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Job Retention Difficulties Following the Clinical Onset of Multiple Sclerosis: Salary Loss and the Role Played by Income Replacement Benefits in Compensating for the Associated Decrease in Income

Maude Espagnacq^a, Emmanuelle Leray^b, Camille Regaert^a, Alice Guilleux^b, Sylvain Pichetti^a, Stéphanie Guillaume^a and Emmanuel Duguet^c

A chronic degenerative disease of the central nervous system, multiple sclerosis (MS) affects around 100,000 adults in France, predominantly young women. Non-fatal in the short term, the average age of onset of MS is between the ages of 20 and 40, and results in job retention difficulties in the long term. Persons with MS can benefit from the long-term illness (LTI) scheme (*Dispositif "Affections de Longue Durée"*, ALD), which entirely covers the patient's contribution to expenses related to the pathology and provides entitlement to additional benefits in the event of sick leave.

Based on a representative sample of French employees, using professional career data from the beginning of their careers until 2015, we compared the professional development as well as the salaries and replacement income linked to the professional activity (unemployment benefit, sick pay, and disability pension) of persons with MS who were beneficiaries of the long-term illness (LTI) scheme with those of the rest of the working population. The results show that despite a favourable employment situation at the time of recognition of a chronic condition, one out of two people had a disability ten years later, and the salary level, which was high before the onset of the disease, fell below the median income threshold two years after the administrative recognition of a chronic condition due to sick leave. This decrease in income was partly compensated by replacement income.

ultiple sclerosis (MS) is a neurological disease that affects young adults, predominantly women: 2 to 3 women for every man (Walton, 2020). Around 100,000 persons suffer from MS in France (Foulon, 2017; Roux, 2020). The first symptoms begin to appear most often between the ages of 20 and 40, and the progression of this chronic condition extends over several decades with acute episodes (attacks), which

progressively degrade the patient's functional status (motor, sensory, visual, and cognitive functions, bowel or bladder control, etc.), followed by a stage in which there is a regular deterioration in functioning without attacks (progressive form). Yet, this pathology is not fatal in the short term. Indeed, excess mortality in patients with MS only starts at ten to twenty years from clinical onset (Leray, 2015; Rollot, 2021). The progressive deterioration

of the patient's state of health and a life expectancy higher than 65 years of age mean that persons affected by the disease are likely to be affected over the long term by job retention difficulties.

^C Paris Est Créteil University (UPEC), Créteil, France.



Institute for Research and Information in Health Economics (IRDES), Paris, France.

The French School of Public Health (EHESP), Rennes, France.

Multiple sclerosis, a risk of loss of employment of which there is little awareness in France

Given the repercussions on the patient's state of health and the associated expenses, there is a specific long-term illness (LTI) code for this disease. The administrative recognition of a chronic condition enables patients to benefit from a complete reimbursement of patients' contributions to expenses related to the pathology and provides entitlement to additional benefits in the event of sick leave (see

Inset). The administrative recognition of a chronic condition is undertaken by the GP with the patient's agreement, either when the diagnosis is made, or when the person's state of health deteriorates or requires therapeutic treatment. The disease, which affects the patient's ability to work, may require the patient to take regular sick leave, possibly for long periods. Furthermore, MS is a disease that prompts the recognition of a chronic condition that leads to the most declarations of invalidity in France: ten years after the administrative recognition of a chronic condition, 23.4% of the persons with MS on the LTI scheme had a disability, and 14% had a disability after three years (Cuerq, 2008). According to Lefeuvre, based on data from the National Health Data System (Système National des Données de Santé, SNDS), in 2013, 30% of the persons under 60 years of age with MS on the LTI scheme received a disability pension, and 21% had taken at least one period of sick leave with sick pay during the year (with a median duration of 29 days of sick leave) [Lefeuvre, 2017]. Abroad, the employment rate of persons with MS varies a great deal in the studies (Raggi, 2015; Wickström, 2013, 2015, 2017; Chen, 2018; Capra,



The role of the French social protection system in the event of an illness or an inability to work

Sick leave (sick pay)

During sick leave, the sick pay provided by the French National Health Insurance system (NHI, Assurance Maladie) becomes effective three days after the beginning of the sick leave (the mandatory waiting period). After this period, the sick pay is paid to the insured person. The amount received is equal to 50% of the average wage calculated over the three months prior to the sick leave. For employees who are subject to the French Social Security System (Régime Général), sick pay is paid for a maximum of 360 days for a period of three consecutive years. Employees covered by the long-term illness (Affection de Longue Durée, ALD) scheme benefit from a longer paid sick leave period for the disease: three to six months (renewable) for a maximum period of three years, and the amount received remains the same.

In addition to the payment of sick pay by the NHI, after a year in a company, the employer has to compensate for the loss of income due to sick leave. The employer must at least ensure that the employee receives 90% of his/her gross salary for the first thirty days, then 66.6% for the next 30 days (the duration of the maintenance of the wage depends on the employee's length of service, with a maximum period of 180 jours¹).

After six months of consecutive sick leave, beneficiaries are classified as having a "chronic illness" by the NHI, for a maximum period of three years. When an employee is classified as having a "chronic illness", the employer no longer has a legal obligation to pay the person's wages. At the end of the chronic illness, the medical adviser for the NHI decides whether an individual is able to work or not. Unfitness for work and invalidity can be recognised by the medical adviser at any time without the three-year waiting period.

According to the collective agreements or the employer's choice, the durations or amounts paid may exceed the employer's legal obligations. The additional wages paid by the employer may be paid directly by the latter or covered by the life insurance paid by the latter.

Recognition of unfitness for work

The medical adviser for the NHI declares the employee unfit for work, regardless of disability status. In the month following the recognition of unfitness for work, the employer must proceed with the employee's dismissal or offer the employee another post. In the event of dismissal, the person may claim a disability pension and receive both a disability pension and unemployment benefit.

Disability pension

The granting of a disability pension depends on the conditions relating to the inability to work and affiliation to the social security system (*Sécurité sociale*): 1. A work or earning capacity reduced by at least two thirds (66%) 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) 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 invalidity.

The disability pension is calculated on the basis of an average annual wage. It is granted by taking into account the ten best years of wages (the amount of the salary taken into account is subject to contributions within the annual ceiling of the social security system, that is $\in 3,428$ per month in 2020).

There are three categories of disability pension: category 1 for persons who are able to engage in gainful employment; category 2 for persons who are no longer able to work; and category 3 for persons who are unable to practise a profession and who, in addition, require the assistance of a third person to perform normal everyday activities. However, the two latter categories do not prevent the recipient from engaging in a professional activity.

The level of the category of pension determines the calculation of the amount of pension received. Category 1 opens entitlement to the payment of a disability pension at 30% of the average wage (with a minimum of €290 per month and a maximum of €1,020 in 2020); category 2 at 50% of the average wage (with a minimum of €290 per month and a maximum of €1,700); and category 3 also opens entitlement to the payment of a disability pension at 50% of the average wage, which is always complemented by an attendance allowance (*Majoration pour Tierce Personne*, MTP), that is €1,100 per month.

Unemployment benefit

The unemployment benefit is less than the person's previous wage (around 57% of the previous wage) and digressive. The maximum duration of the unemployment benefit is two years for persons under the age of 53 and three years for persons over the age of 53.

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.

2020; Heinonen, 2020; Murley, 2020; and Kavaliunas, 2021), from 26% to 74%, according to the duration of the disease, the educational level, and the "local" situation, particularly the health and social protection systems. Few studies using French data and focusing on the link between MS and work are available (Lebrun-Frenay, 2017; Rapport Roche; Fantoni-Quinton, 2016; Ongagna, 2015; Kwiatkowski, 2014). These studies tend to show that MS negatively influences professional life, from the onset of the disease. Even though the symptoms do not seem to be visible, the disease is associated with an employment and income level below those of the general population. This study is distinguished from most of the other studies on the subject as it was based on a cohort of a representative sample of French employees, with data on their professional careers, from the beginning of their careers until 2015. The aim was to compare the professional development, as well as the wages and income replacement benefits linked to the professional activity (unemployment benefit, sick pay, and disability pension), of the persons with MS on the LTI scheme compared with the rest of the population.

Despite a favourable employment situation at the time of recognition of a chronic condition, one out of two people had a disability ten years later

The data from the Hygie database, which enables the study of persons acknowledged as suffering from chronic MS between 1987 and 2013, confirm the female predominance in this disease (2.15 women for 1 man); the median age of persons acknowledged as suffering from chronic MS was 39, and three quarters of the individuals were acknowledged as having a chronic condition after 1998 (see Table 1).

The year prior to the recognition of chronic MS, 88.1% of the persons were employed, 4.5% unemployed, and 7.4% inactive (see Table 2). In addition, 13% had made at least one quarterly contribution while on sick leave and 7.3% were disabled. While the proportion of the MS population that was in employment without any quar-

Characteristics of the study population							
Variable	N	%					
Number of Multiple sclerosis (MS) patients included	961	-					
Gender							
Men	305	31.7%					
Women	656	68.3%					
Age at administrative recognition of chronic MSb		38.8 ± 9.3 Min 20, Max 60					
Age at recognition of chronic MS							
≤ 38 years	505	52.5%					
> 38 years	456	47.5%					
Year of recognition of chronic MS							
≤ 1998	250	26.0%					
> 1998	711	74.0%					
At least one other chronic condition (before or after MS)							
Yes	167	18.3%					
No	745	81.7%					

^b Chronic MS: On the LTI scheme due to MS.

Scope: Persons with chronic MS between 1987 and 2013, who had at least a year of professional activity one year before and one year after the recognition of a chronic condition.

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	Numbers	Activity indicators			(at least terly cor under the	ndicators one quar- ntribution e sick leave ty schemes)	Employment indicator (without quar- terly contributions under the sick leave or disability schemes)	
		Employed	unemployed	Inactive	Illness Disability		scriemes)	
Level T-1		88.1 %	4.5 %	7.4 %	13.0 %	7.3 %	80.3 %	
				Effets	(in points))		
T+1	961	-6.6	-0.3	6.9	+23.6	+5.4	-24.0	
T+2	932	-12.1	+0.7	+11.4	+17.6	+16.1	-23.7	
T+3	868	-17.2	+3.0	+14.2	+10.0	+27.7	-25.1	
T+4	804	-20.6	+1.3	+19.3	+2.4	+33.4	-27.9	
T+5	722	-22.4	+1.4	+21.1	+2.3	+36.4	-29.8	
T+10	442	-28.6	-1.0	+29.6	-4.6	+50.5	-37.9	
T+15	218	-35.1	-1.6	+36.7	-5.9	+58.5	-44.7	
T+20	82	-46.2	-2.7	+48.9	-11.7	+68.3	-50.1	

Reading: At the time of the administrative recognition of chronic multiple sclerosis, 88.1% of the persons were employed, and, a year later, this proportion decreased by 6.6 points, that is an employment rate of 81.5%. Ten years after the administrative recognition of a chronic condition, 59.5% were employed (88.1–28.6), 37.0% were inactive (7.4+29.6), and 57.8% received a disability pension (7.3+50.5).

Scope: People with multiple sclerosis who were on the long-term illness scheme between 1987 and 2013, and who had at least a year of professional activity one year before and one year after the administrative recognition of a chronic condition.

Source: Hygie.

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SOURCE, DATA AND METHOD

Sources and data

The Hygie database has been compiled by cross-referencing the administrative databases of the National Fund for Retirement Pensions (Caisse Nationale d'Assurance Vieillesse, CNAV) and the National Health Insurance Fund (Caisse Nationale de l'Assurance Maladie, CNAM); the database relates exclusively to private-sector salaries. The CNAV databases are based on data from the National Career Management System (Système National de Gestion des Carrières, SNGC), which comprises employees in the National Provider Statistics System (Système National Statistiques Prestataires, SNSP), which provides information on retired people. This database contains information from the Annual Declarations of Social Data (Déclarations Annuelles des Données Sociales, DADS), which is derived from a reporting formality that is compulsory for all firms with at least one employee. In this official document employers provide information annually to the tax authorities and social security organisations relating to each establishment and their employees. The following information is declared for each employee: the nature of the employment and the employee's qualifications, the pay period start and finish dates, the number of employed hours, the nature of the employment (full- or part-time), the amount of remuneration paid, and so on. The data from the National Fund for Retirement Pensions (CNAV) was the point of entry of the constitution of the sample. It was a random sample of beneficiaries aged between 22 and 70 in 2005 (born between 1935 and 1984), who had made at least one contribution to the General Pension Scheme (Régime Général de Retraite) during their lifetime. It was combined with the SNIIRAM data, which relates to the beneficiaries of the French Social Security System (Régime Général d'Assurance Maladié) and included beneficiaries who received healthcare on at least one occasion that was recorded 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 on the individuals' careers, from the point at which they entered the labour market, which for some was more than thirty years ago. 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. The data from the Hygie database made it possible to reconstruct each individual career, and identify long-term illnesses (LTI) and the associated disease. The professional situations are defined according to the annual number of quarters validated in each different labour market status. The data from the Hygie database are available at the national level (the number of quarterly contributions made during employment, and made under the sick pay and unemployment schemes, as well as wages). The real amount of the disability pension was not directly recorded in the database but it can be calculated (see above). Given

the disease studied, we made the simplified assumption that all the disabled individuals were in category 2 or 3 (which represented 80% of the disability pensions). It was therefore assumed that they received a pension that corres-

ponded to 50% of the ten best years of wages, without taking into account the attendance allowance (MTP), which is used to pay for help in performing activities of daily living and not as a wage replacement.

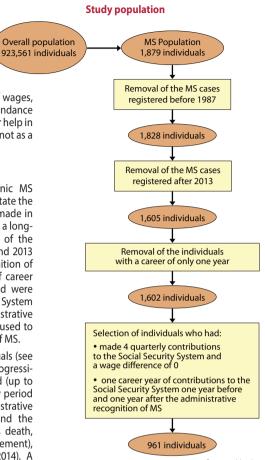
Study population

After selecting individuals with chronic MS (code CIM10 = G35) and in order to facilitate the analysis, a more refined selection was made in order to only retain individuals who had a long-term illness (LTI) between 1987 (date of the creation of the chronic MS database) and 2013 (enough time had elapsed after recognition of MS), and who had at least one year of career before and after the onset of MS, and were insured under the French Social Security System (*Régime General*). The date of the administrative recognition of a chronic condition was used to approximate the date of the diagnosis of MS.

Hence, we had a sample of 961 individuals (see the figure opposite), whose number progressively decreased over the period studied (up to 20 years). For each individual, the study period began in the year prior to the administrative recognition of a chronic condition and the study period ended with the person's death, a change of scheme (including retirement), or the end of available data (31/12/2014). A "control" population was then selected. The control group was composed of persons who did not have chronic MS and who were crossreferenced with MS cases the year prior to the administrative recognition of chronic MS, based on the following criteria: year of birth, gender, salary on entry in the labour market, and the career and medical history. The control individuals could have another chronic condition in order to include individuals who were representative of the general population and not be solely limited to individuals in good health. All the eligible control individuals were included and each control individual could be used several times in order to increase the statistical power of the analyses (on average, 1 case was cross-referenced with 12,207 "twins").

Method

Each year, the probability of being employed, unemployed, or inactive was calculated for each individual, with the sum of the three possibilities being equal to 100%. Unemployment was defined as being on the unemployment scheme for at least one quarter during the year without validating a quarter in employment. Inactivity was defined as not having validated a quarterly contribution during a period of employment or unemployment. We also calculated two annual indicators that related to the person's state of health: at least one quarter on sick leave or with a disability. Lastly, the population "free" of the impact of MS was measured by the proportion of persons in employment, during a given year, without quarterly contributions under the sick leave or disability schemes.

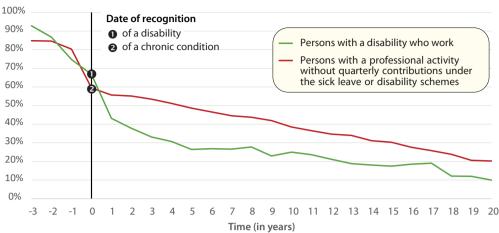


Source: Hygie

In addition, the annual salary percentile (and respectively the income percentile) was calculated, which corresponded with the wage distribution (and respectively the income distribution) of the MS population compared with all the wages in the Hygie database. The income was equal to: wages + income replacement benefits (sick pay, unemployment benefit, and disability pension). These amounts were estimated from the income declared by employers (the DADS). The relative wages were calculated in relation to the median, measured in the Hygie database (the relative income was also calculated).

To identify the causal effect of MS on employment status, follow-up studies were made on MS sufferers over a period of up to twenty years after the administrative recognition of chronic MS, and the differences-in-differences method with matching was used. Firstly, the difference between the professional situation of a case before and after the onset of MS was assessed, which made it possible to measure the impact of MS by eliminating the effects of observable individual heterogeneity. Then, to measure the period-specific effects, the same difference was measured in the control population. The difference-in-differences was then calculated, making it possible to eliminate the effects of individual heterogeneity and the temporal effects associated with changes in the labour market and medical advances. The results from this method take the form of variations over time measured in the MS population and attributable to MS due to the use of a comparable control population (Barnay et al., 2018).





Reading: In the year of the administrative recognition of a chronic condition, 60% of the persons had not made quarterly contributions under the sick leave or disability schemes; ten years after the administrative recognition of a chronic condition, the proportion was 38%. In the year in which they were recognised as disabled, 68% of the persons worked; five years after invalidity, the proportion was 28%.

Scope: People with multiple sclerosis who were on the long-term illness scheme between 1987 and 2013, and who had at least a year of professional activity one year before and one year after the recognition of a chronic condition.

Source: Hygie.

Townload the data

terly contribution validated under the sick leave or disability schemes was significant three years before the administrative recognition of a chronic condition (more than 85%), it plummeted at the time of the administrative recognition of a chronic condition (60%) and regularly decreased over time, attaining 20% after twenty years (see Graph). At the time of transition to disablement, 70% of the persons concerned continued to work, but a very strong decrease

CONTEXT

This initial article is part of the project "Effects of Multiple Sclerosis on Occupational TraJectorles" (EMOJI). The project, conducted in conjunction with the French National School of Public Health (École des Hautes Études en Santé Publique, EHESP), the Université Paris-Est Créteil (UPEC) and the IRDES, and funded by the French Association for Research on Multiple Sclerosis (Fondation pour l'Aide à la Recherche sur la Sclérose en Plaques, ARSEP), aims to study the long-term impact of Multiple sclerosis (MS) on occupational trajectories in terms of MS sufferers' access to employment and financial resources. The project is being implemented using a mixed method, combining a quantitative analysis (presented in this article) based on the HYGIE database and a qualitative analysis based on around twenty semi-directive interviews.

was observed in the following year (a drop of 20 points), while the decrease continued more gradually up to the ten-year point (10% maintained a professional activity). The activity rate of the beneficiaries of a disability pension subsequently became marginal.

The results based on the differences-in-differences method — which compared the evolution over time of the employment of persons who suffered from chronic MS with that of those who did not suffer from chronic MS showed that a year after the administrative recognition of a chronic condition the proportion of active individuals (88.1%) dropped by 6.6 points (see Table 2). The negative effect of MS on employment continued and increased over time, attaining -12.1 points after two years and -28.6 after ten years. Amongst the persons who continued to work over time, a fraction continued their activity without making quarterly contributions under the sick leave or disability schemes: the proportion of these persons was 80.3% the year preceding the administrative recognition of chronic MS, then dropped to 42.4% ten years later, and fell to 30.2% after 20 years. However, the proportion of persons who were unemployed remained relatively stable (between 3 and 5%) and was therefore relatively unaffected by MS, apart from the third year after the administrative recognition of a chronic condition, no doubt linked with dismissal for inability to perform before the transition to disablement (see Inset). The decline in employment resulted in an increase in the number of people with an "inactive" status. Indeed, in the year following the administrative recognition of chronic MS, the proportion of persons who become inactive increased by 6.9 points. Over the years of monitoring data, this proportion regularly increased, attaining +21.1 points after five years, +29.6 points after ten years, and +49 points after twenty years.

MS had a significant impact on the proportion of persons who validated at least one quarterly contribution under the sick leave scheme during the first three years that followed the administrative recognition of a chronic condition (Table 2). A peak was observed the first year (+23.6 points) and the second (+17.6 points), and the impact was less marked in the third year (+10 points). As of the fourth year, the impact was almost inexistant, because the persons most affected by the disease were no longer working. With regard to disability – estimated to be 7.3% at the time

T3

of the administrative recognition of a chronic condition –, the effect of MS was significant and increased over time: +5.4 points the first year, +36.4 points the fifth year, and +50.5 points the tenth year, that is more than one out of two people disabled after ten years and 3 out of 4 after twenty years. The shift of the disease towards disability during the first three years explains the changes in compensation rights: long-term sick leave after six months of sick leave, then a transition to a disability pension within a maximum period of three years (see Inset).

The wages, which were high before the onset of the disease, fell below the median wage threshold two years after the administrative recognition of a chronic condition

Just before the administrative recognition of a chronic condition, the population suffering from MS was in the 56th wage percentile, which means that on average their wages were above the wage-earning population (six percentile ranks above the median wage). Over time, MS resulted in a continuous drop of this rating (see Table 3): it dropped 6 percentile ranks the first year (to the median wage level of the population), 19 percentile ranks in the tenth year, and 28 percentile ranks after twenty years. Hence, the population suffering from MS was in the 37th percentile after ten years. There was also a significant decrease in the relative wages of the population suffering from MS over the period, with the relative wages being equal to 130% of the median wage, shifting to 65% after ten years, and 34% after twenty years. This decrease was consistent with a decline in the ability to work. Indeed, the drop in wages was mainly explained by the periods of sick leave and invalidity (including maintaining a reduced professional activity), because only 40% of the persons after ten years and 30% after twenty years did not experience an interruption in their work during a quarter. But this situation was partly compensated for by the income replacement benefits provided by the French social protection system, when it is no longer possible for a person to work as much as they previously did.

Effects of MS on the wage and income indicators

	Number	Wage percentile	Relative wage	Proportion of income replacement benefits in the total income	Income percentile	Relative income
Level T-1		56	130	16.2	64	151
		Effects (% ranks)	Effects (points)	Effects (points)	Effects (% ranks)	Effects (points)
T+1	961	-6	-25	+11.3	-4	-14
T+2	932	-9	-32	+15.8	-5	-18
T+3	868	-11	-40	+22.8	-6	-24
T+5	722	-14	-50	+28.7	-8	-32
T+10	442	-19	-65	+39.5	-11	-44
T+15	218	-25	-87	+47.7	-15	-63
T+20	82	-28	-96	+58.6	-18	-75

Reading: At the time of the administrative recognition of a chronic condition, the population with chronic MS was in the 56th wage percentile* (i.e. 6 percentile ranks above the median wage); ten years later, it was in the 37th wage percentile (56–19). At the time of the administrative recognition of chronic MS, the income of the MS population was equal to 151% of the median income; ten years later, it was equal to 107% of the median income (151–44).

 * The income was composed of the sum, where appropriate, of the wage, sick pay, unemployment benefit, and disability benefit.

Scope: People with multiple sclerosis who were on the long-term illness scheme between 1987 and 2013, and who had at least a year of professional activity one year before and one year after the administrative recognition of a chronic condition.

Source: Hygie.

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Income replacement benefits cushioned loss of income by 20 percentile ranks

To complete the assessment of the evolution of work-related income, income replacement benefits connected with employment (sick pay, unemployment benefit, and disability pension) were taken into account in addition to the salaries. This population was heterogenous because it comprised both persons who received a full wage because they did not undergo long periods of sick leave, persons who worked and who also received income replacement benefits over the year (a quarterly contribution under the sick leave or unemployment schemes; under the disability scheme with continuation of work), and those who only received income replacement benefits (longterm sick leave; unemployment benefit or a disability pension throughout the year). However, at the point when the chronic condition was administratively recognised, the population suffering from MS was well above the

median income of the population as it was in the 64th percentile (Table 3). At the time of the administrative recognition of a chronic condition this population already received 16% of its income from income replacement benefits. MS led to a regular decrease in the rating linked to income over time: from 4 percentile ranks in the first year to 11 percentile ranks in the tenth year, which means that the population suffering from MS was in the 53rd percentile after ten years and fell below the median income level (49th percentile) after fifteen years (see Table 3). Nevertheless, the reduction in income, which was less significant than the reduction in wages, was attenuated by the increase in the proportion of income replacement benefits: +11 points after one year, +39 points after ten years, and +58.6 points after twenty years (see Table 3). The reduced decrease in income, which included loss of employment-related benefits relative to wages alone, shows that the French social protection system limits the deterioration of the situation of persons with chronic MS.

T4

Effects of MS on the wage and income indicators, stratified according to gender

	Wage in repla		Proportion of income replacement		Income					
	Percentile		Relative		benefits in the total income (%)		Perc	entile	Rel	ative
	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women
Level T-1	65	53	167	107	15,7	13,3	67	54	163	108
		Effects Effects (% ranks) (points)		Effects (points)		Effects (% ranks)		Effects (points)		
T+1	-8	-6	-31	-21	10.4	11.6	-5	-3	-20	-11
T+2	-10	-7	-45	-25	16.8	15.5	-6	-4	-31	-13
T+3	-13	-10	-52	-34	23.0	23.1	-8	-5	-35	-19
T+4	-16	-13	-64	-41	26.5	25.8	-10	-7	-46	-25
T+5	-17	-14	-61	-46	29.1	28.7	-11	-8	-42	-29
T+10	-21	-19	-76	-56	38.6	39.6	-12	-10	-53	-37

Reaidng: At the time of the administrative recognition of chronic multiple sclerosis, men with chronic MS were in the 65th percentile of the overall wage distribution (men + women), that is 15 percentile ranks above the median wage. Ten years later, they were in the 44th percentile.

Scope: People with multiple sclerosis who were on the long-term illness scheme between 1987 and 2013, who had at least a year of professional activity one year before and one year after the administrative recognition of a chronic condition.

Source: Hygie.

1 Download the data

Indeed, the relatively high levels of wages and income ten years after the administrative recognition of a chronic condition were partly connected with the fact that 60% of the persons suffering from MS were still employed (and 42% had no illness or disability), which made it possible to maintain the average income level above the median (see Table 3). But, by comparing the impact of MS on the relative levels of wages and income, it was observed that income replacement benefits partly compensated for reduced earnings: ten years after the administrative recognition of chronic MS, the reduced earnings corresponded with a decrease of 19 percentile ranks of the wage distribution (percentile 37 versus 56), while the decrease was limited to 11 percentile ranks of the income distribution (percentile 53 versus 64). After twenty years, this impact persisted (a decrease of 28 percentile ranks of the wage distribution and 18 percentile ranks of the income distribution). After twenty years, income replacement benefits represented almost 75% of the person's financial resources and the proportion of persons who were still active but who neither made a quarterly contribution under the sick leave nor dis-

ability schemes fell below 30% (see Graph). Hence, twenty years after the administrative recognition of a chronic condition, both the relative wage and income fell below the median, an indication that the contribution of wages to financial resources made it possible to maintain the average income level above the median after ten years. Twenty years after the administrative recognition of a chronic condition, the compensation provided by income replacement benefits made it possible to ensure an income level that placed persons with MS at 25% below the median income, which would not have been possible with wages alone.

Depending on gender, the decline in the employment rate was similar over the ten years¹, while differences in wages and income were observed between men and women – a consequence of the salary disadvantage of women that has been well documented in many studies (see Table 4). The persons with chronic MS who worked were in a better position on the income

scale before the administrative recognition of a chronic condition, in particular men. Men's wages at the time of the administrative recognition of chronic MS represented 167% of the median wage, while those of women represented only 107% of the median wage. The advantage of having an initial higher wage for the persons suffering from MS was practically neutralised for women due to the comparative disadvantage of women in the labour market.

After taking into account income replacement benefits, the initial income difference between men and women did not alter. Since their income was very close to the median income at the time of the administrative recognition of a chronic condition, women's income fell below this level in the first year. Men's income remained above the median income over ten years (see Table 4). The income level difference was not due to the fact that men tended to remain in work longer, because the proportion of income replacement benefits was very similar according to gender and evolved in the same way over time for men and women, increasing from around 15% at the point of the administrative recognition of a chronic condition to around 40% after ten years (see Table 4). Men lost more in wages than women and this phenomenon increased over time: 31 points versus -21 points the first year (see Table 4) and -76 points after ten years for men compared with -56 points for women. The same difference was observed when income replacement benefits were integrated into income. Therefore, it was indeed the largely higher initial wage level of men that explains why their financial situation was better than that of women ten years after the administrative recognition of chronic MS.

The amount of the disability pension reflects the income differences that result from gender and activity sector differences

Before invalidity, the average annual salary over an entire career was $\in 14,900$ constant euros, that is $\in 1,240$ per month, with distinct differences between men ($\in 17,600$ per year) and women ($\in 13,500$), which had

¹ Given the number of persons, it was not possible to carry out gender-based analyses up to twenty years after the administrative recognition of chronic MS.

T5

Average wage of the beneficiaries before disability benefit and average amount of the disability pension according to the characteristics of the recipients

	N	Average wage in the career (constant €) before disability benefit (average)	Amount of the average pension in 2015 (constant €)
Total	408	14,900	8,700
Male	134	17,600	10,200
Female	274	13,500	7,900
Unknown sector	43	14,100	7,500
1. Public administration ^a	98	13,200	7,800
2. Financial sector ^b	97	16,200	9,400
3. Retail, food service sector ^c	76	12,700	7,700
4. Construction, industry ^d	96	17,300	10,200
Before the disability pension			
No unemployment	335	15,300	8,900
Unemployment	73	12,600	7,500
Chronic illness in T-1	92	11,900	6,500
No chronic illness	318	15,700	9,300
Career duration before LTIe			
Under ten years	85	12,600	7,300
More than ten years	323	15,500	9,000

^a Public administration, Education, Human health and social work sectors; ^b Information and communication – Financial and insurance activities – Real estate activities – Professional, scientific, and technical activities – Administrative and support service activities; ^c Trade and repair of motor vehicles and motorcycles – Other service activities – Arts, entertainment, and recreation – Accommodation and food service activities; ^d Construction – Transportation and storage – Mining – Manufacturing industry – Generation and supply of electricity, gas, steam, and air conditioning – Production and distribution of water, sewerage, waste management and remediation activities; ^e LTI: long-term illness.

Scope: People with multiple sclerosis who were on the long-term illness scheme between 1987 and 2013, and who had at least a year of professional activity one year before and one year after the administrative recognition of a chronic condition.

Source: Hygie.

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an impact on the amount of the disability pension. In 2015, this amount — 50% of the ten best years of wages (see Inset) — was $\{8,700\}$ on average per year, that is $\{725\}$ per month, with an average amount that was higher for men ($\{10,200\}$ per year) compared with that of women ($\{7,900\}$) [see Table 5].

As for gender, the disparities reported in the literature were also observed depending on the activity sector, both in terms of the salary level and the level of the pension. The "Financial and scientific" and "Construction, industry, and transport" sectors paid the highest average wages before invalidity: €16,200 and €17,300 respectively, compared with less than €14,000 for the other sectors ("Administration" and "Retail, food service activities, and events"). The disability pensions were therefore higher for the first two sectors (€9,400 and €10,200) than for the

other two (around €7,500). Persons in an "unknown sector" had the particularity of having a higher capped average wage than those working in administration and retail (€14,100), but with a lower disability pension of €7,500, which was undoubtedly due to more discontinuous careers than in the other sectors. The persons with careers lasting less than ten years before the administrative recognition of a chronic condition had particularly low pensions² (€5,200 on average), due to the fact that, as they were at an early stage in their careers, their wage development was limited. For a quarter of these persons, the level of the pension even corresponded to the minimum benefit (i.e. €270 per month).

Although they were recognised as being disabled earlier, persons with chronic MS had higher disability pensions than the beneficiaries of pensions for other reasons

As shown by the preceding results, the income levels decreased over time, in particular when the proportion of income from a professional activity declined, which is logical as all the income replacement benefits were by definition lower than the salaries previously earned. The income of the persons with chronic MS was higher than that of the general population at the time of the administrative recognition of a chronic condition, but the transition to a disability pension was relatively rapid (on average 4.5 years after the administrative recognition of a chronic condition); the subsequent years of work included many periods of sick leave. This raises the issue of the financial consequences of the early onset of disability – with years severely impacted by periods of sick leave - on the level of disability pensions. Hence, the estimates of the levels of disability pension based on the Hygie database were compared with the total amounts of disability pension for MS paid in 2015 under the French Social Security System (Régime General), based on data from the National Health Data System (SNDS). The results were similar: the average pension paid was €8,700 per year, that is €10,200 for men and €8,100 for women, who represented 70% of the those who received a disability pension. Those who received a disability pension after the onset of MS in data from the SNDS were also compared with all those who received a disability pension for other reasons in 2015. While the proportion of the persons in category 1 - persons capable of engaging in remunerative employment (see Inset on p. 2) – was the same in both populations, that is around 20%, persons with MS were most often in category 3: persons incapable of working but requiring the assistance of a third person to perform normal everyday activities (10% for persons with MS compared with 2% for persons who received a disability pension for other reasons). The age at which beneficiaries became disabled after the onset of MS was lower than that of those who received a disability

² For the persons who had less than ten years of contributions, the average of the contributory years was taken into account.

y pension in 2015

T6	
T6	
	According to the second
	Average annual amount of the disabilit

Pension	Mult	iple sclerosis	(MS)	Other pensions			
Pension	Men	Women	Total	Men	Women	Total	
Category 1	7,250	6,270	6,490	6,740	6,090	6,350	
Category 2	10,860	8,740	9,350	10,330	8,430	9,350	
Category 3	10,100	8,070	8,870	9,140	7,920	8,720	
Total	10,170	8,120	8,710	9,730	7,910	8,770	

Scope: Persons who received twelve months of disability pension in 2015.

Source: SNDS 2015.

↑ Download the data

pension for other reasons: 42 years of age for persons with chronic MS compared with 50 years of age (Cuerq, 2008). Hence, the early age at which MS sufferers became disabled and the many periods of sick leave did not have an adverse effect on the amount of the pension of persons with MS, as the latter was higher than that received for other reasons. In 2015, whatever the category and gender, the beneficiaries suffering from MS received higher pensions than the others (see Table 6), above all men, who received, on average, pensions that were higher than €1,000 per year, while the difference was only €200 per year for women. Nevertheless, although the pensions were higher than those received for other reasons, the disability pension levels remained low (on average under €750 per month), including for persons who were in the most favourable situations (men in the industrial, retail, and transport sectors), for whom the average pension was €850.

At the time of the administrative recognition of chronic MS, the persons were in a relatively favourable financial situation with a strong professional anchorage, but less than half of these persons managed to keep their job ten years after the administrative rec-

ognition of a chronic condition. The persons who continued working enabled this population to maintain relative income above wage earners' average income. Indeed, over time, less and less people were able to work as much as they did before, and, despite the fact that the income replacement benefits attenuated the loss of income, they did not sufficiently make up for the loss of wages to stay above the median income. The results also show that some of the individuals continued to work for several years after they became disabled. This situation of disability and employment enabled them to compensate for the loss of wages, but this level of employment decreased quite quickly and became relatively low after ten years. It may be that the restrictive rules relating to the integration of wages with a disability pension (it is only possible to attain a greater income by combining earnings from a professional activity with a pension at the time of the transition to a disability pension) acted as a disincentive to pursuing even a partial professional activity for those who were still capable of doing so, while it seemed to be a favourable factor for maintaining financial resources and had a positive effect on socialisation.

Lastly, despite the fact that disability affected people who were younger than

other beneficiaries, it was thanks to an initially more favourable professional situation that persons with MS had disability pensions that were higher than average. Nevertheless, the average amount of the pension received by persons with MS in 2015 was €850 per month for men and €675 for women. For women, the average amount was lower than the amount paid under the adult disability allowance (Allocation Adultes Handicapés, AAH) [€807 per month in 2015]. The current "uncoupling" reform of the adult disability allowance will enable persons in couples, whose pensions are low, to complement their disability pension with this minimum social benefit. The other possibility is to complement the disability pension with benefits paid under a personal risk insurance policy that has been previously subscribed to, and which covers the risk of invalidity. Such policies may even enable beneficiaries to maintain their wage level during the transition to disability, in addition to the pension. This type of policy is very often associated with life insurance cover, which is mandatory for executives, accentuating the previously observed inequalities between sectors and genders. The next Employer-provided Complementary Health Insurance Survey (Protection Sociale Complémentaire d'Entreprise, PSCE), which will be conducted by the Institute for Research and Information in Health Economics (IRDES) in 2024, will include a section on personal risk insurance policies, including disability cover, and will make it possible to analyse all the risks of loss of income, which was impossible in this study due to a lack of available quantitative data.

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FOR FURTHER INFORMATIONS

- Barnay T., Ben Halima B., Ben Halima M., Duguet E., Lanfranchi J., Le Clainche C., Regaert C., Sermet C. (2018). « Conséquences de la survenue du cancer sur les parcours professionnels: une analyse sur données médico-administratives ». Irdes, Rapport n° 568 et CEET, Rapport de recherche n° 106.
- Cuerq A., Païta M., Ricordeau P. (2008). « Les causes médicales de l'invalidité en 2006 ». Cnam, Rangs de repère, n° 18.
- Fantoni-Quinton S., Kwiatkowski A., Vermersch P., Roux B., Hautecoeur P., Leroyer A. (2016). "Impact of Multiple Sclerosis on Employment and Use of Job-retention Strategies: The Situation in France in 2015". J Rehabil Med. Jun 13;48(6):535-40. doi: 10.2340/1650177-203.
- Foulon S., Maura G., Dalichampt M., Alla F., Debouverie M., Moreau T., et al. (2017). Prevalence and Mortality of Patients with Multiple Sclerosis in France in 2012: A Study Based on French Health Insurance Data. J Neurol. 264(6):1185–92.
- Heinonen T., Castrén E., Luukkaala T., Mäkinen K., Ruutiainen J., Kuusisto H. (2020). "The Retirement Rate Due to Multiple Sclerosis Has Decreased Since 1995- A Retrospective Study in a Finnish Central Hospital". Mult Scler Relat Disord. Oct;45:102360. doi: 10.1016/j.msard.2020.102360. Epub 2020 Jul 4.
- Imbens G. W., Rubin D. B. (2015). Causal Inference in Statistics, Social, and Biomedical Sciences. Cambridge University Press.
- Kwiatkowski A., Marissal J.P., Pouyfaucon M., Vermersch P., Hautecoeur P., Dervaux B. (2014). "Social Participation in Patients with Multiple Sclerosis: Correlations Between Disability and Economic Burden". BMC Neurol. May 27;14:115. doi: 10.1186/1471-2377-14-115.
- Lebrun-Frenay C., Kobelt G., Berg J., Capsa D., Gannedahl M. (2017).
 "European Multiple Sclerosis Platform. New insights Into the Burden and Costs of Multiple Sclerosis in Europe: Results for France". Mult Scler. Aug;23(2_suppl):65-77. doi: 10.1177/1352458517708125.
- Lechner M. (2010). "The Estimation of Causal Effects by Difference-indifferences Methods». Foundations and Trends in Econometrics, 4, 165-224.

- Lefeuvre D., Rudant J., Foulon S., Alla F., Weill A. (2017). "Healthcare Expenditure of Multiple Sclerosis Patients in 2013: {A} Nationwide Study Based on French Health Administrative Databases". Mult. Scler. J – Exp. Transl. Clin.3(3):2055217317730421.
- Leray E., Vukusic S., Debouverie M., Clanet M., Brochet B., de Sèze J. et al. (2015). "Excess Mortality in Patients with Multiple Sclerosis Starts at 20 Years from Clinical Onset: Data from a Large-Scale French Observational Study". *PLoS One*. 10(7):e0132033.
- Murley C., Karampampa K., Alexanderson K., Hillert J., Friberg E. (2020).
 "Diagnosis-specific Sickness Absence and Disability Pension Before and After Multiple Sclerosis Diagnosis: An 8-year Nationwide Longitudinal Cohort Study with Matched References". Mult. Scler. Relat. Disord.
 Jul;42:102077. doi: 10.1016/j.msard.2020.102077. Epub 2020 Apr 13.
- Ongagna J.C., Passadori A., Pinelli J., Isner-Horobeti M.E., Zaenker C., De Seze J. (2015). [Difficulties Experienced at Work by Patients with Multiple Sclerosis]. Rev Neurol (Paris). Nov;171(11):782-6. doi: 10.1016/j. neurol.2015.06.007. Epub 2015 Sep 3.
- Roche: Rapport 2021. https://www.roche.com/investors/annualreport21. https://www.roche.com/investors/annualreport21.
- Rollot F., Fauvernier M., Uhry Z., Vukusic S., Bossard N., Remontet L., Leray E. (2021). "On Behalf of the OFSEP Investigators. Effects of Age and Disease Duration on Excess Mortality in Patients with Multiple Sclerosis from a French Nationwide Cohort". *Neurology*. Jul 27;97(4):e403-e413. doi: 10.1212/WNL.000000000012224.
- Roux J., Guilleux A., Lefort M., Leray E. (2019). "Use of Health Care Services from Patients with Multiple Sclerosis in France over 2010-2015: A Nationwide Population-based Study Using Health Administrative" Data. Mult. Scler. J. Exp. Transl. Clin. Dec 18;5(4):2055217319896090. doi: 10.1177/2055217319896090.
- Walton C., King R., Rechtman L., Kaye W., Leray E., Marrie R.A., Robertson N., La Rocca N., Uitdehaag B., van der Mei I., Wallin M., Helme A., Angood Napier C., Rijke N., Baneke P. (2020). "Rising Prevalence of Multiple Sclerosis Worldwide: Insights from the Atlas of MS, Third Edition". Mult. Scler. Nov 11:1352458520970841. doi: 10.1177/1352458520970841.



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