Rudy’s limitations and passions come to the fore and are made explicit: these mundane aspects of daily life are the very substance of therapeutics in the rehabilitation clinic. Together, clinicians and patients carefully identify, discuss, plan and evaluate how space may be made for activities and people that bring pleasure, fun and purpose. Much like the therapeutic interventions [Maarten van Westen \(http://somatosphere.net/2018/10/opening-up-shrinking-life-worlds.html\)](http://somatosphere.net/2018/10/opening-up-shrinking-life-worlds.html) describes in his contribution to this series, therapeutic challenges, experiments and nudges such as the exercise of the ‘life compass’ work to pull at a lifeworld that has shrunk and organized itself too much around pain – a process that Rudy pointedly calls ‘hospitalization’. One of the desired effects of rehabilitation is thus that the lifeworld of patients enriches and expands. The promise is that living with pain may be more than being sick. When finding out how to live in-with a body that is both fragile or painful, *and* able to appreciate and enjoy, daily life truly emerges as an extraordinary achievement ([Pols, this series \(http://somatosphere.net/2018/09/refraction-of-daily-life.html\)](http://somatosphere.net/2018/09/refraction-of-daily-life.html)).

Thinking with dementia, then, inspires one to think of living well as something that needs endless encouragement and tinkering – and crucially, requires collective reorienting towards. At the same time, clinicians and patients face the difficult fact that sometimes there is no negotiating with

pain, no space where enjoyment may emerge. Living well, then, does not necessarily imply that life will be 'good'. Instead, it signifies a process, an attentiveness, an effort to not succumb to the bad. It signifies care.

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