Artisans of Becoming

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“Speculative Narration”

*Stories are much bigger than ideologies. In that is our hope.*

– Donna Haraway

When you search for “Huntington’s disease” on YouTube, two kinds of results come up. The first are short films produced in the style of an infomercial: in the most dispassionate of tones, they explain HD by way of diagrams that indicate symptoms, clinical progression, and the care options available. The second type of content douses the viewer with countless private clips. For the most part, the production quality of these clips is basic and they bear all the hallmarks of the horror story. Picture a room, covered in dust: a frightfully thin woman appears, wanders about like a crazy person, her obvious distress is upsetting to behold, she flails about, falls, staggers and sways. Such footage is cut together with tales of people with early-onset or juvenile HD. You can watch adorable little kids, running all over the place and yet transforming, slowly, into invalids, agitated at first and then becoming listless, the whole thing accompanied by commentary shot

testing knowledge through with fear and despair from scared parents, children, brothers, and sisters. The HD imagery and discourse circulated by medicine and the public turns the disease into a monstrous and inescapable form of current day possession, and it reaches new intensities in testimonials from the very people concerned by the disease, whether these testimonials are intended as pedagogy and explanation or whether they are simply direct manifestations of solitude and plight.

In October 2013, an altogether different kind of video joined this content: “A Message from Doctor Olivier Marboeuf.” It is a video monologue given by a neurologist in which he recounts the founding of an experimental, multidisciplinary research unit dedicated to HD and its associated tests, conceived collectively by those giving as well as receiving care. Doctor Marboeuf begins his tale by relating how, in light of the position he holds within a French center offering predictive testing, he often finds himself having to announce test results to at-risk persons. He sits throughout the video in his practice, behind his desk. Evidently, he is addressing an audience of his medical “peers” on the one hand and, on the other, people who are concerned with the sickness in some way: at-risk persons, family members, or caregivers.

He explains that he wants to relate his encounter with a patient and her sister along with the effect this meeting had on him. One year earlier, these two women had set a challenge for him that he had never faced before: to call his own practice into question along with everything he believed he knew about Huntington’s disease itself, its symptoms, its tragic nature, and its clinical progression. It all started when he confronted the young woman with the revelation of her unfavorable genetic status,

2 Unité Expérimentale Alice Rivières, “#1 Dr Marboeuf sur la maladie de Huntington (Huntington’s disease),” YouTube, October 21, 2013, https://youtu.be/S1WqbRB9a6Q.
first announcing her CAG count, then going on to provide her with the usual information about the psychological, medical, and social assistance she could receive. This patient reacted in a way that no other patient had before: she burst into rage. In terms both harsh and to the point, she told him that never again under any circumstances did she wish to be in contact with him or anyone from his team, nor did she wish to take up their offers of assistance. And then she left, slamming the door behind her, leaving him utterly thrown.

A few months later, Doctor Marboeuf explains, this patient’s sister called him and scheduled an appointment. The two women turned up together, but it was the sister who led the discussion. She too gave him explicit criticism, taking him on time and again: “How do you know what will happen to my sister?” “How do you know exactly what will happen to my sister in particular?” He relates how he tried to justify himself, by replying that it was his duty as a specialist to inform patients with precision, to be clear, to not raise false hopes and so on and so forth. The sister shot back: “but why don’t you say that you don’t know?” It would not be appropriate given his role as a physician, he said. She pressed the point: “There are people who say that they don’t know.” This is what happens, she went on to explain, in the Dutch city of Apeldoorn at the Atlant Center. She went for a visit and the treatment options she observed were, in her view, nothing short of amazing. People with Huntington’s in residence at the center were in no ways in a pitiful state despite the advanced nature of their condition. They seemed to be living happily. When, at the end of the conversation, he bid adieu to the two women with an “I hope to see you soon,” the sister plainly laid down their terms: “We will only come back once you are able to tell us that you don’t know.” Frustrated, and a little irritated, he let them go, saying it was unlikely the day would come when he would see them again.
He goes on to explain in the video that these encounters nonetheless piqued his curiosity. In June of 2013, he made the most of a conference in the Netherlands to stay an extra day and pay a visit to Apeldoorn and the Atlant Center. “I have to admit, it is impressive,” he concedes. Patients’ day-to-day lives and care were organized, he noted, in a tailored fashion. Upon returning to France, Doctor Marboeuf wondered what he could do. To be sure, given what he had experienced at the Atlant Center, the demands his patient and her sister had made seemed distinctly less egregious. The sister, he has to admit, “is not wrong.” At this point – and with this his creation story draws to a close – he decides to take a proposal to his managers, to initiate a small experimental research unit dedicated to various aspects of Huntington’s disease and its test, a co-construction to be undertaken in concert with patients and their families. In September 2013, management authorized the creation of the unit bearing the name of Alice Rivières. Since March 2014, patients and their families have been working together with caregivers and doctors and, as Doctor Marboeuf announces at the end, this is just the beginning!

Where the closing credits would role, a single sentence flashes up: “Communication posted on YouTube on the 17th of September 2014, from a possible world to be built together.” This sentence alone reveals that the film is not a documentary but a fabulation. First of all, because of the date stamp: the video was initially presented in the context of a world congress on Huntington’s disease held in September 2013 in Rio de Janeiro before being uploaded to YouTube. Doctor Marboeuf’s story would have had to unfold in the future. And if you search a little harder, you will find no sign of the Alice Rivières Unit other than this video. Is it therefore a hoax? No, it’s a lure!

This film is the outcome of a collaboration between filmmaker and Dingdingdong member Fabrizio Terranova and storyteller-cum-performance artist Olivier
Marboeuf. As I have in this book, these two artists took Alice Rivières’s story as their starting point, relaying it in their own way, in keeping with the operating principle that drives Dingdingdong, a collective dedicated to coproducing knowledge about Huntington’s. This principle holds that we actually must “lather” the ideas that animate us, taking them up again over time from various perspectives and thus lending them consistency, a thickness of their own. I have no doubt that this work of taking and retaking, of successive acts of giving form (*mise en forme*) is needed to arrive at the point where concepts are sufficiently specified and, thereby and thereupon, made to become ever more real. While Alice’s story put an obligation before me – to dive into the histories of predictive testing and modern medicine the better to understand their stakes – for Terranova and Marboeuf it presented an opportunity to cultivate a new kind of narrative: “speculative narration.” The ways of doing and the strategies that this narration deploys aim, quite literally, “to gather together the conditions of possibility for making an idea, one for which there can be no guarantees, become true.” This is not intended in a general sense but rather in relation to concrete and specific situations of conflict and powerlessness. Speculative narration therefore intends to contrast “predetermined” paths with stories of how things could be otherwise; the latter rub the former against the grain and influence them. Unlike what usually happens in science fiction, the story Mar-

3 Thierry Drumm, personal communication, 2014.
4 This approach is altogether different from so-called “narrative ethics.” Narrative ethics derives ethical or moral maxims from the analysis of more or less canonical literary texts. Here, the filmmakers explicitly conceive of their video as a form of ethical and political engagement within the field of presymptomatic diagnosis itself. Moreover, they take up “speculative narration” beyond this particular context and are, especially in the case of Fabrizio Terranova, committed to developing this form of practice. See Didier Debaise et al., “Speculative Narration: A Conversation with Valérie Pihet, Di-
boeuf recounts does not take place in a faraway future, whether in temporal or situational terms. Rather, it takes a real situation as its starting point and spins, threads, or weaves it by introducing slight adjustments and prudent additions that, although minor, prove decisive. Hence, no gulf separates historical reality from storytelling reality. Nothing improbable or impossible happens. The point is neither to sketch out a utopia (a non-place) or a uchronia (a non-time), nor to conduct a thought experiment extrapolating upon the effects of various counterfactuals.

Instead, Olivier Marboeuf (the storyteller), a.k.a. Doctor Marboeuf (the narrator), fabulates a situation for the camera based on a future soon to come. In this situation, a number of true-to-life elements – the anger of test subjects, notions of the right to know and not to know, experiences gleaned from Apeldoorn’s Atlant Center – conspire to lay the groundwork for the possibility of creating a research laboratory with the task of inaugurating and investigating new versions of Huntington’s disease. His story foretells every step of the journey needed to achieve this kind of encounter. The strategy he adopts, therefore, is one of narrative awareness raising. Although fashioned from the future, it remains faithful to known, situated, and contested reality. At the same time, by way of an equally situated and effective process of thinking through, this story strives to make the disease and testing for it awaken to another life.

To be sure, the narrator constructed his account from elements that were “given” to him. Olivier Marboeuf did not know about HD before undertaking this work and drew on to what we told him. However, by taking this as a basis for improvisation, he managed to reconfigure these elements on his own terms and produce an original story with the power to surprise his tutors and give their
thinking new purchase. A noteworthy example is the crucial proposition that the sister intervene and specifically demand that the doctor must recognize he cannot know what will happen to his patient. This demand constitutes the piece’s narrative center and can be understood in three different ways.

Firstly, it is the expression of a refusal to become the passive victim of medical knowledge held up as absolute truth. Doctor Marboeuf must not act as if the predictive knowledge he is conveying amounts to the “definitive answer to a question posed once and for all.” Instead, the sister makes a demand that forces Doctor Marboeuf to treat his announcement like an “indeterminate answer to a question prompted and created by a provisional desire to know,” an answer providing a direction, yet which should in no way be taken as an exclusive explanation.

On another level, the sister pushes Doctor Marboeuf to support the idea that HD’s course varies from one person to the next. A fortiori, she enjoins him not to confuse objective knowledge about a condition with the subjective experience of living with this condition. The distinction the English language draws (and the French does not) between the concepts of “disease” and “illness” makes this crucial difference plain to see. Whereas “disease” designates sickness as a medically defined entity and this “by contrast with other diseases,” the concept of “illness” refers to the concrete and personal perspective of the sick person, to “what patients live through and describe.” While sickness as “disease” is the ready object of medical diagnosis, “illness” evokes “the subjective feeling of lack of health that a person holds.”


6 Henrike Hölzer, “Die Simulation von Arzt-Patienten-Kontakten in der medizinischen Ausbildung,” in Szenen des Erstkontakts zwischen
of this distinction (and hence the multiple meanings or plural character of all disease) means coming to terms with some changes. A first consequence is the need to adopt a perspective whereby it becomes possible to take seriously and accompany patients as they suffer from symptoms even in the absence of a recognized, objective, or causally scripted condition in the sense of a “disease” (for example, some forms of chronic pain). Moreover, the disease/illness distinction makes it possible to conceive of and even to conjure situations in which the disease is lived through in less dramatic terms than those predicted by diagnosis or prognosis. In fact, calls to systematically distinguish illness from disease, particularly within the field of nursing and care studies, are often motivated less out of ontological than pragmatist concerns where the aim is to produce concrete effects. Giving full weight to this distinction makes it possible to put all relevant actors in a position to collectively compose diverse kinds of know-how about their sickness, know-how that need not privilege medical or scientific knowledge. According to this logic, patients (from the Latin “to suffer” or “to put up with”) no longer have to passively endure the disease whose active “management” is the sole preserve of medicine. They can instead take up an expert role when it comes to at least one fundamental aspect: how illness is experienced and what its usages are in their everyday life, a form of knowledge that they alone can convey. Such a perspective is paramount: it is a prerequisite to any co-


8 Here, “pragmatism” is to be understood in William James’s sense of the word.
construction of knowledge about Huntington’s and other conditions.

The well-known slogan, “My womb belongs to me,” could certainly be discussed for its simplicity and individualism. But if we understand what started the women moving, it was move like “My womb does not belong to you,” and there any individualist simplification disappears. It is a real “hands off!” shouted at all those who, in the interests of the state or of morality, want to charge of women’s wombs.9

In the same way, thinking with the distinction between “disease” and “illness,” we can hear a nuance in the demand made upon Doctor Marboeuf: “at least admit that the truth of our disease does not belong to you or, at any rate, not only to you.”

There is a third reading of this demand. It can be understood as a way of standing the much-debated at-risk person’s right not to know on its head. This right, when it comes to Huntington’s disease, is conveyed in the Guidelines discussed earlier through the explicit recommendation not to undertake prenatal testing for HD unless the parents are sure they will terminate the pregnancy should the embryo test positive. This would otherwise amount to depriving the child brought into the world of the right not to know, for she would be born in the knowledge she was a gene-carrier rather than an at-risk person. In narratively assembling an inversion of this right together with his patient’s rage, Marboeuf fabulates an interesting version of the doctor’s duty to not only be aware of the limits to his own knowledge but also to expressly convey these to his patients. He will only become worthy of his patients when he is ready to heed this twofold duty.

9 Tobie Nathan and Isabelle Stengers, Doctors and Healers (Oxford: Oxford University Press, 2018), 151.
One of the strengths of Marboeuf’s monologue lies in that he seizes upon what is at stake in our exploration. He does so by refraining from presenting the doctor’s re-orientation as a sudden conversion, instead dramatizing it as an arduous and protracted process. Indeed, as he tells it, Doctor Marboeuf approaches the demand that he say, “I don’t know,” with the skepticism of a medical professional. For this requirement runs against his deontological allegiances. He insists that he must inform. For him, this is a professional duty. He thus reminds us of the existence of a conflict, one in which doctors often find themselves embroiled, “conflicts of interest between, for example, the individual physician’s duties to a patient and his loyalty to the profession, as when his conduct is criticized as ‘unprofessional’ for harming, not his clients, but rather his colleagues.”

Marboeuf’s story therefore draws its speculative power specifically from the fact that it does not wantonly dismiss the duties felt by the doctor towards the medical profession, duties that make sense to him and guide his practice – duties that he would neglect were he to be overcome with compassion or were he to say or even just whisper the words, “I don’t know.” A new possibility can only emerge when Doctor Marboeuf allows the sister’s provocation, which leaves him bereft at first (“We will only come back when you are ready to say, ‘I don’t know’”), to resonate and give him pause. In the end, we cannot know whether or not he says, “I don’t know.” What is truly significant, however, is the narrative shift that resulted in his appropriating this injunction and giving it the authority to become his vocation, his calling. He dedicated the time and effort needed to a project that allowed him to transform this provocation, little by little, into the cornerstone of a research laboratory organized in a truly coproductive manner. From within

the hospital milieu itself and together with representatives from all involved parties, he decided to examine the merits of the professional, familial, and moral duties and demands felt by one and all, along with their reciprocal influences. In short, the research unit that Marboeuf fabulates on the basis of a possible world to be built together is one based on the experience that a person might need to place themselves in jeopardy (se compromettre), to let go of “what they hold dear,” if what counts is becoming responsible, that is becoming capable of answering for one’s own practice and its objects.12

Rewriting Natural History

The moral or political concern running through pragmatism is precisely to preserve, as much as can be, the subject’s ability to act, her confidence in a possible action in the world.

– Didier Debaise13

At first, it seems curious that this fabulation should choose the very caregivers of an establishment dedicated to Huntington’s to say the line “we do not know.” After all, it would seem reasonable to assume that the experienced personnel working there would have a particularly keen and thoroughgoing understanding of what happens after presymptomatic testing and particularly regarding the initial onset of symptoms. When it comes to the collective task of apprehending HD differently, the very crux of the Dingdingdong project, everyone brings their own

11 Émilie Hache, Ce à quoi nous tenons (Paris: La Découverte, 2011).
12 For a discussion of the notion of “response-ability,” see Donna J. Haraway, When Species Meet (Minneapolis: University of Minnesota Press, 2008).
ways of pursuing an inquiry and conveying it. Hence, such inquiries are often communal. They are something of a spring into which no one ever wades alone because each of us is always connected to the rest of the group, even if only to fuel our appetites with fresh data and experiences, putting them to collective work. Accordingly, Marboeuf’s video drew in particular on two fieldwork trips to Apeldoorn along with the discussions and interactions we had with personnel and patients there. If Apeldoorn seemed like “paradise for Huntington’s” to us, it was not because the disease became something pleasant there. Rather, it was because the care this place achieved, through perpetual coproduction with sick people and their kin, was remarkable for always tending toward the general wellbeing of those known there as “residents” rather than toward the management of “patients” and their symptoms.

At Apeldoorn, they cultivate the art of caring, an art whose theory and practice is made to measure. From our two visits, we were able to glean some aspects of this art that will, I hope, show how it is strategically accompanied by a form of “non-knowledge” about HD. Marboeuf the storyteller, following the lead of his patient’s sister, finds among Apeldoorn’s caregivers the ability to admit not knowing what will happen for such and such a gene carrier. In so doing, he translates a whole range of observations about the details of their practices, of clues and experimental ways of composing something from HD’s puzzles that form the caregivers’ very modus operandi. The fact remains that the manner in which people live with Huntington’s at Apeldoorn brings about a less dramatic, tragic, and cruel version of the disease. At Heemhof, which is the Atlant Center’s long-term assisted living center for Huntington’s patients, everything is staked on ensuring that patients, who are admitted when their condition reaches a particularly advanced stage, have the
opportunity to remain or become the creators or protagonists of their own disease.\textsuperscript{14}

In this chapter, I have decided to describe the observations and discussions we had at Apeldoorn in some detail. This choice follows from my conviction that all caregiving situations play a decisive role in lending consistency to the milieu surrounding the test-creature, as much so as the epistemological and ethical prescriptions that structure the medical field. In any case, it is easy enough to imagine that a future with Huntington’s is less terrifying if you foresee staying at a place like Heemhof, rather than ending up, by default, in either a nursing home, which is ill-equipped to deal with a condition that affects relatively young people, or an institution for people born with severe disability, which risks being just as inadequate. Unfortunately, to this day, in France and many other Western countries, these are by far the most common outcomes for HD patients (although the trend may be turning around thanks to the combined efforts of caregivers and patient associations).

The forms of support and care the Atlant Center provides, which manage to make it possible to not only to live with the experience of HD but to live well with it, are the fruit of many years of experience. The center was founded some forty years ago, the Huntington’s unit in 1992, and it continues to improve upon its practices, many of which were devised here. These practices have a range of temporalities. The relationship with a new “client” usually and preferably begins at a time when they are still in the early stages of being sick. In fact, quite often at this time it is the loved ones who desire support, whereas the sick person often plainly refuses contact

\textsuperscript{14} Even though Apeldoorn serves here as a model, there are, of course other facilities (e.g., Hôpital Marin de Hendaye, in France) that tirelessly develop and cultivate similarly rich approaches to patient-care.
with the medical services on offer. “Here, they perfectly understand that helping loved ones to help sick people provides the same amount of relief to both groups and helps to avoid many crises.”

The most active people during this phase are so-called “case managers.” They act as an interface between patients, families, and the institution itself. The nature of their work, in other words, is above all diplomatic. They keep in touch with the family, undertake home visits, and help loved ones prepare the sick person for the need to receive support. “There is always a solution to be found,” says R., whose business card simply reads: *Case manager, Huntington.* R. operates on a case-by-case basis according to “a veritable casuistry: turning each case into an event.” To achieve this, she must use her imagination and find the tone and gestures suited for each situation. For instance, she recounted the case of a sick person who refused to have any contact whatsoever with her but whose family sought her help. As she knew he would regularly go into town for groceries, she decided she would cross paths with him one day as a way of making an initial contact. “There is always something you can help with, even if it’s just something tiny. From there, you can build something.” At first glance, this might seem to be quite an intrusive way of intervening, one that goes against the ethics of consent. Surely you shouldn’t follow a sick person out getting groceries after they have refused to be in contact with you? If we take a closer look however,

16 This role has recently been introduced in France for people with Alzheimer’s disease. A quite distinct version of this duty, known as the “coordinator for a program of care” (coordinateur de parcours de soin), is beginning to emerge for HD and other diseases whose oversight is particularly challenging.
17 Rivières, “Apeldoorn 2012.”
what emerges is the careful and discrete construction of what anthropologists Antoine Hennion and Pierre Vidal-Naquet in their inquiry into home care refer to as a “situational ethics.” Such an ethics achieves expression “within the course of acting itself. [...] To put it crudely, ‘ethics is already within.’ Actors are moral actors, even if they do not follow principles that can be articulated in a detached, general, or absolute fashion.” 18 In effect, every situation of care is shot through with demands we would rather shy away from. It falls upon caregivers to guarantee the security and wellbeing of dependents and to respect their autonomy. At the same time, there is no escaping the fact that people receiving care regularly have to be made to do things they refuse to do or find pointless. Hence, in concrete practice, white lies, tricks, and workarounds frequently sustain the gestures and moves leading to a given goal. 19 Procedures such as these are *pragmatist* in the proper sense insofar as they characterize a practice whose effects are not measured against abstract principles: “not an unprincipled action, the justification for which changes randomly from one situation to the next, but an action whose principles are actualized in the course of its very enactment.” 20

In another stage in which the sick person, their loved ones, and staff from the Atlant Center come together, the

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19 Since the original publication of *Testing Knowledge*, Dingdingdong has achieved an inquiry that dives into the details of the incredible creativity invented by HD-patients, their families, and close ones. See Émilie Hermant and Valérie Pihet, *Le chemin des possibles. La maladie de Huntington au soin de ses usagers* (Paris: Éditions Dingdingdong, 2017).

20 Ibid.
sick person has agreed to work with caregivers but continues to live at home. At this point, their case manager works with them to craft a personalized program of home care, with both emotional and material components. Aside from help with washing, housework, and cooking, consideration is also given to occupational therapy, speech therapy, and psychiatric or psychological support. This is also the time when a discussion happens about equipment that will be useful but need to be ordered in: medical bed, walking frame, wheelchair, shower chair, etc. During this period, some choose to take up the offer of day care, another option Apeldoorn provides, with various support services and activities. This period is by no means conflict-free. R. must make sure to keep her practice fluid and open as order never lasts long. She has to pay constant attention to what is happening in order to spot and identify the slightest mishap and, as quickly as possible, conjure a corresponding proposition. Invariably, it is impossible to guarantee ahead of time that these propositions will succeed. They will prove their worth through their effects, as they are enacted as so many opportunities or “living hypotheses”\(^\text{21}\) for better facing up to the situation at hand. If they fail, then another direction must be found. This thoughtful, pragmatist approach constantly makes do with uncertainties and, as it were, with non-knowledge.

In many cases, the question arises of whether a sick person is ready to move into Heemhof in order to receive care corresponding with their symptoms’ progression and also to relieve their loved ones. Entering Heemhof, which is at a slight remove from the city of Apeldoorn itself, prompts immediate surprise. Nothing about the lighting, the smell, or the soundscape recalls the feelings

\(^{21}\) The expression is William James’s, from The Will to Believe and Other Essays in Popular Philosophy (New York: Dover Publications, Inc., 1956), 2ff.
that tend to go with hospitals or support centers. Residents’ individual rooms, kitchens, three large common rooms, entertainment areas, and various technical spaces open onto a square arrangement of wide corridors bathed in light. Residents can move about freely, they make their way through the corridors on foot or in electric wheelchairs, gaze into the distance, or smoke on the balconies appointed for this purpose. Each of them can arrange their room as they see fit, with their own furniture and selection of wall colors. It is even possible to keep small pets, provided the sick person or their family takes care of them – we made out rabbits, hamsters, and parakeets. We learn that there are as many caregivers working at Heemhof as there are patients in residence. If we take their working schedule into account, this means that during the day there is at least one caregiver for every three patients. Heemhof receives roughly three hundred Euros per patient per day in public funding; patients and their families make up the difference on an income-adjusted sliding scale.

Let us consider three aspects of the practices of living and caregiving that unfold at Heemhof: the color-coded system for collective crisis management, the use of Video Interaction Guidance (VIG)\textsuperscript{22} and the multitude of objects invented to improve ordinary living. These techniques are elaborated as a veritable art of “listening, respecting, nourishing, and even enjoying [jouir] finite bodies.”\textsuperscript{23} M., one of the psychologists, explains the three-color system to us. Working closely with Heemhof’s caregivers and case managers, he supports residents as well as home care patients and their families. In his view, the three-color system enables full time staff to collaborate

\textsuperscript{22} See the comprehensive website of the British Association for Video Interaction Guidance UK, https://www.videointeractionguidance.net/.

\textsuperscript{23} Annemarie Mol, \textit{The Logic of Care: Health and the Problem of Patient Choice} (London: Routledge, 2008).
effectively with doctors, psychologists, and loved ones. Imagine a traffic sign: when everything is fine it shows green, hence green markings appear in the resident’s file, updated daily. When small things start to go wrong and signs of frustration, anger, or impatience emerge the light turns orange. Red signals a full-blown crisis situation. The most important of the three colors is orange: it indicates the moment that calls for attention from the team and loved ones, forcing them to think in order to understand exactly what is happening and to agree on what needs to be put in place to avoid crisis if possible and turn things green again. Going on a walk, organizing a session with the psychologist, a trip to the city, a weekend at home – these different initiatives will each have to prove themselves against a situation bearing the mark of the notorious orange color. The three-color system therefore constantly accompanies loved ones and the multidisciplinary team, it allows and calls for careful, daily evaluation of each resident’s situation and serves as an effective machine for collectively anticipating and averting crises.

Another form of crisis management is the regular use of VIG techniques. Dutch psychologist Harrie Biemans and his colleagues developed this method in the 1980s, which was then conceptually refined and extended by University of Edinburgh ethologist Colony Trevarthen. Biemans was interested, above all, in early interactions between parents and their children. He attempted to understand how dysfunction set in within this prelinguistic relationship and find ways of responding to it.

Since then, the method has gained traction primarily in England, the Netherlands, and Canada, each time in a version adapted to its local context of use: schools, hospitals, or workplace relations. Here is how it works: action sequences unfolding in a given setting (domestic or institutional) are first recorded and then prepared for viewing by someone referred to as a “guider.” Then, most if not
all the people involved in the sequence watch the footage with the guider and analyze it together. From the footage selection phase onwards, however, the focus is less on moments of crisis or failure than on moments of successful communication or interaction. Notably, the usage of video technology allows for the possibility of rewinding, for instance, from a relaxed scene in which mother and child are laughing together. By going back in time, it becomes possible to better understand and make explicit the steps leading up to this pleasant but potentially rare situation, the attitudes, gestures, or words that brought it about. By giving participants the means to take stock of the ways in which some of their interactions are successful, over time they become able to produce and stabilize some of their behaviors in situ, with a view to multiplying such felicitous moments.

At Apeldoorn, this method is put to two ends: first, to focus participants’ attention on the times when their interactions succeed and, second, to turn the times when they experience serious difficulty into learning opportunities. If a given family laments repeated crises, a VIG-trained team is sent in to try and record one such situation. Then, the sick person along with the family, the team of caregivers, and the guider watch and discuss the video all together in order to understand what led to the crisis and what role each of them played in it. In such cases, the recordings become a source of inspiration the better to think through failed interactions with a given resident and to put in place strategies adapted to their needs. The process is repeated as many times as necessary. New caregivers also take part in these VIG sessions and train themselves through the collaborative screening and discussion. For privacy reasons, the videos are destroyed after analysis.

Finally, living with Huntington’s at Heemhof is different in light of the material resources on hand. Residents have an impressive array of equipment at their disposal.
This allows them to keep up a surprisingly broad range of physical activities for as long as possible. Along with standing bicycles for going on walks with their loved ones and many other sophisticated devices (electric wheelchairs, walking aids, a variety of winches fitted to beds, showers, and baths), each sick person gets a “personal communicator.” This is a “smart” touchscreen tablet with accessibility options allowing its continued use into the advanced stages of illness. If desired, the device accompanies Huntington’s patients from the earliest stages and thus constitutes a kind of externalized memory. By way of a digital voice encoder, it enables them to continue to express themselves vocally and converse long after analog speech is no longer an option, using a sophisticated and effective system.24 The team endeavors to convince residents to take up using this communication technology as well as electric wheelchairs as early as possible. Indeed, from their experience, the longer a person waits, the harder it is to learn these skills. If a person makes a few regular trips in an electric wheelchair while they can still walk, these skills are conserved much longer, even into the advanced stages of the disease. During our visits, we also encountered a resident at Heemhof who decided to undergo gastrostomy, that is to make use of a gastric tube to feed himself. Having serious difficulties with swallowing and suffocating – which are frequent issues at advanced stages and made each of his meals time-consuming, unpleasant, and nutritionally inadequate – this intervention allowed him to once again savor the tastes he most enjoyed. While he now feeds himself almost exclusively via gastric tube (for his caloric intake), he is free to eat and drink small quantities of the things that make him truly happy. In other words, he removed what amounted to obligatory force-feeding from his daily life.

24 HD’s motor symptoms lead to difficulties with the vocal apparatus, notably elocution and swallowing problems.
and, without it being systematically associated with the danger of “doing the wrong thing,” he rediscovered the pleasure of enjoying his favorite meal: fries and a cold beer! In so doing, he teaches us that it is possible to situate this move not within a context of palliative care and its systematic association with “end of life” but instead within a context of living, plain and simple.

Alongside these high-tech tools, more mundane objects made on site play a vital role in everyday life. Consider the ashtrays. Wrought from salvaged materials, they are astounding creations. A metal ring is welded onto the rim of a conventional ashtray. A cigarette is held firmly in the ring so that ash falls safely into the ashtray. The filter tip of the cigarette is connected to the end of a gastric probe approximately twenty centimeters in length, which is connected in turn to a rectal probe of about the same length. The plastic tip at the end of this tube becomes the new filter for the smoker who can inhale their smoke thanks to this pseudo-hookah made of various found objects from the institute’s supply cupboards. The ashtray thereby constructed, stamped with the name of its owner, is screwed into a table. Thus, even at an advanced stage and despite violent jerky motions, sick smokers can sit at tables on their balcony and enjoy a cigarette without running the risk of burning themselves or accidentally starting a fire.

It should now be clear, I hope, that at the Atlant Center care is not just about providing alternative treatment to Huntington’s disease that would, itself, remain the same as it ever was. On the contrary, at Apeldoorn, another version of HD is cultivated and made real. What takes place is an intervention into its natural history, not only metaphorically but also in the strictly medical terms of its clinical course. This effect can be most clearly observed in relation to two symptoms, anosognosia and dementia. In the clinical literature, these come across as two more symptoms of a person with HD’s lot. Anosognosia re-
fers to a lack of self-awareness regarding symptoms and it is thought to be present, to a greater or lesser degree, throughout the entire evolution of the disease. As for dementia, it allegedly accompanies the condition’s most advanced stages. What emerges, however, from discussions with caregivers at Apeldoorn is that none of them has observed either of these symptoms among residents. It is true, they say, that they grow slower and slower and that caregivers must have a great deal of patience to get answers to the questions they pose. But as to whether residents are anosognosic or demented, they answer no, not in the least. It is hard to resist the impression that if these symptoms are lacking it is above all because they are given no quarter at Apeldoorn, because HD patients are never addressed as if they were demented or anosognosic. Quite the opposite, staff at the Atlant Center always strive to take things from above, which is to say, to give as many opportunities as possible to their clients “to preserve, as much as can be, [their] capacity to act,” to articulate themselves as actors in relation to what is happening to them – giving us a powerful and moving site of pragmatist morals and politics in action.

25 Debaise, “La pensée laboratoire.”
26 It must be noted that there is at least one important precursor to the care-philosophy practiced at Apeldoorn: The tireless US-American expert in HD-care, Jimmy Pollard – who has rendered his experiences public in a book called *Hurry-Up and Wait! A Cognitive Care Companion: Huntington’s Disease in the Middle and more Advanced Years* (n.p.: Lulu.com, 2008).
Autonomy?

*To the children [her nephews, who are all HD carriers], I say: be proud. You are extraordinary. You have a rare, unknown disease. You are extraordinary.*

— Catherine

From a historical standpoint, the autonomy concept, which is foundational to the right to know as well as to the concept of informed consent, is a consequence of mounting and warranted distrust of modern medicine and its practitioners. As described in previous chapters, since its very beginnings, the epistemological and methodological regime of modern medicine has tended to dissolve the bond between sick people and their conditions while, at the same time, placing distance between doctors and their patients. All too often, doctors treat sickness as a diagnostic entity (disease) and not sick people themselves with their distinct and diverse experiences (illness). This trajectory has been further cemented since the second half of the 20th century, with the technological know-how of intensive care, medical transplants, and reanimation. It reaches new heights with contemporary systems of social security and health insurance, which produce precise prescriptions of the quantum of financial support to be allocated to such and such a diagnosis, treatment option, or provision of care.

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28 In English in the original text.

29 In English in the original text.
In the United States, as far back as the 1960s, a protest movement formed in response to an increasingly technological approach to medicine beholden to the laws of the market, dogmatic and “dehumanized,” and giving less and less room to empathy, intimacy, or any acknowledgment of the values embedded within clinical acts. The new field of biomedical ethics was both the outcome and one of the driving forces behind this protest movement. It pushed for requirements concerning patient autonomy and the right to informed consent, which remain fundamental notions to this day. Autonomy emerged as the self-explanatory founding principle of a movement that followed in the footsteps of similar efforts within political and juridical circles. Guaranteeing patient autonomy, moreover, appeared to constitute a self-evident and robust response to mounting distrust of modern medicine: “Whereas trust had hitherto been the implicit moral understanding governing physician behavior and patient delegation of authority in the age of Johnson and Nixon, patient confidence required both new definition and novel substitutes.”

Nevertheless, upon closer inspection the autonomy concept is problematic in a number of different ways, sometimes even counterproductive. It rests upon an understanding of the patient that defers to the model of the rational, sovereign, and adult citizen, an individual who is able to decide and to act, consciously and with self-mastery – in other words, a non-relational being. Hence, to put it directly: the autonomy concept encourages tendencies within modern medicine identical to those it aims to critique. Indeed, “autonomy as configured in its individualistic stance facilitates the isolation required for positivism to operate freely.” Furthermore, bioethics

31 Ibid., 13.
discourse risks fashioning liberal subject-patients entitled to make rights claims against untrustworthy medicine, much like citizens would against the State. The distrust initially circulating among patients thus began to spread; doctors are now wary of their patients who have become possible future claimants. This is why doctors seek to protect themselves from the threat of legal action, which includes giving patients qua autonomous subjects a document detailing the risks accompanying treatment (for instance, a particular surgery) awaiting a signature as confirmation they have carefully read and understood it.

A similar reversal of fortunes occurred in relation to the patient’s right to know, which is closely connected to the patient autonomy concept. In effect, this right tends to transform itself, surreptitiously, into an instruction or an imperative to know. Within this framework, a subject can only prove herself to be morally responsible if she transforms a genetic risk (e.g., the risk of having Huntington’s or conditions such as high cholesterol, Alzheimer’s, or various myopathies) into certainty. She does so by availing herself of testing and, accordingly, drawing conclusions as to appropriate life choices.

Another entity that emerged from dissatisfactions created by the health system has had, since the 1960s, a much more fascinating evolution in my view. This entity is the patients’ association or, to be more accurate, patients’ collectives of a very particular sort: those whose actions go beyond fundraising for medical and pharmaceutical research, which would otherwise limit them to operating within a resolutely hierarchical logic of knowledge production about a disease. Instead, they have opened the way to other forms of action that consist in cultivating their own skills in relation to the conditions that bring them together. We have already considered the example of the Hearing Voices Network. In recent decades, Deaf people, Autistic people, the AIDS-movement, people with Parkinson’s, and many others have increas-
ingly organized collectively. Heeding the call for “Nothing About Us Without Us,” these movements place the user at the heart of their thinking and their actions – not in the sense of being a “consumer” of medical services but rather a co-constructor of the collective project of making a “user culture” for their given disease or difference of ability.

The user culture, in contrast to instrumental, diagnostically justified uses, is a problem of collective interest that needs collective knowledge. We can call it a collective experience, in the old sense where the expertise first designates knowledge coming from experience and is cultivated in its relations with experience. [...] And this experience has a vital need for its own kind of knowledge that user associations can construct. This knowledge is valuable in itself, but in addition it can make other knowledges recognize that they are all gathered around something – a being? a power? – that belongs to no one, that no one can appropriate or represent.

The making of such collective know-how about what is the liveliest life possible with a given condition does not necessarily aim at calling medical knowledge into question. Rather, it exists in addition to it, so as to rank among expert knowledge formations as a distinctive yet no less pertinent genre. Instead of placing themselves in the position of the victim, those engaged in such a task take


charge, collectively, of setting the stage for their own future. And given the interest they grant themselves along with their own sickness or disability, given the manner in which they conjure ways of doing things with it, they also manage to awaken the interest of others as to what, from their perspective, matters most. This is what happens when psychiatrists ask for training from the Hearing Voices Network. The truth that such collectives bring to light is therefore not limited to their ability to draw attention to the tragedy of the disease or syndrome that befalls them. Rather, this truth appears “in the processes by which [these people] become, on their own terms, something other than victims; it is in their way of meddling with the processes that make victims out of them and thereby creating futures and fabulations rather than complaints or resentment.”

A brief outline of the Atlant Center allowed us to understand that both the autonomy concept and that of informed consent can hinder rather than help with situations of care. For care is precisely not developed in relation to an isolated subject but instead through a constant back-and-forth between patients, caregivers, doctors, and their kin, something that takes into account all of the actors and their various interests, needs, and interdependencies. None of them is, strictly speaking, autonomous. They each learn with and through one another, from within a strongly relational and co-constructed practice of care. Furthermore, the autonomy concept appears to be ill suited to what patient collectives such as voice hearers or people with Autism enact when, pointedly, they draw strength and energy from making what brings them together into a collective thing. At the risk of generalizing, it could be said that the autonomy concept tends to aim

either too high or too low. Too high, insofar as creating the necessary conditions for the relative wellbeing of sick people in care means repeatedly constraining their “autonomous” will, in the strong sense of the term. Too low, because the notion of informed consent, often used as a synonym for autonomy, falls short of the work of patient collectives who lay claim to a culture of their own making. If we are to retain the autonomy concept in spite of everything we have just considered, does it not follow that it should go hand in hand with the making of tools with which to think, tools that might help put medical knowledge in its place (relativiser), in the literal sense of connecting this know-how to other know-how making practices like those of user groups?

What Do the Oracles Tell Us?

A divinatory apparatus is always a creative act. It institutes the interface among universes; it makes them palpable and then thinkable.

– Tobie Nathan

Comparisons with ancient oracles and seers often arise unprompted in discussions about testing for HD and other techniques of predictive testing. Media representations frequently draw on such imagery when describing and analyzing genetic knowledge about the future. It comes up regularly, however, in specialist literature as well. Consider, for example, that in 2001, before the completion of the human genome project, the German parliamentary committee evaluating the consequences of this technology produced a report titled The Genetic Oracle: An Overview of Current Usage of Genetic Testing for Prognosis and Diagnosis. Leading HD researchers themselves make use of images of oracles and divination to think through

35 Stengers and Nathan, Doctors and Healers, 10
the kind of knowledge they deal with and bring forth. Hence, between 1983 and 1993, Nancy Wexler published at least three articles on predictive genetic testing for HD whose very titles drew this connection: “The Oracle of DNA,” “Clairvoyance and Caution,” and “The Tiresias Complex.” Here is how the last of these, published in 1992, begins: “The blind seer Tiresias confronted Oedipus with the quintessential dilemma of modern genetics: 'It is but sorrow to be wise when wisdom profits not.'”

All of these references index the tragedy predicted by ancient prophetic practices, the curses they would produce and human powerlessness before them. The association, therefore, is an almost exclusively negative or pejorative one. In this book’s final section, I wish to pursue a hunch that oracular practices and predictive medicine might be connected in deeper, more interesting ways than these metaphorical transpositions suggest. I submit that a closer look at ancient oracles can heighten our sensitivity and provide instruction as we face up to the challenge of constructing a milieu better suited to welcoming the creature of predictive testing. Making this claim intelligible means following in the footsteps of the concrete practices of oracles. Specifically, we must pay the utmost attention to the many precautions and trials attached to oracular predictions, and which surrounded all those at Delphi and other sites where knowledge of the future was produced and relayed.

The most effective way of bringing into view the pivotal role that precautions played in the construction of prophetic knowledge within ancient divination practices is, without doubt, to recount what happens when consulting an oracle fails. Sometime in the 80s or early 90s of the first century, a tragic accident took place in the temple of Apollo at Delphi, leading to the death of the Pythia, the high priestess who transmitted the word of the deity. During a consultation with the oracle, the Pythia began screaming and yelling as if possessed, and rushed out of the temple’s innermost shrine, the adyton, toward the exit. She died a few days afterward. This incident provoked considerable emotion among the residents of Delphi. It deeply disturbed the temple’s servants as well as families in the city who entrusted their daughters to the temple to be become Pythias. This, at least, is the conclusion Plutarch comes to in On the Obsolescence of the Oracles, his friend Nicander having held the priesthood in the sanctuary at the time. Clearly very affected despite the many intervening years, he recalls the incident as follows:

Finally she became hysterical and with a frightful shriek rushed towards the exit and threw herself down, with the result that not only the members of the deputation fled, but also the oracle-interpreter Nicander and those holy men that were present. However, after a little, they went in and took her up, still conscious; and she lived on for a few days.38

What culminates in this dramatic event? What events led up to it? What caused the Pythia’s violent and terrifying unraveling, which horrified those present and chased them from the temple, and brought about the Pythia’s own demise? Plutarch, who himself would later enter the Delphic priesthood and practice for some thirty years, goes beyond mere conjecture. In his judgment, the Pythia’s death is the clear and direct effect of an infringement committed by the temple’s servants against the rules of the sacrificial ritual preceding consultation.

As it happened, a deputation from abroad had arrived to consult the oracle. The victim, it is said, remained unmoved and unaffected in any way by the first libations; but the priests, in their eagerness to please, went far beyond their wonted usage, and only after the victim had been subjected to a deluge and nearly drowned did it at last give in.39

As often happened at Delphi, a delegation went to the temple to ask the oracle about matters of State. What’s more, it would appear that the envoys enjoyed the privilege of consulting the Pythia before everyone else who had come seeking advice. There was an evident desire to not disappoint these important political figures by making them wait for a subsequent consultation, even though the signs were not favorable, meaning that the divinatory powers of the Pythia were compromised.

The so-called preliminary rituals, the preparations and preliminary precautions taken before all consultations with the Pythia, had an essential place and significance within Delphic liturgy. They entailed a series of steps that bring into full relief the deep sacredness of any act of divination, an act demanding cautious and attentive preparation and accompaniment. The first of these

Delphic preliminaries was setting the date of consultation. Whereas, in the oracle’s early years, “it was but once a year, on the god Apollo’s birthday, when the oracles were given,” a more frequent tempo was later observed. Thereafter, the Pythia could be consulted on the seventh day of each month and, in summer, on the days following as well. “In addition to this, it was also possible to arrange ‘special meetings,’ always on condition that the sacrifices were favorable and thus indicated that the god was ready to form a relationship with the priestess.” To ensure that the signs were favorable and that the oracle could be “operational,” so to speak, before all consultations an animal would be offered in sacrifice. However, other rituals preceded this step, rituals during which each animal was subjected to a specific trial that served to determine whether or not it was to be sacrificed.

For what is to be offered in sacrifice must, both in body and in soul, be pure, unblemished, and unmarred. Indications regarding the body it is not at all difficult to perceive, but they test the soul by setting meal before the bulls and peas before the boars; and the animal that does not eat of this they think is not of sound mind. In the case of the goat, they say, cold water gives positive proof; for indifference and immobility against being suddenly wet is not characteristic of a soul in a normal state.

If the goat flinched, its neck hair standing on end, if the bull ate the meal or the boar the peas, only then was it possible to conclude that the signs were favorable for a consultation. The sacrifice could only commence once

41 Ibid.
42 Plutarch, The Obsolescence of Oracles, 495.
the animal had given its consent by way of these signs. The Pythia was then in a position to make contact with the god Apollo and he, for his part, was ready to confer the requisite predisposition upon the priestess, namely the “inspiration” or breath he transferred to her. Nevertheless, before she could truly be interrogated, those who came seeking advice had also to submit to a series of preliminary rituals. They had to purify themselves, burn a sacred wafer, and, at a later period, give an offering to the priest for another prior sacrifice. Only upon completing all of these rituals were they admitted into the adyton of the temple of Apollo. Finally, the Pythia herself had to undertake a series of ritual acts before assuming her position atop the tripod in the temple. “She would take a ritual bath in the Castalian Spring, drink the waters of the Cassotis, chew laurel leaves and light incense”43 These preparatory measures were integral to undertaking the Delphic oracle. The sacrifices themselves had a divinatory value, indexing whether the conditions were right for allowing the Pythia to fulfill her function and, with Apollo’s aid, answer the questions brought before her. If one of the conditions was not met, no demand should rightfully take place.

Whenever, then, the imaginative and prophetic faculty is in a state of proper adjustment for attempering itself to the spirit as to a drug, inspiration in those who foretell the future is bound to come; and whenever the conditions are not thus, it is bound not to come, or when it does come to be misleading, abnormal, and confusing.44

On the day when the Pythia fled the adyton in the middle of a consultation, the goats awaiting sacrifice failed,

43 Giebel, Das Orakel von Delphi, 18
44 Plutarch, The Obsolescence of Oracles, 499.
as Plutarch told us, to flinch. Despite this, the temple’s servants took the risk of authorizing the consultation. No sooner had the session begun than those present took note of the Pythia’s disturbed inspiration:

She went down into the oracle unwillingly, they say, and half-heartedly; and at her first responses it was at once plain from the harshness of her voice that she was not responding properly; she was like a labouring ship and was filled with a mighty and baleful spirit.45

This story exposes the dangers of trying to conjure foreknowledge by forcing a laboring Pythia to take up her position within the holy of holies. The gift of “the imaginative faculty” or of divine inspiration then swiftly becomes a poison. This pharmacological quality of the foretelling of future events draws successful colloquy with the divine and its failed and death-dealing counterpart into striking proximity, the two separated by a mere difference in dosage. Promising prediction (maintain) and speech that is uninspired, mad, and dangerous (mania) are frightfully close to one another. Divinatory art’s Janus face was constitutive of the Delphic oracle’s protocol.

It is for these reasons that they guard the chastity of the priestess, and keep her life free from all association and contact with strangers, and take the omens before the oracle, thinking that it is clear to the god when she has the temperament and disposition suitable to submit to the inspiration without harm to herself.46

In such light, any consultation with the Pythia came with the additional risk of unraveling the relationship between a god (or goddess) and his (or her) prophet (or

45 Ibid.
46 Ibid., 501.
prophetess), this latter being the one who speaks (-phete) for (pro-) another, who speaks in their name. For even on days when the signs were favorable and when the Pythia did not resemble “a labouring ship [...] filled with a mighty and baleful spirit,” it was clear to see that the labor of divination was, as Plutarch explains, exhausting: “the Pythia regains calm and tranquility once she has left her tripod and its exhalations.”47 The duty of the priest and the rest of the temple’s servants was to make sure that the risky relationship between the god Apollo and the Pythia, between divine foresight and its foretelling, would unfold as serenely as could be. This presumed following the liturgical rules to the letter. Forcing the Pythia to answer a question, to foretell the future and offer advice, despite all of the signs indicating she was incapable of responding (that she was, literally, ir-respons-able) was, therefore, playing with death.

It is easy to imagine that the broken rules that lead to the Pythia’s death not only endangered the seer’s existence but everyone else’s as well. On one hand, because the consultants would endeavor, after the consultation had concluded, to ensure that their actions, whether personal or political, lined up with the oracle’s “harshly” spoken words. This alone could produce fatal consequences in some cases. It was not unheard of, for instance, for the Delphic oracle to influence major decisions about warfare. On the other, wild and demonic divine entities had thus been unleashed, without having been tempered or tamed by ritual techniques; they had been provoked by transgressions of those rules that should have been respected when making contact with divine beings. The danger was therefore that they, in turn, would violently

take possession of those who had invoked them. The danger, in other words, was becoming possessed.

Other oracular practices were subject to strict rules and called for circumspect usage. Whether it was observing birds in flight, interpreting the motion of oil beads on the water’s surface, or reading the entrails of animals sacrificed for fortunetelling, “advising was a skill that corresponded to a reading ability.” This ability needed to be learned carefully. Entrails, for instance, were cast in clay or bronze and stamped with the correct marking. Novices could practice anatomy on these and also pursue inquiries into the correspondences between micro-signs read in the entrails and their implications for the world.

As in medical discourse, the symptoms were condensed into diagnoses and the diagnoses into prognoses. [...] The results were to be analyzed and carefully preserved. Indeed, it was not unusual that an advisor who erred would earn cruel punishment. According to a story related by Herodotus, among the Scythians, failed seers were strapped to a cattle cart and burned alive using bundles of willow branches, the same material with which they would practice divination.

In light of the threat brought about through false prediction, “advisors tried, very early on, to dissociate the quality of their advice from the consequences of the actions they recommended.” For this reason, most of the time at Delphi and elsewhere, advice and prophecy took the form of a riddle. Doing so ensured that the prediction would be followed by an interpretive phase, one for which the

49 Ibid., 64.
50 Ibid., 65.
oracle itself had no responsibility. The advice was disso-
ciated in two steps: “first came the giving of transcendent, charismatic, or medium-like commentary and then came the interpretation of this commentary.”51 While the actual seer (e.g., the Pythia or the Sybil whom the gods inspired) spoke in riddles, a whole host of specialists in reading, translating, and interpreting riddling speech acts stood at the ready around Delphi and in other oracular places. A real prophecy only acquired its meaning and momentum once it had passed through many hands: after it became, as it were, collectivized. In so doing, it was imperative that the proper division of labor was main-
tained, for this simultaneously distributed responsibility for the ensuing prediction. In this context, the production of ever-fragile foreknowledge therefore relied upon the strategic proliferation of actors and functions, for both preliminary and subsequent purposes. Without the coordinated intervention of these various roles, it would not, in fact, be possible to produce this knowledge at all.

The oracles therefore draw our attention to at least two aspects of diagnostic predictions. First, whenever a predictive practice allows itself to subject the person questioning the oracle to scrupulous examination without taking into consideration the concrete circumstanc-
es of the ecological situation, it will inevitably become extremely dangerous. In addition, while it is true that informed production of knowledge about the future requires prophetic speech, at the same time, it calls for a sophisticated and technically refined interpretive art. Plutarch’s description of the Pythia’s death offers a striking demonstration. This analysis takes on a particular contemporary hue if we consider it in relation to non-Western divinatory healing practices, whether ancient or contemporary. For these practices do not pin symptoms onto the sick person but instead always attribute them

51 Ibid.
to beings requiring careful identification. A “diagnosis” corresponds, above all, to the identification of such a being: what is its nature, what are its intentions, how might it be tamed? The answers to these questions are integral to the treatment and rely as much on the healer’s expertise as the cultural group to whom the latter belongs. As such, there is no difference in kind between diagnosis, prognosis, and treatment in such a framework. They form an ensemble involved in ever-renewed ways of collectively practicing the demanding art of negotiating with the invisible.

Plutarch’s text engages a broader set of concerns. A series of interlocutors who happen to be at Delphi give voice to Plutarch’s own thoughts on the matter. These various interlocutors assemble to examine the reasons why, unlike what happened under the Greeks, oracles began disappearing one-by-one during Roman rule. Decreasing population in the areas of major oracular sites would have led to a more limited demand for their services, but also to the withdrawal of the beings in charge (daimones) from their sanctuaries. We would have “unlearned” how to correctly handle the oracle along the way, much like we forget how to use a musical instrument that we leave idle too long. The Pythia – whose speech reveals a “harshness of her voice” and who rushed out of the temple like a fury – only comes up towards the close of this wider discussion. In the most striking manner, she embodies the dangers that threaten to arise from a lack of collective attention to a phenomenon as volatile as foreknowledge. Oracular practice of the kind Plutarch describes is,

52 To be sure, this manner of separating a person from her symptoms is in no way to be confused with the separation of patients and their diseases as described by Canguilhem. Rather, the separation in question relies on an entirely different model of patients, pathologies, and their relation to one another.
53 Nathan and Stengers, Doctors and Healers. See also Tobie Nathan, L’étranger ou le pari de l’autre (Paris: Éditions Autrement, 2014).
in our view, a precedent when it comes to the ecology of diagnostic prediction. The Pythia’s death, in this sense, is an ecological crisis.