The right to be forgotten as a human right
Ending discrimination against cancer survivors
Florence Caeymaex, Ethicist

Illness and vulnerability are part of the human condition. From an ethical perspective, what are the consequences of continuing to define someone by a past cancer diagnosis, and how can we ensure that this experience does not become a permanent identity imposed on them?

Possible follow-up: What responsibility do insurers and other financial institutions have to avoid reinforcing this label and to respect a person's dignity, autonomy and ability to move forward with their life?

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In my presentation, I will try to explore the following question: **what are the consequences of continuing to define someone by a past cancer diagnosis, and how can we ensure that this experience does not become a permanent identity imposed on them?** I will try to answer the question not directly, but by exploring its signification. I will do it by philosophical means, explaining how personal and social identity are entwined and what is at stake when an illness, as personal *and* social experience, challenges one's own personal and social identity. My concluding remarks will be about in our society, and why we need to tackle all sorts of discrimination based on state of health.

I'd like to start with two introductive remarks.

Firstly, I have never experienced serious disease myself. My philosophical and ethical research is conducted, so to say, from the other side of the river. Whatever my efforts, my knowledge is not an experiental one. It differs from the knowledge and thinking developed by the rare philosophers and the more numerous writers, mostly women and feminists, who dared to start thinking with their personal, first-hand experience of disease – something we could therefore also name "illness". In this talk, I will try to convey an experience that is not my own, and to join my thoughts to theirs. In particular, I will draw from the writings of the female philosopher Claire Marin.

The second remark is contextual. I took part in a parliamentary conference last week. The conference was organised by a senator. It focused on cancer survivors return to work. The conference was attended by a number of people from the voluntary sector, non-profit organisations, mostly led by cancer survivors and /or close relations and relatives of dead persons. Their testimony was very precious for me. I came to realize that the individual and social challenges posed by cancer is not at all limited to the onset of the disease, its development and treatments. Instead, the period following the acute phase is truly a challenge: socially and existentially speaking, the timespan of a disease can be incredibly long, and go way beyond the treatment phase. Once someone falls outside the remit of the medical world, then come new social challenges. What I learned is that it can be just as difficult as the preceding stages. The subject of today's conference confirms the importance of this point and highlights that this 'social and personal aftermath' is incredibly long …

I would like to start with some reflections on the **question of personal identity**. My reflexions are based on my favourite philosophical traditions, that of feminist philosophy and the works of philosophers who tried to learn from the social sciences.

Following the philosophical traditions to which I belong, what we name « the self », does not come by itself, as if "consciousness" was just another ability of the human brain, like the ability to calculate with numbers or memorize lists of words. **If the "self" is the faculty to relate with oneself and to reflect on who we are as individual, such faculty or ability is intrinsically linked to relationality.** Developing and maintaining the self for a human being is not possible without continuous maintenance of relationships with others, other human beings (non-human beings can play a role, too). It is within our human, intersubjective interactions that we become who we are. **Without mutual care and expressions of mutual recognition, it is not possible for a human being to become his or herself,** and to shape a sound relation to oneself.

Defective everyday relationships (to be uncared for, to be ignored, to see one's basic needs denied, to be treated differently without justification, to be isolated, to be abused) can be harmful to the relation one has to his or herself. This is true at early age, but it's also true for grown up teenagers and adults. That's why **we are said to be vulnerable: we are interdependent, our lives depend upon each other. Philosophy and ethics of Care paid attention to this aspect of life (Joan Tronto, Carol Gilligan, Pascale Molinier).**

But it is necessary to add that such inter-subjective interactions are themselves shaped by social rules. Our behaviour towards others in not something we just decide individually, at our good will; the recognition and care we receive or give depend on our capacity to adapt to shared social rules and norms. Diverse social expectations spread through our relationships with others and our response to such expectations shapes largely the way we'll be seen by other people, what we could call our social identity. This in turn will shape the relation one has to oneself, in other words, one's personal identity.

Social norms are unavoidable. There is no society without norms, and they apply to many aspects of life: bodily conduct, symbolic and linguistic interactions, ways of learning and working, ways of doing things, physical appearance. Everyone knows how societies organise themselves after gender norms; even if it's not understood and expressed, most of us know enough to navigate with it, either male, female or non-binary. Adjusting ourselves to such norms is part of the play for any human being and each of us fashions his or her own manner to deal with these norms. In the best case, such norms are flexible: there usually is some space left so that we are *at the same time* "recognizable" as a member of society by others, and as a singular, unique person. But as we know, departing too much from a social norm can be risky for a person.

This is where I'd like to come up with illness. Firstly, I will present it as something that impacts the relation to oneself and to the others, relations that are intrinsically connected or intertwined. Secondly, I will turn to health as social norms, questioning what some scholars name "healthism", and to what is does to people who have experienced illness.

It is important to recognize that for humans the experience of serious disease such as cancer represents an existential ordeal: the suffering, the pain – whether due to illness itself or to treatments – the confrontation to the possibility of dying, the possibility of seeing one's own

abilities and capacities temporarily or permanently weakened and transformed. Georges Canguilhem, a famous 20th century philosopher and historian of medicine who was physician by training, explained that we should understand disease both as a deviation or failure from what medicine identifies as the "normal" (vs. pathological) *and* as an existential transformation and challenge for the patient, the forming of "another allure of life" (1943). As if disease was inseparable from illness. Canguilhem questioned the idea of "healing" (guérison, also "recovery"); he philosophically doubted that recovery could mean returning to the life a person had before being ill. He emphasized the irreversibility of the course of life and the irreversible (but continuous) changes a disease imposes to a life.

Claire Marin, a contemporary philosopher who has personally experienced serious illness, speaks about the "violence" of illness (and of the treatments also), about the way it dramatically interferes with the course of life, with our desires, expectations, ambitions. And therefore challenges the personal identity, what she names "the continuity of the subject". In her 2015 book *Violence of Disease, Violence of Life,* she writes:

> Disease disrupts these two aspects: bodily functions break down (organs damaged, destroyed or attacked; hormonal imbalances; proliferation of cancer cells; destruction of the immune system) and the body's normal functioning deteriorates (gait disturbances, speech difficulties, memory problems, mood disorders). The foundations of my way of being gradually fade away. The individual's scope for action is reduced. […] Disease is the loss of a certain margin of manoeuvre in life upon which the individual's sense of freedom is based (2015, 54 & 55).

> It cuts off the spontaneous impulse of consciousness to project itself; it destabilises the individual by preventing them from representing themselves in their usual way. […] Disease cannot be conceived of as a mere digression in an individual's life. Not only does it call their identity into question during the period of pathological activity, but it can also upend their entire history; it leaves its mark, from scars to the immune response, from physiological after-effects to psychological trauma. It becomes part of a new temporal framework, of which it constitutes the point of reference (2015, 67 & 68).

This is only a glimpse of what Claire Marin unfolds in her wonderful book about disease and illness as a personal experience. But from what is told here, we can infer that such an experience

is also a challenge for the family and other close relations; it challenges the working relationships and the various social relations of the patient in general. As I noted at the start of my presentation, human beings are interdependent. The event of a disease affects not only the person, but potentially the whole human ecosystem of care and recognition the person needs. Other persons around us, must adapt to these changes, and it's not easy: the ill person is likely to face lack of understanding, lack of care, anger, pity, distancing, abandonment (as in the famous novel by Tolstoy, *The Death of Ivan Illich*), exhaustion, and so on. Wonderfully it's not always the case, but we know that constant and collective efforts and good practical conditions are necessary to avoid such negative outcomes.

As explained before, social relations are not devoid of certain social norms, and the difference between the normal and the pathological, between health and disease play here a major role – especially in a society marked by the cult of performance and fitness. These norms will affect the way people behave with the ill person.

Those who have experienced a serious disease, or the ones who have a chronic condition are well placed to see how disease is likely to question and fragilize one's place in society. Of course, every life of any living being is averse to disease or injuries, but societies might as well be averse to them. I would like to quote Claire Marin again, in a section where she explains how the distinction between the person and his or her illness is getting blurred, how the illness takes over, pushing the subject's personal identity into the background:

> At a certain level, there is no longer any distinction between the disease and the individual. The patient is no longer merely sick; he is his disease. This is, first and foremost, what the medical approach leads him to realise. He is nothing more than a system of symptoms that correspond to the characteristics of his disease. The patient becomes a more or less legible sign, the expression of her/his pathology. The disease speaks through the patient in the first person, relegating her/him to a secondary role. […] The subject's identity is thus reduced solely to that of a patient (2015, 80)

If people handle this situation differently, whether conflictually or with acceptance, it is quite common that illness tends to become a form of a negative label in social life, imposing the subject to renegotiate his or her own identity accordingly. That is, to navigate an event that has an essentially negative social value. Let's read Claire Marin again:

> Although it primarily concerns the individual, it only becomes an 'illness' when the individual is identified from the outside as 'ill'. The 'recognition' of illness involves an assessment by the community. It is signalled by a failure in social functioning. Illness is a disruption to our ability to fulfil our role within the community.
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> […] Illness is regarded by society as a nuisance; it constitutes an obstacle to activity, a disability. Thus, illness may remain invisible as long as its effects do not impinge upon the individual's effectiveness, the individual being viewed as a 'political' and, above all, an 'economic' being.
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> […] In some cases, awareness of the illness only arises with this external observation of the difficulties or the impossibility of continuing with one's usual activities. Illness is therefore socially defined as the inability to be oneself – or, at the very least, to be oneself in the eyes of others. It calls into question social identity and, with it, social organisation itself. If the patient wishes to recover, it is also to reclaim that part of their identity constituted by their social persona. If we wish for them to recover, it is so that the manifestation of a disorder may disappear. (2015, 93-94)

And it is not an easy task, because on the one hand some social pressures tend to reduce the person's identity to his or her illness (or even to his or her disease), and this for a long period of time. Such reduction is a form of labelling; it can happen in ordinary social relations between people, or through impersonal processes, through the categories used by administrations or the ones used by insurance companies, as shown by the mobilization for the "right to be forgotten" for cancer survivors. But on the other hand, other social pressures supervalorise persons who show the capacity to fight against the illness[1], to affirm their personality or subjectivity against it and their capacity to return as soon as possible to his or her former social persona – sometimes actively ignoring what it really means to have recovered from a cancer or another serious disease : irreversible changes, discontinuity and, often, the transformation of one's own identity

[1] The popular image that has long prevailed and maybe still prevail is the image of war against cancer. In 1978, the American writer Susan Sontag who died of cancer at 71 (in 2004), in her striking essay Illness as a metaphor, wrote about the "military terminology" used to qualify both the cancer as illness (cancer as an assault against the organism) and the medical and social response to it (the need to kill the cancer cells, without killing the patient, the need to defeat cancer and bring the patient to recovery). Such metaphors are not innocent. I don't mean it's unnecessary to find the best treatments to bring patients to recovery, I just want to note that such metaphors tend to establish unquestioned norms upon patients, giving a preference to "good" patients who show determination over "bad" patients who tend to resign themselves to their condition and show less pugnacity.

and perspective on life, work, love, family, and so on. A number of writers who told the experience of their illness (often a cancer) emphasized this socially neglected aspect of it: its transformative and critical power (Claire Marin, Patrick Autréaux, Marie Uguay, Nina Lykke, Eve Ensler, Anne Boyer and many others I met thanks to postdoct researcher Jennifer Bélanger). Going through a disease, experiencing illness is a painful displacement, but it's also a new perspective from where to question prevailing social norms and values, and especially the ones attached to the ideal of health.

The social labelling on the one hand, the active ignorance of the irreversible changes caused by some diseases on the other hand are two aspects of one and the same phenomenon. Some scholars call it "healthism", a term forged the same way "feminism", "ableism" or "racism" were invented. I won't discuss a complex concept here. I just use the word to designate the normative system in which health is posed as a supreme value and illness receives an inescapable negative one – a normative system that devalues the lives that are perceived as injured, damaged, disabled, unfit or weakened. A normative system that prevents us to picture biological vulnerability, diseases, illness, and eventually death as integral to living beings. Healthism is a mindset that prevents us to perceive the transformative nature of serious diseases and to help the ill make sense of the biographical break they must endure (Bury, 1982, Vallet-Renart, 2020/1, n. 9); a system that privileges the ones who succeed to adapt and strive to get back to their "normal", anterior life.

Healthism is behind diverse forms of relegation, marginalization, stigmatisation, exclusion of the lives that are first perceived as, if not reduced to, "ill lives". In other words, healthism is behind what democratic societies name "discrimination": an unjustifiable difference in treatment of individuals or groups because of some characteristics that are socially perceived as negative. I think we are here at the core of the idea of human rights – an ideal of equal and just treatment of each human individual in his or her uniqueness, the recognition of his or her intrinsic value, everyone's right to participate in society and to find the proper conditions to fully develop one's own personality whatever the biographical breaks may be ; that is the right "to be oneself" instead of being merely "a diabetes", "a psychosis" or "a cancer" or an "unrecognizable" person in the eyes of the others and of society.