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Refraction of daily life

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By Jeannette Pols

Attending to what makes up 'the everyday' has long been a challenge for scholars in the social sciences. [1] Researchers from different disciplines and perspectives have explored how mundane things matter, how 'big issues' sit in the small. Feminists, for example, have insisted that 'the personal is political', to show how patriarchal relationships are founded in the mundane ways of dividing up labour. 'Big' actions are mirrored in routine activities such as cooking, cleaning, feeding and caring: who performs these tasks, and what power relations does this reveal? An excellent example comes from Salman Rushdie's novel *Midnight's Children* (1981). In it, Rushdie plays with the metaphor of writing as cooking, narrating how the mother of the family influences all the others through the sly mixings of her curries. There is power in everyday tasks. Other fields have theorised tacit knowledge, which may be easy to perform once learned, but is hard to put into words. How to explain dancing? Once you think about the steps, you stumble. Scholars always end up with problems about how to express the inexpressible in activities that are unspoken. Brushing one's teeth or tying one's shoelaces seem at once hardly worth speaking about and also difficult to put into words.

One way to look at the mundane and everyday is to highlight it, and to show that there are important things going on. This involves a strategy of making the everyday strange. This is a strategy that is often used by anthropologists studying practices close to home. Contrary to the attempt to make the unfamiliar and far away more familiar and understandably close, the strategy here is to look at things that are taken for granted by making them extraordinary. But how to grasp the everyday? How to describe it, how to value it?

Here, paradoxes abound. If the ordinary is made extraordinary, does it still remain ordinary? Can we value little things, without necessarily – in the way that we value them – making them big? Could we let the mundane stay mundane, while maybe mattering in a different way? Highlighting the ordinary risks externalising the ordinary from itself. Can we let it be ordinary? And if so, how?

It requires extra effort to speak about what goes unnoticed. But it can also become like a *Fata Morgana*: if you get too close, it vanishes. Thus we

might need to think with someone like the illusionary giant from the popular German children's novel *Jim Button and Luke the Engine Driver* (Ende 1960). In the story there is a character named Mr Tur Tur, who is an 'as-if-giant' [*Scheinriese*]: from afar, he seems really big and scary, but the closer one gets, the smaller he becomes. Because everybody is afraid of Mr Tur Tur, he lives a withdrawn life in the desert. When the story's heroes Luke and Jim see Mr Tur Tur on their travels, they do not run. And as he comes closer, they find that he is small, modest, and friendly up close.

Dementia too can be like an illusionary giant. It may take the challenging of assumptions to get really close. Its then-smallness can also confront us with new found questions: What does it mean to be a person? How can we fix the gaps in care provision to address structural violence or care migration? Dementia also confronts us with boring things, matters that hardly seem noteworthy in daily life: teeth still need to be brushed, clothes put on bodies, stomachs fed. In the 'big questions' of death and its violences, there is still everyday life to carry on with.

To think with dementia about these questions brings home how the ordinary and the extraordinary are variously connected. We see, for instance, how dementia can make daily life become strange, but also how daily life with dementia ignores the strangeness observed by others. A dog is a dog – [or is it?](#)!

What a strange life!

A first analysis of everyday life with dementia might note how mundane objects such as toothbrushes become strange. The tacit knowing of what to do with them can suddenly vanish. Dementia – an unasked-for breaching experiment – can thus provide ways to detect the issues of daily life through their breakdown. As Foucault taught us, we can learn about the normal through studying the abnormal. By trespassing norms and routines, these very norms and routines are brought to the surface; the automatic no longer works. This was also Garfinkel's favourite methodological tool for norm detection. Norms may be invisible as long as everyone follows them. Yet they become (often painfully) clear once they are ignored. Dementia's breeches may make the machinery of everyday life visible, showing what a big task it is to live this daily life.

[Laura's story](#) about the house shows how upholding everyday life might become a shared endeavour for people living with dementia and their close family and friends. Daily-ness needs to be upheld, though it becomes a huge and difficult task to achieve on one's own. The home, which harbours the things of daily life – chairs to sit on, a watering can, food, clothes – transforms into an obstacle in itself where things get lost.

How to achieve daily-ness, and mundaneness, if when everyday routines are hampered all the time?

Daily life as accomplishment

If mundane objects become strange, daily life becomes the major goal and accomplishment when living with dementia. The activities of daily living, previously taken as a simple precondition for getting ready to do other things (work, enjoyment, studying, planning the revolution), now take up all the energy. They may become the main things that need to be achieved. How can one imagine this as a life worth living? Is it big or small? Is it Mr Tur Tur from afar or from close up? Arguments of scale fail here. The everyday is what is there: it is the task to fulfil for people with dementia and those around them. Some seem to think of dementia and old age as a time for waiting, just being there and waiting for the end to come. But our stories show the richness that can be there in everyday life, the complexity that is disguised by (or located within) the mundane. It is for these activities and events that we try to find words, by making everyday life strange, or by familiarising ourselves with what is strange in that life.

Daily life is often phrased as something that people can 'hold on to'. A routine gives us safety and predictability, it structures our day (Becker 1997: 4). [Susanne's story](#) shows how Mrs Wijngaart struggles to create her everyday life, where exactly what gave her life value is elided in the very attempts to re-create it. Mrs Wijngaart does not want to respond to the carer's invitations because the very desire to help – giving attention to mundane things – make the mundaneness she desires disappear. The mundane is what gives her pleasure. But it cannot be actively forced to matter; it is instead anxiously anticipated, strategically managed, hopefully organised. There is a new and precarious order in what is important and how this can be arranged.

The story also shows the difficulty of being happy with quiet mundaneness. One can easily disappoint others – those for whom life has to be about 'more', who must live a life that transcends everydayness by worthy goals and meaningful relationships. Here, Mrs Wijngaart's move toward the everydayness of existence becomes marked as an exit, a withdrawal.

In dementia, disruptions of the smooth running of things accumulate and become chronic. Not only does the toothbrush become an unfamiliar object, but the person herself also starts to relate differently to things around her. Even if there is no sense of significant change for her, relatives may experience an increasing estrangement. The everyday is made strange by its unquestioned acceptance by the person with dementia. This unacknowledged strangeness becomes the burden of

those who care.

[Silke's story](#) tells of a family where the wife and mother has early-onset dementia. For this family, the everyday has become so unbearable that the husband can no longer shoulder it. Here the breakdown of routines is not a discrete event but all-encompassing. The everyday is not the condition of doing unmarked things, but becomes a tremendous and terrible task for those who perceive its strangeness. It stalls any plan of escaping daily issues and finally effectively imprisons the family within it. For the family members, a way of dealing with the burden of care of this unacknowledged strangeness is withdrawal, which leads to ever new disruptions of relationships. The accumulation of stress is not alleviated or repaired, but runs to the point of spilling over – making Jans, the husband, want to burn down the house. Jans questions whether there is anything left of the everyday he and his family once shared. Family routines and relationships have become fragmented and destroyed; every family member has retreated to his or her own room. The ordinary, in failing to become a liveable daily life, has become the unbearable extraordinary.

The everyday of emotions

The care that family members provide for a person with (early-onset) dementia is often invisible, as Silke learned from Jans. Statements made by outsiders like “Oh, he forgets things from time to time” painfully show family members how little these outsiders understand of the difficulty that their everyday life has become (Hoppe & Singer 1976). “It is not only about the forgetting, but the whole person changes”, Silke learned from a young woman whose mother had early-onset dementia and who was no longer able to show empathy for her daughter. Another woman said that her husband would no longer put an arm around her if she was crying; he remained in his own world, of which she was no longer a part.

What happens to the daily life of emotions of family members in such situations? In the story of Jans it seems like a vicious circle in which emotions are only reinforced. Klaartje, Jans' wife, is angry with her husband and sons, who then get angry at her. Of course they can say that it is the illness that makes Klaartje angry, but that does not eliminate the task of having to deal with the emotion. Saying, from a distance, that they should not let her anger affect them is something that many websites recommend, but it seems a piece of advice that is impossible to live.

Dementia thus brings changes to the familiarity or strangeness of daily life emotions. Practices which were meaningful, like putting an arm around the shoulder of a sad person, sometimes disappear. Tears may evoke frantic reactions of trying to care, without knowing how to do it. And showing one's own emotions may become problematic for family members, as

they do not want to worry or burden the person with dementia with feelings that problematise a daily life that they perceive as mundane.

People with dementia often sail on the compass of their emotional life. They can sense the atmosphere very well. They can also stay in a certain emotion for a long time, even though they might have forgotten why they originally felt that way.

The disappearance of the strange

There is a second paradox, wherein the strangeness rests on the fact that what is strange goes unnoticed. In [Emily's story](#), there is the miraculous transformation of George I into George II. It is a different dog, but nobody seems to mind, or even notice. George II plays his part admirably well, without breaching the daily routines that were established with George I. The successor has become his predecessor.

In [Ingunn's story](#), there is the bewildering play between the familiar and the strange in the private and the public space of the home versus the ferry, spaces that come together in the nursing home. And although Mrs Jansen meets the same people every day, she forgets, and meets them every day anew – and is pleasantly surprised. Guests are invited to stay over, but benches in the corridor seem to suggest a passageway where the residents' stay is only temporary. The place where one lives the everyday thus becomes somewhere else.

There is a link here to [Kristine's stories](#) about spirits, in terms of the paradox of what one might call 'routinised ruptures': breaches that become regular and predictable. According to a conventional understanding of the word 'mundane' as 'worldly', in contrast to the 'heavenly', spirits would be assigned to the supranatural, the special and the eventful. When the Holy spirit comes down and performs healings through the hands of a prophet, this is extraordinary. When the Mami Wata spirit manifests in the body of a priest, this can be considered 'an event'.

But the presence of spirits is dependent on routines and specific ways of doing things. There is an everyday life of living with the spirits which makes the event of their coming into being possible (Lambek 2010). There is a routine of being enraptured. There is also a strategic place for breakdowns. In many different contexts, the phenomenon of the 'wounded' healer is known. Before healers come to learn the spirits and accommodate them, they often go through a series of crises until they have accepted and can domesticate these spirits. A new everyday is then set up, in which the spirit medium follows the taboo of not eating chicken or a born again Christian stops drinking alcohol. Yet when the spirit

appears, the ordinary is gone.

To think about living with dementia as a life with spirits might provide hand-holds to attend to the everyday as the extraordinary in need of care. Certainly, thinking of dementia as a disease of the brain asks for treatments that do not involve spirit possession. Both repertoires provide possibilities for attempts at eradication, either by medication, or by the driving out of spirits. The parallel shows how both attempts are doomed.

Notes

[1] *This refraction has been written by Jeannette Pols; It draws on text produced by [Kristine Krause](#), [Silke Hoppe](#), [Susanne van den Buuse](#) and [Emily Yates-Doerr](#).*

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