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The Financial Consequences of Granting Disability Status to Persons with Multiple Sclerosis and the Viewpoints of those Suffering from the Disease

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Multiple sclerosis (MS) is a neurological disease that affects young adults aged between 20 and 40; the disease develops over several decades. In France, it affects around 134,000 persons. The gradual degradation of the individual's state of health, combined with a life expectancy greater than 65, has a significant impact over the long term on a person's ability to continue working in his or her chosen field. It also raises the issue of financial compensation linked with the difficulties of maintaining a normal professional activity.

For a third of the persons, cessation of a professional activity, after numerous periods of sick leave, preceded the granting of disability status. However, although the persons suffering from MS were soon granted disability status in the years following the administrative recognition of a long-term disease status, the granting of disability status did not mean that people with MS ceased working altogether in the short term. The state of health of these persons obliged them to apply for disability status at an early stage of the disease without completely ceasing their professional activity. The date of the granting of disability status to a person in relation to the development of a professional career, the rules governing the possibility of receiving both a wage and a disability pension, and the diversity of situations concerning private contingency insurance led to very different situations.

The interviews, conducted as part of this research and based on a mixed method, show the complexity of obtaining access to rights and a lower loss of resources for the most knowledgeable individuals. A referral to a social worker or a medical officer of the French National Health Insurance system as soon as the diagnosis has been made, as well as providing people with MS with clear information about the various schemes, would contribute to helping some of the individuals to continue their careers, in particular on a part-time basis. The benefit system is primarily based on the principle of financial compensation for the career pursued before the acquisition of disability status. One of the challenges in future developments of the social protection system – with the aim of achieving horizontal equity – will be maintaining the possibility of pursuing a career despite disability.

Multiple sclerosis (MS) is a neurological disease that affects young adults aged between 20 and 40. Around 134,000 persons are believed to suffer from MS in France (Pierret, 2024), most often women, who are two or three times as likely to suffer from the disease (Walton, 2020). This long-term disease develops over several decades with acute episodes ("relapses") which gradually alter the patient's functional status, followed by a stage in which there is a regular deterioration in functioning with or without superimposed relapses (progressive form). Indeed, the development of MS and the disease course are very heterogeneous, as certain persons can have few symptoms or disability for decades, whilst others cannot walk or see in few years. The manifestations of the disease are diverse: motor,

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visual, sensory, and cognitive deficits, and bowel or bladder control troubles, as well as extreme fatigue. Hence, the gradual deterioration of the state of health combined with a life expectancy greater than 65 mean that people living with MS have to face the challenge of maintaining their jobs in the long term. The issue of financial compensation associated with the difficulty of maintaining a normal professional activity also arises.

In France, in this health situation, the social protection scheme for persons with disabilities makes it possible to partly compensate for loss of income when it is no longer possible for an individual to continue working on a full-time or even a part-time basis. As previous studies have already shown, MS is the disease that leads to the most declarations of disability status (Cuerq, 2008) and only 15% of people living with MS retire without having been declared disabled (Leray et al., 2023; Espagnacq et al., 2023). The disability pension can be complemented, for those who have taken out private insurance or who have employer-based insurance, by income from private insurance (contingency insurance) or national public solidarity for persons with insufficient financial resources (Disabled Adult Allowance, *Allocation adulte handicapé*, AAH).

This study is part of the project "Effects of Multiple Sclerosis on Occupational TraJectorIes" (EMOJI), which is based on a mixed research method that combines a quantitative component, based on data from the HYGIE database, with a qualitative component based on around twenty semi-directive interviews conducted in 2020 with persons suffering from MS (Leray et al., 2023). Based on a database representative of employees, we were able to study the amount of sick leave allowance, unemployment benefit, and the salaries, and estimate the disability pension levels of persons suffering from MS throughout their careers. Furthermore, based on the interviews, it was possible to analyse the individual situations from the patient's perspective, as this information was not available in the data from medico-ad-

DEFINITIONS

Sick leave, daily allowances and long-term diseases

During an episode of sick leave, the benefits paid by the French National Health Insurance system (*Assurance maladie*) occur three days after the start of the sick leave (waiting period). After this time, the daily allowances are paid to the insured person (if he/she has been registered with the Social security for one year and has worked at least 150 hours over the three months leading up to the sick leave, or has received an income equal at least to 1,015 times the minimum hourly wage over the six months prior to the period of sick leave). The amount received is equal to 50% of the average wage calculated over the three months leading up to the sick leave. For employees covered by the Statutory Health Insurance Scheme (*Régime général de la Sécurité sociale*), the payment of the daily allowance is capped at 360 days per period of three consecutive years. The employees having the long-term disease (*Affections de longue durée*, ALD) status benefit from a longer payment period for periods of sick leave related to the illness: three to six months renewable over a maximum duration of three years, but the sum received remains the same. Furthermore, after six months of sick leave, the insured person switches to the "long-term disease" status (the criteria of the duration of activity or contribution levels changes and have to respect those presented below in the framework of the disability pension). This status enables the individual to continue to receive the daily allowances after 360 days of sick leave, with the maximum period remaining three years from the date of the first period of sick leave. Hence, it is not possible to receive the daily allowance for more than three years. After this point, to receive Social security payments, the person has to apply for a disability pension.

In complement to the payment of allowances by the French National Health Insurance system, after one year in the company, the employer is obliged to compensate for the loss of income resulting from the sick leave. The employer must maintain a minimum gross remuneration of 90% of the wage for the first 30 days, then 66.6% the following 30 days (the duration of the maintenance of the wage depends on the employee's seniority in the company, with a maximum of 180 days[1]). Hence, when the person shifts to the 'long-term diseases status, the employer no longer has a legal obligation to maintain the salary. According to the collective agreements or the employer's choice, the durations or amounts received may exceed these legal obligations. The wage supplement paid by the employer may be directly paid by the latter or by the contingency insurance that covers it.

The disability pension and declaration of physical incapacity

The obtention of a **disability pension** depends on the conditions relating to the inability to work and affiliation to the social security system: 1. A work or earning capacity reduced by at least two thirds (66%), whatever the professional activity, after a non-occupational accident or illness; 2. Affiliation to the social security system for at least twelve months on the first day of the month during which the sick leave occurs (leading to disability status) or the disability is recognised. A person must also have paid contributions on the basis of earnings at least equal to 2030 times the minimum hourly wage (*SMIC horaire*) over the twelve civil months prior to the labour disruption, or have worked at least 600 hours over the twelve months prior to the labour disruption or the recognition of disability. The disability pension is calculated on the basis of the average annual wage. It is based on the ten highest years of wages (the amount of the wage taken into account is subject to contributions within the limit of the state social security's annual ceiling).

There are three categories of disability pension: category 1 (30% of the capped average wage of the ten best years), category 2 (50% of the capped annual wage), and category 3 (50% of the capped annual wage, to which is added the constant attendance allowance).

Recognition of unfitness for work is granted by the occupational doctor when the employee's state of health (physical or mental) has become incompatible with the post he/she holds within the company. It is only when the occupational doctor declares that no reorganisation, adaptation, or transformation of the employee's job is possible, even though the employee's state of health justifies a change or adaptation of the post, that the doctor is able to consider that the person is physically unfit for their job. The official medical recognition of physical unfitness obliges the employer to look for ways to rehabilitate the employee. Nevertheless, the employer may decide to dismiss the employee if he or she can justify that it is impossible to offer them a job compatible with his or her state of health, or if the employee refuses the job. The employer may also dismiss the employee if the declaration of physical unfitness for work specifically states that maintaining the person in the job would be seriously prejudicial to his/her health or that his/her state of health is an obstacle to any kind of rehabilitation.

Hence, there is no direct link between the disability pension (assessed by the Social Security system on the basis of work capacity "in the absolute of the individual") and the declaration of physical unfitness for work (declared by the occupational doctor in relation to the post occupied by the employee). Hence, a person may continue to work even if he/she receives a disability pension, and a person declared physically unfit may not receive a pension. These different elements attest to the complexity of the benefit system, which can – due to a lack of knowledge of the persons concerned –make it difficult to access the various allowances at the time of the diagnosis.

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[1] Since the wage records in the HYGIE database took into account the additional pay paid by the employer, it was not necessary to impute it.

ministrative surveys. Indeed, as shown by the interviews, the complexity of the social protection schemes (the duration of sick leave entitlement, the transition to a long-term disease status, entitlement to a disability pension, declaration of physical incapacity for work, etc. (see Inset "Definitions") was exacerbated by the equally complex rules of private contingency insurance (personal sickness and disability insurance schemes, or employer-funded schemes, are free to set the terms and conditions of allocation, with possible qualifying periods). These different situations make access to benefits potentially difficult, especially as the professional career prior to the illness may also have an impact on the amount of the pension (discontinuous career, part time, temporary employees, many changes of employer, etc.). Lastly, the management of the illness at the time of the diagnosis (frequency and duration of the sick leave, resignation, change of employer, the salary at the time of the transition to a disability pension, etc.) may also have an effect on the final level of the resources.

Data about careers drawn from administrative sources made it possible to study the financial situation prior to and at the time of the granting of disability status, and in the longer term. These sources only included data relating to wages, the daily allowances paid by the French Social Security system in case of unemployment and sickness, and the additional wages when sick leave is paid by the employer. The data also made it possible to estimate the amount of the disability pension. However, information relating to the wage supplement paid by the contingency insurance in case of disease after the mandatory period covered by the employer (see Inset "Definitions"), the wage supplement paid by the contingency insurance in case of disability, and the income supplement paid by the family branch of the French Social Security system (Disabled Adult Allowance, *Allocation adulte handicapé*-AAH), Active Solidarity Income, *Revenu de solidarité active*-RSA), bonus, etc.) was not available. The interviews helped to shed light on the non-visible aspects of this medical-administrative source, in particular other types of income, the management of access to rights, and the patient's point of view about their overall situation.

CONTEXT

This second issue of *Questions d'Économie de la Santé* ("Issues in Health Economics") is part of the project "Effects of Multiple Sclerosis on Occupational TraJectorIes" (EMOJI). This project, which involved the French National School of Public Health (*Ecole des Hautes Études en Santé Publique*, EHESP), the Paris Est Créteil University (UPEC), and the IRDES, funded by the French Multiple Sclerosis Research Foundation (*Fondation pour l'aide à la recherche sur la sclérose en plaques*, Fondation ARSEP), sets out to study the long-term impact of multiple sclerosis on occupational trajectories in relation to access to employment and resources. It was developed using a mixed method, combining a quantitative analysis based on the HYGIE database and qualitative analysis based on twenty semi-directive interviews. The entire report is available on the IRDES website. The authors would like to thank the Fondation ARSEP, which provided the financial support for this research.

Less frequent granting of disability status for recently diagnosed persons

In the HYGIE database, 42% of the 961 persons identified with a MS long-term disease status are recorded as having received a disability pension during their career (Espagnacq et al., 2023). Disability status is most often granted in the years immediately following the administrative recognition of a long-term disease status (60% of the persons were acknowledged as disabled within three years). Ten percent of the persons who were not long-term disease acknowledged as disabled were recognised as having a long-term disease status in less than three years, as too little time may have elapsed after the diagnosis for them to be acknowledged as disabled. For the persons who were not acknowledged as disabled (not deceased and not retired), the average time period for the attainment of disability status after the recognition of a long-term disease status was ten years. Furthermore, adjusted to take into account the year of birth, the age at which a long-term disease status was recognised, and the gender, the oldest persons had a higher probability of being granted disability status than the youngest persons, and the persons who were recognised as having a long-term disease status after 2001 had a lower probability than those who had been acknowledged this status prior to 2001 (see Table 1).

A number of phenomena may account for these results. The youngest persons were able to benefit from innovative treatments at the time of the diagnosis and/or in the first years of the disease course, which enabled them to delay the granting of disability status. In addition to this medical factor, there have been improvements in the diagnosis of MS, which involves spotting the less severe cases and a more systematic and early granting of long-term disease status (in order to benefit from disease modifying therapies). These two elements therefore mechanically prolong the time period between the recognition of a long-term disease status and the granting of disability status. Even if the quantitative results from the HYGIE database show that the most recently diagnosed individuals are less likely to be granted disability status, it is not entirely unlikely: 25% of the persons diagnosed after 2006 were acknowledged a disability status half of whom during the three years following the recognition of a long-term disease status. Although not representative, the qualitative survey shows that the new treatments do not eliminate the risk of granting of disability status: half of

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Factors associated with having disability status

		Estimation (odds ratio)	Confidence intervals at 95%	
Gender	Women	*Ref.*	*Ref.*	*Ref.*
	Men	1.13	0.83	1.54
Year of birth	Before 1954	**2.68*****	**1.65**	**4.36**
	1954–1963	**2.19*****	**1.53**	**3.14**
	1963–1972	*Ref.*	*Ref.*	*Ref.*
	After 1972	**0.35*****	**0.24**	**0.51**
Year in which the MS was acknowledged as a long-term disease	Before 1996	1.43	0.87	2.36
	1996-2001	*Ref.*	*Ref.*	*Ref.*
	2001-2006	**0.63***	**0.42**	**0.97**
	After 2006	**0.46*****	**0.31**	**0.68**

* : significant at 5% *** : significant at 0.1%.

Reading: Compared with persons born between 1963 and 1972, those born before 1954 had a 2.68 times greater risk of being declared disabled, adjusted for the gender and year of being granted the administrative recognition of a long-term disease status, all things being equal.

Scope: Persons granted Multiple sclerosis (MS) long-term disease status (between 1987 and 2013) and who received a disability pension.

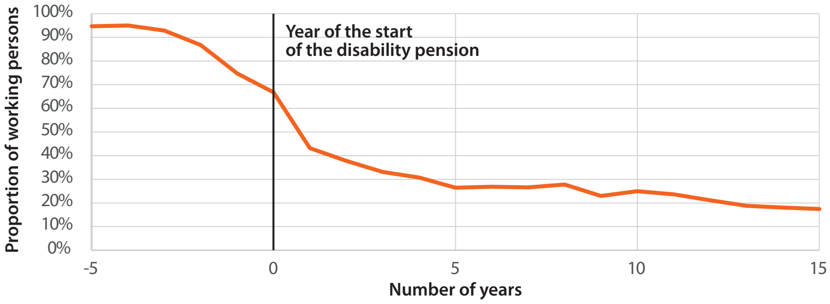
Source: HYGIE.

the interviewed persons had "recently" received their diagnosis (under ten years ago) and were undergoing treatment; only two of them were "not yet" officially granted disability status. For the others, the attainment of disability status occurred in the years following the diagnosis, as was the case for the oldest cases (Leray et al., 2023).

The decrease in professional activity begins several years before the attainment of disability status

Before the granting of disability status, all the persons suffering from MS were not involved in a professional activity: 5% of them received no wage five years before the attainment of disability status (see Figure 1). As previous studies have demonstrated, there is a significant reduction in professional activity after the recognition of a long-term disease status (Espagnacq et al., 2023); in addition, there is an average waiting period of four years between the recognition of a long-term disease status and the start of the disability pension. Both factors led to a "net decrease" in activity in the two years leading up to the granting of disability status, attaining 70% of persons who received a wage in the year of transition to disability status (see Figure 1).

F1 **Proportion of working persons according to the duration of the disability status (excluding deaths and retirement)**



Reading: A year after the attainment of disability status, 40% of the persons who received a pension also received a wage.
Scope: Persons granted Multiple sclerosis (MS) long-term disease status (between 1987 and 2013) and who received a disability pension.
Source: HYGIE.

The allocation of a disability pension, whatever the category, is not incompatible with work (see inset “Definitions”). Indeed, the year following the start of the disability pension, 40% of the persons still had a professional activity. This percentage subsequently decreased, attaining around 30% of people still working after five years. Then, over the next five years it was relatively stable, with a gradual decrease resulting in a proportion of professionally active persons of around 20% fifteen years after the attainment of disability status. Although it decreases over time, the attainment of disability status does not imply a total cessation of work, especially during the initial years (see Figure 1).

The quantitative source does not provide information about the amount of time

SOURCES AND METHOD

In terms of mixed method strategies, a sequential approach was adopted. It involved beginning with the quantitative phase to orientate the implementation of the qualitative phase, with the aim of enrichment and complexification. According to Aguilera (2021), "the enrichment strategy aims, in theory, to enrich the quantitative approach by highlighting the processes or mechanisms that it could not reveal. Qualitative analyses were conducted, with the aim of illustrating and complementing the quantitative results by identifying the precise causal mechanisms at play". Furthermore, the strategy of complexification ‘aims to qualify the statistical analysis, and even amend it by underlining the importance of other factors or other processes involved, which were not observed or observable in the preceding phase. The qualitative phase interacts with the quantitative result without necessarily taking it at "face value".

From the outset, the project "Effects of Multiple Sclerosis on Occupational TraJectorIes" (EMOJI) was conceived by combining a quantitative and qualitative approach. The quantitative study was based on a medico-administrative database that associated data from the pensions insurance scheme and data from the French National Health Insurance system (*Assurance maladie*) [source: HYGIE database]. This concerned a random sample of beneficiaries aged between 22 and 70 in 2005 (hence, born between 1935 and 1984), who had contributed at least once to the General Pension Scheme (*Régime général de Retraite*) during their life. It was combined with data from the National Inter-Regime Information System on Health Insurance (*Système national d’information inter-régimes de l’Assurance maladie*, SNIIRAM) for those covered by the French Social Security System, and included beneficiaries who received healthcare on at least one occasion that was recorded by the Frenc National Health Insurance system in the years 2003, 2004, and 2005. This sample was complemented by the services recorded for these individuals between 2005 and 2015, thus giving it a longitudinal dimension. The retrospective dimension was obtained through information about the individuals’ career when they entered the job market, which for some was more than thirty years beforehand. A career biography was available for each individual (quarterly contributions validated in employment, unemployment, sick leave, or retirement, and annual earnings data). The HYGIE database was updated with the addition of new data in 2009. In total, the 2005 and 2009 cohorts represent 533,951 and 379,763 beneficiaries respectively. The data is updated annually, and the last available year is 2015. Nevertheless, as this database is an administrative source, it does not include contextual data or socio-economic elements relating to the person and his/her entourage. Furthermore, only the income from work and the daily allowances (unemployment benefit and sickness benefit) are available. This data was used to calculate the disability pensions (Leray et al., 2023). This is why it was decided to combine a statistical analysis with data taken from semi-directive interviews conducted in 2020 with persons suffering from multiple sclerosis. The collection of qualitative data per interview provided rich and contextualised information that helped with the interpretation of the quantitative measured results relating to a large number of persons but limited in terms of available information.

The IRDES report no. 589 (Leray et al., 2023) describes in detail the project, method, and analysis per theme of the interviews outlined in this article.

people continue to work, because only the amount of the salary is available; in contrast, the interviews tend to show that the attainment of disability status is accompanied by a reduction in the person's working time. They also highlighted the diversity of the situations at the time of the attainment of disability status. The main cause of the total cessation of professional activity was principally the person's state of health (for example, Émilie and Murielle). But, depending on the possibilities in a company, flexible work arrangements may allow for a partial continuation of the professional activity (Michelle), and the person's attitude is also important as it may be an obstacle (Pascale, Céline) or a "facilitator" (Cécile) for the person's continued employment after the obtention of the disability pension (Leray et al., 2023).

Émilie, a communication manager, alternated periods of sick leave over three years – due to hospitalisations – and resumptions of her work, before being dismissed for inaptitude and receiving a category 2 disability pension.

> "[I had] regular episodes [of sick leave], while taking stock of the situation. They were trying to stabilise my state of health, but this never happened. (…) I was out of work for three years, in fact. I was very disappointed that I was less productive and I felt that my performance at work was disappointing. (…) And when we gradually opted for the dismissal solution [for inaptitude and declared disability], I must say that at that point I was ready to move onto doing something else with my life."
>
> **Émilie, 41 years old**
> Diagnosed in 2016, divorced, 2 children,
> €1,400/month (disability pension and contingency insurance)

Murielle's case shows that the nature of the professional activity, without vocational rehabilitation, may be an obstacle to maintaining the person in employment. She was an auxiliary and worked in the operating theatre of a small cosmetic surgery clinic. Before the allocation of the disability pension, she was on sick leave for two years. Her state of health resulting from the sequelae of the relapses meant that she was never able to go back to work.

> "I was unable to walk for over eight months and afterwards I had to walk with two crutches, and even used a wheelchair. My movements are less precise and I tremble a lot. All the surgical interventions are over. I couldn't expect my boss, who'd always been very kind towards me and paid me a good wage, to wait for my recovery. Anyway, I would never have recovered as you can see."
>
> **Murielle, 48 years old**
> Diagnosed in 2005, currently undergoing a divorce, no children, €1,000/month (disability pension and Disabled Adult Allowance, or AAH)

Conversely, the case of Michelle, who was an auxiliary nurse prior to the diagnosis, shows that when the post is adapted, the person is able to keep their job.

> "There was no post in which I could be rehabilitated, given the gravity of my multiple sclerosis. So I was declared unfit for my work as an auxiliary nurse. (…) I explained my case to them and there was a half-time post in the archives department, where they couldn't find anyone because it was part time. So, the occupational doctor said: *'It would be ideal, but I'll also give you disabled status to ensure you have a wage supplement and that your income doesn't decrease too much'.*"
>
> **Michelle, 48 years old**
> Diagnosed in 2014, married, 2 children,
> €1,250/month (works part time, disability pension and contingency insurance)

Cécile's case shows that maintaining the person in their post may necessitate a reduction in the level of responsibility and adaptations to the post, while taking into account the employee's point of view.

> "I continued in my post of director of the child care centre for more than a year [after the diagnosis]. (…) And really it was too much for me. After that, I was offered a post as… I had been a director for ten years… I was offered the post of assistant director in a larger nursery because as they said: *'there's less stress as an assistant director'*. (…) but it didn't go well. And going from being a director to an assistant director, even though it was in an entirely different type of organisation, feels as though you are regressing and that's no good! I couldn't handle it psychologically. I wanted a post that was 80% of my former job, so the doctor declared a category 1 disability. On that basis, my employer offered me a management post in the early childhood department, where I work as a project manager."
>
> **Cécile, 53 years old**
> Diagnosed in 2005, married, 1 child,
> €3,000/month (80% activity and disability pension)

Pascale's case attests to the difficulty of keeping one's job when the employer does not support this decision.

> "My employer played on the fact that the medical officer had placed me in the second disability category. He said to me: *'the trouble is that you have a serious condition'*. (…) In fact, I was harassed. They did everything they could to persuade me that there was no way I could go back to my old job. (…) I threatened them, as I had a solid case. They ended up apologising and basically told me: *'We'll pay you to do nothing while we create a tailor-made post'*. (…) After one year, during yet another restructuring of the company, they did find me a management post in a department called the Transformation Department."
>
> **Pascale, 50 years old**
> Diagnosed in 2013, divorced, 1 child,
> €2,800/month (active; 3 half-days per week, disability pension, and contingency insurance)

Just like Céline, who was in dispute with her director at the time and had many periods of sick leave.

> "… She told me: *'The only solution is a dismissal'*. Because, due to my problems this is what I negotiated with my director, because, anyway, I had a category 2 disability. (…) I suggested that I only work part time. That's how we settled the dispute… "
>
> **Céline, 45 years old**
> Diagnosed in 1997, married, no children,
> €1,200/month (works part time and cat. 2 disability pension)

Very frequent and long periods of sick leave leading up to the allocation of a pension

As outlined in the inset "Definitions", the rules governing compensation by the state insurance scheme mean that you cannot receive compensation for a condition after three years. In principle, it is not possible to receive more than 360 days of compensation payments over a three-year period, unless the sick leave is linked to the recognition of a long-term disease status or if the person's sick leave is associated with a "long-term disease". Depending on one's seniority in the company and the duration of the sick leave period, the employer has an obligation to maintain a minimal part of the wage (which decreases over time). Hence, after three years of sick leave, in the event that the person is unable to resume their professional activity, the declaration of disability is the only way to continue receiving an income that replaces the Social security income. The request for disability status may be made earlier if the person's state of health matches the criteria of the disability pension, that is to say a stabilised state of health and a loss of two thirds of the capacity to work.

The data from the HYGIE database made it possible to study the number of sick leave episodes three years before the attainment of disability status: the average number of sick leave days was 72 days three years before, 165 days two years before, it therefore doubled in just one year –, and in the year before the granting of disability status, it attained 243 days. However, few persons (around 5%) had three years of sick leave before the start of the disability pension. The interviews shed light on this situation: the start of the disability pension followed long periods of sick leave or successive episodes of sick leave, sometimes without a return to work, as was the case for Murielle, Michelle, and Pascale, without waiting for the maximum three-year period. The issue of the cessation of sick leave payments was occasionally evoked to request a disability pension (see Céline's case). The interviews also helped to shed light on the role played by the doctors or social workers in helping the persons to attain disability status and ensuring they maintained their entitlements.

> "And fifteen days later I lost the use of my legs. Just like that, and so, afterwards, I was unable to stand up for eight months, and I even lost my sight, there were many things (…) and eventually I was granted disability status after two years of sick leave."
>
> **Murielle, 48 years old**
> Diagnosed in 2005, currently undergoing a divorce, no children, €1,000/month (disability pension and Disabled Adult Allowance, or AAH)

> "In fact, I never went back to my old job. I never even had the time to say goodbye to my uniform and my colleagues. That was the last time I did my job. In fact, I became ill in November 2014 and I only started working again in May 2016. I was on sick leave for one and a half years (with attainment of disability status at the same time)."
>
> **Michelle, 48 years old**
> Diagnosed in 2014, married, 2 children, €1,250/month (works part time, receives a disability pension and contingency insurance)

> "My sick leave lasted a long time and, because, as I've explained, I suffered from one relapse after another, I was hospitalised. So as always as I'm a single mother, I made sure that I was hospitalised, but only in the daytime. [... I dropped off] my child before school began and I left her in the evening and picked her up at 7 p.m. And I got on with the rest of my day. But, of course, I became very tired, so my sick leave was prolonged and prolonged, and prolonged, and that eventually led to an interview with the CPAM doctor [French local health insurance fund doctor], who said to me: *'Look! Given the state of your health…'*. (…) Initially, I was granted disability status by the Social security system."
>
> **Pascale, 50 years old**
> Diagnosed in 2013, divorced, 1 child, €2,800/month (active; 3 half days per week, disability pension and contingency insurance)

Gilles' case shows that when the person's health makes it impossible to maintain a professional activity, it takes a while to accept the situation.

> "[His doctor] *'You are going to lose everything with this'*. And, at first, I didn't want to accept it (…). And even at the beginning of 2017, I wasn't ready. And then after yet another flare-up, I said to myself: *'OK…'*. I'd finally accepted the idea! And so, in June 2017, she [his GP] said *'We're going to apply for disability status'*."
>
> **Gilles, 53 years old**
> Diagnosed in 2014, divorced, 2 children, €3,100/month (disability pension and contingency insurance)

Céline requested a rapid recognition of disability status (six years after the diagnosis) because she was afraid of losing her allowances.

> "On the advice of my father [a doctor], I had planned ahead and made my request for recognition of disability status, as I had been sick for one and a half years, every three months, and I was definitely going to lose my entitlement to the daily allowance, with regard to this disease."
>
> **Céline, 45 years old**
> Diagnosed in 1997, married, no children, €1,200/month (works half time and a cat. 2 disability pension)

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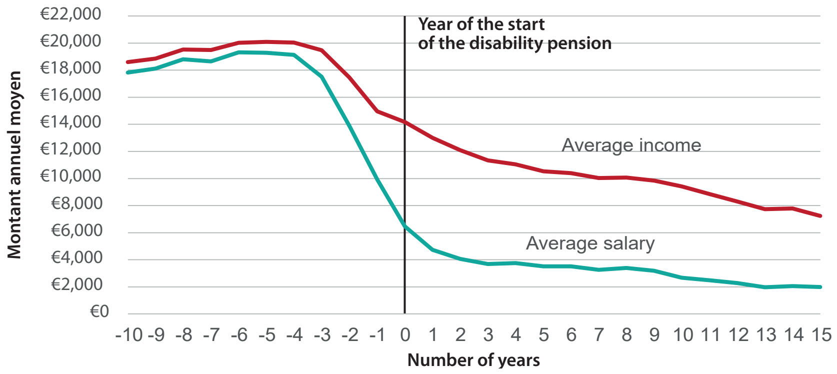
Resources of those receiving the disability pension at the start of the disability status



Reading: Two years prior to the start of the disability pension, the average annual salary was 14,000 euros and the income, including the daily allowances for sickness, unemployment benefit, and the employer's obligation to maintain the wage, and the wage (for those receiving a salary), was on average 17,800 euros per year. Two years after the attainment of disability status, the average annual salary was 4,000 euros and the income, including the wage, the disability pension, and any sickness or unemployment daily allowances, was on average 12,000 euros per annum.

Scope: Persons granted Multiple sclerosis (MS) long-term disease status (between 1987 and 2013) and who received a disability pension.

Source: HYGIE.

Claire's case highlights the important role played by the social worker, who helped her avoid losing her disability pension allowance after a contractual termination.

> "I had to take sick leave because the first relapse was pretty tough. (…) So, over the one and a half year period, I juggled between episodes of sick leave and attempts to resume my job, and then at some point I realised that I really needed to wipe the slate clean. (…) We decided on a mutual termination of contract with my employer. That was it! Because she understood my situation, and we got on very well and formed a great team, and I found that really reassuring because I didn't feel guilty, embarrassed, or bothered with regard to the work team. (…) It was the social assistant who motivated me to apply for the RQTH* and ask for the disability pension."
>
> **Claire, 39 years old**
> Diagnosed in 2016, single with no children, €1,300/month (unemployment benefit and disability pension)
>
> * Recognition of disabled worker status

Before the attainment of disability status, the person's resources have already decreased

Although the level of pension is set at less than half of the wage of the best years of the career of the individual receiving the pension, this does not, in reality, necessarily imply (even without receiving all the income) a sudden loss of income for the persons concerned. Indeed, several years before the start of the disability pension, the average annual income had already decreased, shifting from an average of 14,900 euros per year to 9,900 euros one year before the allocation of the disability pension. However, the income level – including, in addition to the wage, unemployment benefit, sickness benefit, and the mandatory wage supplements paid by the employer one year before the allocation of the disability pension – was close to the career's average annual salary (14,200 euros). Indeed, Figure 2 shows that the loss of income (without taking into account funding from private contingency insurance or from national solidarity schemes such as the Disabled Adult Allowance (AAH) or the Active Solidarity Income (RSA)) began three years before the attainment of disability status.

As demonstrated above, the loss of income was due to the reduction in professional activity resulting from long periods of sick leave. The reduction in resources was partly made up by the Social security daily allowance and the compensation paid by the employer for the shortest periods of sick leave (taken into account on the Figure), as well as by the private insurance companies that take over if the employer or employee has taken out a policy (not taken into account on the Figure). Hence, the resources provided by sick leave pay (and to a lesser extent from unemployment benefit) already constituted a non-negligible proportion of the resources of these persons before the attainment of disability status. Indeed, these allowances represented less than 5% of these resources five years before the disability status; then they represented 10% three years before, 20% two years before, and 40% the year before the disability status (see Figure 2). While the proportion of unemployment benefit was stable over time (around 7% before the disability status), the proportion of the daily allowance for sickness increased significantly over the three years before the granting of disability status, attaining 50% of the person's income one year before the start of the disability pension.

As Julien explains, according to the collective agreements, a loss of income is possible in certain situations during long periods of sick leave.

> "The private contingency insurance only guarantees 75% of the gross income now, so I only receive 75% of my gross wage. They no longer cover my previous income. (…) when you have a period of sick leave, the private contingency insurance [sickness] complements the Social security daily allowance up to a certain percentage, for a certain length of time. So, for three months of the year, they cover 100% and afterwards everything depends on one's seniority in the job. (…) In my case, according to my company's collective agreement and given my thirteen years of seniority (…), they cover me at 100% of the wage for three months and after that at 75% of the gross wage.’
>
> **Julien, 52 years old**
> Diagnosed in 2016, married, 3 children, €3,500/month + bonus (professional activity + disability pension)

The income support allowances after the attainment of disability status were mentioned by the persons who took part in the qualitative section, some of whom even stated that they had major supplementary income sources, such as contingency insurance (sickness or disability) and the Disabled Adult Allowance (AAH), which enabled them to limit their loss of income.

In Michelle's case, the medical officer of the French National Health Insurance system suggested that she asks for disability status in order to obtain a half-time position, which enabled her to maintain her income. Céline (mentioned above), who had just changed to a category 2 disability, managed to negotiate a shift to half-time work with her director, without a loss of income, to avoid dismissal. Cécile also maintained her wage by shifting to disability status and by maintaining 80% of her professional activity. The case of Pascale, who wanted to continue to work to maintain "social contact", shows that it was primarily contingency insurance that enabled her to maintain her standard of living. The disability allowance may attain the level of the person's wage before the disability status, as explained by Pascale and Gilles, as the latter was well informed about his contingency contract before his disability status. Conversely, Murielle's case illustrates the important role played by income from national solidarity schemes (the Disabled Adult Allowance in her case) when the disability pension is insufficient.

> "I'm well paid considering it's a part-time job if you look at the ratio. (…) It's around 1,200 euros, 1,240 euros. And to think that I used to get 1,450 euros after eighteen years of seniority."
>
> **Michelle, 48 years old**
> Diagnosed in 2014, married, 2 children, €1,250/month (works part time, disability pension, and contingency insurance)

> "They maintained my director's wage, for example. Even when I became an assistant director my wage didn't go down. (…) I carry out 80% of my previous job and it's paid by the employer, and the rest is supplemented by the Social security payments. So from a financial point of view, nothing's really changed for me."
>
> **Cécile, 53 years old**
> Diagnosed in 2014, married, 1 child, €3,000/month (professional activity and disability pension)

> "That's why I'm telling you that I've had a lot of luck, because I had this contingency insurance which helped me to keep going financially. I was able to keep my previous salary."
>
> **Pascale, 50 years old**
> Divorced, 1 child, €2,800/month (80% professional activity, disability pension, and contingency insurance)

> "So right now, I receive the equivalent of my wage. (…) I was fortunate enough to be an executive and had good contingency insurance. This was really important, because,subsequently, I knew people who didn't have any cover – they were employees but they had almost no cover. I was on a really excellent scheme. Well, the company had an excellent contingency contract so I wanted to find out what would happen. I was a little worried during the consultation with the medical officer, because I realised that everything would only be ok if I was at least given a category 2 disability."
>
> **Gilles, 53 years old**
> Diagnosed in 2014, divorced, 2 children, €3,100/month (disability pension and contingency insurance)

> "When my status changed to disability pensioner, I didn't get much, because, unfortunately, as I worked in the operating theatre, I got a lot of bonuses, which wasn't taken into account in the disability payments. That said, I also got the Disabled Adult Allowance and received financial help from the MDPH*. And at the time I received 1,800 euros per month. (…) So my wage has been halved. (…) Now I'm not even bringing in 1,000 euros per month."
>
> **Murielle, 48 years old**
> Diagnosed in 2005, currently undergoing a divorce, no children, €1,000/month (disability pension and the Disabled Adult Allowance or AAH)
>
> * Departmental Home for Disabled People (*Maison Départementale des Personnes Handicapées*)

Reduced income loss for persons better informed about their rights

The interviews have shed light on the fact that being well informed about sick leave periods, the allocation of the disability pension, and the possibilities of accessing the contingency insurance were all advantages when it came to avoiding a drastic income reduction. Indeed, well-informed persons managed to maintain their lifestyle, while other situations illustrate the fact that the onset of the disease may lead to precarity. The cases of Kévin and Mathieu, who did not receive a disability pension, are a good example. Indeed, although a category 2 disability pension enabled Murielle to financially get by, it is likely that if Kévin had been oriented towards a disability pension or training schemes that were more suited to his state of health his financial situation would not have been so difficult. As he is now receiving the Active Solidarity Income (RSA), he no longer meets the eligibility criteria. Just like Mathieu, a former interim worker who became unemployed when he learned of his condition, and who received no information about his entitlements and did not apply for a disability pension. These two persons both suffered from professional isolation and an absence of interaction with social workers and doctors to help them with their applications, as both seemed to be unaware that they could obtain a disability pension, which was not brought up during their interview.

> "I was a team leader. I had a managerial post. So, after the diagnosis I was unable to continue in my post. (…) Consequently, I started looking at other training schemes that would give me a qualification, such as the job of a building engineering consultant. I'm looking for work right now. (…) At the moment, I receive the Active Solidarity Income (RSA), because I'm no longer entitled to other benefits. (…) I'm just taking each day as it comes. There are many things I'd like to do and which I can't do because I haven't got the means."
>
> **Kévin, 42 years old**
> Diagnosed in 2006, single, no children,
> €550/month (Active Solidarity Income or RSA)

> "I was an interim worker until my operation. Then, it all stopped. (…) in fact, I signed up for unemployment benefit. (…) You can be on sick leave if you're unemployed. In fact, the amount is the same as when you're on sick leave. Put simply, the Social security payments are calculated on the basis of the unemployment benefit, which means I get around 400 euros per month. Actually, I don't even get that – it's more like 360 euros."
>
> **Mathieu, 42 years old**
> Diagnosed in 2018, married, 2 children,
> €360/month (unemployment and sickness benefit)

The situation of Michelle and Karine shows that the "choice" of career (such as a part-time job) or family situations, even prior to the onset of the disease, can have consequences on the level of the pension.

> "The Social security takes the last ten years of wages, works out a ratio, and decides how much you will receive per month. That's it. They don't care if most of your career was full time; I was penalised because one and a half years before I became ill I had my second son, and I was only working at 80%. So my wage dropped and I was getting an allowance from the National Family Insurance Fund (*Caisse d'allocations familiales*, CAF), except that these allowances from the CAF are not really regular income, so I've lost out."
>
> **Michelle, 48 years old**
> Married, 2 children, €1,250/month (professional activity, disability pension, and contingency insurance)

> "So, at that time, my husband's job had been transferred to Orléans... I was receiving the jobseeker's allowance. And then, as soon as the disease was announced I started receiving Social security payments instead. (…) So, before being granted disability status, I was with the national Employment Agency [*Pôle Emploi*]. Then I was on sick leave and that turned into the Disabled Adult Allowance and a disability pension. I received both. (…) Yes, I must have had that at the beginning. Then after two or three years they stopped that. (…) as my husband works, even if we weren't bringing in a fortune we were over earning. (…) We don't have a fortune now – it must come to around 2,700 euros."
>
> **Karine, 45 years old**
> Diagnosed in 2008, married, 2 children,
> €850/month (disability pension)

Furthermore, before the 2022 reform relating to the possibility of receiving income from a professional activity and the disability pension, the situation was very disadvantageous for persons who had low salaries just before the attainment of disability status, whatever the reason (low wages or wages reduced by periods of sick leave, or due to part time work or resignation). Although the reform led to an improvement in the situation of certain people, by taking into account the wage of the ten best years and no longer the situation prior to the declaration of disability, which benefitted persons who had reduced their professional activity before the attainment of disability status, other cases remained problematic, such as that of Céline:

> "I've kept 100% of my original wage. However, my original wage is now calculated based on a youth employment salary from twenty years ago and the principle of the disability pensions. (…) My original wage was 1,200 euros a month because I was on a youth employment scheme when I first started working. (…) I cannot go higher than this original wage. So if I get a wage rise my disability pension will go down."
>
> **Céline, 45 years old**
> Diagnosed in 1997, married, no children,
> €1,200/month (works part time and cat. 2 disability pension)

Indeed, the regulations involve two calculation methods (the most favourable situation is taken into account): the combination of a disability pension and wage cannot be higher than the last year of work before the attainment of disability status or the average annual gross wage of the ten highest years of wages (a new idea in the reform). This improvement means that a deteriorated professional situation cannot be prejudicial to an applicant before the attainment of disability status. But, in Céline's case, as the original wage that was used to calculate her disability pension was low, any wage progression in her career after the attainment of disability status would lead to a reduction in her disability pension. So, the regulations still lead to a form of "low-wage trap" for those individuals who were granted disability status at the start of their careers.

* * *

The quantitative analyses have shown that the persons suffering from MS were rapidly granted disability status, in the years following the recognition of a long-term disease status. The granting of disability status does not necessarily imply that work comes to a complete halt in the short term for all the persons receiving the disability pension. Furthermore, for a third of the persons, their professional activity had already stopped before the attainment of disability status, brought about by significant periods of sick leave. The qualitative interviews shed light on this phenomenon. The person's state of health explained the many periods of sick leave, in particular at the start of the disease. The interviews also show the complexity of gaining access to benefits and the fact that a misunderstanding of the latter may have an impact on access to the disability pension. Indeed, the acknowledgement of disability status is not a simple process and people need to be helped by doctors (GPs or medical officers) or social workers to ensure that they do not lose their benefits and receive them on time. This observation would suggest a systematic orientation towards social assistance or the medical officer just after the diagnosis to be able to better prepare the reduction in the person's professional activity if necessary, while limiting income loss as much as possible. Clear information about the provisions for sick leave and a disability pension, with or without the continuation of a professional activity, would certainly enable better planning ahead and help people prolong their career.

The regulations relating to a combination of a salary and a disability pension for persons with low wages who are shifting towards disability status (including the ten highest years of wages in their careers) may seem restrictive. This is a common situation, especially for persons suffering from a debilitating disease, which implies the granting of a disability pension early on in their careers. Thus, for these situations, the regulations discourage the maintenance of the person in their job, with the risk of losing their entitlement to the disability pension or contingency insurance, even while working part time. In addition, the supplementary contingency payments paid by the private insurance companies are very often dependent – even though this is not obligatory – on the existence of allowances paid by the Social security system. The loss of the latter also leads to the loss of the contingency payments and may discourage the continuation of a professional activity. The capping of the combination of a wage and a disability pension combined with the functioning of the supplementary contingency insurance market raises the question of horizontal equity, by discouraging ascendant careers after the attainment of disability status. Medical progress in the disease management and innovative treatments for multiple sclerosis will no doubt make it easier to practise a professional activity, perhaps on a part-time basis, after the attainment of disability status. Consequently, with the aim of achieving horizontal equity, one of the challenges of future developments in the social protection system will be to give persons who suffer from the disease the same chances as other workers. ◆

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