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Committee on Social Affairs, Health and Sustainable Development

Discrimination against persons dealing with chronic and long-term illness

Rapporteur: Ms Martine Wonner, France, ALDE

Draft report[1]

I. Draft resolution[2]

1. Chronic and long-term illnesses are the result of non-communicable diseases that often require long and expensive treatment for the community. They are the main causes of general and premature mortality. They alter the lives of at least a third of the European population. This percentage increases with age as these diseases strike the most vulnerable more frequently. They are more common in women than in men and are particularly frightening when children are concerned. The prevalence of multi-morbidity is increasing due to the aging of the population, but also to the combined effects of poverty, pollution and global warming.

2. Chronic and long-term illnesses are obstacles to dignity, well-being and self-fulfilment. Often difficult to diagnose, they can be particularly disabling in their most critical expressions, when they are not fatal. They are a source of discrimination and hinder the affected who may be deprived of their autonomy, as well as their rights to participation and full integration into society. Because of their direct and indirect effects, they harm the "full and equal enjoyment of all human rights and all fundamental freedoms", fall within the scope of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and involve obligations on the part of the States Parties to the convention.

3. Through their various public policies (health, social, research, employment, education, etc.), the authorities are able to limit the number and consequences of chronic and long-term illnesses. The CRPD offers an innovative vision of disability and disabilities. Some countries have indeed taken up this challenge, applying different strategies. Others have chosen to deny the existence of these diseases, at the risk of leaving patients to face their vulnerabilities alone and maintaining inequalities.

4. Neither are chronic and long-term illnesses the result of a reasoned choice. It is thus not acceptable that they are considered by certain actors in society as risk factors. In order to fight against the arbitrariness suffered by patients, it is necessary not only to adopt the paradigm shift proposed by the CRPD, but also to systematically tackle the obstacles caused by these diseases, which prevent patients from living their lives, and to rally around a common objective: the preservation of the dignity and well-being of patients. The voice of patients must be heard throughout the preparation, implementation and evaluation of public policies related to chronic and long-term diseases. Patients cannot be satisfied with equality when their wish is primarily to preserve their right to well-being and self-fulfilment. It is not for them to adapt to society, but for society to adapt to them, with due regard for reasonable accommodation.

5. Each individual is called to contribute to the general well-being, without hindrance. In order to remedy the profound social disadvantage experienced by people with chronic and long-term illnesses, the Assembly reminds Council of Europe member States of their commitments made on the occasion of the ratification of the CRPD. It invites them to continue their efforts in the fight against exclusion, by adopting strategies that revive the spirit that marked the birth of our public health systems and are aimed at strengthening the role of the welfare state, in order to improve the effectiveness and resilience of health systems, and ensuring universal access to health. The current health crisis has reminded us that administrations must be prepared to respond to the unexpected while being attentive to changes in society and eliminating obsolete regulations. The Assembly invites Liechtenstein to accede to the CRPD so that no European country remains outside this

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[1] Reference to Committee: Reference no. 4487 31 January 2020.

[2] Draft resolution unanimously adopted by the Committee on 1 December 2020.

framework, which is innovative and adapted to the needs expressed by people encountering obstacles in their immediate social and physical environment.

6. The Assembly urges the member States of the Council of Europe, on the basis of the provisions contained in the CRPD and examples of good practice resulting from co-operation between peers:

6.1. to strengthen the capacities of screening and prevention concerning chronic and long-term illnesses and to adopt a holistic approach, which is regularly reviewed and adjusted, and involves all sectors of the administration for the well-being of individuals, the fight against inequalities and vulnerabilities. The authorities must fight against diagnostic errors so that, after a certain period, which should not be longer than one year, each patient is able to exercise their rights again without hindrance;

6.2. to support and develop the offer of care and services allowing the preservation of well-being and self-fulfilment, while allocating sufficient resources and funds to achieve this objective, which is legitimate for everyone within the jurisdiction of the European Court of Human Rights, in particular when it comes to the professional sphere, by strengthening the resources of occupational medicine, which is often the patient's first interlocutor at the time of diagnosis or return to work. Once again, this Assembly calls on the national authorities to establish access to universal health care;

6.3. to ensure that the obstacles preventing chronic and long-term patients from exercising their legitimate right to dignity, well-being and self-fulfilment are subject to sufficiently dissuasive sanctions to enable patients to exercise their rights to well-being and fulfilment, in their professional or private life. It is not for the patient to adapt to society, but for society to adapt to the patient;

6.4. to conduct, in partnership with civil society, evidence-based and effective awareness-raising campaigns on chronic and long-term illnesses among the general public, ensuring the right to a normal life through the full enjoyment of human rights and fundamental freedoms;

6.5. to involve all stakeholders in policy development, evaluation and implementation, including people with chronic and long-term illness and their families, including by sharing the results of impact evaluation. The real consequences of certain diseases still seem too little-known (Lyme disease, etc.).

7. The Assembly suggests that the member States of the Council of Europe do more to control the removal of obstacles to the rights of patients living with chronic and long-term illness, in order to encourage actors in the private sector to share the same approach with a view to fighting against discrimination suffered by patients because of their status. It recommends evaluating patient protection systems such as the “right to be forgotten”.

8. The Assembly stresses the important role of parliaments. It invites them to promote the principles contained in the CRPD, to adopt legislation in line with the convention, to ensure the allocation of sufficient budgetary resources, to encourage the public authorities to adopt appropriate national strategies and action plans, and to demand accountability for their effective implementation. It also encourages parliamentarians to contribute to awareness-raising actions on an individual basis.

9. The Assembly recognises that people with chronic and long-term illness and their families are severely and disproportionately impacted by the measures taken to combat the novel coronavirus during the current pandemic. Thus, it calls on the member States of the Council of Europe to pay particular attention to their needs, in view of these circumstances, including after their recovery, insofar as Covid-19 could be the cause of chronic illnesses.

10. Finally, in the context of the Covid-19 pandemic and in anticipation of the revision of Directive 2000/78/EC, the Assembly encourages the European Union to accede to the revised European Social Charter before extending its powers in the area of health, in order to monitor and improve the state of health in the EU. It also reiterates its encouragement to the remaining Council of Europe member States to sign and ratify, as soon as possible, the revised European Social Charter.

II. Explanatory memorandum by the Rapporteur, Ms Martine Wonner

1. Introduction

1. Chronic and long-term illnesses are the result of non-communicable diseases that often require long and expensive treatment for the community. They are the main causes of general and premature mortality. They alter the lives of at least a third of the European population. This percentage increases with age as these diseases strike the most vulnerable more frequently. They are more common in women than in men. They are particularly frightening when children are concerned. The prevalence of multi-morbidity is increasing due to the aging of the population, but also to the combined effects of poverty, pollution and global warming.

2. Since 1946, the World Health Organization (WHO) has defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". The European Social Charter (revised) states in its principles that "Everyone has the right to benefit from any measures leading to the enjoyment of the highest attainable standard of health". According to the OECD, "Health is, according to the OECD, to be and to feel well, to enjoy a long life free from physical or mental illness, and to be able to participate in the activities one desires. Chronic and long-term illnesses are barriers to well-being because they impede the "full and equal enjoyment of all human rights and fundamental freedoms". Therefore, they fall within the scope of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

3. The UN Convention on the Rights of Persons with Disabilities (2006) recognises that "the concept of disability is evolving and that disability results from the interaction between persons with disabilities and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". According to Article 1, "Persons with disabilities include persons with long-term physical, mental, intellectual or sensory impairments ...". The extent to which these impairments incapacitate a person depends on the level of barriers encountered in society.[3]

4. The latest edition of the OECD report "How is life?"[4] published in June 2020, indicates that well-being has not improved in all its dimensions since 2010. This is particularly the case in health, which is one of the 11 dimensions measured by the organisation. While more than a third of the European population suffers from chronic illness[5], the report also reveals that 6% of adults have recently experienced depressive symptoms. One in eight people experience more negative than positive emotions during a normal day. Chronic and long-term illnesses are a breeding ground where inequalities and vulnerabilities thrive as these diseases hit the most vulnerable the hardest.

5. In January 2020, the Committee was seized for report on the basis of the motion for a resolution "Discrimination against people with long-term illness" (Doc. 15011) tabled by a group of parliamentarians led by Ms Béatrice Fresko-Rolfo (Monaco, ALDE). The ambition of the parliamentarians is to measure the discrimination suffered by people who have experienced cancer or are still undergoing treatment, but also by patients with chronic and long-term diseases (Lyme disease, chronic inflammatory bowel diseases, autoimmune diseases, etc.). Despite the progress in medicine and the accumulated knowledge about these diseases, which are increasingly common in society, some people remain stigmatised. They are subject to blindness by societies that struggle to recognise their situation. This reality exposes a gap between an anti-discrimination policy that overlooks affected people and the reality of rights that patients cannot fully exercise to reconcile their personal and professional life despite the disease. The effectiveness of the social rights of the chronically and long-term ill is clearly questioned on both normative and material levels. It is up to our societies to guarantee human dignity, quality of life and equal access to rights for all. I have been appointed by the Social Affairs Committee to work on this subject.

6. As Rapporteur, I would like to remind you that the Parliamentary Assembly promotes breast cancer awareness every year. In this context, the Social and Equality Committees held a joint public hearing on 30 September 2019 on life and quality of life after breast cancer, concerning breast cancer patients when they try to return to a "normal life" while medical treatment is still on-going. Being confronted with cancer forces them to overcome situations that should no longer exist in an inclusive society, unjustly depriving them of opportunities to realise their life plans. There is a wide variety of chronic and long-term diseases (Lyme borreliosis, Crohn's disease, Charcot's disease, inflammatory colitis, multiple sclerosis, type 1 diabetes, lupus, etc.) which are often disabling physical disorders, impacting society's perception of these patients, preventing them from fully enjoying their rights and excluding them. The Assembly has adopted a gender-based approach

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[3] All Member states of the Council of Europe have ratified the CRPD, with the exception of Liechtenstein.

[4] OECD (2020), How's Life? 2020: Measuring Well-being, OECD Publishing, Paris, https://doi.org/10.1787/9870c393-en

[5] OECD, Health at a Glance: Europe 2018, chapter 3, figure 3.22 : Self-reported chronic condition http://dx.doi.org/10.1787/888933834680

in its reports. Because of my training as a psychiatrist, I decided to extend the scope of this report to cover all the stigmatisation of people suffering from disorders linked to psychiatric illness, sometimes leading to exclusion, as they are also deprived of dignity and self-fulfilment.

7. The Secretariat of the Social, Health and Sustainable Development Committee launched a survey on the legislative and institutional framework organising, at national level, the fight against discrimination against people suffering from chronic and long-term illness, through the European Centre for Parliamentary Research and Documentation (ECPRD) in August 2020. The questionnaire had received 28 responses by 11 November 2020[6], from the parliaments of 23 member States. In preparing the questionnaire, I wished to analyse discrimination against and inequalities suffered by people with chronic and long-term illness; to identify examples of good practices to remedy such discrimination, particularly with regard to the diagnosis of mental illness; to observe access to employment for chronically ill and long-term patients; and to measure dignity with the existence of legislation on the "right to be forgotten". The full analysis and the questionnaire can be found in document AS/Soc (2020) 51. A summary is appended.

8. On 22 September 2020, the Committee held a public hearing with the following experts[7]: Ms Matilde Leonardi, Director of the Neurology and Public Health Unit, Carlo Besta Neurological Institute Foundation IRCCS (Italy); Mr Kawaldip Sehmi, Director General, International Alliance of Patient Organizations (IAPO) and Mr Ignacio Doreste, Advisor, European Trade Union Institute, European Trade Union Confederation (ETUI).

2. The reality of discrimination against people living and working with a chronic and long-term illness

9. Every 15 seconds, a woman is diagnosed with breast cancer somewhere in the world.[8] This disease affects women's lives and still kills too many people. In the United States, the breast cancer death rate has decreased by 40% since the late 1980s, and today there are more than 3.8 million breast cancer survivors.[9] According to World Health Organization statistics, one in eight women in Europe is at risk of developing cancer before the age of 85; approximately 20% of breast cancer patients are under the age of 50, and about 36% between the ages of 50 and 64. To better fight the disease, patients need psychological support during the illness but also after recovery. This support can also be useful to the patient's family and friends. For many patients, returning to work means returning to a normal life, but the consequences of cancer are severe and can include fatigue and lack of concentration and memory. Patients are often not sufficiently aware of the procedures and standards that can help them adapt their work to their specific needs. Some survivors need to learn a completely new type of work because cancer has made them unable to perform their previous tasks. Some managers and co-workers are uncomfortable with cancer patients, which may end up isolating them. More than half a million women in Europe are affected. Through the Pink Ribbon campaign, almost $100 million has been raised since 1992 against this disease and its effects, which primarily affects women. More than 1000 monuments have been illuminated around the world to raise awareness of the cause of breast cancer and to honour those affected by the disease. The Council of Europe contributes very actively to this campaign every year.

10. Mr Doreste stressed during the hearing that there was no consensus on a single definition of chronic and long-term diseases in Europe. The information provided by the ECPRD also confirms that the collection of data is neither uniform nor systematic, nor does it allow for an understanding of situations of comorbidity. Nevertheless, chronic and long-term diseases are widely perceived as obstacles to well-being. In the words of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), they undermine the "full and equal enjoyment of all human rights and fundamental freedoms". As Ms Leonardi noted during the hearing, they must be distinguished at the level of "functioning"[10] to ensure that no one is left behind. The functioning approach is promoted by the World Health Organization (WHO) on disability. As the disease cannot be changed, the environment must be adapted to the needs of the patient for participation but also for full and effective integration into society.

11. The incredible progress of medicine in the diagnosis and treatment of cancer, chronic and long-term illnesses must not hide the difficulties encountered by patients in order to guarantee them a return to a normal

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[6] Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Poland, Portugal, Romania, Slovak Republic, Slovenia, Spain, Sweden and Turkey.

[7] http://www.assembly.coe.int/LifeRay/SOC/Pdf/DocsAndDecs/2020/AS-SOC-2020-PV-06-ADD-en.pdf

[8] GLOBOCAN Facts and Figures 2018, quoted by Estée Lauder Companies, https://www.elcompanies.com/

[9] Facts and figures from the American Cancer Society,2019-2020

[10] As adopted on the occasion of the Resolution WHA 54.21 of 22 May 2001. See also the dedicated page on WHO's portal https://www.who.int/classifications/icf/en/

life. For example, one in two people in Great Britain, born after 1960, will have to face cancer at some point in their lives and will not only remain scarred in the flesh but will have to face the roughness of society to be able to continue their professional and private life, despite the disease. The aftermath of the disease can lead to difficulties in returning to work, as employers are not sufficiently informed or are often reluctant or ill-equipped to adapt workstations and adapt the pace to the condition of sick employees. Employment protection for reasons of illness is often circumvented. People who have experienced cancer also suffer discrimination in their private lives because of the disease or treatment, including after remission. This adds a psychological dimension to the pain and difficulty.

12. The first of the discriminations against the chronically and long-term sick concerns employment. The voluntary decision to apply for or remain in a job may be contrary to the regulations in force or to the employer's interest. Diabetes patients are still administratively barred from certain professions.[11] However, the associations denounce that “drug treatments (increasingly effective insulin) and medical devices (insulin pumps, and in particular continuous glucose measurement) have undergone major therapeutic and technological advances, adapted to the needs and lifestyle habits of diabetics. However, certain regulatory texts are totally disconnected from this reality and deny that these devices allow patients to carry out their activities”. According to WHO, the European continent is facing a real diabetes pandemic. Some 60 million people in the WHO European Region suffer from diabetes, about 9.6% of women and 10.3% of men aged 25 and over.

13. Lyme borreliosis is the most common zoonosis in Europe, with between 650,000 and 850,000 cases per year in the European Union, and a higher incidence in Central Europe. In its resolution of 2018/2774[12], the European Parliament has already noted that there is no European consensus on the treatment, diagnosis and detection of Lyme disease and that national practices vary. The disease is sometimes initially asymptomatic and can remain so for several years, which can sometimes lead to serious complications and irreversible damage similar to that of a chronic disease. Many patients are not diagnosed quickly and do not have access to adequate care. They often feel helpless and ignored by public authorities while some continue to present persistent and disabling symptoms. To date, the disease has not been recognised throughout Europe in its chronic form despite the significant medical, social and economic cost. It leaves patients isolated and vulnerable, particularly before diagnosis.

14. Patients suffering from chronic inflammatory bowel diseases such as Crohn's disease and ulcerative colitis are not only marked by the symptoms of their disease but also by the cumbersome treatment aimed at alleviating their suffering. These diseases have long been perceived as shameful diseases, leaving patients to retreat to their homes. The disease undermines the dignity at work of those affected due to the chronic disorders but also to the iterative surgical interventions to palliate the progression of the disease. Patients are subject to discrimination in the workplace despite domestic legislation against violence and harassment in the workplace, despite their decision to remain in active employment.

15. Similarly, people affected by psychiatric illnesses or psycho-social disorders (such as those on the autism[13] spectrum) face difficulties in fully enjoying their lives due to diagnostic errors and delays, often long, since these diseases are still insufficiently identified, especially among women, and in any case not sufficiently recognised by employers. Patients with psychiatric disorders (bipolar disorders, schizophrenia) not diagnosed by general practitioners or other front-line professionals due to lack of training struggle to access a fulfilling professional and private life, sometimes to the point of exclusion, even though they can benefit from rehabilitation and support care allowing them to return to a normal life. A better understanding of these diseases calls for greater acceptance by society.

16. People with chronic, long-term or cancer remission often face difficulties on the credit and insurance market. They cannot realise their projects even though their resources are sufficient. Schemes exist in some countries that impose a 10-year period beyond which people who have overcome the disease are no longer required to declare their illness to insurance companies. However, companies can access information through backdoor channels and reject a credit application without justifying their opposition. In a context where life expectancy has increased, it is legitimate to question the meaning of a contract where all risks are avoided. The disease also affects the retirement pension of patients. In a society where "ageing well" is a concern, they are plagued by irregular contributions that obstruct the level of their income at the time of the legal retirement age; disability status may appear, with regret, the only possible recourse for a dignified life. The information

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[11] https://infos-diabete.com/diabetiques-exercer-metier-reves/

[12] https://www.europarl.europa.eu/doceo/document/TA-8-2018-0465_FR.html

[13] Report by Ms Sevinj Fataliyeva (Azerbaijan, EC/AD) on “The treatment of people with autism and their families”, Doc. 15177.

provided by the ECPRD revealed that patients are still too often deprived of a retirement pension, suffering a double penalty, with their illness.

17. The question of the remission of a chronic and long-term illness remains problematic due to different interpretations depending on the patient or the society around the patient. Remission does not necessarily mean healing. The disease always occupies a place in the patient's life, which society often refuses to recognise. This discrepancy is the source of discrimination and frustration for a person who thought to turn the page and continue his or her personal reconstruction. These discriminations undermine the mental health of patients and hinder their efforts to rebuild their lives. These people feel a sense of isolation that is a breeding ground for relapse.

3. Returning to a normal life

18. Faced with the lack of consideration of their specific situation, patients have united in groups and associations able to carry their cause to public authorities and private companies. Some groups, however, do not have a big enough network or enough weight to be considered an essential intermediary. The consideration of their situation and the consultation of the sick cannot be further ignored by the legislator for the necessary revision of the texts having an impact on them. It must also be heard by private companies in the name of their social responsibility.

19. Scientific progress makes it possible to make an ever earlier and more accurate diagnosis. It is necessary to guide health professionals through the measurement of the different symptoms of the disease and the activation of a protocol taking care of the patient. The peculiarity of certain psychiatric diseases and certain chronic diseases is that they are almost asymptomatic. Patients may experience “medical wandering” (to describe the period during which a diagnosis is delayed, or simply the absence of a relevant diagnosis). The reality is that these people know they are sick but are deprived of the protection to which they are entitled. Sometimes patients with Lyme borreliosis or psychiatric disorders may have to endure delays of more than one year (or even several years) to put a name to their disease and consider their life in spite of it. Patients and their families face misunderstanding and especially non-recognition of their situation until a diagnosis activates the protections guaranteed by the legal framework. Without an active preventive policy that puts into place awareness campaigns for the general public and health professionals, public authorities and civil society associations have not turned to routine and large-scale screening of asymptomatic diseases. Non-diagnosis of the disease may be a cause of desocialisation. Isolation is a breeding ground for worsening symptoms of these diseases. The awareness needed to reduce ignorance about these diseases must be provoked.

20. The European Social Charter (STE 35 and STE 163) provides a legal arsenal that guarantees the protection of people with disabilities but also allows them to claim a satisfactory standard of living. The situation of chronic and long-term patients often falls under standards that are inconsistent or contrary to the higher standards described in the Charter. At the request of civil society, some countries have adopted laws concerning the “right to be forgotten” in order to permit cancer patients to stop declaring the illness after a certain time lapse, thus allowing access to loans or life insurance. This right seems to now exist almost uniformly across Council of Europe member States, having been integrated into EU legislation. However, in order to measure the truly beneficial effects and to assess the guarantees proffered as concerns the integration of patients, the Council of Europe should be able to support the efforts of civil society, following an assessment of the exercise of this right.

21. The Social Charter states that “All workers are entitled to fair working conditions”. Far too many people are discriminated against in the workplace after remission from cancer or diagnosis of a chronic or long-term illness. They are too often perceived as people at risk or frightening. The protection to which they are entitled is hampered in its implementation because of the employer's lack of preparation for the reception of a person who has been affected by cancer, or another chronic or long-term illness. Applications for workstation development or the decision to continue a professional activity should not be a barrier for these individuals. Employers' awareness efforts should be supported to encourage the appointment of staff to manage occupational health situations in order to be the interlocutor, mediator and above all the guarantor of well-being at work.

4. Chronic and long-term patients facing Covid-19

22. Covid-19 causes comorbidities, as do chronic and long-term diseases. Chronic and long-term illness cause over-vulnerability to the virus. As we begin to realise that the disease not only causes the excess mortality of vulnerable people, we discover that it is also the cause of conditions, still little known, which are the direct consequence of the effects of Covid-19 through the persistence of symptoms or irreversible damage done by the virus. These adverse consequences could lead to new chronic and long-term diseases.

23. During the hearing, Mr Sehmi stressed the impact of the Covid-19 pandemic on chronic, long-term patients and their loved ones. The pandemic is not only a source of additional stress, but also a source of direct and indirect discrimination.

24. Last June, this Assembly already called on member States to intensify their efforts "to ensure free access to high-quality public health care guided by the needs of patients rather than profit, regardless of gender, nationality, religion or socio-economic status".[14]

5. Conclusions

25. Reading the information provided by the ECPRD makes it possible to distinguish two public approaches to chronic and long-term diseases by national administrations. On the one hand, there is the health approach to detecting and accompanying the sick and, on the other hand, the social approach responding to the imperatives of integration and accommodation in order to resume a normal life. The survey also suggests hybrid models. These pathways are part of the CRPD framework.

26. Health systems should, with sufficient budgetary resources, be able to offer adequate protection. Nor should these diseases be seen as risk factors, or risk doubly stigmatising the sick. As envisaged in Article 26 of the CRPD "in order to realize their physical, mental, social and professional potential, achieve full participation in all aspects of life", the needs of patients must be met from the point of view of functioning, as recommended by WHO, in order to achieve and maintain maximum autonomy. The role of public policy is not only to build resilience but to develop the possibility of post-disease growth, regardless of access to disability status or not.

27. It is clear that the rights of patients are not always respected in the context of chronic and long-term diseases, even if it is also clear that this is not necessarily a deliberate intention of the States or the social actors that are companies, whether as an employer or as a provider of financial services (insurers, banks, etc.). Even if second-generation rights are not enforceable everywhere, it is up to the Parliamentary Assembly to identify irregularities and rally to the cause of people with chronic and long-term illnesses. The situation of these people is unfair as they must endure the consequences of their illness, even when in remission with regard to cancers; or after diagnosis of chronic and long-term diseases, whether physical or psychological. It is a question of placing the cursor of remission and diagnosis at the same level for patients and the society around them so as not to inflict double punishment on the sick, to assure them of their place in society and to encourage the emergence of a society capable of taking this reality into account without violating their integration.

28. Chronic and long-term diseases pose real problems for our societies that exceed the financial cost alone. I regret that they are not always approached with the necessary empathy. Some chronic diseases are persistently misdiagnosed, or even deliberately side-lined. I am thinking of the endometriosis from which suffer, on average, by one in ten women, and whose effects can be particularly impactful,[15] while not being sufficiently well known by health professionals. 80% of women with this disease experience limitations in their daily tasks and 40% have fertility problems. It is an incurable disease that alters the lives of women suffering from it socially, professionally and economically (chronic fatigue, anxiety, loss of self-confidence, fertility issues, difficulties in fulfilling their professional obligations, etc.). In July 2020, French parliamentarians introduced a bill to make the fight against endometriosis "Great National Cause 2021".[16] This proposal responds to a request from civil society and seeks to push the authorities who have been considering[17], for several years, to include endometriosis onto the list of LDAs. Fibromyalgia is also one of those common illnesses, especially among women, which everyone knows but which is not yet officially considered by health authorities as an illness.

29. Despite limited competences, the European Union is a major player in the fight against chronic and long-term diseases, as well as playing an important role in the implementation of the CRPD. It also helps member States to implement the Convention. The 2010-2020 (EU) European Disability Strategy focuses on eight priority areas: accessibility; participation; equality; employment; education and training; social protection; health; and external action. Its focus is on accessibility, mobility and equal treatment at work and in

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[14] See Resolution 2329 (2020) "Lessons for the Future of an Effective, Rights-Based Response to the Covid-19 Pandemic"

[15] Liberation, 18/11/2020, Endometriosis: "Some women feel compelled to resort to strategies to hide their illness at work" https://www.liberation.fr/france/2020/11/18/endometriose-certaines-femmes-se-sentent-obligees-de-recourir-a-des-strategies-pour-cacher-leur-mala_1805995

[16] http://www.assemblee-nationale.fr/dyn/15/textes/l15b3206_proposition-loi

[17] EndoFrance, White Paper on Endometriosis and Employment, November 2020, https://www.endofrance.org/wp-content/uploads/2020/11/Partenariat-EndoFrance-Livre-Blanc-MP-V2-121120.pdf

employment, where it is most relevant to bringing about change. It has led to significant gains in mutual recognition of disability status. Through its responsibility as a standard promoter, the European Union has helped to generalise the concept of reasonable accommodation promoted by the CPRD. In the current context, EU intervention is desirable while it is limited by the framework provided by the treaties. In order to contribute to the alignment of standards, I think it is desirable that the European Union should not only quickly accede to the European Convention on Human Rights but also to the European Social Charter.

30. In the context of a health situation disrupted by Covid-19, the European Union should be able to expand its powers to support the dissemination of good practices in the fight against chronic and long-term diseases. The consultation of the ECPRD allowed our Committee on Social Affairs to gather information on the implementation of the “right to be forgotten”, which is an example of good practice. Thanks to this right, patients in remission of cancer have been able to return to a normal life by being able to borrow money without having to declare their illness to the insurer. This right is a major contribution by the European Union in favour of the rights of the sick. The protection of personal data has made a leap forward. I am in favour of proposing an evaluation of the exercise of this right in Europe, to measure its benefits and more clearly identify its limits for the well-being of the sick.

31. The Council's Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and work[18] prohibits all discrimination on the basis of disability and establishes the principle of equal treatment. Article 5 states that patients must operate in an “appropriate and reasonable” environment. In anticipation of the revision of the directive and in view of the current situation, it is the responsibility of the member States to implement the means and budgetary resources necessary to preserve the individual well-being of the sick and to ensure that the right to health protection is guaranteed. As our colleague, partner for democracy Mr Allal Amraoui, noted at the hearing, it is necessary to allow occupational medicine to play its role, and it is up to the employer to ensure that the working environment is adapted to the needs of the sick. These principles should also be beneficial to all private sector players. Individuals affected by a chronic and long-term illness are entitled to much more than dignity, the sick have the right to flourish.

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[18] https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:fr:HTML

Appendix: Summary of responses to the European Centre for Parliamentary Research and Documentation questionnaire

1. The Secretariat of the Committee on Social Affairs, Health and Sustainable Development distributed a survey on the legislative and institutional framework organising, at national level, the fight against discrimination against people with chronic and long-term illnesses, through the European Centre for Parliamentary Research and Documentation (ECPRD) in August 2020. It received 28 responses on 11 November 2020[19] from the parliaments of 23 Member States: Austria, Belgium, Bulgaria, Croatia, Cyprus, the Czech Republic, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Poland, Portugal, Romania, the Slovak Republic, Slovenia, Spain, Sweden and Turkey.

2. Regarding the legislative and political framework, the questionnaire revealed that 12 vs. 10 countries have specific legislation for people with chronic and long-term illnesses and that 17 vs. 5 countries have a national strategy. Some countries have both a law and a strategy (Austria, Bulgaria, France, Germany, Hungary, Ireland, Lithuania and Romania). While some countries have a general framework based on social policies on disability (Austria, Finland), others have adopted a health care-centred approach (France). Austria described an established approach to the rights of patients and the prohibition of discrimination in the private sphere and in the professional environment. On the other hand, and as of 2011, France has defined a limited list currently incorporating 30 pathologies or long-term conditions. This list has been revised several times from 25 to 30. Thus, Lyme disease was added while high blood pressure was reclassified as a “risk factor”[20]. Some LDAs are “exonerated” or not (the cost of care and treatment is totally covered by the standard national health insurance), depending on the level of dependence caused by the disease. In this case, the status of the patient is close to that of the disabled person. Germany distinguishes between chronic and long-term illness. While the former falls into the field of disability, the second falls under labour law. It has defined 21 pathologies. Chronic diseases were included in Sweden's 2014-2017 National Health Strategy. In its plan for the development of the welfare state (2016-2023), Estonia establishes as a goal the sustainability of social welfare. Its mission is to preserve its natural, economic, human and social capital simultaneously and for each individual. It is based on the OECD definition of well-being.[21] Romania has addressed this issue from the perspective of the fight against discrimination following an ordinance published in 2000: AIDS patients can become refugees.

3. Only four countries have a specific law establishing a “right to be forgotten” (i.e. allowing these people not to report their illness). Nonetheless, the “right to be forgotten” appears from the reading of several responses as a contribution of the European Union through Case C-131/12 Google against Spain and Article 17 of the General Data Protection Regulation (RGPD).[22]

4. 14 vs. 6 countries acknowledge that long-term illness is included in the calculation of pension rights. However, there are significant variations from country to country. The validation is often conditioned by a possible disabled status as reported by the Czech Republic, or sufficient payments to the funded pension system as in Ireland.

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[19] In some bicameral parliaments, both chambers responded. The lower house of the Austrian parliament, having sent the questionnaire to several administrations, provided several responses. The Slovenian Parliament indicated that it did not wish to respond to the questionnaire.

[20] debilitating stroke spinal cord insufficiency and other chronic cytopenias; chronic arteriolopathies with ischemic manifestations; complicated chistosomiasis bilharziosis; severe heart failure, severe rhythm disorders, severe valve heart disease, severe congenital heart disease; active chronic liver disease and cirrhosis; severe primary immune deficiency requiring prolonged treatment, infection with the immuno-deficiency (HIV) Type 1 diabetes and type 2 diabetes; severe forms of neurological and muscle disorders (including myopathy), severe epilepsy; hemoglobinopathies, haemolysis, constitutional and acquired severely acquired chronicles; haemophilia and constitutional conditions of severe haemostasis; coronary heart disease Severe chronic respiratory failure Alzheimer's disease and other dementias; Parkinson's disease; hereditary metabolic diseases requiring specialized prolonged treatment; cystic fibrosis; severe chronic nephropathy and primitive nephrotic syndrome; paraplegia; vascularitis, systemic lupus erythematosus, systemic scleroderma; Progressive rheumatoid arthritis; long-term psychiatric conditions; haemorrhagic colitis and Crohn evolutionary multiple sclerosis; evolutionary structural idiopathic scoliosis; severe spondylarthritis; organ transplants; active tuberculosis, leprosy; malignant tumour, malignant condition of lymphatic or hematopoietic tissue.
https://www.ameli.fr/paris/assure/droits-demarches/maladie-accident-hospitalisation/affection-longue-duree-ald/affection-longue-duree-ald

[21] https://www.oecd.org/fr/statistiques/initiative-vivre-mieux.htm

[22] https://gdpr.eu/right-to-be-forgotten