CHAPTER FOUR

Queer(y)ing dementia

The question of how to address the mentally and physically anomalous states of transformation that occur throughout any life course is one that has been increasingly embedded in disability theory and policy. Moving away from the medical model that sees only the treatment of a putative pathology as the central concern, contemporary thinking, as I illustrated in Chapter 1, has increasingly focused on the phenomenology and affect of differential forms of embodiment without resorting to hierarchies of value. When it comes to conditions that are usually associated with ageing, however, research that steps outside the strict biomedical approach is less well-established and reflects what is almost a social taboo in the global North in failing to acknowledge what is likely to happen as we get older. Nonetheless, elder care has become a pressing topic in feminist thought in particular and there are strong signs of a move to add a queer dimension to our understanding of what it means to grow older. To date, the majority of research papers that put queer upfront exclusively address the experiences of LGBTi individuals and communities. In contrast my own focus on dementia queers the field by disturbing its familiar narratives, definitions and concepts from a non-normative perspective that operates regardless of the specific sexual identities in play. The point is to explore how the category of supposedly failing health that is named as dementia and the practices that emerge in institutional care could be – and are already – queered by the intervention of technological and organic prostheses.

What is widely in play with regard to the 'failures' of ageing bodies is a deficit model that implies that those affected are especially vulnerable and have a shaky hold on what counts as fully human. As Braidotti notes, the humanist model is highly restrictive and marks non-normative others as 'disposable bodies' (2013: 15). For that reason work advancing the register of gender or sexuality into the field of dementia studies is already to queer the terrain,[1] just as it once did with conventional disability studies, and similarly some of the material ways of engaging with people with dementia, such as through music, movement and touch mark precisely the break with normative models that queer intends.[2] These are valuable perspectives that open up new ways of conceptualising the problematic and at very least introduce relationality into the scenario of dementia, but they fail to fundamentally challenge the meaning of the human. The point of engagement then becomes to restore human dignity and human rights (Cahill 2018; Shakespeare *et al* 2019). More promising approaches include collaborative art projects, such as those initiated by the Artful Dementia Research Lab (Lotherington 2019), which question the distinction between self and other, or theoretical approaches such as that of Bulow and Holm (2016) who recognise vulnerability as a condition of all human becoming that cannot be expunged by the ideology of 'successful ageing'. The recognition that preserving or reinvigorating a sense of selfhood in people with dementia is not the most coherent response – though the insistence on continuing citizenship (Bartlett and O'Connor 2010; Phinney *et al* 2016) is a vital principle for pragmatic reasons – opens a path to alternative understandings of embodiment itself. In this chapter, I want to think about dementia, not as an exceptional state marked by a loss of independence, but in terms of the prosthetic nature of all embodiment. The claim that our bodies are entangled with an array of external and internal prosthetic devices is widely accepted, but what makes that queer is when the technological aids on which we rely become irreducible, albeit often temporary, components of the assemblage that is identified as a person. Going further, what I am calling visceral prostheses – that is ostensibly non-self elements that are located within the body, particularly in the microbiome and through microchimerism – disrupt standard corporeal status even further. Before turning to the underacknowledged bio-processes at work, I will outline more closely the normative context of dementia.

In the conventional and entrenched terms of the global North, the putative declines associated with the embodiment of dementia and similar states has signalled a personal status of irreversible cognitive degeneration that results in an increasing inability to maintain the functions of everyday living, and that eventually ends in death. In the absence of significantly effective biomedical treatment, the most that can be hoped for are empathetic carers who might explore beyond verbal capacity to elicit a recognisable interaction through the use of music, touch, dance and so on. What is rarely questioned, nonetheless, is that dementia signals a breakdown in normative communicative competence that diminishes and finally renders beyond reach the subjectivity of the one affected. In recent years, however, there has been an upsurge in potential biotechnological interventions in the form of prostheses that claim to offer those with dementia some tools for maintaining contact with their previous sense of self. Some of these are purely mechanical aids such as robotic carers or quasi-animal companions, but I shall look too at some of the more organic interventions that I also class as prostheses in the sense that they augment an existing materiality.

The most recognised of the latter are animal-assisted interventions by means of which those with dementia, either in care homes (Yakimicki *et al* 2019) or sometimes in the community (Richie *et al* 2019), are afforded access to animal companions. Such living external prostheses are less queerly inflected than robotic carers – though the scope for that analysis remains – but they also raise troubling and rarely addressed ethical concerns that go beyond the issues I want to raise here.

There is a long history of exploring drug therapies in relation to dementia, and particularly in the context of Alzheimer's disease, but there has been little sign of success in slowing the development of the condition and none of halting it altogether. Every few years there is excitement at the prospect of a new type of intervention but it is rarely sustained. Currently there is some exploration of the potential of brain implants as visceral prostheses to support deep brain stimulation (DBS) which may counter the loss of memory. As so often, the initial research has been funded by DARPA (US Defence Advanced Research Projects Agency) for deployment with battlefield soldiers, with use in the field of dementia being a secondary spin-off. To date, results have been inconclusive though research is ongoing and hopes for a breakthrough are still hyped in the press, despite any positive outcomes being limited to those with mild Alzheimer's disease. My own alternative to such medico-technological fixes and as an addition to robotic scenarios is directed instead to the biological resources of the interior of the body. In the second part of this chapter, I will turn to more visceral mediations which could devolve on interventions offered by the potential manipulation of the microbiome. And on a more existential level I will suggest a radical appraisal of the state of dementia in the light of both the technologies of robotic care and the implications of micro-biology.

All this happens broadly speaking under the auspices of modernist biomedicine which as a subset of the socio-cultural imaginary is wedded to the idea of the singular self who is defined ideally by the qualities of autonomy and rationality, even in the face of the multiple breakdowns of those concepts in infancy, ill-health, disability and dementia. In 2020, the WHO estimated that around 50 million people have dementia, with figures rising rapidly year on year. The percentage of the general population aged sixty and over with dementia is between 5 and 8 per cent, with nearly 60 per cent living in low- and middle-income countries (who.int/news-room/fact-sheets/detail/dementia). The WHO takes up a characteristically Western perspective that dementia is a universal category, though it is clear that there is no consistent response in how the condition is evaluated. The experience of dementia is far from universal but is always socio-culturally inflected. In some ethnic communities where family relations, rather than the individuals, are given the greatest importance, as is the case in many traditional East Asian cultures, elderly people, so long as they are still seen as participating in family life, may not feel stigmatised or shamed by being dependent on others (Cipriani and Borin 2014). Dementia is typically seen as a normal part of ageing in contrast to Westernised societies where the high regard for self-sufficiency and independence, and fear of specifically cognitive decline, mark it as a condition of gross disruption in need of therapeutic interventions. In the global North, where the healthy adult life is marked by routine, self-management, predictability and a grasp of temporal affairs, well-being is already aided by an array of devices such as time-pieces, buses and cars, computers, spectacles, text messages and authorised protocols. As such, it might be said that the normative life course necessarily co-evolves with prosthetic practices. It is already clear that the use of external prostheses raises some questions regarding the nature of individual selfhood, but my suggestion is that internal organic prostheses more radically disrupt the modernist notion of the atomistic self who – in the case of dementia – has putatively slipped beyond communicative access. I shall look then at recent developments in both technology and biomedicine, and theorise the significance of those enhancements, in part by turning once again to the Deleuzian notion of assemblages.

Robotic technologies

I want to start my enquiry with a mode of intervention that is becoming familiar. The use of quasi-animate digital/mechanical aids has been at the forefront of dementia care for many years and is expected to provide benefits not only to those with dementia – and that of course remains a contested category – but also to their families and professional carers. There are four categories of robots that can be deployed in dementia care: rehabilitation robots, service robots, telepresence robots and companion robots. The first two categories can assist, for example, with lifting and positioning non-ambulatory patients, with negotiating simple functions like activating machinery or picking up fallen objects, finding personal articles, by responding to simple verbal instructions, and may also engage in formalised greetings. Telepresence models are designed to have a monitoring and surveillance function that can transmit biomedical data about the status of the user with dementia to nearby carers or to distant clinicians, while the primary purpose of companion robots is to have a positive impact on the ability to sustain social relationships. All sorts of ethical and practical considerations abound: the Foucauldian overtones of robotic forms of constant scrutiny may give us pause for thought, and there is much concern about the possible dangers of replacing human with mechanised or digital care. For robotic engineers, however, care robots are widely seen as a friendly bonus, as a pragmatic technology that is intended to supplement not supersede the interhuman aspect of the caring situation (Khaksar *et al* 2016).

At root, much of the anxiety concerns the supposed insult to autonomous agency, but clearly for anyone with a neurocognitive condition, the question of autonomy as such already has diminished validity. What takes its place is the injunction to respect the dignity and intrinsic value of every human being whatever their physical or cognitive status (Bacaro, Mazzoleni and Virgili 2018). That approach has long driven much disability theory that is organised around the inalienable claim to human rights, and although it should provide a necessary layer of protection against discrimination and abuse, there are good reasons to underline its limitations. It is not just that the approach fails to secure the interests of those it seeks to protect – because that might be a simple category mistake rather than a flaw in the principle – but that it is grounded in an extremely limited liberal humanist understanding of what constitutes worthwhile life. The very concepts of rights, dignity, interests and so on are deeply normative and inherently reference a standard in which the human being is indeed autonomous, separate and distinct from its others, and capable of rational thought. The philosophical critique of that standard is now very long-standing, but has yet to filter through to the practicalities of dementia care. The issue for scholars in the field is that even when care is delivered conventionally through human to human interaction, the inevitable dependency of the one with dementia already problematises her agentic singularity and demands a degree of cooperation that is not necessarily dependent on mutual contract. If another intervenes in my everyday decisions and increasingly comes to organise my time, direct my movement and manage my affects, then that intervention is no longer an adjunct, but more of an enveloping presence that displaces my own subjecthood. Although these temporal developments are far from unusual in the duration of a life span – we were all dependent infants, we all get ill or disabled – they remain a matter of concern to conventional notions of the self. In contrast, feminist philosophy in particular has been insistent that relationality should trump autonomy and that we should recognise and celebrate mutual vulnerabilities (Shildrick 2002; Käll 2017).

The problem is that far too often advanced dementia may well evoke an unbalanced one-sided relationality, but that is the case only if we think that the condition transmits nothing of value. Wherever the balance of dependency lies, what frames the normative model is that the interaction is between two or more human beings. What the evolving technologies of the twenty-first century add to the ethical and ontological amalgam is a demand for a reappraisal not just of the somatechnical interface of the human self and other, but of the boundaries between human and non-human. It could be argued that any prosthetic device that augments or takes over functionality poses a challenge to the sovereign self of the Western logos, but all the more so when it appears to be a living entity in its own right. My focus here is on what are termed emotional care or empathy robots which are designed precisely to enter into not just practical but affective relationship with their users. Their agency – in the conventional rather than new materialist sense – may be an illusion, but their animacy does generate very real responses and effects, both emotional and somatic, and that alone unsettles and queers the confines of the human. There are many types in use, and most researchers are in agreement that having a human-like appearance enhances acceptance and efficacy. As Schmetkamp puts it, 'for our cooperative and collaborative interaction with robots – particularly in the medical or health care context – a strong human likeness might be crucial in these interactions succeeding' (2020: 882).[3] This seems to me to slot all too easily into an unquestioned assumption of anthropocentric superiority, and accordingly I will focus on both humanoid and non-humanoid examples of robotic technologies, each of which intends the fantasy of live interaction, albeit working in slightly different ways.

PARO is a small fur-covered robot resembling a baby harp seal that is about the size of a human infant, can squeak or coo with pleasure, cry with discomfort, flap its flippers, open and close its eyes, react to sound and touch, and appear to sleep (Figure 4.1). Its varied responses give a strong sense of a living, emotional being – albeit an infant one – capable of happiness, distress and surprise, largely in reaction to the touch and voice of the human user. The point of PARO in dementia care is to stimulate the cognitive attention of users and to create a sense of interaction that can counter problems of isolation, aggression and depression that affect many residents of care facilities (Wada *et al* 2008). The intimate encounter with PARO, which mostly seems to take the form of stroking or cuddling the robotic seal, is intended to be therapeutic, not just in calming and pleasing the user but in setting up a sense in which the seal itself appears as a vulnerable being in need of care, thus provoking a response and sense of agency in the person with dementia.[4] PARO is a technologically sophisticated and relatively expensive prosthesis that is in use in many countries worldwide and is, for example, currently estimated to be present in 80 per cent of Danish care institutions, despite its high cost of over $6000 for each unit.

Several small-scale studies have pointed to the benefits of PARO, not as an interaction between human and non-human that challenges affective boundaries, but as a utilitarian prop in which success is measured in terms of how far users improve their abilities to engage in social communications – whether physical, verbal or visual – with other human beings in care settings (Šabanović *et al* 2013). In an entirely and typically humanist understanding of what counts, Sherry Turkle (2011a, b), for example – who enthusiastically pioneered research into digital technologies many years previously – is one who now feels dismayed by the lack of authenticity in what she calls 'empathy machines', and she doubts whether PARO offers anything more than an illusion of connectedness. As she explains, 'we ask technology to perform what used to be "love's labor": taking care of each other' (2011b: 106–7) and goes on to speculate that sharing 'feelings' with animate robots accustoms the user to a reduced range of emotions tied to those that the machine can simulate. As becomes clear, Turkle, like many other commentators,[5] is unquestioning in privileging HHI (human–human interaction) over HRI (human–robot interaction), and at the heart of her ethically based distaste is the belief that although a symmetrical encounter

FIGURE 4.1 *Seal-type Robot 'PARO'. Courtesy of AIST, Japan.*

may be implied, 'there is no such symmetry between human beings and even the most advanced robots' (2011b: 85). One could not disagree on Turkle's own terms, but I wonder about the implicit assumption that interactions should be symmetrical. In the course of any life that may be the exception rather than the rule, and in the specific case of people with moderate or advanced dementia – who constitute the greatest proportion of care home residents – it is difficult to see how any relationship could be symmetrical. Once, however, the encounter is thought in terms of mutuality, or perhaps more accurately commensality, that particular ethical problem disappears.

In the light of those supposed ethical issues, I want to consider a recent large-scale research project into the effects of using PARO which was conducted in several Australian care facilities, where, as the authors state, over 50 per cent of all residents with dementia are reported to have behaviours such as physical aggression, agitation, vocal disruption and chronic mood disturbance (Moyle *et al* 2017). Such negative symptoms inevitably lead to additional stress in care staff and reduced empathy with the causal condition, which in turn is reflected back in the frustration and agitation of residents which 'may lead to the additional regular use of antipsychotic medication' (Moyle *et al* 2015: 2). In some jurisdictions, though not including Australia, PARO is explicitly classed as a medical device, but in all operative settings, the hope is that it will counter disruptive affects and lessen the need for pharmaceutical interventions. The introduction of PARO into the lives of care home residents for a period of ten weeks was intended to test whether an animate robot was more sustainably therapeutic than either an equally cuddly but inanimate – and therefore more affordable – Plush Toy (actually PARO with all the functions disabled) or a program of usual therapeutic care.

The outcomes were, unsurprisingly, mixed although the members of the PARO group were shown to be considerably more engaged with the object on a visual level, somewhat more engaged on a verbal level, and overall experienced greater pleasure and exhibited less agitation. Clearly there was initially a strong novelty effect for individual users of both PARO and Plush Toy, but pleasure in particular remained significantly raised after five weeks for the PARO group. The supposedly counter-observation that PARO users also displayed increases in levels of anger was related to interruptions in activities, to other residents interfering with the robot toy, and finally the removal of PARO after the allocated 'play' period. In facilitating prolonged individual engagement with the robot, the research project had in any case set up a model not intended by the adopting care home for whom, as Tergesen and Inada put it, '(p)atients are meant to use [PARO] in a group setting to decrease social stress, not play with it in isolation or as a replacement of interacting with people and animals' (Tergesen and Inada 2010: np). That there were few sustainable effects discerned at a fifteen-week follow-up after the final withdrawal of the prostheses after ten weeks of hands-on contact is surely to have been expected, though Moyle and her colleagues make no comment. While they are clear that the intervention provided alternative models of communication to the usual care interactions, the hope seems to have been that the improvements would readily translate to human–human encounters. Had the human–machine sensory interactions been seen as valuable in their own right as exchanges that queered the limits of normative human behaviour, then the abrupt withdrawal of PARO would surely constitute a serious ethical misstep. The engagement and pleasure that PARO – and to a certain extent Plush Toy – evoked in residents were simply treated as a means to a definitively human-centred end, rather than as a demonstration of the constrictions of an anthropocentric outlook.

The question raised here extends to whether the companionship and comfort afforded by a 'real' animal are equally devalued. In the context of disability more generally, the non-technological status of assistance animals – which are usually dogs – is no less prosthetic in the sense that I use the term and has found great favour both as emotional support and as helping with everyday tasks. The well-known memoir by Rod Michalko (1999) about his relationship with his dog Smokie – who negotiated Michalko's sight impairment – takes a phenomenological perspective that gives full value to the mutual interface between human and animal. Several studies have outlined the benefit of deploying visiting dogs in care homes, but the problems of hygiene and effective management have precluded most programs for resident animals. Are, then, robotic animals – that require technical maintenance but no daily burden of grooming, exercise, feeding and disposal of excreta – the way forward? One study by Thodberg *et al*

(2016) set out to compare the effects on a sample of 124 Danish care home residents of interacting with a dog, a robot seal (PARO), and a soft toy cat, albeit affording access to the different 'animals' for the extremely limited period of twelve ten-minute visits. It is worth noting that unlike many similar introductions, the deployment in Danish care facilities was assessed by the research team not just for the impact on social communications and personal agitation, but for a more general uplift in residents' mood and improvement in sleep patterns (Calo *et al* 2011). In the Thodberg project it was established that the presence of any 'animal' in addition to a person is more stimulating than a person alone, and that robotic animals can be almost as effective as real animals. The finding that the dog and the robot seal triggered substantially more physical contact, verbal communication and eye contact compared to the toy cat 'suggests that the ability of the animal (or the object) to interact and give feedback affects the response, even though the interest for the robot seal decreased during the intervention period' (Thodberg *et al* 2016: 118).

A scoping review of fifteen similar studies conducted worldwide confirms the Danish experience and points to several positive outcomes for animal-assisted interventions using both real dogs and a plethora of robotic animals including PARO, Nao, NeCoRo and JustoCat (Aarskog, Hunskår and Bruvik 2019). In a majority of the research projects that were analysed, significant improvements in behavioural and psychological symptoms, depression and mood, quality of life and 'other' unspecified areas were recorded. Although the authors set out to establish 'which elements in animal-assisted interventions (e.g., physical touch), could be the potential causal pathways for long-term effects' (2019: 109), nothing more is said of the tactile dimensions of the encounter which leaves a possible crucial gap in the research. It is important to remember that residents with either moderate or severe dementia may become non-verbal, while touch – which is the very first perceptual sense to develop (Anzieu 1989) – remains relatively unimpaired. Given that there is wide acceptance that offering human to human tactile care to those with dementia or who are near to death is of great benefit, it is hard to understand why the haptic relation between those people and 'cuddlesome' aids should not be given more value. Nonetheless, sceptics of the digitalisation of dementia care continue to privilege the human (Jenkins 2017) above any evidence of the efficacy of robot interventions. Yet there are good reasons to rethink what touch might entail, and to speculate on which encounters promote the well-Being of people with dementia.

Bioscientifically, touch is thought of as multisensorial and is closely connected to bodily awareness. In other words, whenever we touch or are touched, we use our bodies in wider ways, the effect of which is registered beyond the immediate skin surface sensation. It could even be said to enhance a sense of agency insofar as 'touch seems to require active exploratory movements, and these movements are often guided and voluntary' (Fulkerson 2020). Phenomenologically, touch, unlike sight, is quintessentially an interactive sensation between sentient beings, in which the moment of touching is indivisible from being touched. Again unlike sight, touch crosses the boundaries of the proper rather than creating distance. It is precisely where the ontological separation of self and other; human and animal; animal and machine; living and non-living might be overcome. It is the site where people with dementia might 'enact a posthuman "flat ontology" rather than a humanist hierarchical one' (Quinn and Blandon 2020: 27). And as the Danish study notes, 'the residents with severe cognitive impairment were more likely to touch [and talk to] the animal than those with a mild impairment level' (Thodberg *et al* 2016: 117). In their ethically alert critique of animal-assisted interventions (AAIs), Nick Jenkins and colleagues point out that approaches to facilitating human–animal interactions within care environments position animals ostensibly 'as sentient forms of prosthesis for disabled people', which 'highlight the roles that speciesism, human exceptionalism and bounded individualism have played in the subjugation of humans and nonhumans alike' (Jenkins, Ritchie and Quinn 2020: 6–7). Their understanding of prostheses is a more conventional one than I propose, but I fully concur with the gist; yet, I wonder too how robotic animals might fit into the sentiment. Can we think touch as queering and pulling together what are usually irreducible and hierarchical categories to create a novel kind of non/living assemblage that reconfigures the meaning of human itself?

With that in mind, I turn to one well-known example of an animate humanoid robot. The NEC product PaPeRo is a small but fairly heavy and bulky baby-faced human-like robot which has been widely used in aged care facilities in an effort to improve the quality of life of the residents, including those with dementia. PaPeRo is decidedly not cuddly (Figure 4.2). It has many tactile sensors that enable it to converse, to respond appropriately to friendly or aggressive touching, move around, recognise individual users and engage in simple games. It can also – if one is prepared to stretch the imagination – sing and dance. Like PARO it is deployed to provide sensory stimulation, entertainment and encouragement to social engagement with carers, family members and peer groups. It is more than likely that PaPeRo does deliver therapeutic benefit to some of those with dementia, but as a 'living' model it is far less convincing than PARO even in the normative aim of enhancing strictly human interactions. Nonetheless, the authors of a major and recent study assert that the PaPeRo models they work with (sweetly named Sophie and Jack as gender balance requires) are superior to pet-like robots: although the latter 'can provide entertainment and company similar to a pet for older people, the interaction of PwD with these robots is lacking' (Chu *et al* 2017: 8). Once again we are alerted to the limits assigned to meaningful interaction. The affection and care displayed towards PARO and related prostheses like the much simpler and award-winning battery-operated Joy-for-All cat produced by Ageless Innovation, and the calming of agitation that several studies have shown, simply do not count. The priorities for PaPeRo are made clear as the authors continue: 'From the HRI [human-robot interaction] perspective, social engagement can occur between social robots and PwD and eventually facilitate HHI [human-human interaction] in aged care facilities' (Chu *et al* 2017: 9–10).

For all the hype, PaPeRo is rigid, very slow to move or respond, and – if intended to mimic human behaviour – entirely unconvincing. I am not used to my companions randomly breaking into song or dance, and would

FIGURE 4.2 *PaPeRo robot at Nagoya Expo Centre 2006 (Photo: Jennifer. CC-BY-SA 2.0).*

be slightly alarmed should they do so. Either the conditions of dementia genuinely infantilise or that is the only way that those who provide care environments can make sense of the changed affects and capacities. That depressing resort to normative categories is fully exemplified in the study observation that everyone liked to play bingo with Jack, and 'Sophie is able to make people smile and laugh as well as causing them to be open to talk and interact with robots and/or people around them' (Chu *et al* 2017: 15). In being programmed for verbal interaction, what PaPeRo and competing robots like Pepper can do is to lead exercise routines or stimulate group activities like playing games, although there is also some scope for individual face-to-face sessions. Unlike animal models, their feedback consists in algorithmic articulations of encouragement, which in turn rely on the hearing and language capacities of residents rather than on the more universal response to touch. Some humanoid robots like Pepper have an inbuilt touchscreen interface but it is a purely mechanical element of the encounter that is unlikely to arouse positive affect in and of itself.[6] Once again it appears that the use of therapeutic robots revolves around a very Western and modernist understanding of what constitutes the self rather than considering the needs of the embodied self as, at very least, relationally constructed within the complex environment of humans, non-human others, inanimate materials, biomedical context and so on. There is in any case very little record – even accounting for the specific difficulties – of what those with dementia might prefer, and the stress is often on management within normative boundaries. Calo and colleagues, for example, are keenly aware of the limitations voiced by robot sceptics, but what they bemoan is the paucity of studies that 'investigate the process of how to use the robot effectively to meet *clinical* needs' (Calo *et al* 2011: 23, *my emphasis*).

Whether the robotic prostheses are animate or inanimate, humanoid or animal, issues of their cultural sensitivity and acceptability raise questions about the modernist assumptions behind their design and use.[7] Those familiar binary categories are in themselves questionable distinctions, with animacy in particular – the appearance of having sentience – being culturally troublesome. Traditional Japanese beliefs, for example, widely invest the quality in supposedly inanimate objects such that what counts might be the generation of affect rather than liveliness as such. A new multidisciplinary and international project is currently underway to address precisely that type of misunderstanding. CARESSES (Culture-Aware Robots and Environmental Sensor Systems for Elderly Support) has the goal of designing care robots that adapt the way they behave and speak to the culture of those with whom they interact. According to the dedicated website (http://caressesrobot.org/en/project/) the aim is to 'take into consideration the person's cultural values, beliefs and attitudes about health and illness as well as their self-care practices' and to 'be sensitive about the user's attributes like language, accent, interpersonal skills, communication skills, ability to trust others and to be compassionate to others'. This constitutes an important expansion of the terrain though how far it will address different expressions of affect remains to be seen. The dimensions of the problem are neatly outlined by Calo and colleagues' review of the deployment of PARO in different geocultural locations. As they note, 'in Asian countries, Japan and Korea, people accepted Paro as a pet, but not for therapy. In European countries, the UK, Sweden, and Italy, people accepted Paro for therapy, but not as a pet. In the US and Brunei, people accepted Paro as a pet and for therapy' (2011: 23). It is not simply that there may be different attitudes towards robots, but that the specific cultural relationship between humans and pets influences whether animal robots are experienced as therapeutic. The lower status of pets – popular though they are – in Asia mitigates against trusting in the robot as a therapeutic device. In addition we should be aware that not only may certain people have a fear animals, but that in many cultures and classes, dogs and cats (and probably seals) have little acceptance as pets and may be seen as unclean.

A further culture-based complication devolves on the limits of what constitutes an understanding of the self. Although Japan is seen as the heart of the robotics industry, the relationship between 'self' (the one with dementia) and 'other' (the robot) in that country does not mirror Western humanist concepts.[8] Unlike notions of the sovereign self whose disappearance drives fears of dementia from a Western perspective, it is not the loss of autonomy that disturbs the Japanese sense of well-Being. In the traditional Japanese discourse, the self is not a fixed and independent entity but emerges from a network of interdependent relationships, a view that reminds us of Merleau-Ponty's 'flesh of the world'. In that context, the progress of dementia – sometimes referred to by the concept *boke* – signals the danger that the person's responsibility to share obligations with others and not to become a burden is likely to break down. As Traphagan explains, *boke* is a 'fundamentally antisocial' debility that is stigmatised not for the cognitive and physical failure it may accompany but for the moral failure it signifies' (2000: 4). What is at stake, then, is the failure to maintain the self as an intersubjective and irreducibly connected entity. Dementia care in Japan has until recently been largely private and home-based, but with an increasingly ageing population, institutional care – with the increased likelihood of robotic interventions – is more common. It gives the opportunity to reconfigure *boke* as having value within a new relational context that draws together human, animal and machine as the environment in which selfhood continues to have meaning. And as Tanaka (2015) points out, selfhood may not be expressed in a verbal manner, but through embodied interactions, and nonverbal signals. In what is evocative of Deleuzian assemblage, each element emerges only in relation to the others rather than being given meaning by a central self. Effectively robots are as significant as any other constituent, including the human person. This is well-illustrated by Jong-min Jeong's reflections on a familiar therapeutic activity: 'Drawing, for example, consists of particular kinds of social and creative components in practice that include materials, organizational bodies, staff, tools, environment, music, a wheelchair, coffee, biscuits, individual moods and residents, to name just a few in care home settings' (2020: 364).

The problem, then, is not that PARO, Joy-for-All Cat, aibo, PaPeRo, Nao, Pepper and all the other therapeutic robot prostheses fail to deliver beneficial psychological, physiological and social effects, but they are being assessed against distinctly humanist and Western standards. Robotic technologies at any level disturb notions of human individual and demand more appropriate – and effectively queering – analytic tools. Above all, dementia itself signals changes to the sense of self that are ongoing and destabilising within normative conventions, so rather than focusing on efforts to revive the self, we might instead look for the opening up to the different and positive perspectives that such transformations provide. Could dementia, the state of being literally 'out of mind', signal more positive possibilities, as madness already does in critical disability theory. Floyd Skloot catches just that potential: 'Forced out of the mind, forced away from my customary cerebral mode of encounter, I find myself dwelling in wilder realms of sense and emotion' (2003: 21–2). The use of a plethora of robotic forms that at very least simulate life indicate that *human* interaction is not the limit of what might constitute living well. As Amelia DeFalco (2017) and Nick Jenkins (2014, 2017), among too few others, have recognised, robot care prostheses pose a fundamental challenge to human exceptionalism. If the technology that drives robots is itself an irreducible facet of our posthuman world, then we should surely ask how far that demands a posthumanist ontology, epistemology and ethics. As Jenkins comments, 'moving beyond humanist approaches to dementia will require more than technological innovation. It will require significant changes in the underlying ways in which we think about personhood and neurocognitive disease' (2017: 1494). Technology alone can never settle the problematic of dementia, but it does suggest that the continued focus on the modernist ideals of explicitly human personhood will stultify the amelioration by robotic prostheses of what is widely seen as an end to meaningful life.

At the simplest level, our faith in the stability of being gives way to the transmutations of becoming always in the context of multiple others; what we know and understand is slippery, impermanent and irreducible to single truths; and how we should act depends on our immersion in an expansive field of inter- and intraconnections that yield no universal ethical principles or protocols. Nonetheless, to go beyond the notion of human rights does not result in having no ethical position at all, but relies on thinking through our responsibility to the relationality and interdependency of all forms of matter. Critical scholarship around dementia has begun to turn increasingly to such posthumanist accounts that yield a keen awareness of assemblage theory (Andrews and Duff 2019; Quinn and Blandon 2020). The contestation of the category of human itself is firmly underway, and robotic forms are just one instance of the breakdown of normative boundaries. DeFalco seems to have mistaken PARO for a dog, but it matters little when she writes that animal robots 'raise the spectre of queer, destabilizing intimacies that cast doubt on the very condition of the human' (2016: 5). It is precisely with that insight in mind that I want to offer a theoretical expansion of the significance of our human entanglement with what I am classing as prosthetic others, first as external entities in the forms already referred to but also as the visceral presence of otherness within, not simply as a philosophical exposition, but as a biological, naturally occurring phenomenon. Where success in conventional dementia care appears to devolve on how far an originary self can be protected or recovered, the question I address is whether we can reconceptualise the body, and the embodied self, as part of a dynamic – but not necessarily organic – system of interdependency to the extent that it can never be thought as having a foundational or atomistic form. My next step involves a change of register to the now familiar ground of the microbiology of visceral prostheses, and the claim that in theorising dementia we should not ignore developments in the bioscientific understanding of the multitudes of non-self cells that circulate in the human body.

The impact of micro-biologies

The ongoing research on the human microbiome and on microchimerism which both entail the rethinking of biological orthodoxies – particularly those proposing a singular genetic signature of what counts as human – is of crucial relevance to my queering of dementia. As I have laid out in previous chapters, bioscience and biophilosophy can work together to contest both the thresholds of supposedly singular life and the very notion of species boundaries. The growing acceptance of the genetic diversity of each individual decisively challenges the distinction between self and non-self, but can what follows from that failure of distinction be relevant to the question of dementia? Nick Jenkins' assertion (2017 *quoted above*) that we need to rethink both personhood and neurocognitive disease hints at the move that challenges the disciplinary separation of philosophy and biology. At very least we are compelled to reassess the apparently simple linear temporality of birth, life, death, and to ask whether augmentation itself – manifest not only through robotic prostheses but in cellular life – already radically destabilises and disorders the humanist notion of an enduring and distinct self. The bioethics and the practical consequences of such a notion will require a profound reconfiguration of humanist values, but on an existential plane the move is one away from the pressing imminence of the supposed degeneration and death associated with dementia to a more affirmative mode that concerns itself with the persistent vitality figured by dynamic augmentation.

In recent years, as the dimensions of the human microbiome have become a familiar trope to the lay public, the intense bioscientific research that could radically disrupt the very sovereignty of human beings remains largely unspoken. Instead the major focus remains centred on how changes in the microbiome have widespread implications for human health and disease. Of the many conditions thought to be related to the status of the microbiome, dementia has been high on the list, and although the pragmatic enquiry has the potential to reorganise beneficial biomedical interventions, I also want to flag up the more philosophical implications of thinking micro-biologies in that same context of dementia. On the empirical level, it is too early to talk about established causal effects, but intensive research indicates a high degree of association. For several weeks in 2019, *Medscape* (Syrek 2019) listed gut bacteria and the brain as the top trend in biomedical searches.[9] To briefly recap, what research on the microbiome reveals is that the human body is no longer identified with a unique and singular genome that distinguishes it from other organisms, but consists, on a cellular level, in a complex and multifarious assemblage of bacterial, fungal, parasitical and viral elements, the majority of which carry their own DNA. There is no fixed template; each individual interacts constantly both with external environmental agents and within the body where different microbial communities are in a state of cohabitation. The naturally occurring assemblage of the normatively identified human host and the myriad other species living in or on it constitute a distinct ecological entity referred to as the holobiont (Simon *et al* 2019).

In good health, the mix of microbiota – predominantly gathered in the gut – is relatively stable and indicates a high degree cooperation and usually mutual benefit, but at the same time, imbalances are implicated in a range of conditions – diabetes, depression, lupus and a variable range of other physical and neuro-cognitive conditions that constitute dementia (Hill, Clement *et al* 2014; Alkasir, Rashad, Jing Li *et al* 2017).[10] It is now established that human beings rely on active microbial viscera for their own well-being, although there is no genetically predetermined microbiome but rather a life-long fluidity. As they grow into adulthood, and depending on their context and geolocation, most people will have developed a more varied and essentially protective array of microbial prostheses than their younger selves, but over the age of sixty microbial diversity begins to decline. The composition of the microbiome is always affected by dynamics such as diet, practices of hygiene, infections, medications – especially antibiotics – and even physical activity. As the body ages, exposure to several of these factors is likely to change, creating imbalances that may result in dysbiosis (Jeffery *et al* 2016). Dysbiosis refers to the state in which the gut microbiome can contribute to and perhaps cause chronic diseases, although it could be that the changes are a response to existing ill-health. What is clear is that significant alterations in the gut microbiome have been strongly linked to age-related diseases like dementia, and on a very simplistic level there is some evidence that probiotic supplements can improve cognitive function and memory in such scenarios. Several recent studies that investigate whether faecal microbiota transplants can alleviate and/or slow the progress of Alzheimer's disease are underway (Hazan 2020) with some promising results.

Dementia in all its forms is very common worldwide and increases greatly with advanced age, but what is known of the very elderly who remain in good health? A recent study showed that the microbiomic composition of centenarians is significantly different and more diverse than that of the average elderly population in having what are identified as more beneficial microbes (Biagi *et al* 2016). The emerging picture is not just about the biomedical prospects of managing the microbiome to effect continuing health or the amelioration of an existing condition but speaks to a radical acknowledgement that the human being is irreducibly entangled with countless non-self organisms that together constitute a holobiont. Where biology itself recognises the fundamental nature of an embodied and interlinked hybridity, we are encouraged to step beyond the empirical considerations alone to queer what is meant by the very concept of human being. In conventional terms, some specific conditions like dementia are feared precisely because they appear to undermine or destroy a supposedly stable state, but as a biophilosophical perspective makes clear, that the sense of self is always already insecure.

To further complicate and reinforce that understanding, I will turn again to another type of visceral prostheses – microchimerism – whose basic concepts amplify the sense in which we must think of ourselves as hybrids. Beyond the classical representation of chimerism as a synthesis of forms that nevertheless preserves visible morphological distinctions within a single body, microchimerism operates at the unseen but equally disconcerting cellular level. Microchimerism is most probably ubiquitous, and, as I outlined in Chapter 3, because bodily tissues may encompass cells that remain genetically distinct from one another, the state both maintains and contests the separation of self/non-self. In human beings, the incidence of microchimerism may be either naturally occurring or iatrogenically induced, but whatever the provenance, such transformations challenge the familiar dogma of genetically homogenous entities. In offering a radically new insight into *intra*corporeal diversity, microchimerism suggests that the conventional narrative of a relatively simple and fixed genetic identity established at conception and secure until death begins to disintegrate. The seemingly inexorable decline of the one affected by dementia may turn out to have far more complex connotations in both the biological and philosophical registers than the usual understanding of the human life span allows.

Both the microbiome and microchimerism signal modes that open up the terrain and speak directly to the inherent ambiguity of visceral prostheses and the absence of a singular genome. They indicate that there is no fixed standard of corporeality that simply declines in older age. The theoretical interest is clear in that eventually the impact of such knowledge must disorder the socio-cultural imaginary of the autonomous clearly defined individual that underpins modernist assumptions about our place in the world. The question asked of those with dementia – what has happened to their selfhood? – becomes of concern for us all. Such changes in self-perception will be slow, but in the meantime the microbiome has already entered the public understanding of science, and pressing practical issues of healthcare, including our response to dementia, may need to be rethought. The shift already underway is that if dementia can be shown to be related to a *microbiome* deficient in particular organisms, then potential treatments might include dietary manipulation, or the emerging field of faecal transplants, but it is equally possible that dementia and its related conditions are intertwined with the *microchimeric* nature of the body, particularly through cellular transmission initiated in pregnancy. At present, specific research is limited and there is no conclusive evidence to indicate that the microchimerism associated with pregnancy is related to cognitive diseases. It has been established, however, that foetally derived cells do pass through the blood–brain barrier to take up enduring residence in the maternal brain.[11] The unresolved puzzle is why Parkinson's disease appears to correlate with a higher than average incidence of brain microchimeras, while research into Alzheimer's disease shows the exact opposite that higher levels of foetal cells in the brain are found in those who do not have the disease (Chan *et al* 2012). Beyond the direct neurological effect, it is necessary to consider how microchimerism is interlinked with immunity which may suggest a new understanding of dementia.

To recap, the inclination to see the otherness of microchimeric cells as a threat that is properly countered by the body's immunological system fails to recognise evidence that microchimerism – like the microbiome – may have the beneficial effect of boosting immune responses. The high, and possibly ubiquitous, incidence of the enduring microchimeric co-existence of foetal and maternal material in any body, or the circulation of non-identical DNA after transplantation, for example, indicate not simply intercorporeality – still less simple augmentation – but the irreducibility of embodiment to singular and fixed modes. This may seem far from the issue of dementia, but those with the condition – and their carers – often have strong feelings that they are no longer singular selves (Kontos 2005). In biological terms, dementia may exemplify one outcome of the operation of the immune system in conjunction with what is most likely to be a maternal–foetal source of microchimerism (Kelly 2012). Clinical research suggests that pregnancy reduces the risk of Alzheimer's disease. As Molly Fox explains, 'evidence for pregnancy-induced long-term improvements in immunoregulation comes from studies of fetal microchimerism. Fetal cells are semi-allogeneic to the mother's genetic identity, and after a pregnancy, fetal cells remain in the mother' (Fox *et al* 2018: 523). It has long been known that pregnancy protects against many autoimmune disorders due to temporary hormonal changes, but with microchimerism – and this goes beyond Chan's research on the brain, referred to above – the result may be that later in life, the mother is protected against developing Alzheimer's disease, the most common form of dementia, and perhaps others.

On the conventional level the effect is unexpected: the immune response signals a self-defensive *rejection* of 'foreign' intrusion and is activated to eliminate the putative threat of otherness whenever the body encounters intrusive non-self antigens. But when microchimerism does not trigger such a response, it could signal either an unexplained failure in the immune system or an active concurrence that delivers beneficial effects. In recent years, microchimerism has been newly named as a potential explanation of many autoimmune diseases – which describes at least some forms of dementia – on the grounds that the body's immune system is not *mistakenly* attacking its own cells, but is responding to the non-self cells within. From that perspective, microchimerism exposes the self to the potential destruction of autoimmune diseases, but that reading ignores evidence of beneficial effects and simply reflects a wholly modernist way of understanding the biological constitution of the human body in which self and other are oppositional. As I explained in Chapter 3, the discovery of significant incidence of non-self DNA at the site of trauma or damage supports both the intimation that microchimerism can be pathological and the realisation that chimeric cells might gather where tissues are threatened with negative changes to multiply and boost existing protective immunological responses. Dementia, for example, is known to be strongly associated with inflammation, and in some cases with infections, and it may be that microchimerism enables a greatly enhanced response. It does not suggest any particular therapeutic interventions, but reminds us again that our entanglement with others at a cellular level may also be necessary to the body's homeostatic balance. I will not pursue the details of this argument further here, but return to the wider focus on the biophilosophy invoked by thinking microchimerism and the microbiome as an innovative modes of visceral prostheses.

Biophilosophy and dementia

Once again, the thread of Deleuzian philosophy throws light on the problematic. To break with the notion of the sovereign subject of modernity who exercises freedom, choice, rationality and individual agency, that is everything that denied to those with dementia, is not to disown the inevitability of pain, suffering and dissolution. For Deleuze and Guattari, the process that they name as unravelling is a necessary element in the state of becoming (1984, 1987), in which the vulnerability of any subject position is clear to see. An unravelling of the self is precisely what is feared in dementia, but what if the process were neither good nor bad, but simply a continual transformation that marks the multiple and shifting webs of interconnections and entanglements characterised as assemblages? Whether organic and inorganic in nature – the micro-biology and robotic prostheses alike that operate in tandem with dementia – these are the relations that constitute life itself. As Guattari puts it, '(assemblages) do not recognize distinctions between persons, organs, material flows, and semiotic flows' (1996: 46). In taking account of multiple heterogeneous orders, Deleuzian thought is concerned with an irreducible hybridity of form and function and with the effects of mutual interactions. It is not that normative elements play no part, but that they no longer occupy a hierarchical position of dominance that figures autonomy and rationality as more valuable than the dependency and inarticulacy that characterise dementia. What is especially notable is that in an assemblage, it is the component parts, not a pre-given human subject, which determine the nature of possible connections. Where interfaces themselves generate meaning, we can begin to think in terms of distributed agency that supersedes the merely human.

DeleuzoGuattarian theory may appear abstract but it produces wholly material and political effects. It signals that when a body is produced as debilitated – as in dementia – it does not stand alone, and nor do the conditions of production remain static. The medical humanities have only recently begun to appreciate the Deleuzian perspective, but assemblages are highly significant in enabling us to think differently about embodiment in ways that reclaim devalued bodies that have been declared incapable (Shildrick 2009). For Deleuze, in any case, what is at stake is not functional efficacy or the expectation of a singular life prolonged. Dementia, remember, is a terminal condition, but a Deleuzian approach points beyond to an incorporeal impersonal vitalist force towards which my own experiences merely contribute. In contradistinction to the humanist ideals of modernist societies that try to regulate what is owed to and deemed appropriate to any given body, that alternative perspective advocates an embrace of uncertainty and radical change. What matters is to sustain becoming, however that plays out, even in the face of disability, dementia and impending death. Over a life course, the self-same 'I' is not insignificant; and my own sustainability matters, as it encompasses not simply pleasures, but also the endurance of breakdown, distress and suffering. Yet it is not the limit; flourishing does not only refer to the conditions of living but has a wider meaning in which the event of death enables life itself to recompose under new relations of sustainability.[12] Our possible futures can never be fully certain, but even in the face of apparent dissolution, an ethics of affirmation sees the positive potentials of transformation.

On the level of theory, the traditional philosophical goal of seeking to identify what life consists in has been redirected in the posthumanist context towards exploring how life might undergo a transmutation to something no longer determined by human exceptionality. Perhaps that is precisely the template to employ as we queer(y) dementia. Once the condition is reconceived as a network of relations that supersede the closed boundaries of the conventional life course, the deployment of prostheses – both mechanical and external and viscerally organic – could be reimagined as constituting an assemblage that offers an alternative to individual and normatively realised human selfhood. Specifically, a postconventional perspective on dementia that rethinks robotic technologies, and recognises the multiplicity of the microbiome and the genetic diversity of the microchimeric body, entails a radically different biophilosophical approach that actively seeks to 'enter into modes of relation with multiple others' (Braidotti 2015: 34). The biomedical context of dementia focuses on the human body, but the inexorable trajectory of posthumanism suggests a new ecology of life that fully embraces non-human others. By reimagining the illusory singularity of embodiment and the temporality of the life course, we are enabled to escape entrapment in the somatic status of dementia as a terminal condition. The possibilities of transformation, of continuous augmentation, through the medium of external and internal, mechanical and organic prostheses, represent not so much positive choices but rather the queer ecology of life, whether human or otherwise. The vulnerability of everyday living and the ruptures that mark a personal life span are inescapable, but the recognition of radical interdependence is not simply one option among many; it always already epitomises the chimerical ambiance in which we live. As we engage with posthumanism, the productive entanglements between corporeality and time within and across species switch attention from static being to ecosystems of becoming. And in opening up the parameters of the augmented self, dementia signals not an end to life, but a release from the rigidity of the sovereign self and an affirmation of continued becoming.