

NO TITLE [INTRO]

SARAH PIERCE & SARA GREAVU

This project hinges around community and deals specifically with dementia, as a condition that is both intimate and shared. Through various forms, the project follows the protocols of dementia, without any prior medical knowledge. We did not learn about dementia's symptoms first and then go looking for subjects. Rather, we arrived at our project clumsily, beginning with a meeting in 2015, at Creggan Day Centre in Derry, where we, as artist and curator, were introduced to a small group of people with dementia. The individuals were living at home cared for by a family member, and for the most part were experiencing dementia's early to mid-onset rather than its later stages. Through the dynamic of an initial group conversation, we noticed the professional care-givers were uniquely adept at ameliorating awkward moments, creating a conversational pace in which any given topic was exhausted after one or two minutes. The exchange was routed, always, through the facilitator who was able to assemble a full conversation out of scraps, pointing people in the correct direction. The conversation was conditional; certain topics enabled. The group that day were regulars who came to the centre each week for a set period of time. In the middle of the session, a woman in her seventies arrived with her husband whom she was bringing for the first time, so on this day the group included a carer who was part of a couple with a person with dementia. The conversation shifted, not in a negative sense, but in a way that made us want to think more closely about a structural relationship in dementia, when the carer is not a professional but is a relative with knowledge of the subject's history and personal narrative. How does this relationship become part of a condition? We left after about an hour with a promise to return another day, and as we drove through Derry, it seemed to us that, perhaps, dementia was less a topic and more a methodology that we could use to hold the project – that would potentially hold us in another way of working.

From this point, early on, we began to loosely inventory the unexpected and immediate effects of working in an area that carries with it many agendas, experts and professional tags. We began with an idea that dementia presents a number of identifiable tendencies, that we named 'protocols', in group situations, each of which exposes a radically forming *self* in-the-moment: repetition, insistence, withdrawal, and confabulation. Carers, when confronted with these protocols, exhibit corresponding 'impulses' that equally *re-form* in the moment: administrating, yielding, protecting, and correcting. This mirroring or symmetry shifted the focus, or rather refracted it through a kind of double vision, where the scene of dementia was not fixed in a single human being with a diagnosis, but where the same interaction presented simultaneous, overlapping events, identities, and images.

We began awkwardly and intently with the premise that by considering dementia as something *other* than a diagnosis, we might discover a methodology that would test our perceptions of what dementia is and how it

works on all of us, not just the single subject. We sought a way to work that recognises dementia as something generative – and by this we mean as capable of leading to ideas, other ways of acting, and new identity formations; that, rather than being characterised through loss (loss of function, loss of a future, loss of normalcy) would allow instead for a radical re-examination of how we move through this world. Without glossing over the drastic and painful aspects of dementia, we simply did not adhere to a generally accepted notion that dementia resides in deficit. Instead, the dementia subject became our way to understand what is lost when we limit our understanding of a person to a bracketed, cohesive and coherent understanding of personal narrative. We called upon dementia as a way to hold or sustain a project and in doing so we sought to ask, ‘What is lost when we are identified by what is not recuperable, recoverable, or is deemed insufficient?’

Oliver Sacks, who has written about the many functions of the brain, proposes a concept of personhood where to *be* ourselves we must *have* ourselves; We must possess our life-stories, and this includes being able to recollect the “inner drama” in the narration of ourselves. Elsewhere in Sacks’ work, he questions these same ideas about personal narrative to characterise the realities that people with brain disfunction invent, from moment to moment, as incredibly constructive and brilliant ways of modeling what makes a person *a person*, so to speak. Perhaps beyond, or even behind, the ‘deficits’ we identify as the disease, there resides a deficit *outside* the subject – a shortfall in our ability to incorporate the subject’s “inner drama” into a diagnosis. A disease structured through loss cancels out what is *present*, there, apparent and functioning, but differently. It would be trite to say that through loss something is gained. The dementia experience holds abundant daily difficulties, often accompanied by grief. But, it is also true that difficulty brings us to a larger project shared by many who seek out new subjects in the world. Our concern in this project was never about tracking *a condition*, our protocols never appeared as *indications* of a diagnosis, a deficit, or disfunction. To the contrary, we came to rely on repetition, insistence, withdrawal, and confabulation as codes of conduct, where a response to a given situation was bound to a position, a point-of-view, an ethics and a politics.

This problem of the subject is particular to diseases and diagnoses that have to do with a person’s mental faculties. With dementia, the persistent narratives around *loss* are sometimes expressed by the subject (and there are a number of self-advocacy groups who are vocal and articulate about the lived experience of dementia), but are more common to those who encounter the subject. People whose relationships with the dementia subject have changed often find it difficult to reconcile a coherent narrative between the person they once knew and this *other* person with altered memories and changed ways of speaking, acting and holding time. We, at times, felt unsure if we could talk about the elephant in the room. Ethically this presented a number of issues; and added a level of difficulty to the project. Our relationship with the subject

was often administrated and managed by others who were with us and against us, at once inside and outside the project.

What is a challenge turned into a boon – unease and difficulty became a theme. The exercises that we developed for the groups, aimed at pairs and small groups of subjects and carers, are misleading if read simply as instructions to follow. What cannot be scripted is the high degree of improvisation and modification that takes place while each exercise is being facilitated. Because people with dementia are often asked to perform small tests when seen by doctors during regular visits, some exercises feel like tests, while others feel open and easy. The exercises have no outcome – other than to produce a moment of interaction between a carer and a person who has dementia. This is crucial, because during these exchanges the person with dementia can lead and the carer can follow; carers can relinquish the impulse to administer, correct and protect, for a moment. And otherwise, there is no reason to do the exercises. They may have collateral effects (and affect) such as bonding or relaxation. They are designed to hold or suspend an activity in the present, in the immediacy of doing. We used the term *muscle memory* to think about types of activities that the body does without thinking, that we are slow to forget: opening a letter, answering a telephone, blowing out candles on a birthday cake. Where memories disperse, we improvise.

The project has been marked by *difficulty*. This is not proposed as a problematic or a complaint, exactly, but noted to explain that *difficulty* became almost a structuring principle for the work. At each phase of the project there were obstacles that made us stop, rethink, reroute, recalibrate, start over, try again. It could be said that this is the structure of any self-reflexive practice but there was a mounting sense over the course of the 18 months that this difficulty was somehow essential to the framework of the project in the same way that the protocols of dementia were essential to a methodological structuring of the work.

Even finding the vocabulary to talk about the project in a way that captured something of its structure and specificity – without foreclosing on other possible ways of describing it – was difficult. Throughout, we encountered shifting ground in our field of work: authority and territorialism, fears, sensitivities, unstable ideas around identity, inconsistency – along with many technical glitches where temporary malfunctions or interruptions seemed to mirror the stop-start of our relationships within the project. Delays engendered delays: groups' schedules moved on; individuals we were working with moved into care facilities and new people joined; expectations of timescale were mismatched, mutable.

Our thinking was also shaped by the writing of Alison Kafer on 'crip time', or temporalities of disability in her book *Feminist, Queer, Crip* (Indiana Press, 2013). Offering an expansive understanding of 'crip time', Kafer elaborates on how disability can be seen to have a multivalent effect on one's orientation to time. 'Crip time' can be discerned in medical language around

disability that understands conditions through a 'curative' temporal lens: How long has the disability persisted? When, if ever, will it be cured? The phrase is also widely understood among the disabled community as a wry way of acknowledging that *extra* time (as set against a presumed normative standard) is often needed for people with disabilities to prepare for and accomplish everyday tasks – leading to an unavoidable flexibility around timekeeping.

But it is more than just a need for 'additional' time. Kafer argues that disability engenders a fundamental alteration in how bodies are understood in relation to the regulations of time: to futurity, to the 'stages' of life, to ideas around longevity and abbreviation of life, to presumptions of 'loss' and the *before* and *after* of disability.

To be at ease is to be without discomfort – to be less serious or dire, more able and free from worry or awkwardness. To work easily then, is somewhat of an oxymoron, since work is activity that requires some level of mental or physical effort. Of course there exists an etymological comparison between a concept of un/ease and dis/ease – but for us the uneasy and the difficult were not obstacles to *work through* or get over. They were places to stick. To get stuck. Our attention was brought to the parameters and limits of the project; to the demographics of our 'target' group; to the institutional, intellectual, infrastructural specificities we were thinking about; and to the fact that the community we were interested in was a *reluctant* community, who, in some cases, were not aware of the 'group' to which they belonged.

Community eludes the project. Our reasons for being in dementia were never therapeutic. We weren't there to make anyone better; we weren't there to make ourselves better. Community resonated through the project in the gaps, when we realised that, like any project, the work (social-work, art-work) is not the subject.

NOT TITLE [OUTRO]

SARAH PIERCE

And what of the subject? A subject formed in dementia? A subject whose personal narrative presents, in the present, in the non-stop everyday?

This book draws upon a period of activity that hones in on dementia, on the one hand as a marked *disorder*, but with a potential to *reorder* and *restructure* what we consider to be and how we construct a concept of a personal narrative. As we gathered research together by writers and thinkers from Jack Halberstam to Audre Lorde, Alison Kafer to Lee Edelman, Oliver Sacks to Svetlana Boym, these writers began to riddle through each other, in a community of texts that figured in and reconfigured, reworked and undid each other. Coincidentally and sadly, around the time of the start of the project, the world lost both Sacks and Boym. It seemed to matter that nostalgia, as the focus of Boym's work, reorganises how we understand the present, and that dementia as a problem of the brain *and* the mind for Sacks, organises a state of being where the past is misplaced.

I devised the seven exercises to manifest in different registers in the project. The book and the exhibition can be understood as separate narrative choices, each one containing embedded protocols and impulses which extend through a larger community of family, friends, acquaintances, and strangers that have been involved in various capacities with what has happened here. At a crucial point late in the project, I reached out to an artist who is known for his performance work among a generation who came of age in the seventies. I wanted his help developing the exercises on camera, a request declined, but not without an explanation:

*Really I never act as an interpretive artist only
as a generative one.
Always to experience this body as site inside metaphors
and concepts imagined.
Not an actor, to act directed by others but to be inside
the depth and meaning sought in making work.
(Being and doing)
Possibly contentious also the confusion between actions
in art and patients with degenerative loss of mindfulness,
risking offence perhaps to both.
Does art have any social purpose or is it at best
and at worst simply for itself?
Go with care.*

The question of the exercises became a question of art; how to attend to the interplay of protocols and impulses that arise in practice – repetition and administration, withdrawal and protection, insistence and

yielding, confabulation and correction? Being-difficult too, is a quality that refuses to gloss over the risks of letting complex things happen.

During the months of September to December, 2016, the artist John Beattie worked to facilitate on-the-ground workshops in Derry to do the exercises with individuals with a medical diagnosis of dementia and their carers. Some of this video, along with materials produced in the workshops is on display in the exhibition. Additional video based on the exercises was produced with my parents, Anne and Russell Pierce. The exhibition also includes ceramic works from the solo exhibition *Lost Illusions* (2013). A core element of this work is a collection of ceramics held at the Banff Centre made by artists attending workshops who, for whatever reason, left them behind. The original ceramics have been replaced in the exhibition with matching pieces, crudely made in their resemblance, so that now for each absent piece there is a newly present one. Thinking again of analogies between a subject as a coherent, recognisable self and an artwork as a discrete, finished thing, the exhibition calls upon a past work, to disrupt the continuity of a present one – the exhibition is a disturbance.

And yet it is fitting that a past project lends to this way of forming an exhibition. Artworks involve forms of address that both represent and dissemble their own institutionalised, reconstituted and co-opted parts. The book, like the exhibition, calls upon others to return answers regarding what it means to make, act and think through associated behaviours such as making difficult work, being a difficult person, the difficulty of thinking and doing, difficult situations and being in ‘difficult’ bodies.

From the outset we wanted to include writers in the project, and the four writers who have contributed to the book are the four we initially set our sights on: Claire Potter, Jacob Wren, Mason Leaver-Yap and Karl Holmqvist. Each agreed to contribute new texts to the project. As writers, each makes a pronounced and formative detour away from a socialised, normative understanding of what it means to be in a body. A radical shift can be seen as related to a concept of art-making that eschews the cult of the artist in favour of the artwork as one of many signs and symbols within a total system of art. While the term ‘loss’ so regularly is called upon to describe the dementia subject, we noticed a hyper-presentness that works against orthodox notions of a future. The commissioned texts move us, with care, to a notion of *presence* in the work, which includes the presence of the artist, the status of that body in making work, and what that does to some of these ideas.

Sara Greavu has written elsewhere that “a joke is a complex and fugitive thing.” Somehow this phrase lingers in a project where the mind leads to unexpected places. We can differentiate between the rehearsed delivery of a joke that is intended to make us laugh, and those spontaneous ones that take us by surprise, that operate in the moment because every factor has come together, and we can note the contingent, repetitive and “interlocking set of factors” that for us, in that moment, brings about laughter. The title

of the project, *No Title*, refers to works by the artist Willem de Kooning, after he was diagnosed with Alzheimer's. In using it, we are setting up a joke of sorts, that relies on an insider's knowledge of de Kooning's project – the insistences, repetitions, confabulations, and withdrawals. But we are also serious in thinking about what the title, *No Title*, has to say about personal narrative and biography. In the case of de Kooning, the artist's genius is constituted in connection to a subject – the 'woman' who is always there, even when she is not present in the work. This absent-presence produces a blind spot that keeps us from seeing what else is there. We forget that sometimes a subject is hiding in plain sight.