Anne-Lyse Chabert

BEYOND DISABILITY

A Matter of Listening

Disability Studies

Collection Editor
DAMIAN MELLIFONT

LIVED PLACES
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Abstract

Beyond Disability is a collection of essays in which Anne-Lyse Chabert reflects on her life as a person affected by a neurodegenerative disease. By going back and forth between the daily struggle of her life and her role as a philosopher, which requires her to distance herself from her own experience, she derives lessons about how to live fully in today's society. This work demonstrates how, by listening to illness, to oneself, and to everyone around, it is possible to go beyond one's own conditions of possibility and to carve out a path through existence.

Key words

Testimony/life narrative, disability, experience and research, ableism, inclusion, adaptation, vulnerability, dependence, accompaniment, freedom

Content warning

This book contains explicit references to, and descriptions of, situations that may cause distress. This includes references to and descriptions of the following:

- Death and euthanasia
- Dementia
- Degeneration of the body

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Learning objectives

- Realize that it is only in moments of crisis that the real relationships of an ecosystem unfold and that they are silenced as long as the ecosystem appears to be functioning.
- No longer consider tiredness only as a burden but also as our way of being human.
- Give dependency the opportunity to become a creator of bridges with others.
- Use our freedom in the life assigned to us.
- Learn to listen to a disabled person or a sick person who will have a lot to teach others.

Foreword by André Comte-Sponville

This book shook me to the core, as it will you and many others because it is a book brimming with courage and intelligence because of its unique blend of depth, heights, and perspective; its remarkable analytical capability; its intellectual rigor; its admirable reticence; its wealth of spiritual strength; and its soaring thinking, all displayed while closely espousing the intimate suffering of a body!

I first met Anne-Lyse Chabert a decade ago at a philosophy workshop—probably one organized by my friend Francis Wolff at the École Normale Supérieure on the Rue d'Ulm: a pleasant young woman with intense eyes and a bright smile. She was already using a wheelchair then but still was less disabled than she has become since. We got into the habit of exchanging occasional missives and met again, particularly when she was called for a viva to defend her doctoral thesis in 2014 and then again in 2018 when she was awarded the Prix de l'Académie de Médécine for her book *Transforming a disability through everyday life experiences.*[1]

Gradually a sort of friendship developed between us, despite the difference in age and the fact that our homes were so far apart. To put it bluntly: there are few people, except my close circle, about whom I think as often as I think about Anne-Lyse, let alone with such intense feeling.

Actually, I don't know anyone else who has to lead such a difficult life or whom I so much admire for the way she lives it.

She is 37, a philosopher, and at present, the head of research at the SPHere (Science, Philosophy, and History) laboratory of the University of Paris-Diderot and at the CNRS. However, since childhood she has suffered from a rare genetic disease that gradually increases in impact: Friedreich's ataxia. This neurodegenerative disease leaves intellectual faculties unimpaired but impinges on particular cells in the nervous system, gradually reducing the subject to a state of disability, which affects the whole motor system. First, the body grows clumsy, progressively losing skills: walking, writing, speaking, and most other ordinary activities of one's daily life become increasingly impossible, at least without external assistance.

In Anne-Lyse's case, she recalls that the first symptoms manifested when she was around ten years old: "I was able to walk, to ride a bicycle, to play the piano." Then, gradually, everything started to become a struggle:

> The progressively degenerative disease which gradually disabled me led me to ask an absurd question: when did my disability really begin?—was it when my mother began to grow increasingly worried about the tumbles I took in the school playground?—was it when my handwriting began to get worse when the disease first began to manifest in its earliest phase?—was it when, after much hunting around for a diagnosis, I finally came home with a diagnosis signed and sealed and could at last put a name to my specific disorder, though the future boded nothing but ill?—was it when, at the age

> of around fifteen, I was granted my first disability card?—was it the first time I wore orthopaedic footwear?—was it when I started to use a walker?—was it later, at around twenty, when I first began to use a wheelchair?—or was it when I first went outside in my wheelchair? When did a fundamental difference emerge between myself and the "world of the well", to the extent that I could now begin to describe myself as "a person living with a disability"?[2]

I quote these lines from Anne-Lyse's previous book to give you an idea of what is entailed in grappling with a disability, particularly a degenerative one, which demands a constant process of ongoing readjustment, courage, creativity, and "making-do", (which is what this book is about) in order to enable the individual to gradually recover some degree of sustainable personal, tailor-made equilibrium if the environment is not strewn with obstacles but is, rather, as far as possible, an enabling one. This was the subject already addressed by Anne-Lyse in her doctoral thesis, which she returns to in this new book.

Just as for Bergson, the disorder is only a form of order that causes disappointment or springs a surprise and, just as a pathology, for Canguilhem, is "a form of normality of a different order and on a different scale," so a disability is but another form of normality. It has, quite simply, to be coped with, as best one can; "someone afflicted with a disability, is initially disturbed by it, then, in so far as possible, tends to restore the disturbed life balance and, in so doing, creates a new, quite unexpected and unsuspected, order, which, despite not obeying the accepted canon, is nonetheless real". There is nothing in existence that is unnatural, wrote

Montaigne before Spinoza: “whatever exists is, by the very fact of its existence, natural”.[3] Whatever exists is normal when measured against its own singularity rather than by comparison with something else (for, as Spinoza might have said, it is normal for the blind not to see.)[4] “A comparison is not an argument”, as the saying goes. The opposite is also true, and all the more so.

This is not just a matter of theory. It is also a matter of ethics, a practical matter, and an existential one. Specifically, for Anne-Lyse, it means preserving, to the greatest possible extent, her personal autonomy and her freedom, requiring of her that, faced with any fresh deterioration of her condition, she once again reorders the environment in which she leads her daily life and that she reinvents that daily life with the means at hand, any means available to her. This does not mean that her disability and dependence are to any degree reduced (we should not, she points out, confuse “independence” and “autonomy”), nor does it mean that they will not continue to deteriorate, with all the attendant suffering and anxieties, which we can discern and which she makes no attempt to conceal. This is all part of what Anne-Lyse, echoing Clément Rosset, calls “the cruelty of bare reality”, in other words: its “irrevocable singularity, for which there is no fix”.[5]

Walking? It has been a long time since she was able to walk, unassisted at least. Reading? Reading is getting more difficult, or at least less practicable, due to the loss of ocular motricity resulting from her disease. Dictating to someone (her “typing assistant”)? Even that is becoming more and more of a struggle, due to problems with elocution arising from issues related to motricity, which make speaking an exhausting undertaking for her and her speech hardly comprehensible for the untrained ear. This is, she confesses, the hardest part: "the immeasurable suffering of not being able to make oneself understood by others".

She is still, notwithstanding, "the author of her own words", designing to this end, with her assistant, "a completely different approach to writing and reading".

With her usual unfailing honesty, she recalls as a "minor set-back" that this new method of writing was arrived at with much difficulty and much hullabaloo, after a long, very distressing, extremely painful, and stressful process of trial and error, for the autonomy which she is continually remastering does not cancel out her dependence, which is getting worse.

Consider the effort and expenditure of energy required to focus, persist, and concentrate in order to put together this collection of essays at my prompting. Can you imagine what it must have meant for her to be in lockdown due to the COVID-19 pandemic? "Never", she writes, "have circumstances so forcefully and acutely brought home to me the extent of my fragility: I was dependent on others when it came to any minimally normal daily activity, even essential ones, like drinking, eating, going to the bathroom, or washing and dressing myself before taking on the challenge of yet another day."

And yet we hear from her not a word of complaint, nor of denial, nor of self-justification; not any more than from Clement Rosset (who had nothing like the same obstacles to tackle). Like Auguste Berque, Anne-Lyse asserts that "Reality is not the property of any individual. You have to take it or leave it". And Anne-Lyse, quite magnificently, "takes it" for all it's worth.

Accept her disease? That is certainly not her intention. She neither accepts nor rejects it; she *works with* it. She will only agree to "'welcome" it, as she puts it, in order to fight "with" it, rather than "against" it. On this point, she has written some admirable passages that put me in mind of Etty Hillesum (fight tough but don't grow hard), full of lessons on how to live and how to approach life, valid for us all, whether able or disabled. What does she show us? She shows us that it is possible to weather a practically total physical dependence while preserving the essential, which is independence of mind.

"*Resistance*" and "*resist*", she writes on several occasions. Resist what? First and foremost: downheartedness, losing heart, succumbing to sadness, or to whatever it is in us that would want to give up, to lie down and die. It reminds me of what Laurent Bove noted about the "spirit of resistance" in Spinoza's masterpiece: "resisting the very real process of decay or decomposition, expressed as sadness ('to the extent that a person succumbs to sadness, that person is to that extent destroyed'), resistance being the endeavour to reorganize life, to reorganize oneself, to reorganize bodies".[6] This is what Anne-Lyse does every day. Collapse under the fatigue, the grief, the angst, to the point where one just "wants to give up the ghost"? Anne-Lyse, too, has been through all that. "And then an incredibly powerful force coming from my subconscious brought me back from the brink, despite myself: I chose life, a better life." Wise teachers throughout the world and at all times have taught this same lesson, all the more powerful in this case as it reaches us from someone in the great depths of a massive disability.

What a powerful life wish for this young woman! What capacity and yearning for happiness and what a gift for it!

"One thing for sure," she writes, "I never for a moment felt that I was lacking or missing anything. While my disability has always obliged me to adapt my environment to take account of the ongoing alterations in my sensory and motor capabilities at any one time, I have never had the impression that my life was in any way 'deficient' compared with what it was before. It had undoubtably become more difficult, more restrictive, but not for all that diminished." Once again, this puts me in mind of Spinoza, who points out that we only consider a blind person to be deprived of sight because we compare them to others or to their former self, while, in fact, they are not lacking anything because they are completely what they are: perfect, whole beings.[7] A deprivation is nothing, for reality as a whole is all there is. Anne-Lyse Chabert asserts this and helps us to understand it: "We cannot say that someone living with a disability is missing some ability, just as we would not say that we are missing a sense of magnetism, or the ability to fly, or the sharp hearing of a blind person; we are, quite simply, not thus endowed." What can reality be missing, or lack, when the reality is the totality of all that is? As Spinoza puts it, "for me reality and perfection are one and the same". Anne-Lyse writes:

> A life cannot be weighed and measured. Nor can it be compared or contrasted with anything else, because it does not lend itself to enumeration. I only had to watch carefully to realise that every time a path closed to me, others opened up. And they were only open and accessible to me. I was the sole vehicle, and alone responsible, for my life.

> A body is not a mere juxtaposition of organs, nor is it less complete in someone with a disability than in someone "normal" and "healthy" in mind and body. It is surely an error to take the measure of someone's life in terms of what they are capable of doing without taking into account the intensity of their experience of life. Should we not take as our starting point the notion that each and every life is experienced as a kind of minor miracle?

Let not this last term give rise to any sort of misunderstanding; although Anne-Lyse Chabert does admit to an interest in transcendence, she thinks and writes as a philosopher, that is to say, "free of any religious reference". Then why does she talk of a miracle? It is an echo of a powerful phrase by Rainer Maria Rilke, which she includes as an epigraph in *Transformer le Handicap* (transforming disability): "I feel there is a great miracle abroad in this world: every life is a life lived."[8] Despite this disabled or disabling body? Not at all; rather, thanks to it, with and through it, indeed, for there is no alternative:

> My body is not a dead-weight; it is not a burden with which I have been loaded, far from it; quite the opposite: it is the vehicle which enables me to feel, to think, for one always thinks with the whole of one's body in everything one does in life. [. . .] My body is above all my window onto the world [. . .]. True, it is getting slower and slower and more and more clumsy, but it is my mind's job to make up for this through a ceaselessly renewed effort at patient adaptation. [. . .] I see my body now, and always have done, as a great and loyal fellow traveller and companion, a team-mate who is always there for me, always at the front line of the struggle, who at the

> same time shares with me the gift of the life I am living.
> It is my bosom friend and closest ally.

Here we can truly appreciate the extent to which Anne-Lyse is a philosopher in the true sense of the term: for, in her, the courage to go on living is closely bound up with delight in thinking; like Montaigne, she asserts that "One must love life", however difficult and unfair that life may be, but with a "battling", tenacious love rather than a love fulfilled and a "courageous", rather than a love resigned. This, I think, is what most moves me: "it was when I took up the cudgels and entered the ring", she writes, "that I was able to start living".

And let us not forget the politics of it. Because what this little book, in all its grandeur, shows us is that disability is always a place where society and an organism meet, where a shortcoming, whether innate or acquired, encounters an environment that may be and should be managed.

One never lives alone, isolated from the world and the city, which is the "ring" you enter when you have taken up the cudgels. This "ring" is always intersubjective, social, and historical, and hence, political, for all of us, whether we are disabled or not, dependent or not (and sooner or later we will almost all become dependent), and we will have to ensure that the environment in which we live and which we share is made increasingly "habitable for everyone". Fairness and respect for fellow human beings require this. And these two concepts most certainly go hand in hand. As Anne-Lyse writes in her conclusion, it is up to us to decide what sort of world we "want to build" together.

This is why this book, which distills so much wisdom, is also a book about our rights and duties as members of society, a book that encourages us to think and engage in discussion, while at the same time, it is full of things for us to admire. Anne-Lyse Chabert, both as a writer and as a philosopher, sets herself up as a spokesperson for all those among us who are living with a disability and most especially those who, as she puts it, "are often inarticulate and unable to express themselves and, as a result, are never really heard and heeded". This is a book that provides a public service. It is addressed to all of us, to help us understand, to make us think and engage in discussion, and perhaps even to do something. Even when I do not agree with her (on euthanasia, for instance), the positions Anne-Lyse sets out help me to hone my own: she gives me insight, even into myself, and she soothes me even when dealing with such a thorny issue that stirs such deep feeling. Such is her ability to explore subtle nuances and to radiate calm, compassion, and open-mindedness.

But that is quite enough, if not too much, by way of introduction. Let her have the floor now to have her say in her very own strong, sweet, fair-minded, voice. Her writing reminds me of Rainer Maria Rilke's *Letters to a young poet*. To conclude, allow me to recall what was written by the poet in question, Francis Xaver Kappus, in his preface to the book in question: "When a prince is about to speak, everyone should fall silent".[9] I say that this should equally apply when the prince, as in the present case, is a princess:

> My ways of life are natural to me: in forming them I have never ever called in the help of any erudite discipline; but when I was seized with the desire to give a public account of them, weak as they are, I made it my duty to help them along with precepts and examples, so that I could publish them more decorously. I was

then astonished myself to find that, by sheer chance, they were in conformity with so many philosophical examples and precepts. Only after my life was settled in its activity did I learn which philosophy was governing it! A new character: a chance philosopher, not a premeditated one!

Montaigne, *Essays*, II, 12. English translation
by Michael Andrew Screech, 1991.

We must accept our existence to the furthest point possible; everything, even the unheard-of, must be possible therein. That is, at root, the only courage required of us: to be brave as regards the strangest, the most alien, the most inexplicable of our experiences. That human beings have been, in this sense, cowardly has done immeasurable damage to life; […] the 'world of the spirit', death, all those things related to us, have been so completely pushed from our lives by our daily defensiveness, that the senses with which we might grasp them have atrophied. […] But the fear of the inexplicable has not only made poorer individual existence; it has also limited human relationship […]. For it is not indolence alone that causes human relationships to repeat themselves, with such unspeakable monotony […]; but fear of some new, unforeseeable experience to which one believes oneself unequal. Yet, only those who are ready for everything, who exclude nothing, even the most incomprehensible, will live the relationship with another as something alive, and exhaust their own existence in so doing.

Rainer Maria Rilke, Letters to a young poet,
Letter VIII, 12 August 1904.

Acknowledgments

To humility, that restless, questing, seeking after the depths, which we must continually be calling back in order to defy that irresistible drive.

May it continue, with its humanity, to afford us comfort in our lives.

At every moment, open up your whole being to the possibility of a tremendous crumbling downfall.

I extend my heartfelt gratitude to my friend, André Comte-Sponville, for having encouraged me to go ahead with this book, which I was constantly putting off.

My gratitude also to Makino, who departed too soon. His calligraphy makes an appearance in this book; may his patience, while pursuing his work, continue to serve as an inspiration for all those who have shared, in one way or another, in all or part of his journey.

My warmest greetings and confirmation of friendship to Martine, one of my teachers at school, who at the time was determined to keep me up to the mark when it came to the demands of our beautiful French language despite the many early manifestations of my disorder. I was overjoyed to see her again after so many years. Many thanks for her endeavors in furthering the humble development of my most eager plans. And through her I would also like to pay tribute to all the other teachers who did likewise: their straightforward honesty and diligence have been exemplary and instrumental in setting their pupils on the right path.

And to all those I love, whose assistance I appreciate—too many to list individually here—they are the ones who keep me going on this journey, and I am profoundly grateful to them all. And to life; to the felicity of quite simply just being here.

Finally, to whoever is holding this book in their hands: I owe them the freedom to have been able to encounter myself. I hope those reading my writing will be able to enlarge on an open page the scope of their own hearts.

Introduction

Entering the ring to wrestle with my disease

> It is the destiny of every human being to be a unique individual, to find their own way, to live their own life, and then to die.[10]
>
> Oliver Sacks

"Fine, so you accept it": how jarring to me were those words spoken several years ago now by a close friend with the very best of intentions. To think that I was accepting was worse than to misunderstand me; it was to fly in the face of what I most demanded from life. Ten years later those words repel me just as much. I still do not really accept my disease. Is it then that I refuse it? To lay the question open to other possible replies, I would reformulate it in terms of a different alternative than acceptance or refusal: I have never given up fighting against my disease; but perhaps it is more accurate to say that I have accepted the idea of struggling with it rather than against it, since I could not live my life without its mediation. In other words, it was when I entered the ring that my life could begin.

Using this image in speaking of my disease as something confronting me is doubtless just a kind of metaphor to express what

I feel: the disease is part of me. I don't think of myself as ill each day as I wake; I am alive, that's all. Only someone looking on from the outside and making a comparison with what might be a "normal" life could make that distinction and describe each of us as "ill" or "well". It is up to us to believe or reject that description, even if unconsciously. And if there is a door to be unlocked so that things can proceed in harmony with the person's surroundings so that an ideal balance can be achieved, that is for the patient themself to do according to whether or not they agree to face up to the peculiar difficulty of their life or indeed to whatever difficulty each of us faces in life.

The neurodegenerative disease that has been my companion for some 20-odd years now clearly highlights the possibility of refusing confrontation with the difficulty: ever since my disease was diagnosed, it has been repeated to me over and over that it will evolve, affecting all forms of muscular activity all the faster if I do not regularly practice the movements that are threatened by the dependency it engenders. It was basically very simple: the more I accepted my disease—acceptance meaning doing nothing and letting it overcome me—the more all my motor neurons would deteriorate and disappear. How could anyone expect me to accept that?

Far be it from me to have ever intended to give up that struggle. On the contrary, at every moment I had to put obstacles in the way of this visitor from the shadows because I wanted to stay alert and seize all the possible ways of taking part in life that were offered to me to try, however abruptly presented or frightening they sometimes might be. In other words, I had constantly to challenge the future in order to forge ahead by maintaining to the utmost the physical capacity of the body I inhabit. It was my job to learn each time to be patient, to reorganize my daily life to accommodate my increasing dependency, and to integrate the new constraints imposed on me by the evolution of my disease. And to be ready to yield and with confidence abandon an earlier equilibrium that no longer corresponded to my ever-changing situation, moving on toward a new state more in tune with it, though still in the future.

The only way I would differ from an ordinary person would lie in the fact that the rhythm of my existence would diverge from the average career of my fellow human beings—if indeed there really did exist an average. Above all, there would always be the shocking need to struggle against obstacles created by human beings, to be constantly called on to forge the ways and means of just living my life. The fact that a pseudo-lethargy would have been imposed on me, cutting me off from normal intercourse by means of those very obstacles tending to make self-fulfillment impossible for me, which was for me the supreme offense, the single most monstrous insult to my being. An insult that, by reducing my being to a juxtaposition of cells that were going to degrade *to the point of necrosis*, would have made such a life void and without interest. Yet can one in fact say anything different about any one of us: from the moment of birth does not every human being begin to die?

Indeed, from a "normal" point of view, one differentiating the sick from the healthy and adopting a narrow conception of life, I was nothing more than a body with a faulty DNA that the spirit would inevitably have to watch wasting away over time.

That was not the life to which I aspired. Fully living my life, as I think I have often proved, was not just a question of being able to move about, nor even of just having organs that functioned; to borrow that fine expression of Oliver Sacks facing the ordeal of terminal cancer, we have all to find our own path, our own unique position from which we engage in the hand-to-hand combat with life. It was simply a matter of not trying to elude the present moment but of plunging into it wholeheartedly, not trying to escape or opt out. And if only we could be grateful for it, life would offer us so much to live for, whatever kind of tune we were called to dance to.

Today, possible new therapies—of which I have been told so much and which those who are embarrassed when my disease is explained to them make so much fuss of—are not what I most look forward to. I let things take their course, preferring just to look forward to the future because it is still always life leading the dance even in confrontation with the torments of disease. If a treatment presents itself, it will be an occasion once again to adapt myself to it, and, I dare to hope, I shall be sure never to forget, never to turn my back on my earlier experience. But whatever possible medical progress may or may not be made, one thing is clear to me: I have no desire to be divorced from myself.

I have often given up the idea of writing for publication. No, surely, I felt I had no talent for writing about myself. I have needed several years before being able to distance myself sufficiently from what I wrote to read it as the simple reader I would doubtless have been even just a score of years ago. Not that it would have helped to see myself after the interval of a few years, for I am today considerably more dependent as regards mobility than formerly. On the contrary, I am convinced that at the time such a sight would have overwhelmed me, eating away at and destroying the least of the ambitions I might have nourished.

But fortified by those extra ten years, I shall try to set out my own intimate experience that may destroy the prejudices associated *a priori* with a major handicap. And such a major handicap is from now on the hallmark of my life, this neurodegenerative disease having accompanied me for these last decades. So I hope that this book will be a force for others by showing from the inside what mostly can only be seen from the outside. These chapters really open the door into my universe for those who can read them with sufficient attention.

So, I gathered together my various papers, not without a critical eye, some having been written more than five years ago. I thought I should add my philosophical research work, as it clearly reflects the state of mind with which I approach the situation of disability that is for me like a mountain always to be scaled, ever to be overcome. Amazingly, even though experience has been my taskmaster, my demands are still the same despite the time that has elapsed. As that time has gone by and I have moved from paper to paper, I have given pride of place to the thanks and the tributes that are so essential in our lives. You have to be able to smile at life before the good news can begin to spread.

I would add that most of these texts and especially the links between them were written despite the difficulties of communication I refer to in the book; this laborious communication must constantly be reinvented; it is always a work in progress, always an additional handicap over and above the purely visible one. Language is what allows us to reach out to one another.

So I speak with difficulty? No problem! Whenever possible, one must have the courage to find roundabout ways of achieving the same ambitions.

Lastly, to be clear, my readers can read this book in any order, or rather, they can create their own order. Each of these papers reflects my small world in its own way and by itself. I already find it difficult to recount events sequentially and to describe my life chronologically, so I grant you, dear reader, that freedom. And anyway, that is not the essence of what draws us together; I just want to share a little intimacy. It is for you to make of it something fabulous that will accompany you your whole life.

I have organized this collection along four axes, as it were, the four compass points, that spring from the heart of my experience and from which I try to deduce the essence of what links us all together.

The first of those compass points, "Personal life", comprises the texts in which I consider the relationship between mind and body; I give here some indications of my very recent experience of being dependent on another person. In general, I try to make clear how our bodies modulate our perception of reality and affect it, bringing different experiences into our lives.

The second, "Devising solutions" brings together some papers in which I describe the meaning I attach to life, but also to death and the opportunities, not always offered, to discover our own sources of happiness.

A third section questions our "Institutions" and our environment, still from the particular point of view of my daily life with its problems. What is the degree of "freedom" one needs in life?