

RESEARCH PORTFOLIO 2024

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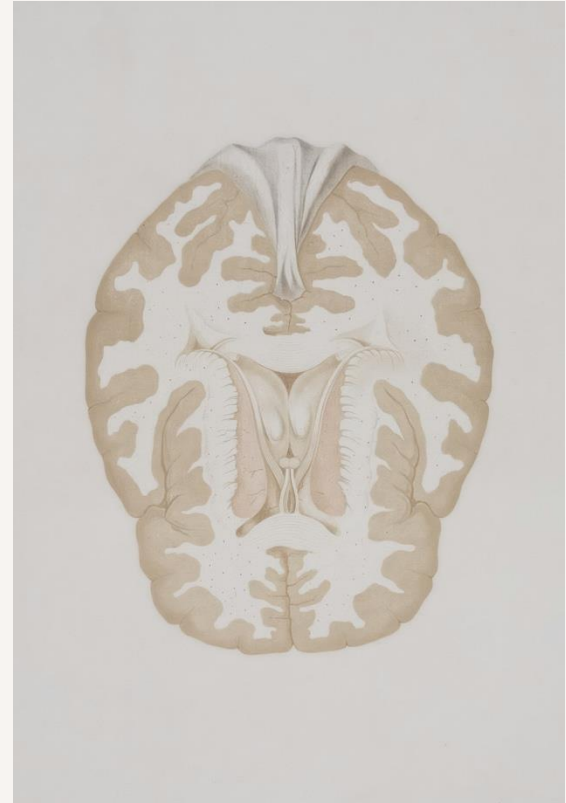
Happiness Research Institute  
& Jascha Fonden

# THE NEURODEGENERATIVE TOLL ON HAPPINESS

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# INTRODUCTION



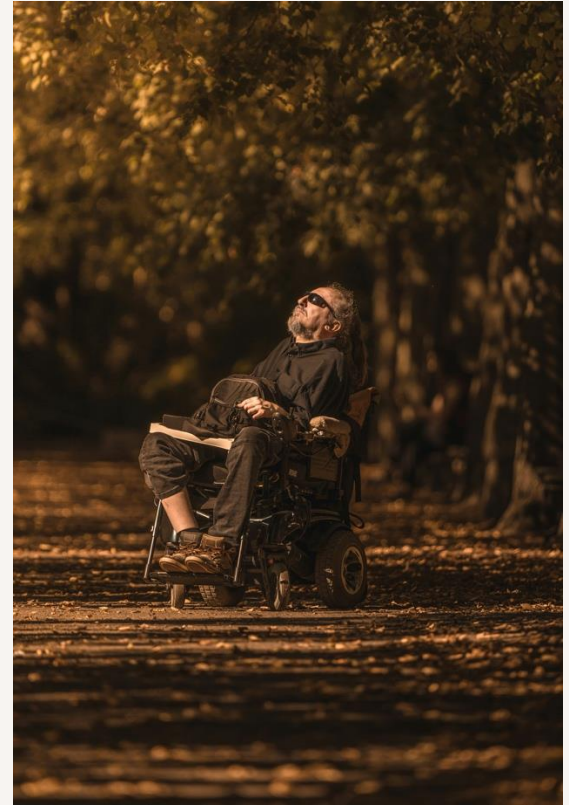
# Why a Report on the Wellbeing of Patients with Neurodegenerative Diseases?

The world is changing rapidly.

Just a few decades ago, progress meant having something to eat. Now we have everything our grandparents once dreamed of, but we face more elusive problems, like loneliness, self-esteem issues driven by social media, or mental health challenges.

In the past, healthcare success was measured by survival rates. Now, it's about how well patients live with their chronic conditions.

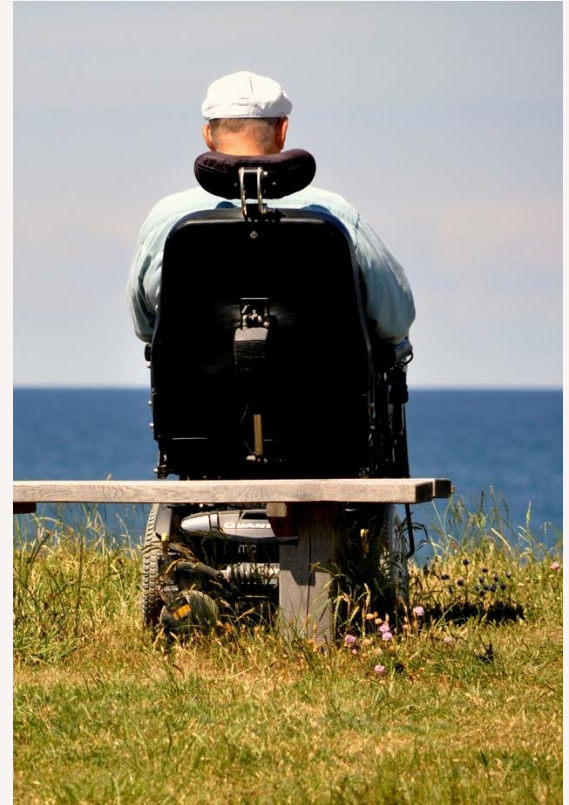
This is the context in which this report is written and why we've decided to focus on what truly matters to patients with neurodegenerative diseases.



This report is based on the responses of several thousand people across Europe to a single, fundamental question: "*How satisfied are you with your life?*" This simple question encapsulates everything that truly matters to those who answer it—Am I healthy? Do I have a loving family? Do I wake up with a sense of purpose?

All patients with neurodegenerative conditions share a common set of symptoms, yet not all of them cope with their illnesses in the same way. In this report, we aim to discover what sets apart the patients who remain happy from those who suffer the most.

While it might seem that such a broad question could be misleading, the aggregated results across large populations reveal patterns that are both consistent and insightful. For instance, this report helps us understand why Parkinson's patients are happier in some countries than in others, or why women with neurodegenerative diseases generally feel more isolated than men.



Throughout this portfolio, we will focus on Parkinson's disease, multiple sclerosis, and muscular dystrophy, as these are the primary areas of interest for Jascha Fonden.

Guided by a mission to enhance quality of life and bring joy to those who need it most, Jascha Fonden was born from a deep-rooted compassion in a small local community and has since expanded its reach across Denmark.

The foundation stays true to its founder's values, offering support that goes beyond necessities, aiming to bring dignity, joy, and quality of life to people facing significant challenges. Whether through funding research projects, supporting institutions, or assisting individuals directly, Jascha Fonden's goal is to make a meaningful difference, particularly for those overlooked by other resources. By staying close to the changing needs of society, the foundation remains committed to addressing essential needs and fostering inclusive, respectful communities where everyone can thrive.



# CHAPTER OVERVIEW: WHAT'S INSIDE

## 1. Happiness across neurodegenerative diseases

Determining which neurodegenerative disease among those prioritized in Jascha Fonden's mission—Parkinson's, multiple sclerosis, or muscular dystrophy—has the greatest effect on personal happiness and population wellbeing.

## 2. Regional effects: a European overview

Examining how the impact of each disease on happiness varies across different European countries and the underlying reasons.

## 4. The caregivers challenge

Exploring the emotional and psychological effects of these diseases on caregivers and their roles in supporting patients.

## 3. Demographic disparities

Investigating how age and gender influence the experience of happiness and wellbeing among patients with these conditions.

## 5. Protective factors & lifestyles

Identifying lifestyle choices and factors that can help patients maintain better wellbeing despite the challenges of their conditions.

# DATA OVERVIEW: SAMPLE AND SCOPE

<b>Number of respondents</b>	This report is based on responses from 301,597 individuals across Europe.
<b>Respondents in Denmark</b>	The report features responses from 26,036 individuals in Denmark.
<b>Number of countries</b>	The data includes information from 21 different countries.
<b>Number of patients</b>	The survey includes feedback from 2,557 Parkinson's patients, 370 patients with symptoms similar to those of muscular dystrophy, and 860 multiple sclerosis patients.
<b>MD patients proxy</b>	Due to limited data on Muscular Dystrophy patients, we have used information from individuals with similar mobility issues or muscular problems as a proxy.
<b>Years covered</b>	The data in this report comes from surveys conducted between the years 2004 and 2018.

All data comes from: *Survey of Health, Ageing, and Retirement in Europe (SHARE)*. Some sections of this report also use data from the *European Quality of Life Survey* and the *Michael J. Fox Database*. Wherever these data are used, it will be explicitly indicated.

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## Defining the Patient Footprint for Muscular Dystrophy (MD)

In our database, we do not have specific questions designed for MD patients. To address this, we have identified a set of symptoms that allow us to create a "patient footprint," representing individuals whose challenges and lifestyle closely resemble those of MD patients. This patient footprint includes the following characteristics:

- Male
- Uses a wheelchair
- Experiences difficulty walking
- Struggles to stand up from a seated position
- Unable to lift objects heavier than 5 kilograms

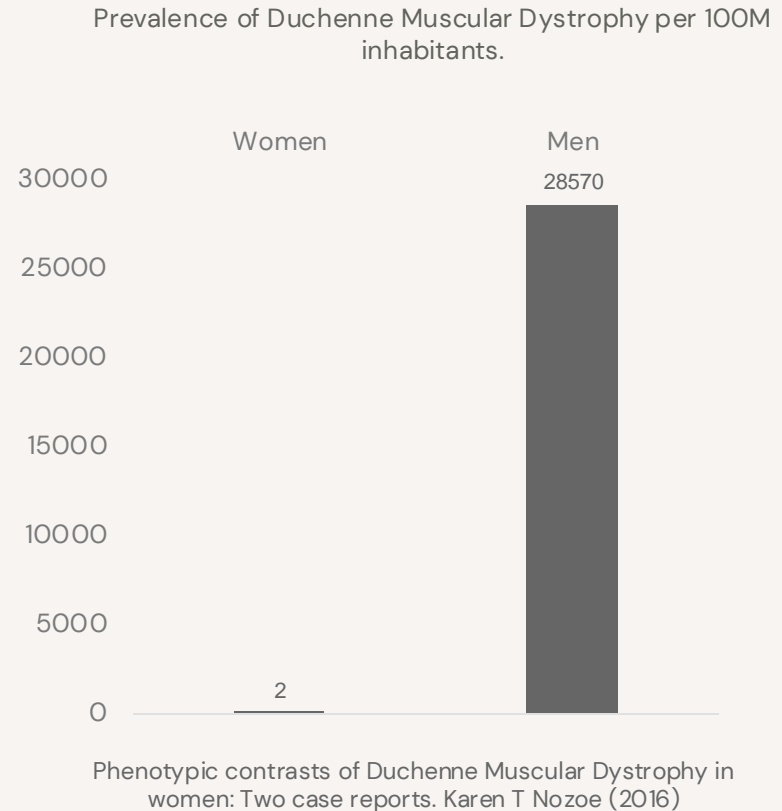
To ensure these issues are not simply age-related, we have selected only individuals who have reported living with a chronic illness throughout their entire lives. We identified a total of 370 individuals meeting these criteria. While some of them may not have a formal MD diagnosis, their mobility challenges closely mirror those faced by MD patients. For the purposes of this report, when we refer to MD patients, we are discussing these 370 individuals with a highly similar profile.

Since our database does not specifically indicate which respondents have muscular dystrophy, we had to identify these individuals indirectly based on their characteristics.

Given that Duchenne muscular dystrophy—the most common form of muscular dystrophy—affects almost exclusively men, we determined that gender was a reliable exclusion criterion for women who exhibit symptoms similar to muscular dystrophy but do not have the condition itself.

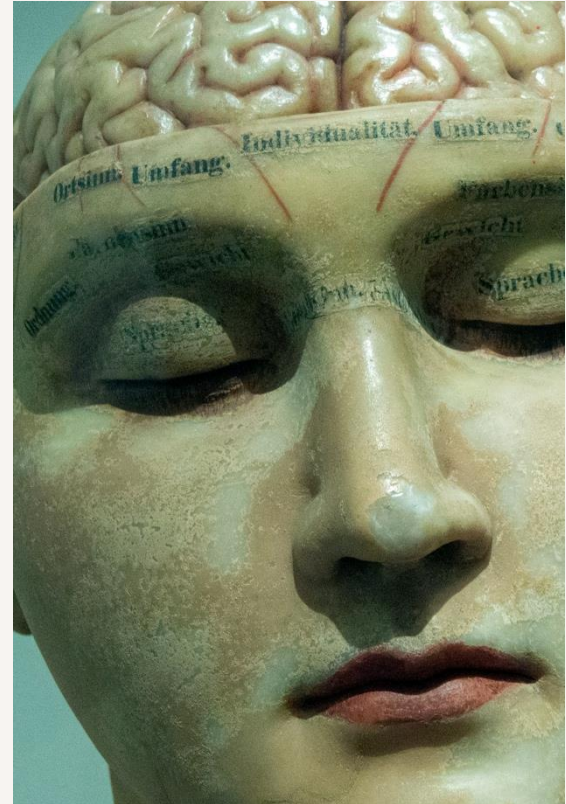
However, it is important to highlight that this filter is applied strictly to calculate the average wellbeing level of the patient group. For all other analyses (e.g., prevalence rates), we consider all cases, including both men and women.

The reason for this specific filtering approach for muscular dystrophy is due to its absence in our database—a limitation not present for Parkinson's and multiple sclerosis.



# 01

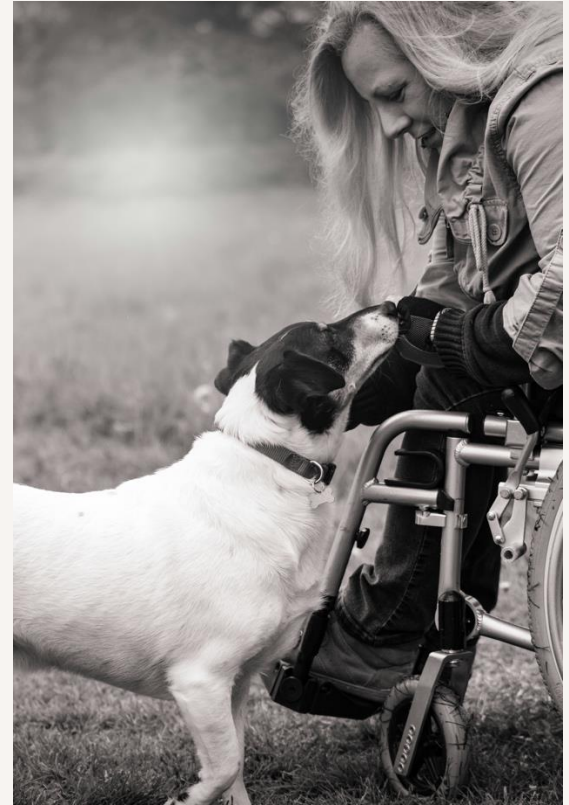
## HAPPINESS ACROSS NEURODEGENERATIVE DISEASES



## Guiding Individuals and Policymakers: Understanding the Disease Impact

Analysing the impact of a disease on wellbeing serves two key audiences: individuals, who can use the insights to improve their own quality of life, and policymakers and institutions, who can identify where to invest resources to benefit the largest number of people.

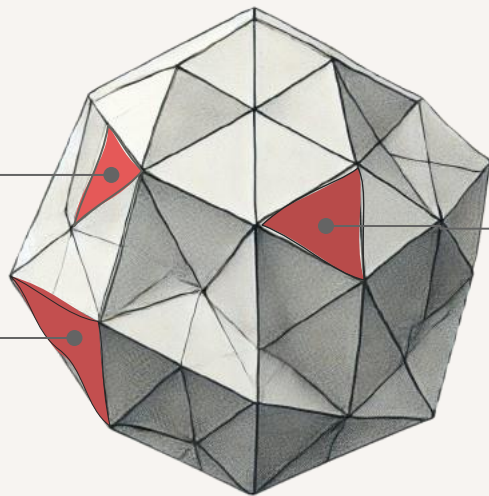
In this chapter, we shed light on both the individual and national perspectives, and explain the method used to calculate WALYs (Wellbeing Adjusted Life Years).



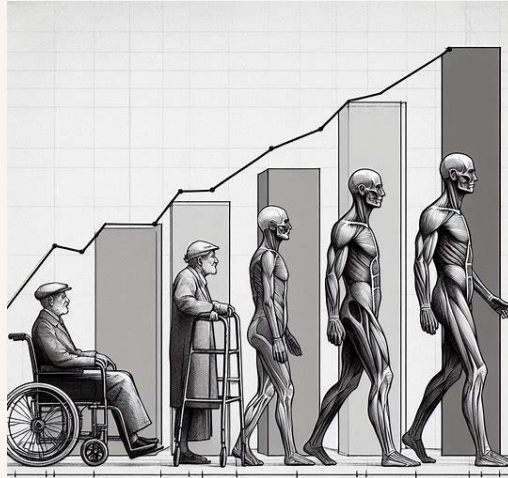
## In this chapter...

In this chapter, we'll explore how we calculate the effect of illness on wellbeing and quantify the wellbeing loss experienced by patients with neurodegenerative conditions.

We'll also examine how these diseases impact the general population, considering both the individual burden and the prevalence of each condition.

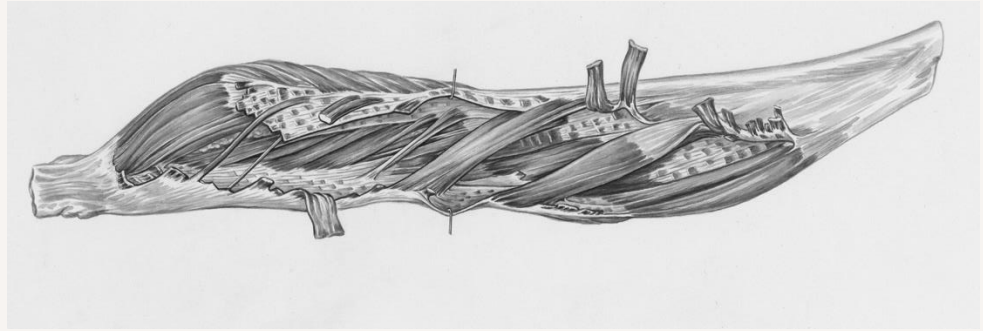


Additionally, we'll analyze how various life circumstances—such as unemployment, divorce, or financial losses—affect wellbeing, to gain an intuitive understanding of the impact these diseases have on patients' lives.



## LIFE SATISFACTION IMPACT

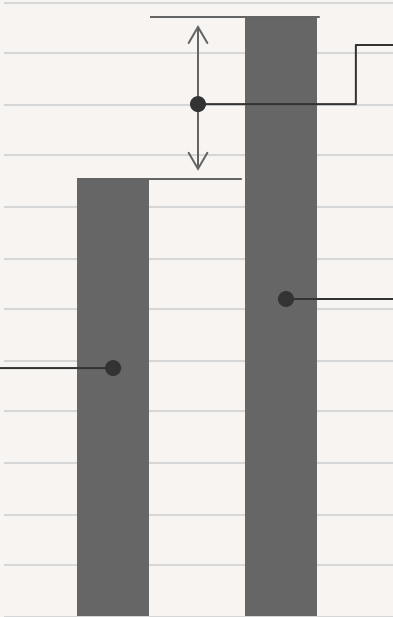
The impact of a disease on wellbeing is estimated by measuring the difference in life satisfaction between patients and healthy individuals.



# Methodology Overview: Calculating Life Satisfaction Impact

## Actual life satisfaction

Average life satisfaction score based on responses from all patients.



## WALYs

Difference between the life satisfaction of patients and their healthy counterparts, expressed as a proportion of the healthy standard.

## Potential life satisfaction

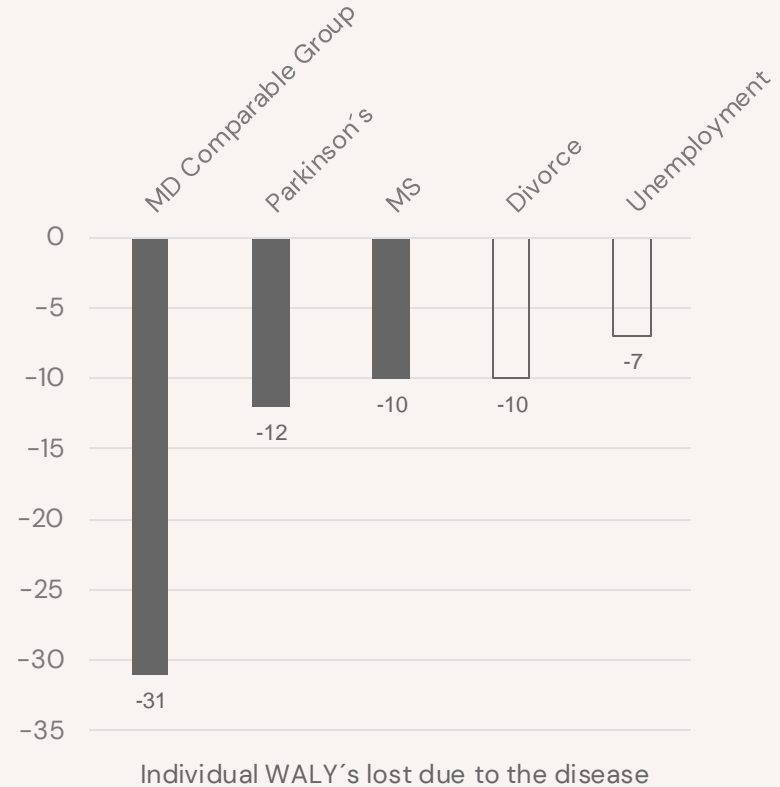
Average life satisfaction of healthy individuals with similar age and economic conditions as the patients.

$$WALY_{S_{lost}} = 1 - \frac{\textit{Actual life satisfaction}}{\textit{Potencial life satisfaction}}$$

## Comparing Each Disease's Impact on WellBeing

The following chart illustrates the percentage of wellbeing lost to each disease. Muscular Dystrophy (MD), the most severe of the three, results in a loss of 31 WALYs, meaning that someone who develops MD will experience 31% less wellbeing compared to individuals of the same age and conditions without the disease. For instance, if a healthy person in Denmark typically rates their life satisfaction at 8 out of 10, a person with MD might rate it closer to 5.5.

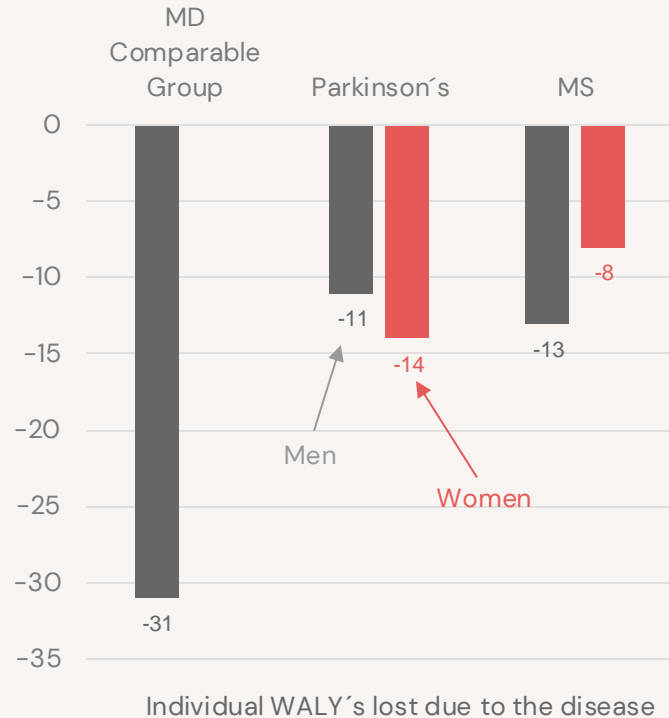
A person with Parkinson's is almost twice as unhappy as someone who has lost their job, and living with MS brings suffering comparable to the stress and emotional turmoil of going through a divorce.



## Gender Differences in the Impact of Diseases on Wellbeing

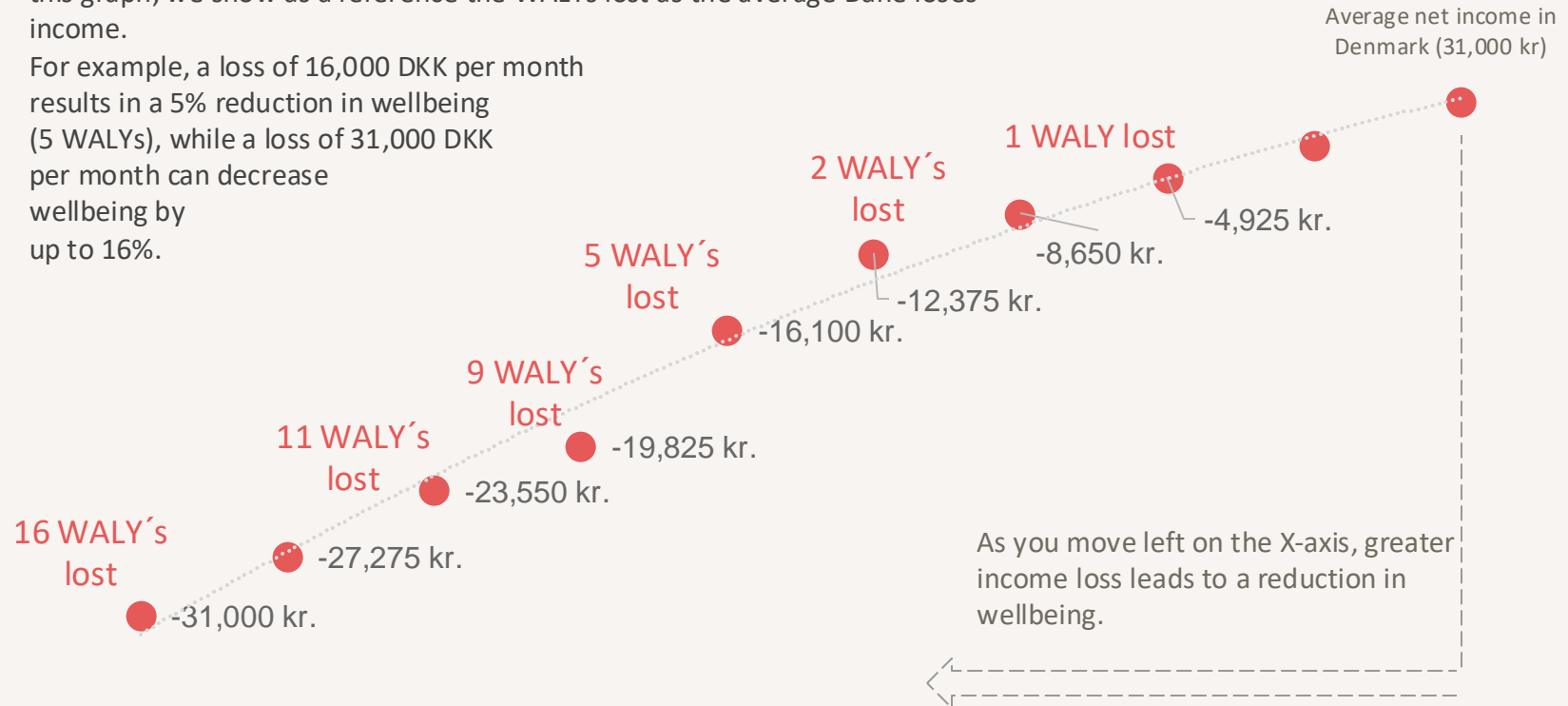
Diseases also have different impacts on the population depending on gender. As we can see in the following graph, Parkinson's disease slightly affects the wellbeing of women more than that of men, with women losing 14% of their wellbeing—3 percentage points more than men. In the case of multiple sclerosis, the opposite is true.

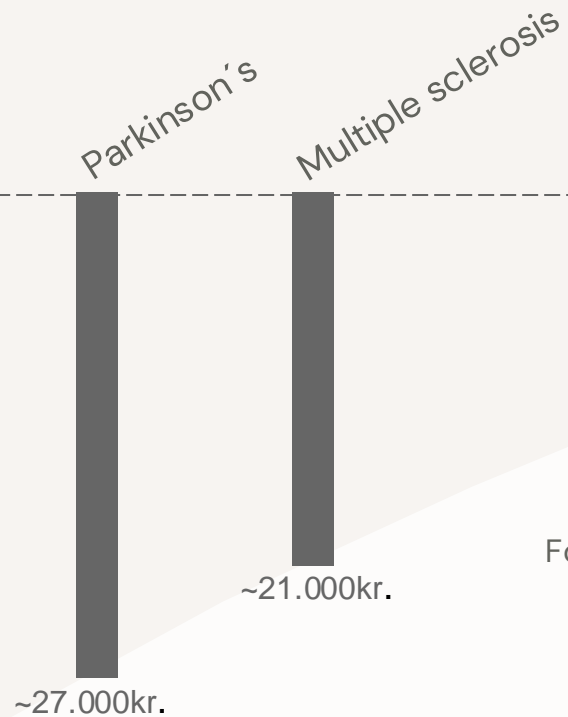
In the chapter on demographic differences, we will analyze the reasons behind these variations. One of the reasons why women with Parkinson's are slightly less happy than men is that significantly more women live alone. This is also true in the general population due to men tending to die earlier, but in the case of Parkinson's patients, this trend is even more pronounced.



The loss of wellbeing is not always easy to grasp without a comparison. In this graph, we show as a reference the WALYs lost as the average Dane loses income.

For example, a loss of 16,000 DKK per month results in a 5% reduction in wellbeing (5 WALYs), while a loss of 31,000 DKK per month can decrease wellbeing by up to 16%.





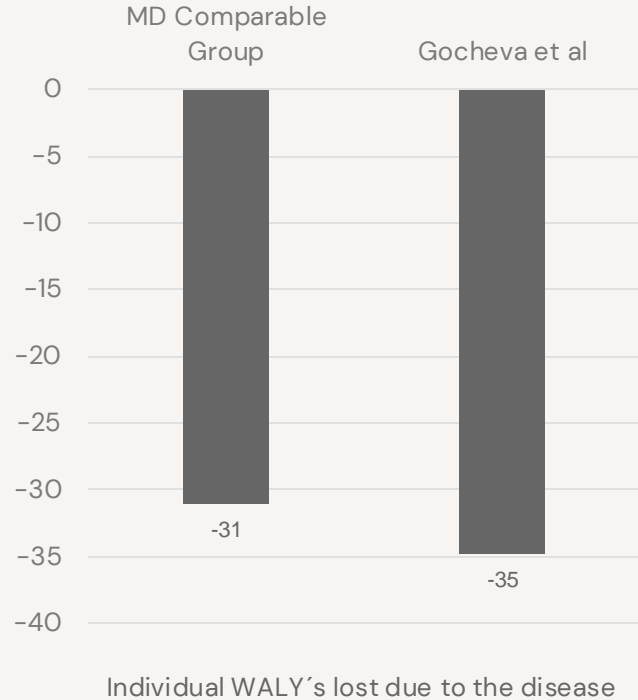
In this way,  
we can roughly compare  
WALY's to a monetary value.  
A person with Parkinson's endures as  
much suffering from their disease, as a Dane with  
an average salary of 31,000 DKK losing 27,000 DKK  
(in other words, living on just 5,000 DKK per month).  
For someone with MS, the effect is equivalent to losing  
21,000 DKK.

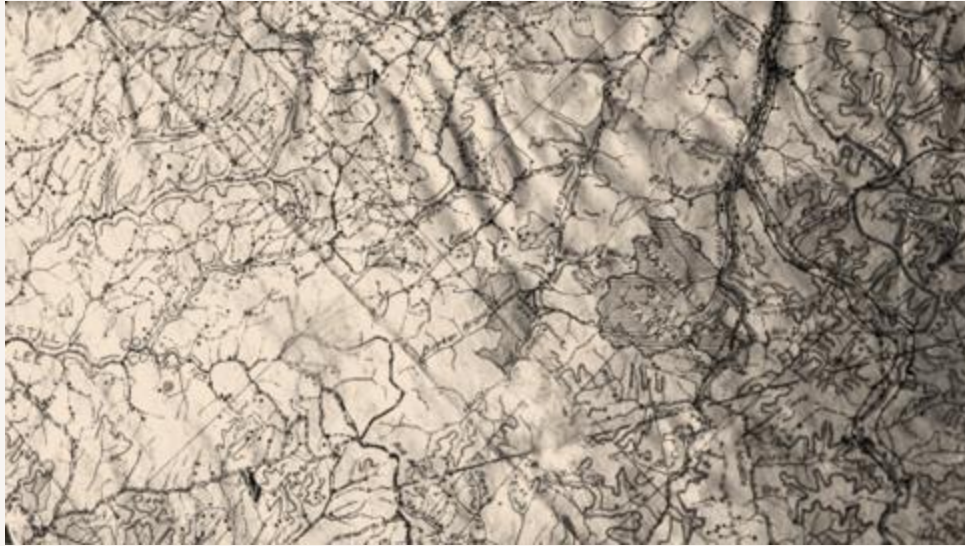
In the case of MD, wellbeing loses reaches 31 WALYs, a figure that goes beyond the scale of what we can equate with available economic data.

Since our sample does not consist of actual patients with muscular dystrophy but rather individuals with similar symptoms, we wanted to compare our results with those of other studies. For this, the WALYs study requires two relevant data points: the life satisfaction of patients and the life satisfaction of healthy individuals within the same age range.

Unfortunately, none of the studies we reviewed used life satisfaction as a metric, and most of them lacked control group data. To see the studies analyzed, please go to section 2.1 of the Appendix. The only study that met the criteria for calculating WALYs is shown in the graph.

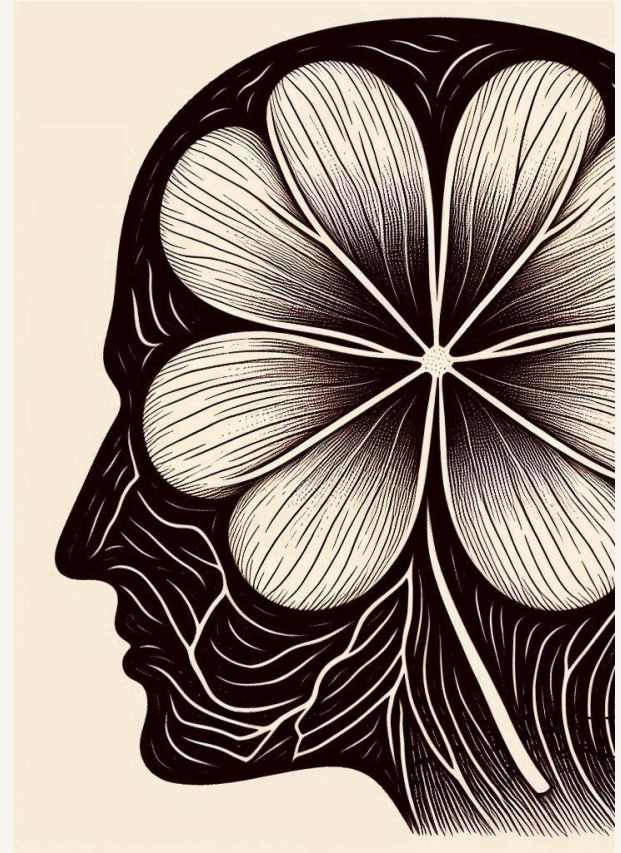
This study estimates, using the Health-Related Quality of Life (HRQoL) metric, that MD patients have an average score of 54.66, compared to 83.83 for healthy controls. This means MD patients experience a 34% reduction in wellbeing compared to what they might achieve if they did not have the disease. Our study concludes that these patients lose 31% of their wellbeing.





## NATIONAL WELLBEING IMPACT

The national wellbeing impact aggregates the individual effect of a disease across all patients in a given country and adds the disease's death toll.



# Estimating National Happiness Impact

## Impact per Country

We estimate the number of patients in each country and multiply it by the disease's impact on wellbeing.

## Premature Mortality Assessment

We also calculate the number of individuals who die prematurely due to the disease.

## Combining effects

The total impact is determined by adding the effect on wellbeing and the impact of premature mortality.

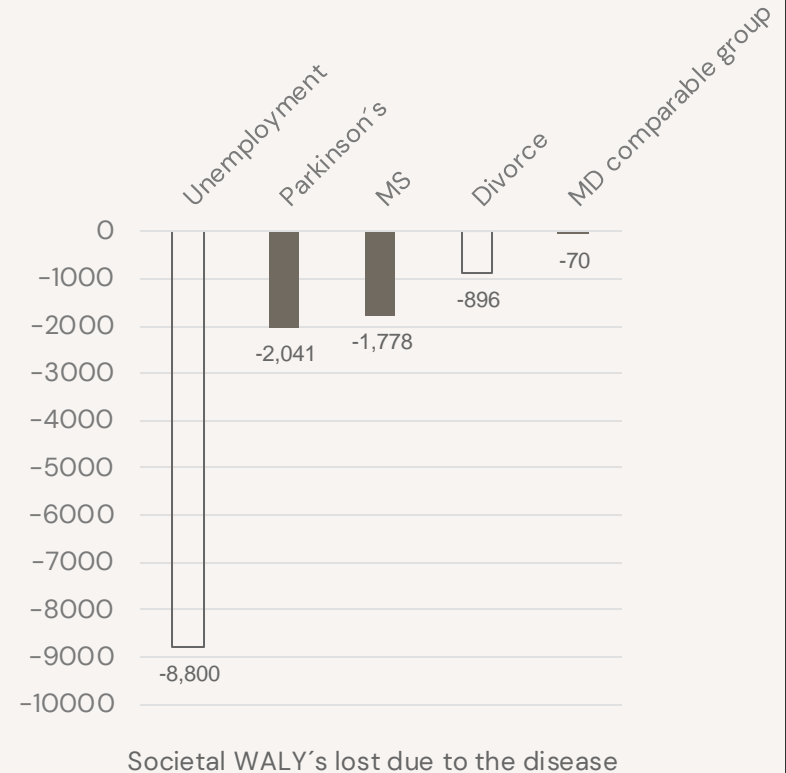
$$WALY_{S_{lost}} = \sum WALY_{S_{while\ alive}} + \sum \text{Premature deaths}$$

## National Wellbeing Impact by Disease

In this chart, the individual impact of each disease on wellbeing has been multiplied by the number of patients in Denmark, and we've also accounted for the number of premature deaths caused by each disease annually. This gives us a clearer picture of how each disease affects the overall wellbeing of the nation.

Although Parkinson's disease has a lesser effect on an individual's wellbeing compared to MD, its overall impact on national wellbeing is greater because there are significantly more patients affected by Parkinson's. Parkinson's disease accounts for a loss of 2,041 WALYs in Danish society, approximately one-third of the impact caused by unemployment.

Following Parkinson's, multiple sclerosis (MS) leads to a loss of 1,778 WALYs—more than twice the suffering generated by all divorces in Denmark.



## SUMMARY

### HAPPINESS ACROSS NEURODEGENERATIVE DISEASES

If we don't analyse the impact that different diseases have on people's wellbeing, these issues can easily go unnoticed. While GDP rises, thousands of individuals may quietly endure their struggles, feeling abandoned by the system. This is why measuring wellbeing is as crucial to guiding our societal decisions as any economic metric.

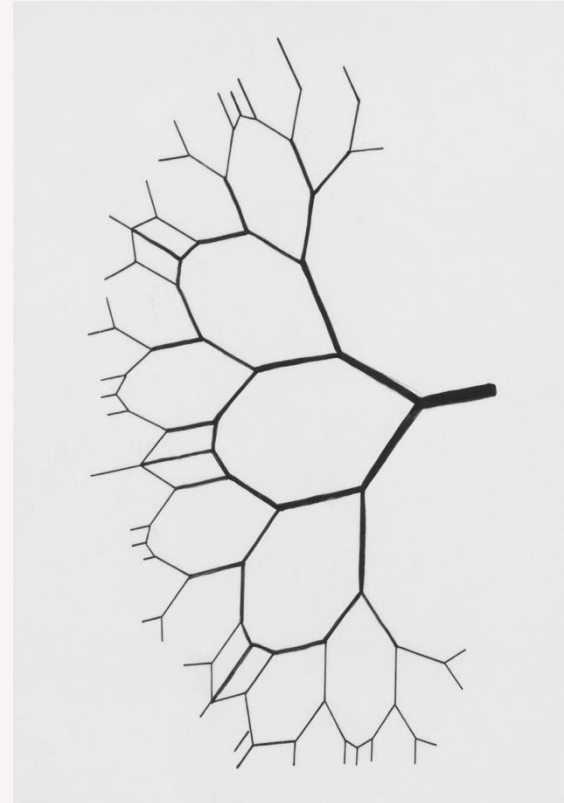
As we have seen, a person facing mobility challenges similar to those with muscular dystrophy is 31% less happy than someone of the same age without these problems—an impact that is three times worse than going through a divorce and four times worse than being unemployed. Any effort to improve the lives of these individuals would have an enormous impact on their quality of life.

At a broader level, despite the relatively low prevalence of Parkinson's disease, its effect on total wellbeing is nearly three times greater than the combined impact of all divorces in Denmark.

In total, these three diseases account for ~3,800 WALYs, an effect comparable to almost halving the unemployment rate in Denmark. If dedicating our efforts to employment policies has significant effects on national wellbeing, investing in these diseases should be equally prioritized on our national agenda.

# 02

## REGIONAL EFFECTS: A EUROPEAN OVERVIEW

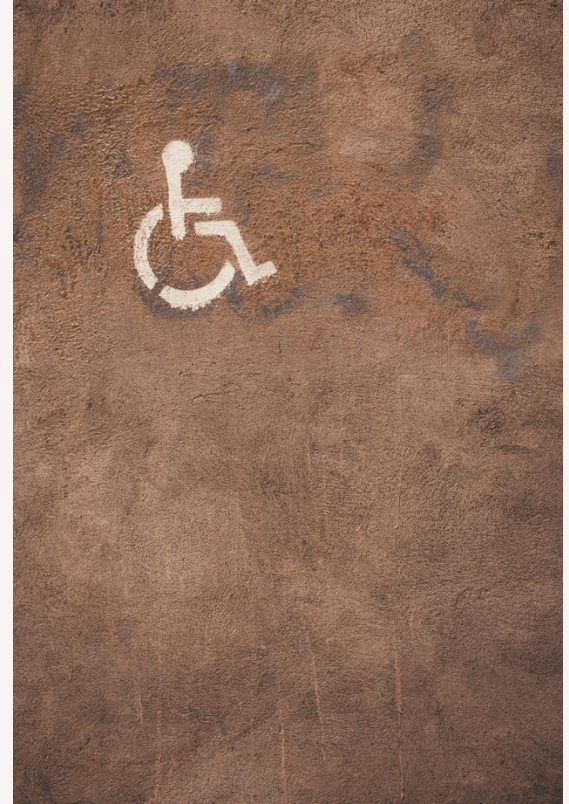


## Lessons from Across Borders: Enhancing Patient Wellbeing

In this section, we explore how patients with neurodegenerative diseases experience their conditions differently depending on the country they live in.

In regions where the disease carries less stigma, social support is stronger, or public assistance is more substantial, the impact of the disease on wellbeing can be less severe.

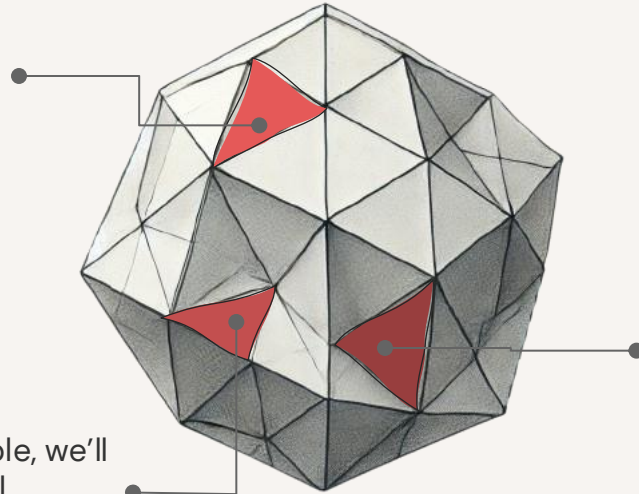
We analyse which countries show the smallest gap in wellbeing between patients and healthy individuals, providing insights that Denmark can apply to improve the lives of its own citizens.



## In this chapter...

In this chapter, we will study wellbeing differences among patients in various countries to identify which policies are more effective and which are less so.

Where data is available, we'll also examine regional differences within Denmark, focusing on factors like transportation quality and access to healthcare.



Lastly, we'll look at specific case studies of initiatives that have successfully improved patients' lives across different areas of need.

## WALY's Lost Per Country

This map shows the wellbeing lost by patients in each country.

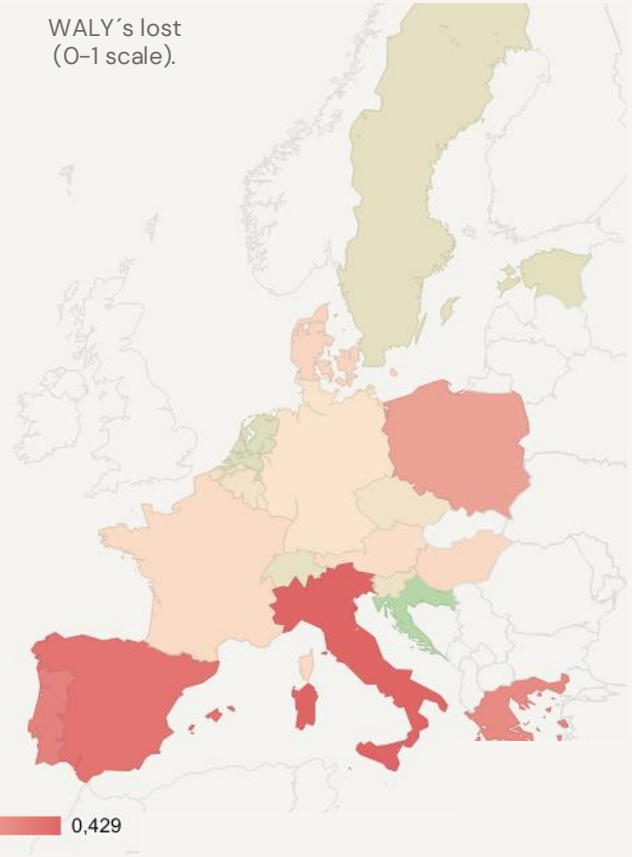
According to our data, the worst country is Italy, where patients lose 0,43 WALYs compared to healthy counterparts within the same country. It is followed by Spain (0,40), Portugal (0,38) and Greece (0,37).

The best country is Croatia, where only 0,02 WALYs are lost, followed by Netherlands (0,14), Estonia (0,15) and Sweden (0,16). Denmark is halfway with a total of 0.25 WALYs lost.

Due to the low prevalence of these diseases, the number of respondents is very limited in each country. To gather more data and draw more reliable conclusions, we have combined data from the three diseases.

0,024  0,429

WALY's lost  
(0-1 scale).

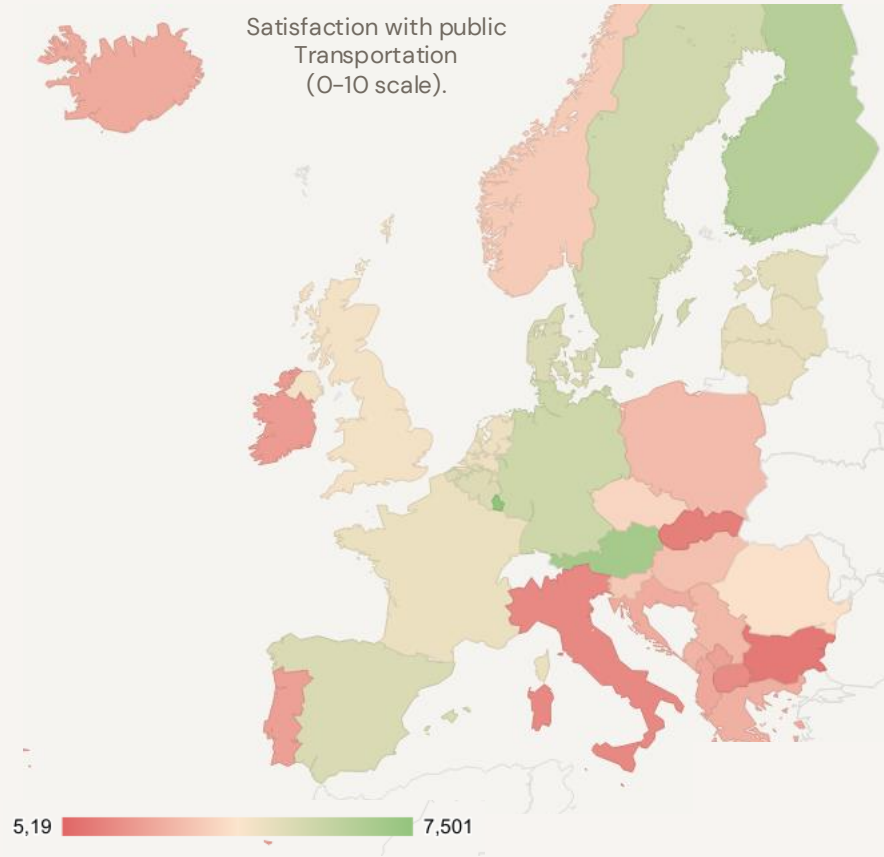


## Public Transportation Satisfaction Across European Countries

Given that mobility issues are the main challenge for patients with neurodegenerative diseases, an efficient and accessible public transportation system is crucial to maintaining their independence.

In the following chart, we can observe the level of satisfaction with public transportation in various European countries, based on the European Quality of Life Survey. The scale ranges from 0, representing the lowest possible satisfaction, to 10, the highest. As we can see, the map doesn't perfectly align with the map of WALYs, but many Southern European countries like Italy and Portugal show very low satisfaction, while countries like Denmark, Sweden, and Finland have some of the highest levels.

The countries with the greatest satisfaction with public transportation are Luxembourg (7.5), Austria (7.3), and Finland (7.11). On the other hand, the lowest satisfaction is seen in Cyprus (5.18), Malta (5.25), and Bulgaria (5.26). Denmark ranks as the sixth-best country (out of 39 countries), with a score of 6.7.

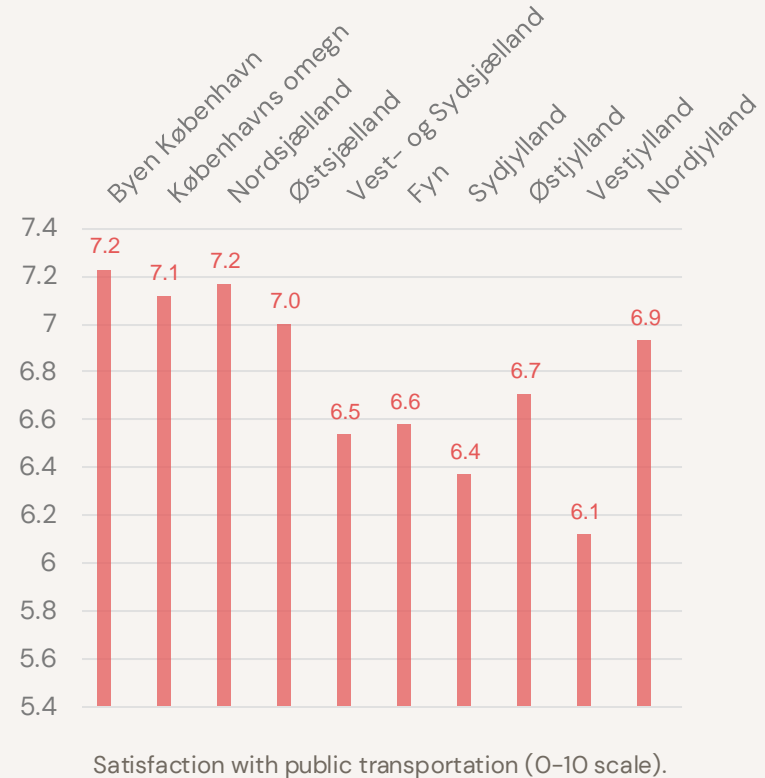


## Regional Differences in Public Transportation Satisfaction in Denmark

While Denmark is well-positioned in terms of public transportation quality, not all regions within the country share high levels of satisfaction. As shown in this chart, Vestjylland, Syddjylland, Fyn, and Vest og Sydsjælland report medium levels of satisfaction with public transport, similar to countries like Hungary, Slovenia, or Turkey. In these regions, greater investment is needed.

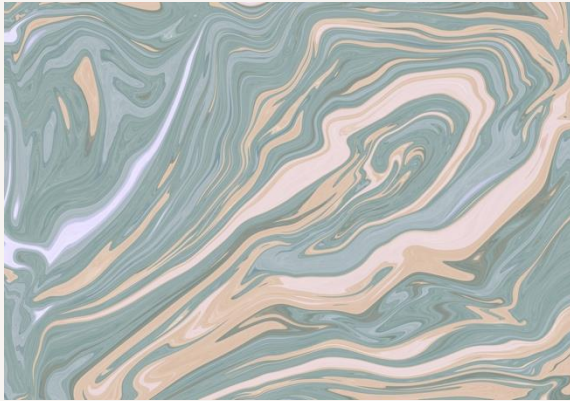
Copenhagen and its surrounding areas have the highest satisfaction levels, comparable to those of the best-performing European countries.

According to data from the European Quality of Life Survey, a person in the Nordic countries with mobility issues can lose up to 5% of their life satisfaction if their satisfaction with public transport drops from 8-10 to 5 or less in a 0-10 scale. This may seem like a small decrease, but it is equivalent to the loss in life satisfaction that an average Dane would experience if their monthly net income were reduced by 16,000kr.



## Problem Overview

Data shows that the main differences in the quality of life for Parkinson's patients across countries are primarily due to ease of access to stores, leisure activities, medical care, and social interactions with friends.



## Innovative Solutions for Enhancing Mobility for People with Disabilities

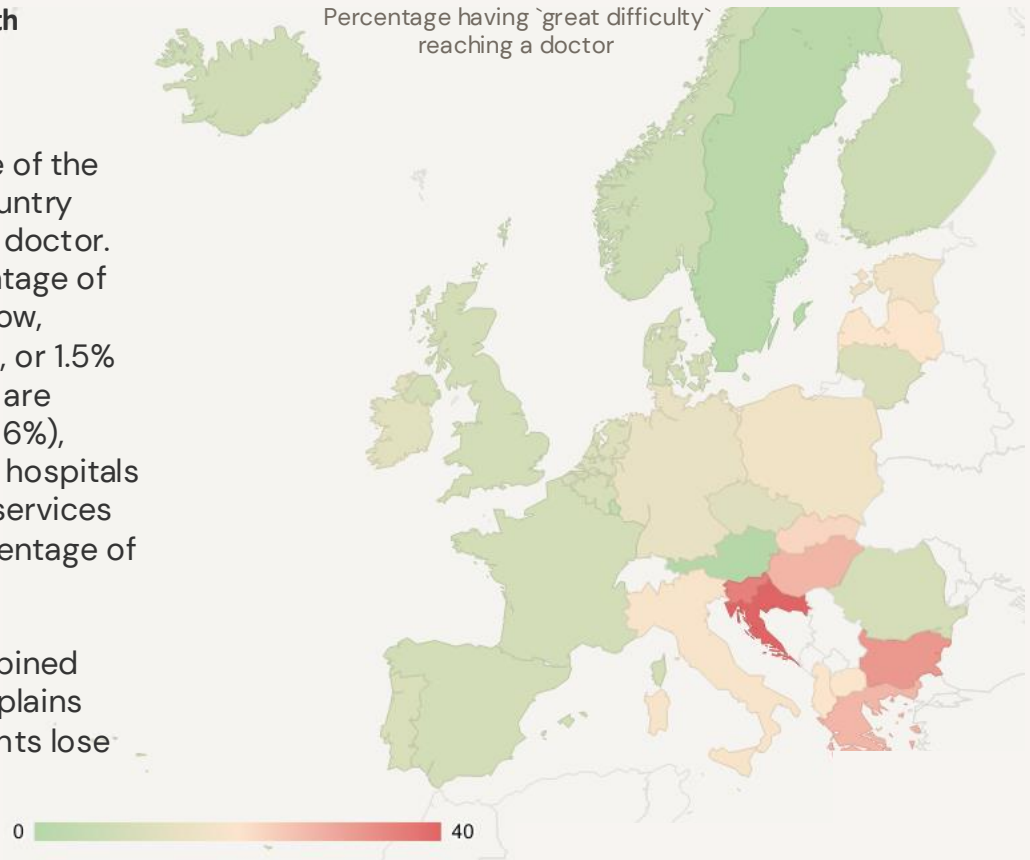
The possibilities to improve the lives of people with reduced mobility are vast, ranging from the more obvious, such as ramps and elevators for access to transport, to less conventional options. One example is the use of tandem bicycles, which allow caregivers to ride alongside patients, as was implemented in the Gävle project, in Sweden, where these bikes were introduced to promote inclusive recreational transportation. Another case can be found in Canada (Push to Open), where similar initiatives have been employed to make outdoor activities accessible for disabled individuals. Additionally, training courses for young people to help them identify urban environment issues for disabled people can play a crucial role in creating a more inclusive society.

For studies and examples of transportation improvements proven to be effective, please see Section 3.2 in the Appendix document.

## Challenges in Accessing Healthcare for People with Reduced Mobility Across Countries

In the following chart, we see the percentage of the population with reduced mobility in each country who report having great difficulty reaching a doctor. As we can see, in most countries, the percentage of people who cannot access a doctor is very low, around 8% (8.4% in Denmark, 10% in Portugal, or 1.5% in Sweden). The worst-performing countries are Turkey (40%), Croatia (40%), and Slovenia (36%), reflecting the lack of healthcare centers and hospitals in these countries. Implementing telehealth services in these regions could greatly help that percentage of patients who struggle to reach a doctor.

Once again, the distance to the doctor, combined with dissatisfaction with public transport, explains why Italy is one of the countries where patients lose the most WALYs in all of Europe.

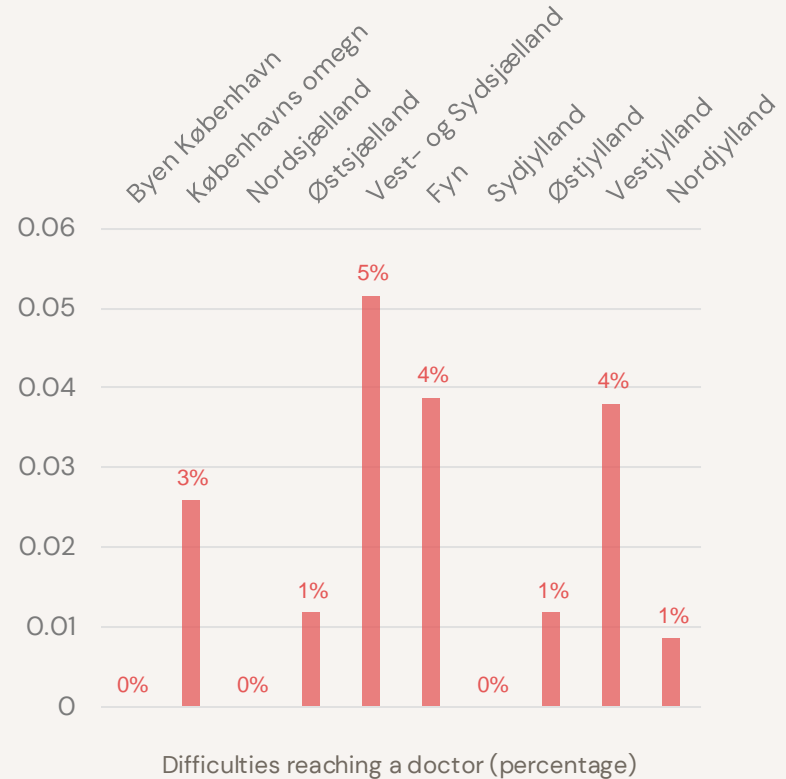


## Access to Healthcare in Denmark's Regions

When comparing regions in Denmark, we observe that Vest and Sydsjælland, Fyn, and Vestjylland are the areas where the highest number of people feel it is very difficult to reach a doctor. In this graph, we have selected the percentage of people in the general population who express this difficulty, as the number of patients with reduced mobility per region was too small to draw statistically reliable conclusions.

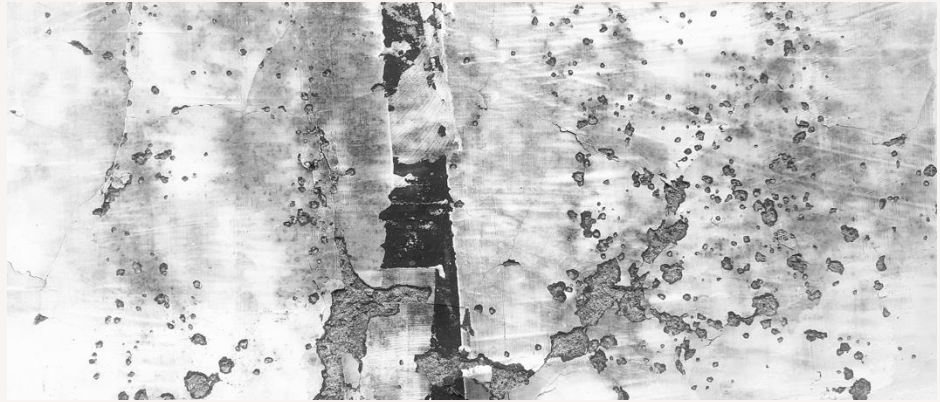
In Byen København, Nordsjælland, and Sydjylland, there were 0 respondents who had issues reaching a doctor. Although the number of respondents decreased when divided by region (76, 71, and 137 respondents in each of these three regions), the sample size is still large enough to be considered reliable.

A patient with reduced mobility who does not have a doctor nearby experiences 11% less wellbeing than one who does, making this a crucial point for improving patients' quality of life.



## Problem Overview

Patients with neurodegenerative diseases, such as Parkinson's, multiple sclerosis, or muscular dystrophy, often face significant challenges in accessing medical care.

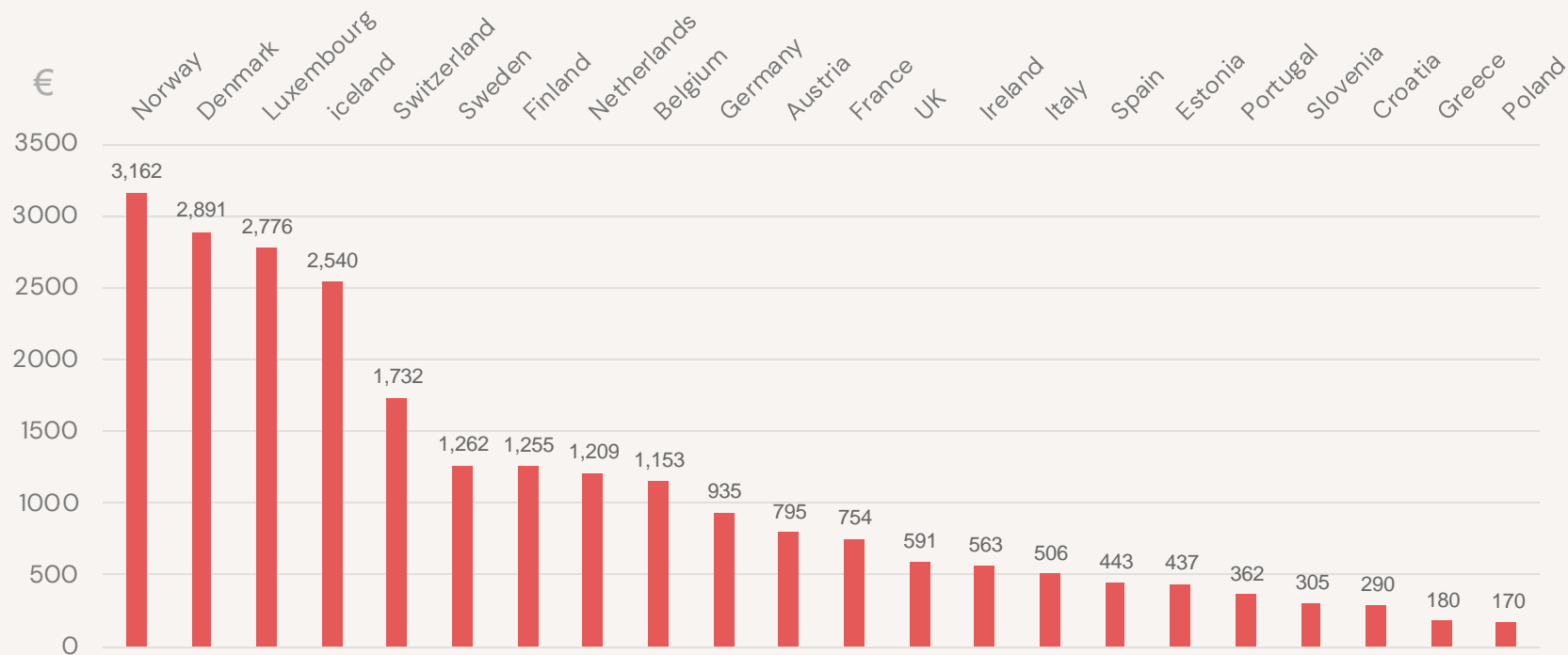


## Practical Cases:

Home Monitoring and video consultations are the key applications of telehealth. Home monitoring enables healthcare professionals to monitor neurodegenerative patients remotely, ensuring early detection of deteriorations. In addition, patients with neurodegenerative conditions often need frequent check-ups to adjust treatments or therapies. Video consultations reduce the need for them to travel to medical facilities,

For studies and examples of tele-health solutions, please see Section 3.1 in the Appendix document.

## Disability benefits per country



Disability benefits higher in Nordic countries and lower in South Europe. Eurostat.

## The Welfare State: A Shield Against Suffering for People with Disabilities

The strength of the welfare state in the Nordic countries is undoubtedly one of the key factors that contribute to a significantly better quality of life for people with disabilities compared to those in Southern Europe.

The difference is stark; while in Spain or Italy, individuals with disabilities experience up to a 40% loss in wellbeing due to their conditions, in countries like the Netherlands or Sweden, the loss is only around 15%.

In Denmark, despite its strong social policies, patients are positioned between the north and the south, with a 25% reduction in wellbeing.

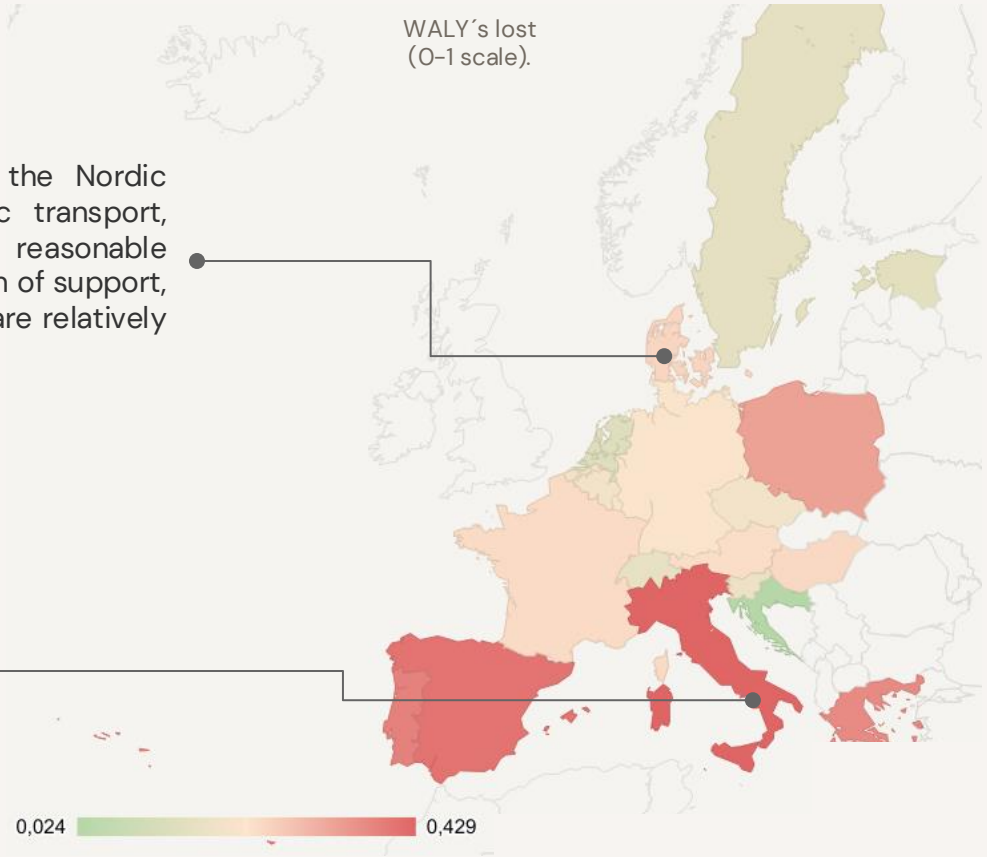


## Nordic countries

As we have seen so far, the Nordic countries have good public transport, healthcare centers within a reasonable distance, and a strong system of support, which ensures that patients are relatively satisfied with their lives.

## South Europe

In southern countries, especially in Italy, the public transport system is very deficient, social support is limited, and there is a shortage of healthcare centers. This leads to patients in Italy having some of the lowest levels of life satisfaction.



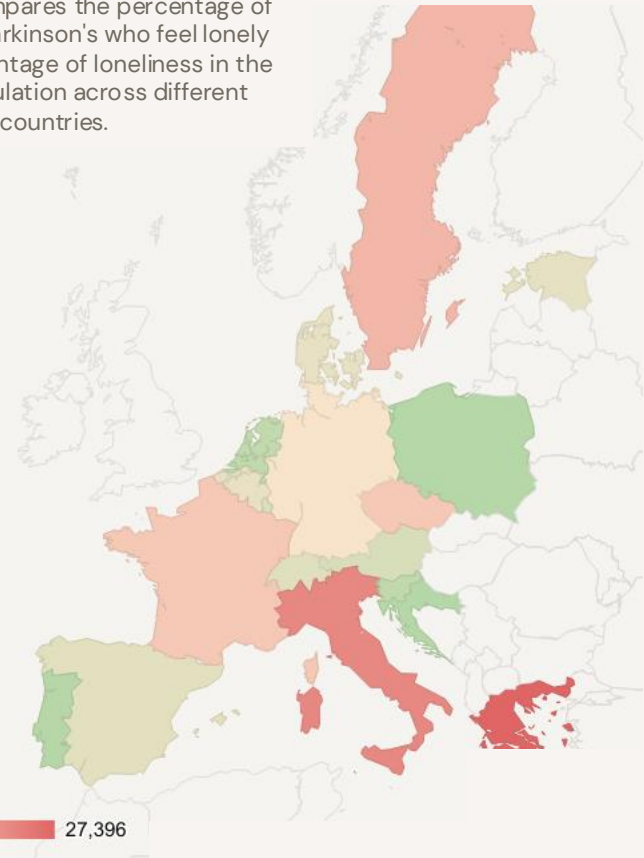
## Loneliness Among Parkinson's Patients Compared to the General Population

In the following chart, we observe the percentage of people with Parkinson's who feel lonely, compared to the general population. The countries with the worst results are Greece and Italy. In Greece, 16% of the general population feels lonely, while 44% of the Parkinson's population experiences loneliness—a difference of 27 percentage points. In Italy, the difference is 23 percentage points (33% for Parkinson's patients, 10% for the general population). The countries with the best results are the Netherlands, Slovenia, and Portugal. In Denmark, only 2% of the general population reports feeling lonely, but this rises to 7.6% among Parkinson's patients.

Loneliness is one of the factors that most significantly affects wellbeing. A patient who feels lonely is 25% less satisfied than one who does not.

This graph compares the percentage of people with Parkinson's who feel lonely with the percentage of loneliness in the general population across different countries.

-6,881  27,396



# SUMMARY

## REGIONAL EFFECTS

The differences observed between countries highlight a significant opportunity for policymakers, urban planners, architects, and communities to enhance the lives of patients with neurodegenerative diseases and mobility issues. Key interventions include:

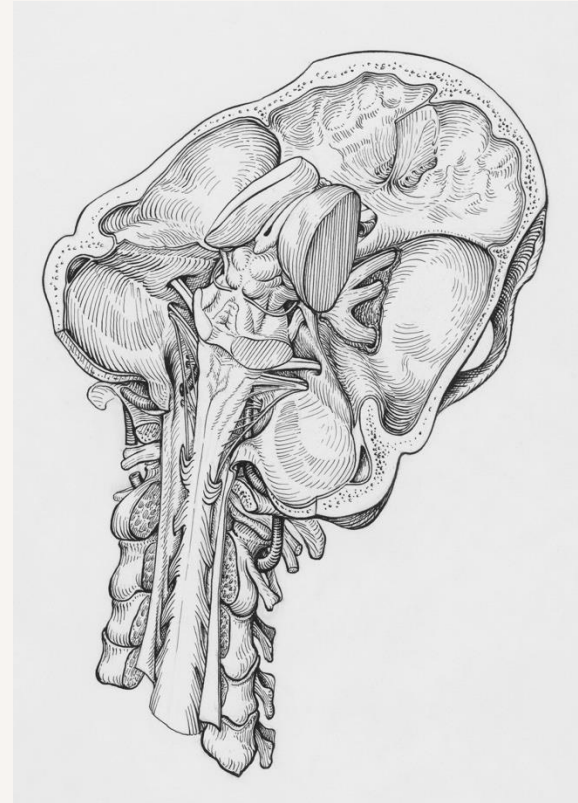
- **Enhancing Accessibility:** Installing ramps and elevators to facilitate mobility.
- **Upgrading Transport Networks:** Improving the transportation infrastructure to ensure that it is accessible and efficient.
- **Implementing Tele-Assistance:** Utilizing technology to provide support and care remotely, reducing the need for physical mobility.
- **Fostering Socialization Opportunities:** Creating environments and programs that encourage social interaction for those with limited mobility.

These measures are not only beneficial for patients with specific health conditions but also address the broader issue of loneliness and isolation among the elderly. This is a significant source of distress in our society and remains largely undetected by conventional measures of progress. While GDP may continue to rise, a substantial number of individuals may feel isolated and alone, overlooked by current progress indicators.

This approach emphasizes that true societal advancement is measured not only by economic growth but by the wellbeing and inclusivity of all community members, especially the most vulnerable.

# 03

## DEMOGRAPHIC DISPARITIES

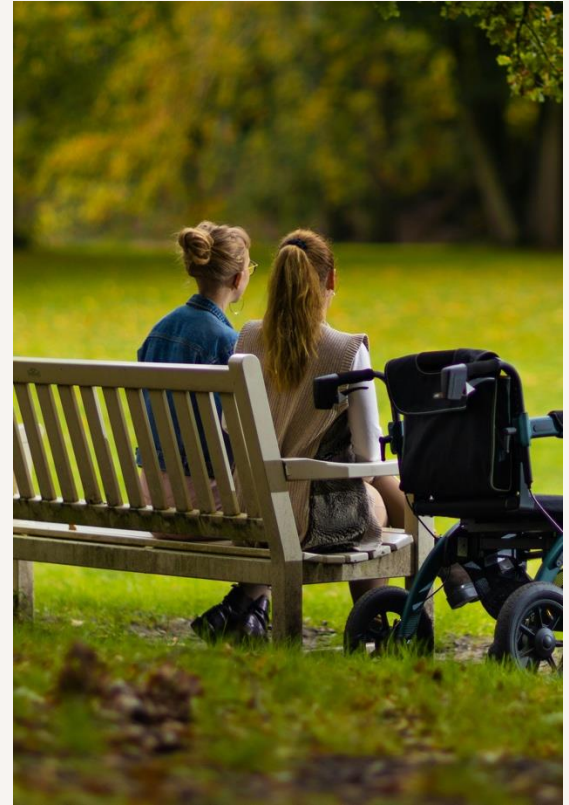


# Understanding the Demographic Divide: Tailoring Support for Diverse Lives

Diseases impact us differently depending on whether we are men or women, young or older.

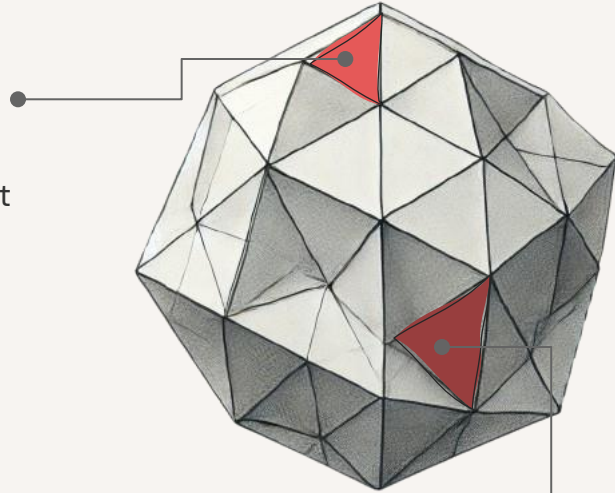
Understanding the variations in wellbeing across different demographic groups is crucial for grasping the complexities of life with these diseases and for offering personalized support to each individual.

In this chapter, we will explore how wealth has tremendous potential to improve the lives of patients, but its impact diminishes once patients reach a certain level of affluence. We will also analyze which places are better to live in and at what ages the disease has the most severe effects.



## In this chapter...

In this chapter, we will examine wellbeing differences among men and women, people of various ages, and individuals across different income levels.

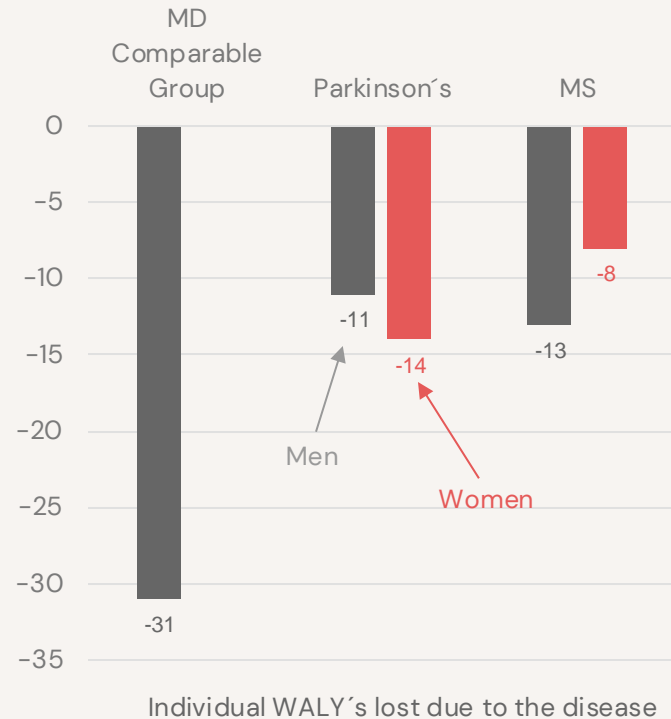


We will also delve into the reasons why more women with Parkinson's tend to live alone—an imbalance that cannot be fully explained by differences in life expectancy between men and women.

## Gender Differences in the Impact of Diseases on Wellbeing

As we saw in the second chapter, the differences between men and women with diseases like Parkinson's or Multiple Sclerosis are not very pronounced. Men with MS seem to be more affected by the disease than women, and women with Parkinson's appear to lose more wellbeing than men. However, the difference is so small that it could be attributed to simple statistical variability.

Despite this apparent similarity in the effect that the disease has on the wellbeing of men and women, in the next slide, we can see that women face a problem that men do not: the lack of support from their partners.



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## A Hidden Injustice: How Gender Roles Leave Women Without Support

**Men are more likely to leave women when their partners are ill.** Data reveals that there are far more women with Parkinson's and multiple sclerosis living without a partner than life expectancy differences can explain. About 17-18% of men with Parkinson's don't live with their partners, a figure that remains consistent with the general male population. However, for women, the percentage jumps from 34% in healthy women, to 49% when they develop Parkinson's. This 15% gap isn't solely due to life expectancy differences – it likely reflects men choosing to leave their partners during illness.

In the case of MS, the difference is less pronounced but still present; while the percentage of men with MS living without a partner is the same as that of healthy men, 19%, MS seems to create a barrier for women in forming or maintaining relationships. Among women with MS, 42% live alone, compared to 39% of the general healthy female population.

This trend is supported by studies showing that men are more likely to divorce women when they have serious illnesses like cancer or multiple sclerosis. In fact, there's a six-fold difference: while 20.8% of women experience separation or divorce when they fall ill, only 2.9% of men face the same situation when they are sick [*Check the "Demographic Disparities" chapter in the appendix file for more detailed references and data*]

On a more positive note, for women, not having a partner at home seems to have less of an impact on their overall wellbeing than it does for men. Women's life satisfaction drops from 6.6 to 6.3 when living without a partner, while men see a bigger decline, from 7.0 to 6.0.

DEMOGRAPHIC DISPARITIES

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Percentage of women with  
Parkinson's living alone

49%

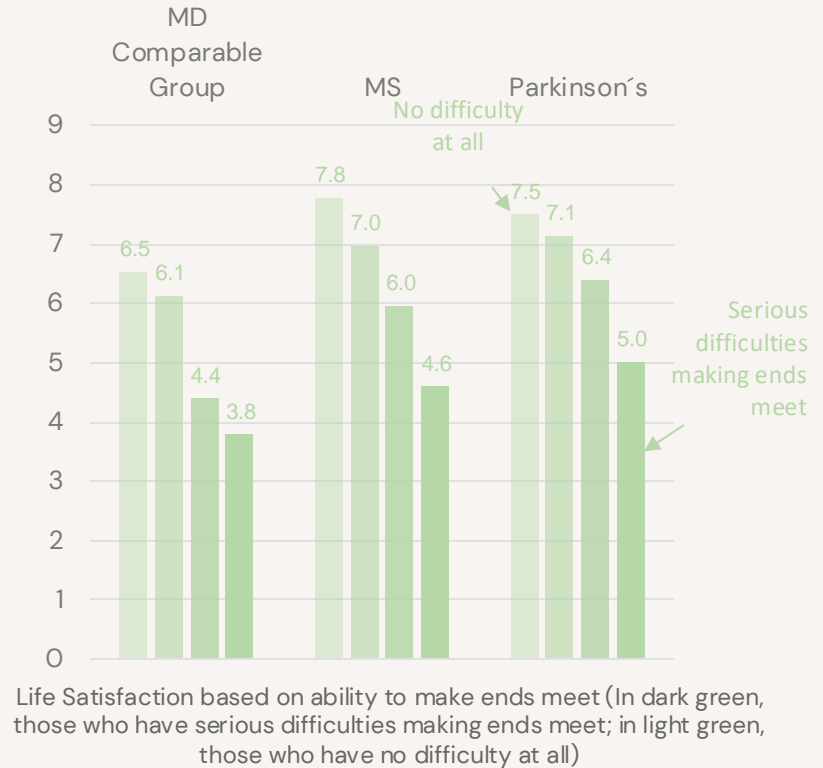
Percentage of men with  
Parkinson's living alone

18%

## Life Satisfaction Across Income Groups

In this graph, we can observe the differences in wellbeing among various groups based on their ease of making ends meet financially. As we can see, the financial capacity of patients is a crucial factor in their wellbeing. For example, although MS patients are generally much happier than MD patients, MS patients who struggle to make ends meet are less happy (4.6) than MD patients who can easily make it to the end of the month (6.5).

In this graph, we have used the life satisfaction scale directly, as it better reflects the differences in wellbeing. The life satisfaction scale ranges from 0 to 10, where 0 represents the worst possible life and 10 the best.

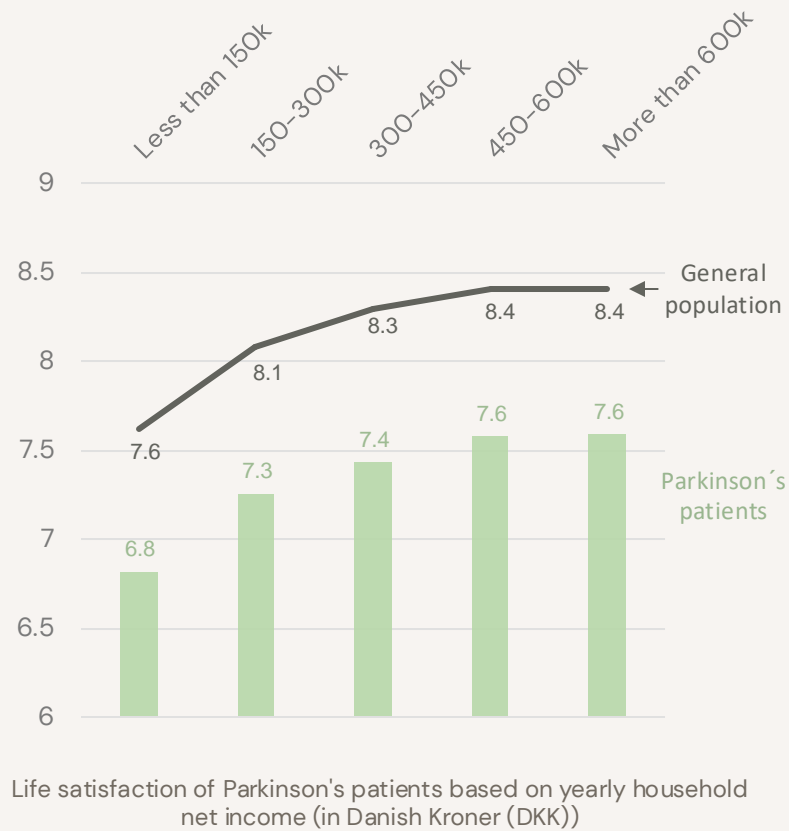


## Diminishing Returns in Wellbeing: The Impact of Household Income on Parkinson's Patients

When comparing life satisfaction among Parkinson's patients based on household net income, we observe a well-known phenomenon in the field of wellbeing economics: the so-called diminishing returns. This refers to the tendency for wellbeing to increase at a slower rate as income rises.

In the case of Parkinson's patients in Northern Europe, wellbeing rises quickly from those earning less than 150k DKK annually to those earning 450k DKK. However, we find no significant difference in wellbeing between those earning 450 DKK and those earning more than that amount.

If society aims to improve population wellbeing in the most efficient way, wealth should be redistributed to lift those earning less than 150k DKK out of poverty—a group that accounts for 32% of the population in our sample.



A long wooden pier extends from the bottom left towards the center of the frame, leading into the ocean. The pier has a metal railing on the left side. The water is a deep blue-grey color, and the sky is overcast and grey. The overall mood is somber and contemplative.

“

“We are poor. We have to raise money for necessary expenditure for my son as a priority; this puts a constraint on the family income. Of course, we can live minimally enough. But, if we want a good-quality life, we cannot get it, because I have to care for my son”.

The experience of parents of adult sons with Duchenne muscular dystrophy regarding their prolonged roles as primary caregivers

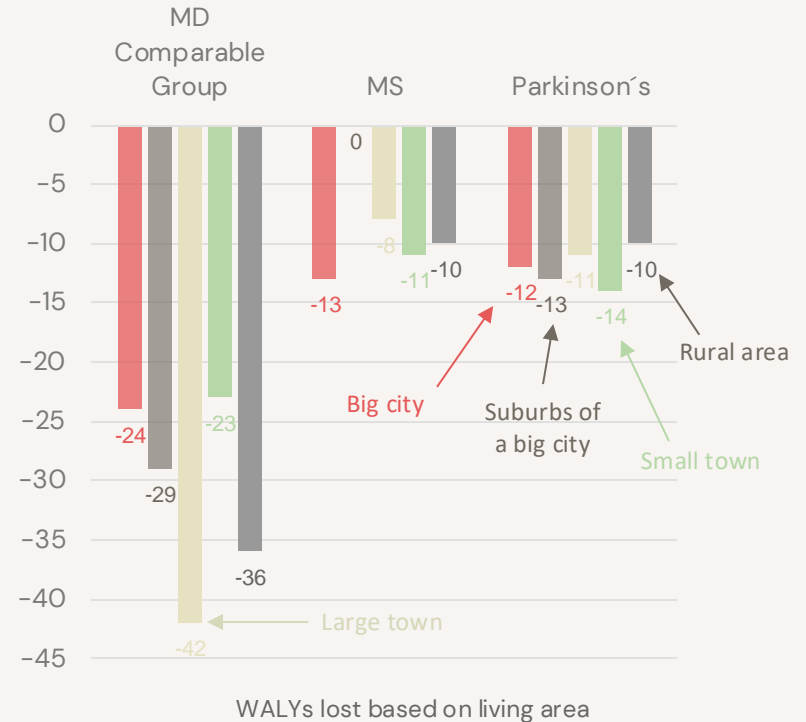
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## The (*Inconsistent*) Impact of Living Area on Patient Wellbeing

When comparing wellbeing based on the area in which patients live, we do not see a clear pattern. For patients with symptoms similar to muscular dystrophy, it appears that the worst place to live is a large town, where patients lose 42% of their wellbeing compared to healthy people living in the same type of city. After that, the worst place would be a rural area (-36%), followed by the suburbs of a big city (-29%). The best places to live seem to be either a big city or a small town.

In the case of Parkinson's, the wellbeing lost is similar across all locations, while for MS, the best place to live appears to be the suburbs of a big city, where patients are just as happy as the general population.

Based on these results, the main conclusion we draw is that the size of the city one lives in does not have a clear impact on the wellbeing of people with mobility issues.



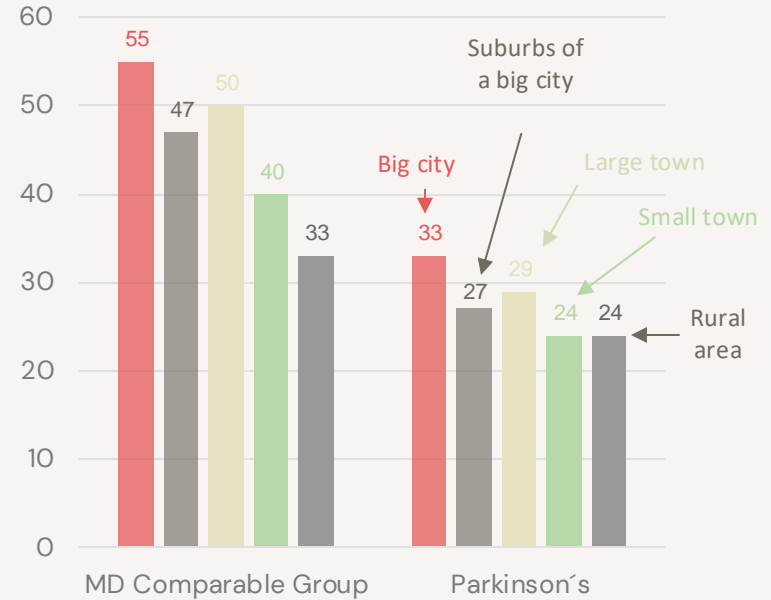
## The Impact of Living Area on Loneliness

The effects on wellbeing that a patient's living environment can have are shaped by two opposing factors. On one hand, larger cities offer more accessible services for patients with reduced mobility, which significantly enhances their independence. On the other hand, smaller towns and villages foster closer-knit communities, allowing patients to feel more integrated, which can reduce feelings of isolation. The contrasting results we observe when comparing WALYs lost among patients based on whether they live in larger or smaller urban areas may be due to this clash of factors.

When analyzing patients' loneliness based on the size of their city, we find that, indeed, in large cities, patients generally tend to feel lonelier than in rural areas or small towns. More than half of the patients with symptoms similar to those of MD patients feel lonely in large cities, whereas only 33% feels lonely in rural areas.

Interestingly, patients in the suburbs of large cities report feeling less lonely than those in the inner city. This reflects a well-known pattern; suburban areas often have homes with shared gardens, which allow neighbors to interact naturally, fostering a sense of community that is harder to achieve in apartment buildings without common areas, as often found within cities.

Percentage feeling lonely based on living area

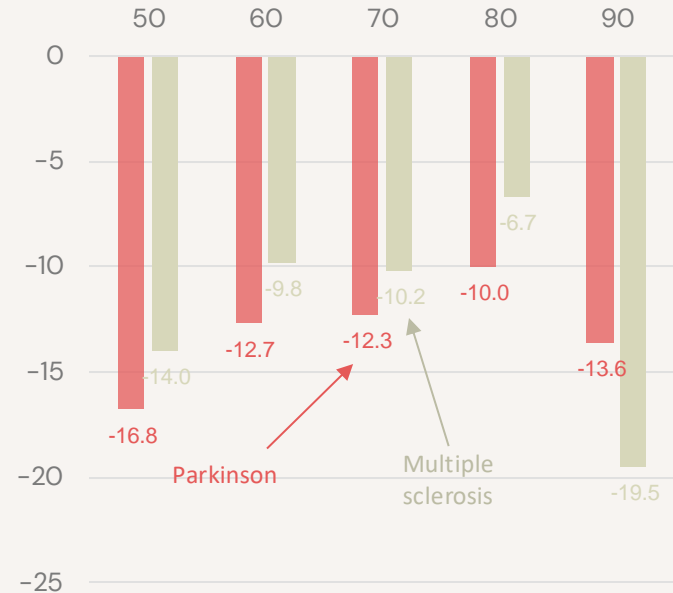


## WALYs Across Age Groups for Patients Over 50

In the following graph, we see how WALYs evolve with age, starting from 50 years onwards.

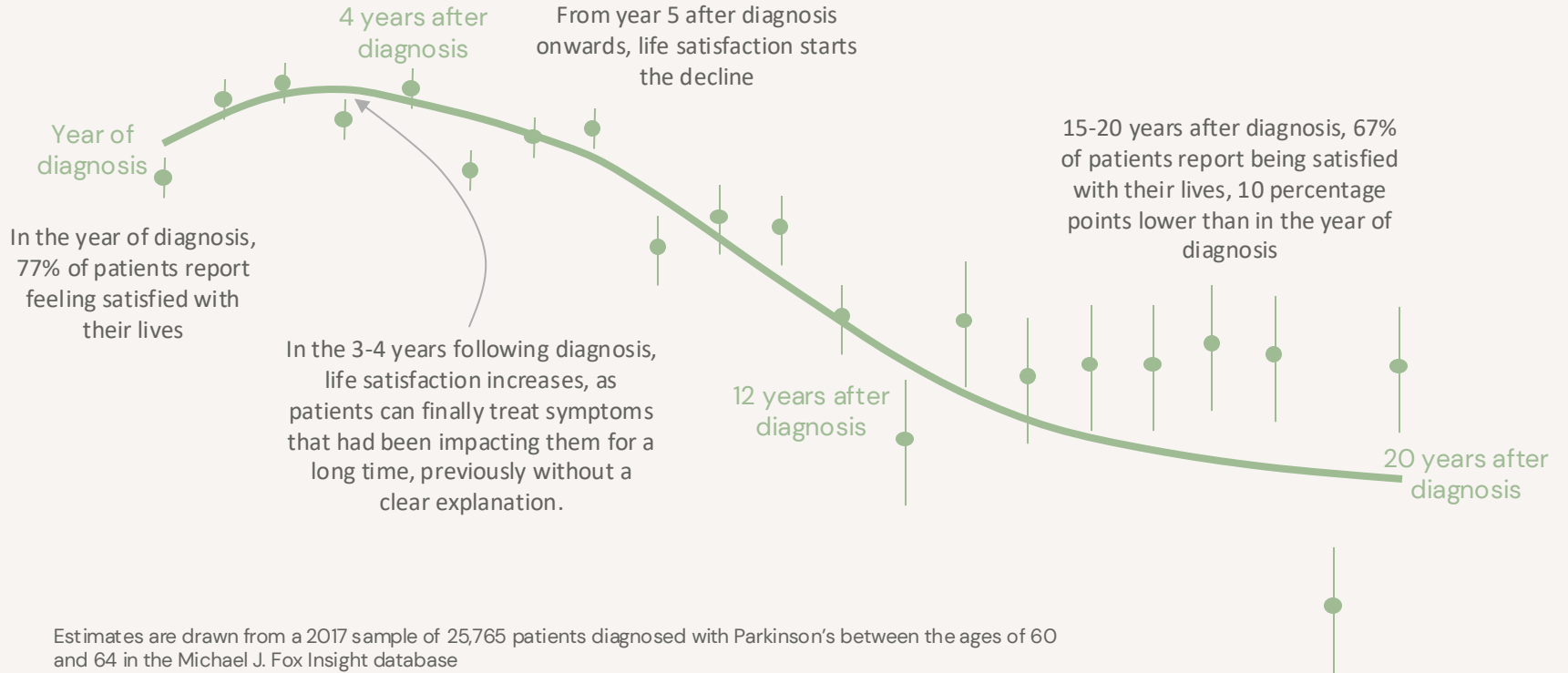
As shown, the impact of the disease on wellbeing diminishes over the years, likely because the effects of aging in the general population begin to resemble the issues faced by patients. It is only upon reaching 90 years of age that the effects of the disease once again have a more significant impact on wellbeing.

It is important to clarify that this graph represents the average WALYs lost at a specific age but does not provide information on the progression of wellbeing from the year of diagnosis onward. In the next two slides, we take a closer look at how wellbeing develops over the years, starting from the year the patient was diagnosed.

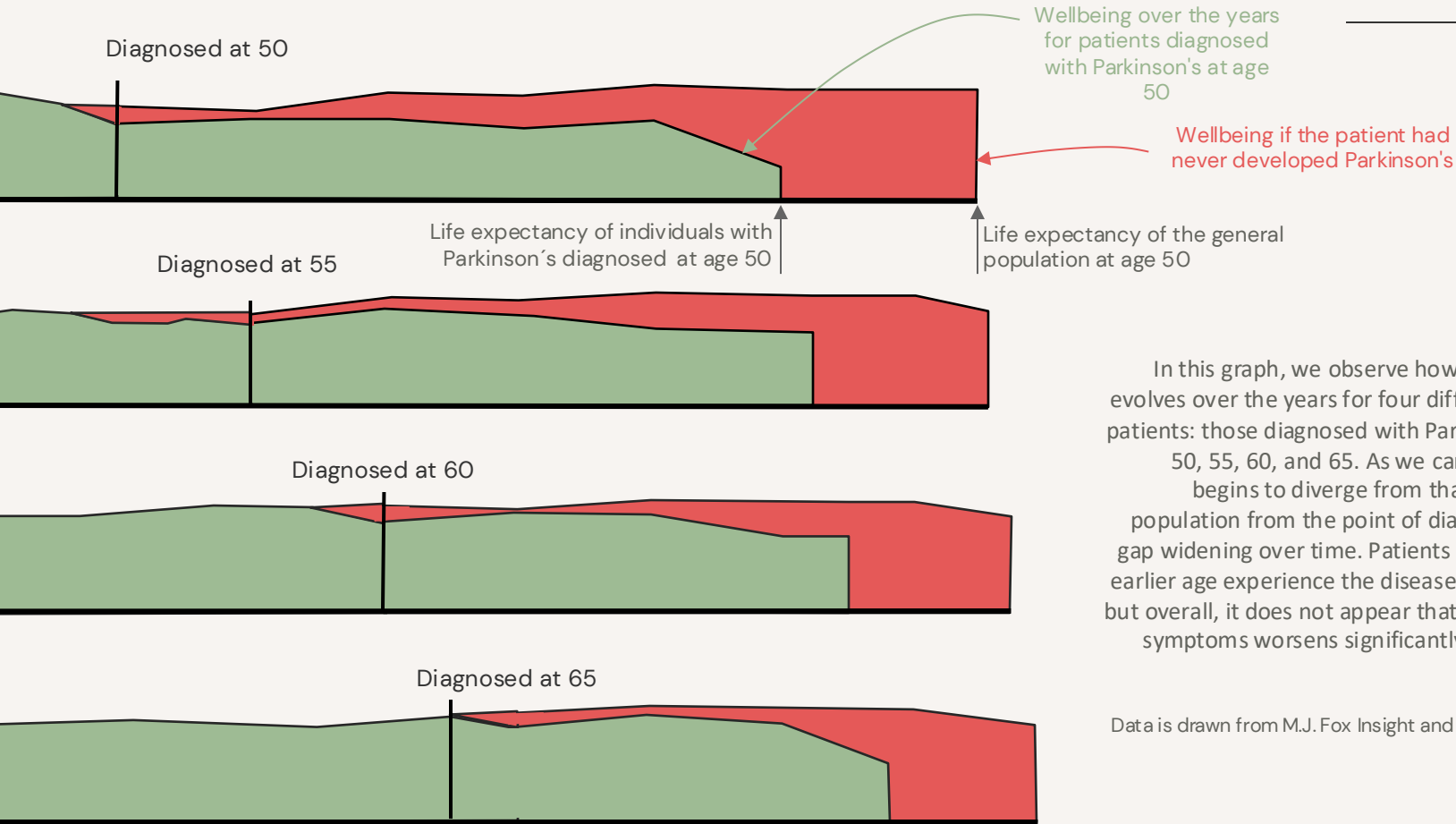


WALYs by age, starting from 50 years old.

## Percentage of Parkinson's patients who say they are satisfied with their lives, by years since diagnosis



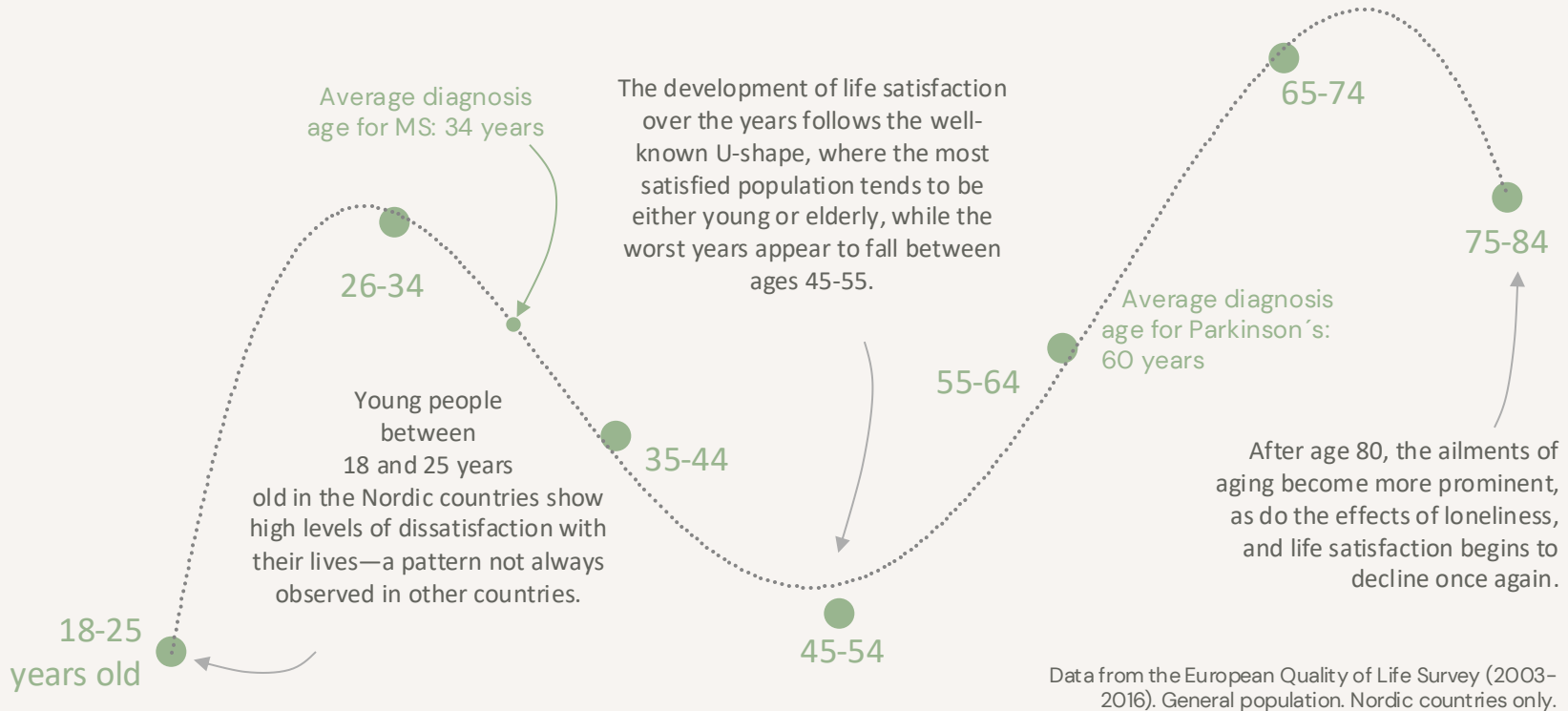
Estimates are drawn from a 2017 sample of 25,765 patients diagnosed with Parkinson's between the ages of 60 and 64 in the Michael J. Fox Insight database



In this graph, we observe how life satisfaction evolves over the years for four different groups of patients: those diagnosed with Parkinson's at ages 50, 55, 60, and 65. As we can see, wellbeing begins to diverge from that of the general population from the point of diagnosis, with the gap widening over time. Patients diagnosed at an earlier age experience the disease for more years, but overall, it does not appear that the intensity of symptoms worsens significantly with an earlier diagnosis.

Data is drawn from M.J. Fox Insight and the Global Burden of Disease.

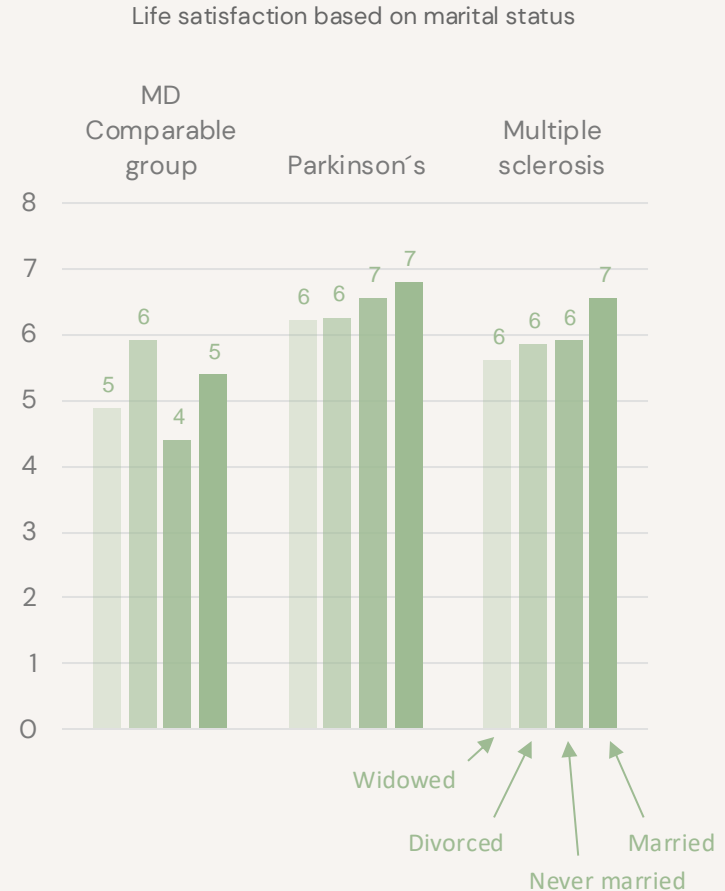
# Life Satisfaction's Ups and Downs: A Nordic Perspective on Age and Happiness



## Wellbeing Differences Based on Marital Status Among Patients

The differences in wellbeing between married, unmarried, divorced, and widowed patients are as expected. Married individuals living with their spouse are the happiest, followed by those who never married and those who are divorced. The least happy group is the widowed.

However, for patients with symptoms similar to muscular dystrophy, the differences show a slightly different pattern. Divorced individuals reported higher wellbeing than married individuals, and widowed patients reported greater wellbeing than those who never married. These differences are difficult to interpret intuitively and may be due to statistical variations, as the sample of divorced MD-like patients in our study was only 15 people, and the "never married" group included just 24 individuals. More data is needed to draw robust conclusions.



## SUMMARY: demographics disparities

The study of demographic differences reveals interesting insights into neurodegenerative diseases. One striking finding is that where a person lives matters less than we might expect. Whether it's a big city or a small town, Parkinson's and MS patients don't seem to feel much different in terms of wellbeing. This likely highlights the importance of a close-knit support system—partners, family, and perhaps a few close friends—rather than the broader environment.

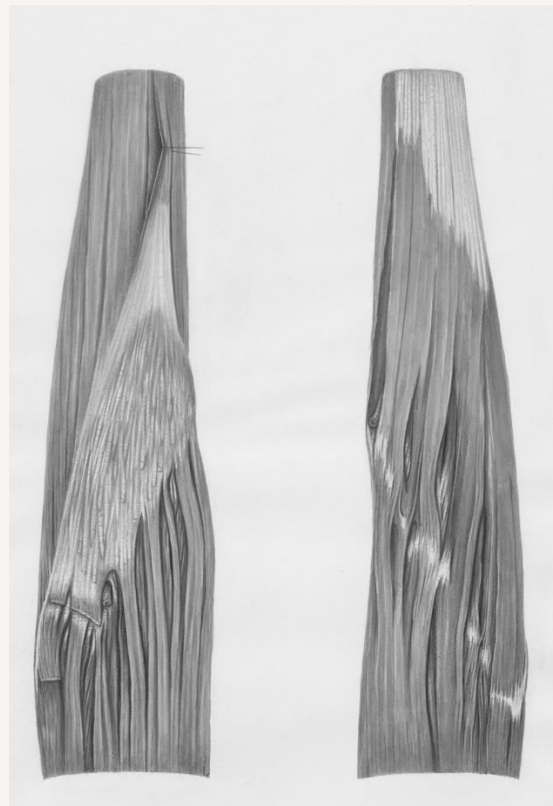
However, we do observe significant differences for muscular dystrophy patients, with a striking 20 percentage point gap in wellbeing between those living in a large town versus a small town. One might assume this is due to proximity to essential services like shops or health centers, but interestingly, patients are actually happier in big cities than in large towns. This paradox suggests there are factors at play that we don't yet fully understand, and further research is needed to uncover the reasons behind these patterns.

When it comes to age, the data shows that diseases take a heavier toll on younger individuals, with its impact diminishing as patients grow older. This aligns with a well-documented phenomenon in happiness research—the “U-shaped” curve of happiness over the lifespan: people are happiest when they are young, experience a dip around midlife (40–50 years), and regain happiness as they age. Despite the physical challenges of aging, retirement, along with a calmer and more mature outlook on life, often helps older adults manage physical issues better. This trend reverses, however, when health problems become severe, particularly in patients over 90.

As for wealth disparities, the data is clear: any patient earning 450,000 DKK per year reaches a level of material security where additional wealth no longer improves wellbeing. Below this threshold, however, material deprivation does negatively impact wellbeing. This highlights the importance of wealth redistribution to ensure that everyone can achieve a basic level of financial security essential for their independence.

# 04

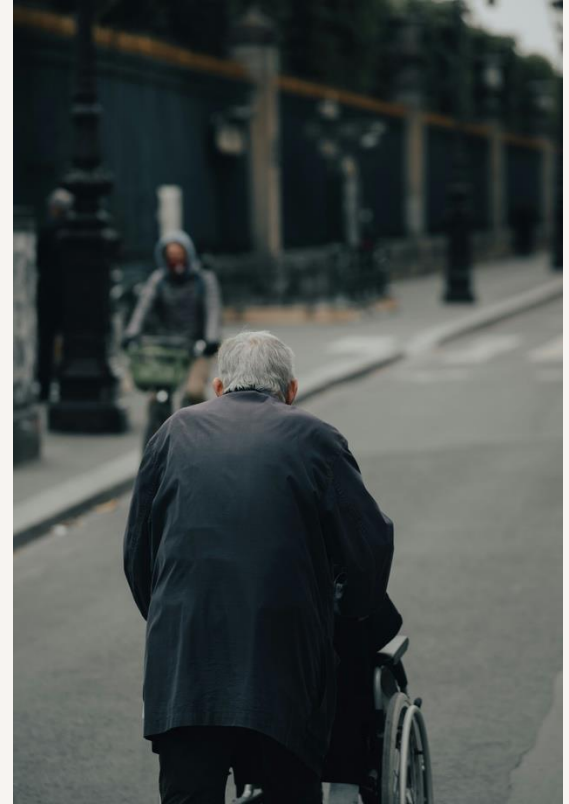
## THE CAREGIVERS CHALLENGE



## Beyond the Patient: The Wider Impact of Neurodegenerative Diseases

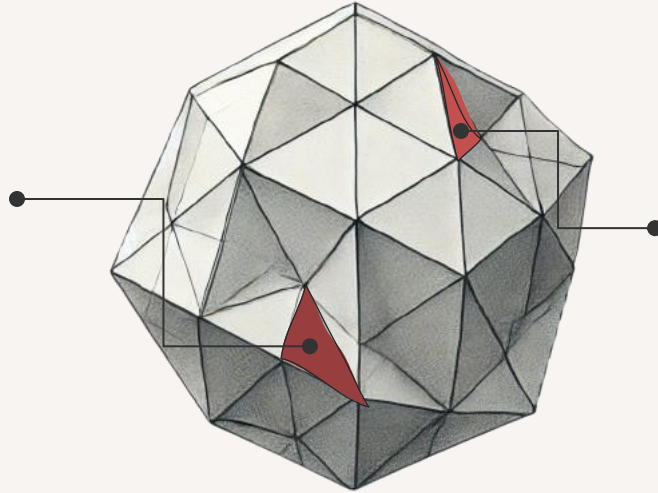
The impact of diseases on the wellbeing of the population is not like a drop in the middle of the ocean, affecting only the person who suffers from it, but rather like a ripple in the sea—it primarily affects the person who suffers from it, but it also extends throughout the community.

In this chapter, we examine the broader impact of these diseases on the community, including the partners, caregivers, and families of those affected.



## In this chapter...

In this chapter, we explore how different neurodegenerative diseases affect the wellbeing of patients' partners, examining variations between male and female caregivers.

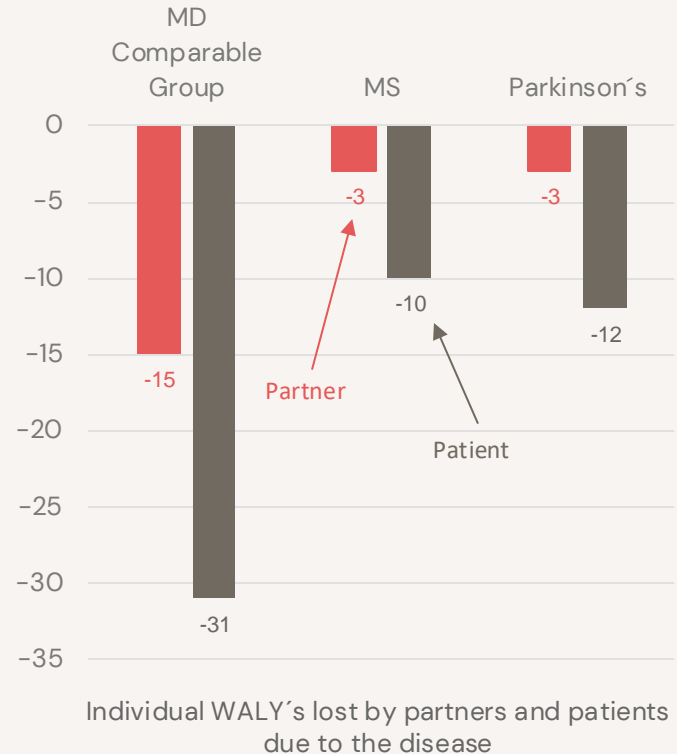


We also investigate the specific impact of muscular dystrophy on the parents of patients and discuss practical steps that healthcare professionals can take to provide them with the best possible support.

## The Hidden Impact: How Disease Affects the wellbeing of Partners

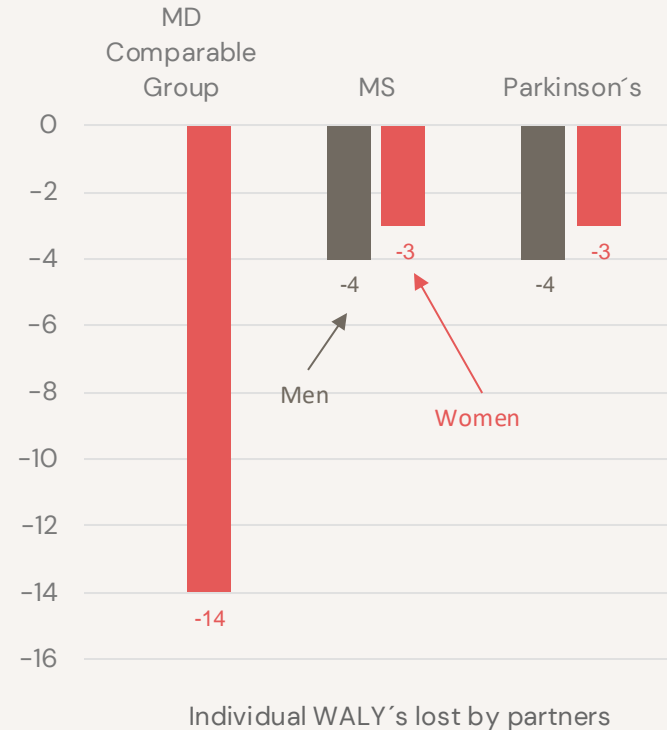
The following chart presents an analysis of the impact on the wellbeing of partners of patients with Parkinson's disease, multiple sclerosis, and mobility issues similar to those seen in muscular dystrophy.

In this case, the partners of patients with conditions similar to muscular dystrophy experience the greatest impact, losing 14% of the wellbeing they would have if their partner were healthy. Meanwhile, the partners of patients with multiple sclerosis and Parkinson's disease experience a smaller loss, with only a 3% decrease in their wellbeing.



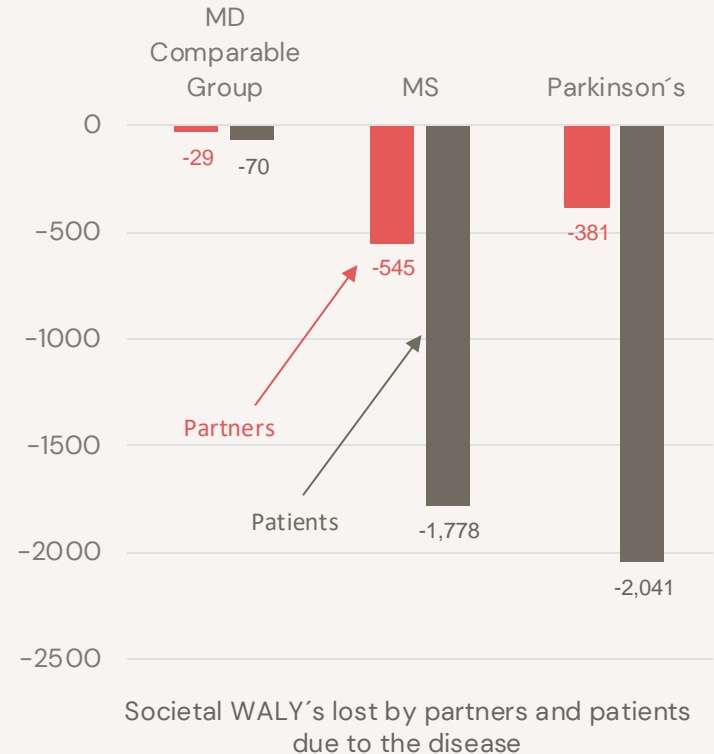
When comparing the wellbeing of the partners of these patients based on whether they are male or female, we do not see any clear differences. While it is true that in both Parkinson's and multiple sclerosis, men are slightly less happy, the difference is so small that it could simply be due to normal statistical variation.

In the case of patients with symptoms similar to those of muscular dystrophy (MD), we only found one patient with a male partner, so we were unable to make the calculation.



While the impact of these diseases on caregivers is much smaller than the burden on the patients themselves, in many households, multiple people suffer the consequences of a loved one's illness. In the average Danish home, around 2.1 people live together, meaning that while many live alone, others share their lives with a partner, and in some cases, three or more people live together with a patient.

By considering the average number of people living with each patient and the WALYs they lose, we see the societal impact shown in the chart: MD caregivers lose 29 WALYs across Denmark, MS caregivers lose 545, and Parkinson's caregivers lose 381. When we add up all the WALYs lost by both caregivers and patients, the total toll on Denmark's happiness from these three diseases amounts to 4,844, more than five times the suffering caused by all divorces in Denmark.



Though Parkinson's disease manifests in physical symptoms, the most valuable support for patients and their families, in the absence of a cure, is emotional and psychological support.

“

*He can get very depressed at times and actually that can be very depressing for the carer. Oh, I find it very difficult. I think the most difficult is when they get depressed.*

McLauchling et al (2010). Living and coping with Parkinson's disease: perceptions of informal carers.

One of the greatest challenges faced by partners and family members of Parkinson's patients is the guilt and sadness of seeing their loved ones suffer. Part of this suffering is a natural part of adapting to the illness, but a large portion stems from avoidable factors, such as isolation. Depressive symptoms are not a natural progression of Parkinson's disease; they are the result of becoming socially isolated due to reduced mobility. Creating supportive environments for patients and their families, where they can connect with others in similar situations, is the best way to help family members understand that there are many others like them.

To better understand the burden involved in caring for Parkinson's patients, please refer to section 5.1.1.1. of the appendix document.

Being a caregiver for a patient isn't always a negative experience; it can bring a profound sense of commitment that adds meaning to the caregiver's life. Caregiving can foster strength, resilience, and appreciation, as partners develop new skills and a purpose through this journey. It can also strengthen the bond between patient and caregiver, as they navigate challenges together, finding joy in mutual support and growing closer through shared experiences. This journey can deepen intimacy, build trust, and reinforce the essential role they play in each other's lives.

To better understand the burden involved in caring for Multiple Sclerosis patients, please refer to section 5.1.1.2. of the appendix document.



*"I think it has brought us closer"*

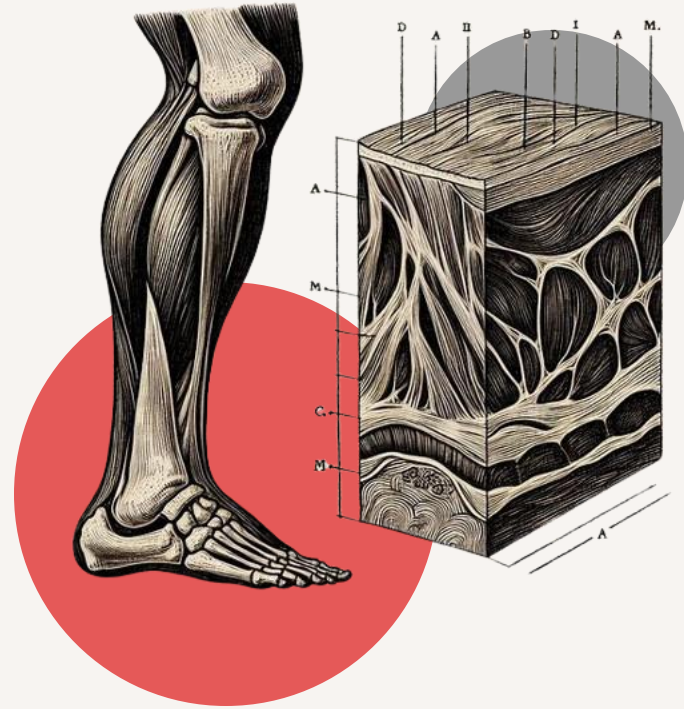
*"I'm happy with what I've done... I've been forced to be a better person"*

*"I do see myself as his carer, I'm very proud to be that"*

*"Still journeying the journey together... I just think it's worth the journey"*

*Appleton et al (2018). Our disease: a qualitative meta-synthesis of the experiences of spousal/partner caregivers of the people with multiple sclerosis. Scandinavian Journal of caring science.*

# MUSCULAR DYSTROPHY



“

*Family membership may change because my children will become adults soon. Perhaps I will have a grandchild. If so, my daughter may be occupied with her baby. We (she and her husband) may be older. I am anxious that our family can't help XX (her son with DMD) like we have been able to thus far*

The experience of parents of adult sons with Duchenne muscular dystrophy regarding their prolonged roles as primary caregivers. Miku Yamaguchi, et al (2017)

Many parents of children with MD worry about growing too old to care for their sons, fearing that there may be no one else to take over as their children's needs increase with age. Financial burdens are a constant concern, as long-term caregiving limits their ability to work, and expenses related to specialized care continue to strain family finances. Caregivers often feel their lives are constrained, unable to pursue personal goals or experience independence.

Possible solutions include providing access to respite care and resources for long-term planning, which can offer aging parents peace of mind about their children's future. Financial assistance programs are essential to alleviate the ongoing economic burden of caregiving. Additionally, tailored counseling and support groups can help caregivers cope emotionally, regain a sense of identity, and connect with others facing similar challenges.

To better understand the burden involved in caring for Muscular Dystrophy patients, please refer to section 5.11.3. of the appendix document.

The study *"Parents' Perspectives on Coping with Duchenne Muscular Dystrophy"* by C.L. Webb –who herself is a parent of a child with Duchenne Muscular Dystrophy– emphasizes the critical importance of listening to parents as the foremost experts on the day-to-day challenges of this condition. The study delves into the coping strategies families employ to manage their children's illness.

**Families focused on the present with a 'one day at a time' philosophy.**

*"The only way I can get through this mentally and keep my sanity is just to do it one day at a time".*

**Families developed coping resources based on personal strength.**

*"My son's diagnosis changed me profoundly as a person. I am now a trained Disability Advocate. I'm very active with disability advocacy for children and adults with all types of disabilities. I returned to school to become certified in special education because I had an insider's understanding of children with disabilities".*

**Families attempted to live as normal a life as possible.**

*"We are in the process of moving across town to be close to our son's school. We want him to be in that neighbourhood and have just as normal a life as possible, stressing relationships with others".*

**Families reduced the risk of crises by having a proactive attitude regarding the care and services for the child's condition.**

*"Be very proactive. Keep your son walking as long as possible. When he can't walk anymore, put him in a stander for part of the day and make sure he sits correctly in his wheelchair to prevent scoliosis".*

## Recommendations for professionals who work with parents of patients with DMD

Appreciate the parents' instincts and give credence to their concerns.

Be aware of the grief process, handle the diagnosis with empathy especially concerning genetic inheritance and offer suggestions for working through the initial shock.

Work cooperatively and collaboratively with parents: To obtain the necessary equipment as the disorder progresses to check often for understanding, and provide necessary interventions to ensure follow-through in learning  
To utilize multisensory approaches to instruction  
To ensure universal accessibility for children with DMD

Webb, C. L. (2005). *Parents' perspectives on coping with Duchenne muscular dystrophy*

The study titled "**Characterizing the quality-of-life impact of Duchenne muscular dystrophy on caregivers**" provides critical insights into the profound impact of Duchenne muscular dystrophy on family caregivers, particularly focusing on the quality of life, financial strain, and personal sacrifices involved.

The study underscores the heavy toll that DMD places on caregivers, especially as the disease progresses. It calls attention to the importance of institutional support, highlighting the need for comprehensive caregiving assistance, financial aid, and psychological support to alleviate the burden on caregivers.

**Sacrifices by Other Family Members:** The study highlights that non-DMD siblings also bear a significant burden, giving up social activities, sports, or travel to accommodate the needs of their sibling with DMD. Families often face a delicate balance between attending to the care of the DMD child and maintaining a sense of normalcy for other children.

**Mental Health Struggles:** DMD caregivers report worse mental health and wellbeing compared to caregivers of healthy children. They face increased emotional strain, particularly when caring for teenagers, as caregiving responsibilities intensify with the child's age. Emotional, financial, and physical burdens escalate as children transition into non-ambulatory phases.

**Financial and Career Constraints:** Many caregivers have had to curtail their professional ambitions, reduce working hours, or give up their careers entirely. The financial impact is compounded by the need for home modifications and healthcare costs, with significant difficulty paying bills reported more frequently among DMD caregivers.

**Resilience and Positivity:** Despite these challenges, caregivers demonstrate notable resilience and positivity, with consistent levels of positive emotions reported across all age groups. This reflects an inner strength and a shift in values and priorities as caregivers adapt to the ongoing demands of DMD care.

## SUMMARY

### THE CAREGIVERS CHALLENGE

The impact of neurodegenerative diseases on caregivers' wellbeing highlights a crucial reality: patients aren't the only ones who need support. We often overlook the person standing behind the wheelchair or sitting quietly by their side at the doctor's office—they, too, need physical, emotional, and financial help.

Among the issues observed in this chapter are the feelings of guilt and sorrow that come from watching a loved one deteriorate and feeling helpless, the isolation and loneliness that caregiving often brings, and the fears about the future as we age and may no longer be able to care for our child. On top of this, there are financial strains and physical aches that come from tending to another's needs even when our own bodies hurt.

The toll caregiving takes on partners amounts to a loss of 3 WALYs for Parkinson's and MS, and 15 WALYs for MD—not enormous numbers, but it's important to remember that this impact is multiplied across families, affecting siblings, parents, children, and spouses. For all these reasons, providing relief to caregivers is nearly as important as caring for the patients themselves.

# 05

## PROTECTIVE FACTORS & LIFESTYLES



## Why Some Patients Thrive: Uncovering the Keys to Wellbeing

Not all patients experience their diseases in the same way: while some may fall into depression, others manage their physical limitations with stoicism and a positive outlook.

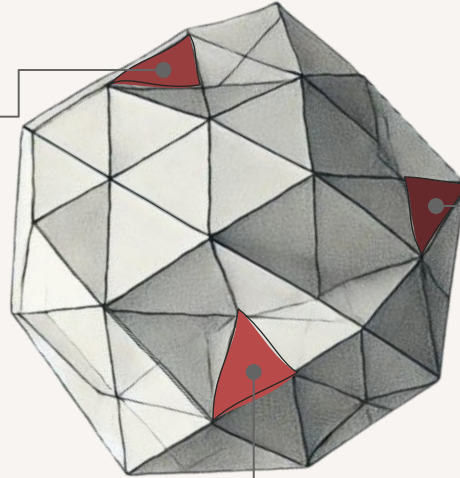
This difference isn't always a matter of personality; it often depends on factors like the support patients receive from their community.

In this chapter, we explore the key differences between patients who maintain happiness despite their illness and those who do not.



## In this chapter...

In this final chapter, we examine what sets the happiest patients apart from those who struggle more with their condition.



Additionally, we investigate lifestyle habits that may reduce the likelihood of developing these neurodegenerative diseases.

We also look into lifestyle choices and interventions proven to address some of the most significant challenges for patients.

PROTECTIVE FACTORS

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# PARKINSON'S DISEASE



While mobility issues are often seen as the biggest challenge for those with neurodegenerative diseases, not all symptoms have the same impact on quality of life. By comparing the wellbeing of healthy individuals and those with Parkinson's, we can identify the symptoms that, if addressed, would bring the greatest improvements.

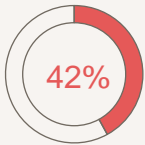
The data speaks for itself: one of the most significant issues for Parkinson's patients is the inability to eat hard foods. This affects 42% of the Parkinson's population, reducing their life satisfaction from 6.89 to 5.6. Finding ways to improve their ability to enjoy meals could have a profound impact on their overall happiness.

Other major challenges that diminish their wellbeing include sleep problems, difficulty making simple phone calls, fear of falling, feeling excluded from their community, and struggling to use the internet. Addressing these issues can transform the daily lives of patients and greatly enhance their quality of life.

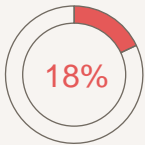


## Problem Overview: The Challenge of Eating Hard Foods for Parkinson's Patients

One of the key issues for Parkinson's patients is the difficulty in eating hard foods.



42% of patients report having difficulty eating solid foods.



This reduces the wellbeing of those affected by 18% compared to those who can eat without difficulties.

“

*Both patients and relatives talked about decreased socialisation. Patients avoided having lunch or dinner with other people because of problems eating without spills or mess. They felt embarrassed if others were looking at them.*

Wressle 2007. Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living

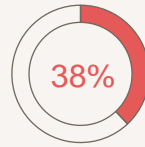
## Practical Cases: Real-world Solutions for Parkinson's Patients

Self-stabilizing utensils, designed to help Parkinson's patients manage motor function limitations while eating hard or solid foods. The use of such utensils has been shown to significantly improve the dining experience and reduce the difficulty of consuming solid meals for patients.

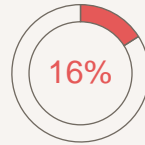
For studies and examples of utensils proven to be useful, please see Section 6.1.1.1 in the Appendix document.

## The problem

Parkinson's disease (PD) patients frequently suffer from sleep disorders, which significantly impact their quality of life. While sleep difficulties affect most patients with PD, women tend to experience these challenges more acutely. The sleep disturbances in PD can include difficulty falling asleep, maintaining sleep, vivid dreams, and sleep fragmentation. These issues exacerbate the symptoms of the disease, leading to increased fatigue, depression, and decreased cognitive function, making daily life significantly more challenging.



38% of patients report having sleep issues.



This reduces the wellbeing of those affected by 16% compared to those who sleep properly.

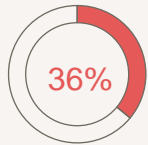
## Effective Treatments for Sleep Issues in Parkinson's Disease

One of the most effective treatments for sleep disorders in Parkinson's disease combines melatonin supplementation with Cognitive Behavioral Therapy for Insomnia (CBT-I). Melatonin helps regulate disrupted sleep cycles, while CBT-I addresses insomnia's behavioral aspects. This combination has been shown to reduce nighttime disturbances in patients.

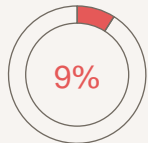
For studies and examples of sleep treatments, please see Section 6.1.1.2 in the Appendix document.

## The problem

Parkinson's disease affects movement and balance, making patients particularly vulnerable to falls.



36% of patients report fears of falling down.



This reduces the wellbeing of those affected by 9%.

“

*Sometimes, I think about what would have happened if I had fallen here, or what if I had fallen... Nobody knows where I am. (...) I thought, if I had fallen... and had been lying there, then maybe I would have been lying there for a long time.*

Stina Jonasson et al 2018. Experiences of fear of falling in persons with Parkinson's disease – a qualitative study

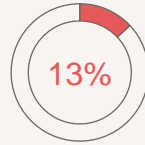
## Solutions to Reduce the Fear of Falling in Parkinson's Patients

Specialized physical therapy programs like LSVT BIG and PWR! teach patients to make larger, deliberate movements, improving balance and stability. Assistive technology, such as fall detection systems, offers real-time feedback and emergency support. Additionally, modifying the home environment—removing tripping hazards and adding safety features like grab bars—can greatly reduce the risk of falls and improve patient confidence

For studies and examples of interventions proven to be useful, please see Section 6.1.1.4 in the Appendix document.

## The problem: Overcoming Communication Barriers in Parkinson's Disease

For many Parkinson's disease patients, the simple act of making a phone call can become a daunting challenge. Speech difficulties, tremors, and reduced motor control isolate them from loved ones and the world, leading to feelings of loneliness and despair. With the right interventions and technological support, patients can regain their voice, reconnect with others, and live fuller lives, breaking the chains of isolation.



13% of patients report having difficulties communicating over the phone.



This reduces the wellbeing of those affected by 20%.

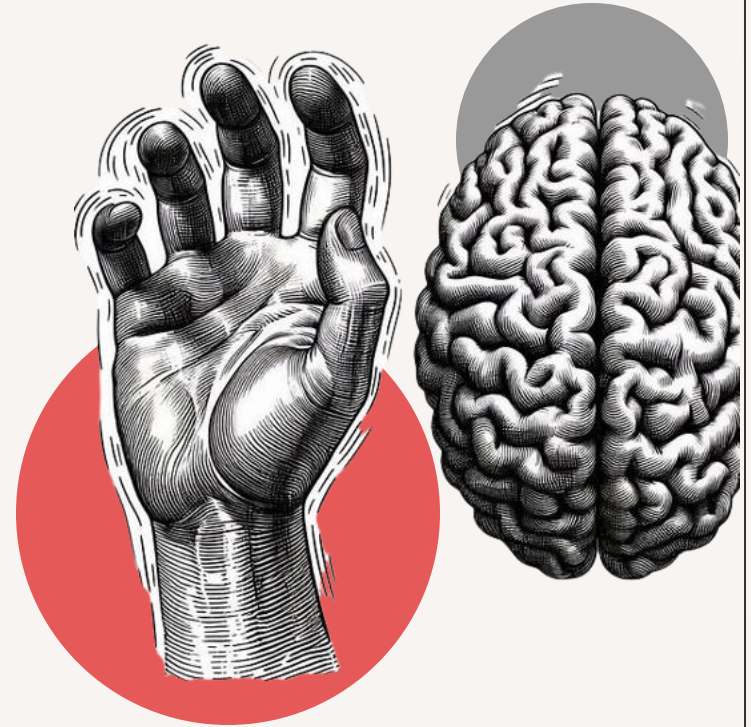
### Solutions for Improving Communication in Parkinson's Patients

Patients with Parkinson's often struggle with communication, including making phone calls, due to reduced speech volume, unclear speech, and slower cognitive processing. These issues are linked to both motor impairments and cognitive difficulties, such as trouble organizing thoughts and understanding fast-paced conversations. Speech therapy and tools like the SpeechVive™ device, which prompts louder speech, can help.

For studies and examples of communication treatments, please see Section 6.1.1.3 in the Appendix document.

The inability to communicate over the phone is just a symptom of a much larger issue—social isolation, the main challenge for Parkinson’s patients. Around 20% of them feel “left out of things,” partly due to mobility issues that prevent them from attending social gatherings, but also because of difficulties speaking loudly and clearly, and the fear of embarrassment while eating. These are the key areas we must address to improve patients’ lives, as feeling excluded leads to a 34% drop in life satisfaction compared to those who don’t feel this way.

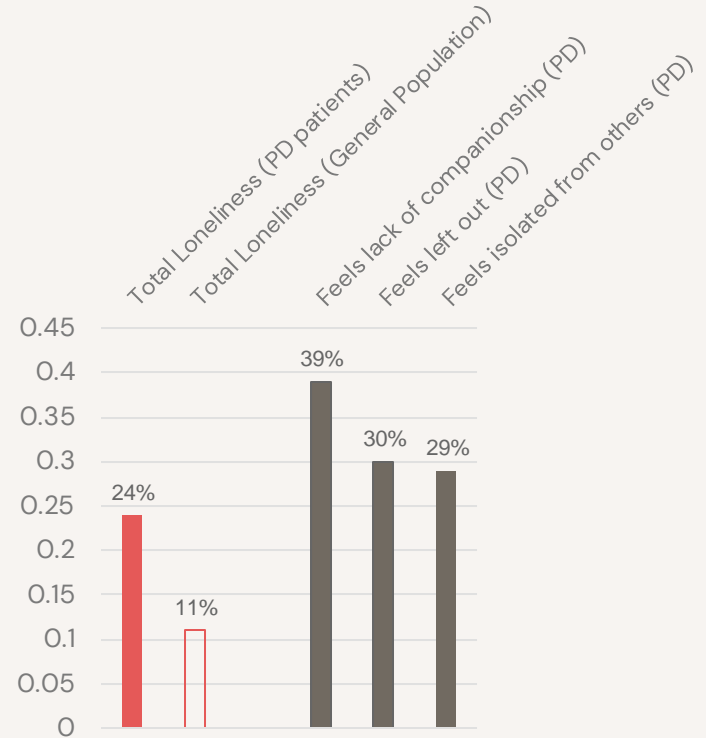
To combat this, a collective effort is needed from all parts of society: private companies can develop devices to amplify speech and create utensils that make eating easier. Institutions can fund these innovations. Equally important is the role of urban design. Architects and urban planners should create spaces that encourage informal encounters with neighbors, helping patients build relationships through everyday interactions. Wide pedestrian zones filled with seating can transform neighborhoods, allowing a resident who spends the day in front of the TV to occasionally chat with neighbors.



## Loneliness and Lack of Companionship in Parkinson's Patients

People with mobility issues, such as Parkinson's patients, suffer from isolation and, most notably, as the data shows, lack of companionship. As seen in the graph taken from Tino Prell et al. (2023) *'The impact of loneliness on quality of life in people with Parkinson's disease,'* 39% of patients report feeling a lack of companionship often or some of the time.

When adding the scores from the three questions of the UCLA Loneliness Scale (the most widely used tool to measure loneliness in the population), we see that the percentage of patients experiencing loneliness is double that of the general population. This result is highly significant, given that loneliness and social isolation are the factors that most reduce happiness.



Total loneliness represents the percentage of individuals who scored 6–9 on the UCLA Loneliness Scale, which ranges from 3 to 9 (3 indicates the lowest level of loneliness across the three UCLA questions, and 9 the highest).



### Problem Overview

Patients with neurodegenerative conditions, face severe isolation issues. Social withdrawal and lack of companionship are common, greatly impacting their mental wellbeing and quality of life

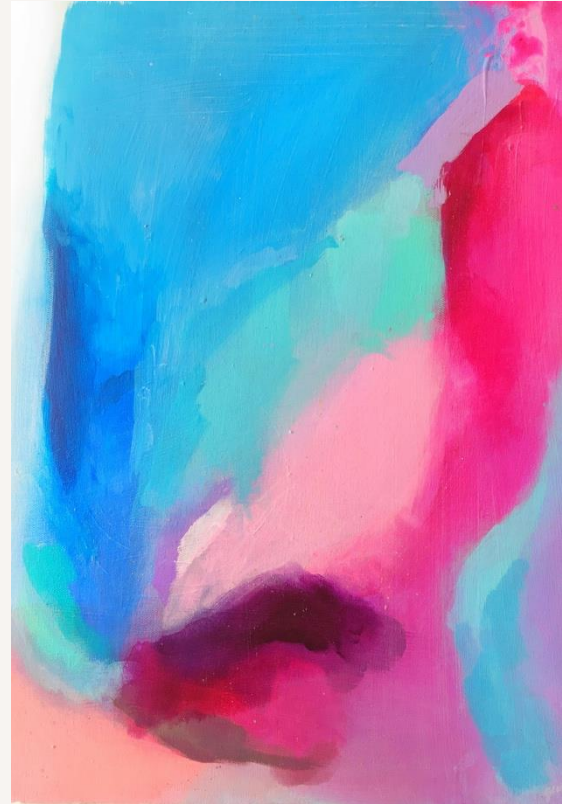
### Practical Cases:

Several impactful interventions have successfully reduced loneliness among neurodegenerative patients. One standout is a communication skills program for Parkinson's and MS patients, which improved their ability to engage socially. Additionally, a study on telehealth services for MS and ALS patients during the pandemic showed how regular virtual contact significantly reduced social isolation. Likewise, a dance/movement therapy program for MS patients improved both physical control and social engagement, boosting wellbeing [for more references to studies, see Appendix, Section 3.3.]

## Preventing Parkinson's Disease Through Lifestyle

Recent large-scale studies show that Parkinson's disease can, to some extent, be prevented by promoting certain lifestyle choices. These studies, which follow thousands of people over many years, have identified key behaviors that reduce the risk of developing Parkinson's.

Researchers track individuals who do not have Parkinson's at the start, asking them annually about their lifestyle habits such as physical activity, diet, sleep, and more. As time passes, some individuals develop Parkinson's. By comparing the lifestyle factors of those who develop Parkinson's with those who do not, researchers can pinpoint the habits that most effectively reduce the risk.



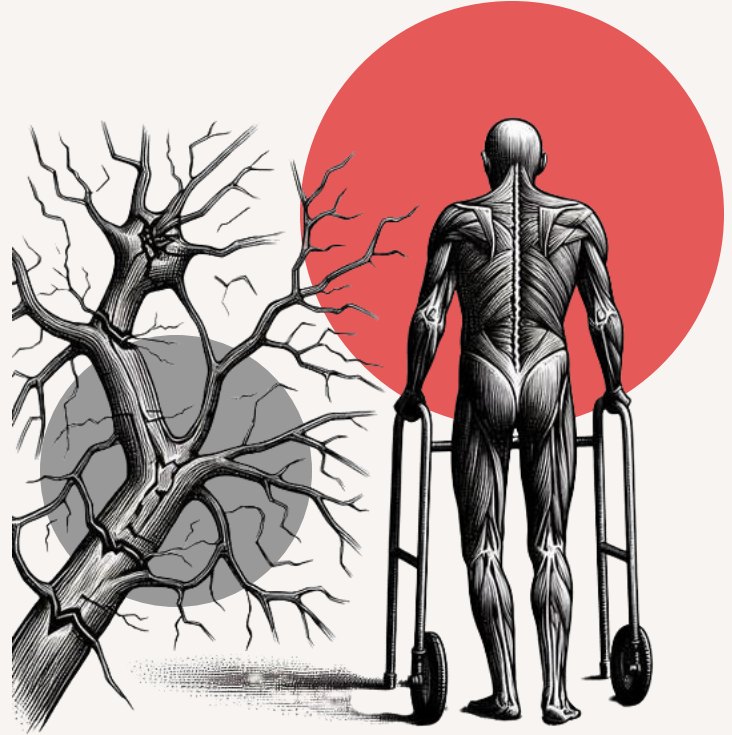
## Key Lifestyle Factors to Prevent Parkinson's Disease

	Impact on Parkinson's Risk	Explanation
Vigorous Physical Activity	Reduces risk by 16%	Regular vigorous exercise enhances neuroplasticity and reduces neuroinflammation, protecting against neurodegenerative processes.
Low-to-Moderate Sitting Time	Reduces risk by 11%	Limiting sedentary behavior helps maintain better brain health and reduces degeneration, keeping the brain active and resilient.
High Sleep Quality	Reduces risk by 11%	Adequate, restful sleep allows for brain detoxification and repair, key factors in slowing or preventing neurodegenerative diseases.
Small Coffee Consumption	Reduces risk by 12%	Moderate coffee consumption provides caffeine, which has neuroprotective properties and is associated with a reduced risk of Parkinson's.
Small Red Meat Consumption	Reduces risk by 14%	Red meat, in small amounts, provides essential nutrients like iron and vitamin B, which support neuroprotection.
Current Smoking	Reduces risk by 35%	While smoking carries other health risks, nicotine has been shown to offer neuroprotective effects that may delay the onset of Parkinson's.
Alcohol Consumption	Increases risk by 29%	Excessive alcohol consumption increases oxidative stress, which accelerates neurodegeneration and heightens the risk of Parkinson's.
Vitamin D and Uric Acid Levels	Potential protective effect	Higher levels of these compounds are associated with reduced risk due to their roles in maintaining brain health and reducing oxidative damage.
High Cholesterol and Triglycerides	Increases risk	High levels of LDL cholesterol and inflammation markers are associated with higher risks of neurodegenerative conditions, including Parkinson's.

Nicola Veronese (2024). *Contribution of Nutritional, Lifestyle, and Metabolic Risk Factors to Parkinson's Disease*

PROTECTIVE FACTORS

# MULTIPLE SCLEROSIS



## Key Factors Affecting Wellbeing in Multiple Sclerosis Patients

The paper "*International Differences in Multiple Sclerosis Health Outcomes and Associated Factors in a Cross-sectional Survey*" analyzed data from 2,366 participants, who came from 37 different countries in Australasia, Europe, and North America, and provided self-reported information on their health, lifestyle, and MS-related outcomes via an online survey.

The text explores modifiable variables and their impact on health outcomes, specifically Quality of Life (QOL), disability, fatigue, and depression. The most important factors influencing the wellbeing of individuals with MS are high levels of physical activity, smoking and social support.

You can find the most important factors in the next table.



# Key Factors Influencing Quality of Life in MS Patients

Factor	Effect on Physical QOL	Effect on Mental Health QOL	Effect on Other Outcomes
Current smoking	-7 to -8 points	-7 to -8 points	2.2x higher odds of depression
Moderate/high alcohol use	+3 points	+2 points	-24% odds of disability, -38% odds of fatigue, -29% odds of depression
High physical activity	+15 points	+7 points	-72% odds of disability, -71% odds of fatigue, -60% odds of depression
Moderate physical activity	+Some improvement	+Some improvement	Lower odds of disability, fatigue, and depression
Vitamin D supplementation (1-5,000 IU)			-30% odds of fatigue
Vitamin D supplementation (>5,000 IU)			-38% odds of fatigue
Social support (2+ people)	+4 points	+7 points	-55% odds of depression
Overweight BMI	-3 points	-3 points	+38% odds of fatigue
Obese BMI	-6 points	-5 points	+93% odds of fatigue, +45% odds of disability
Healthy dietary habits			-19% odds of fatigue, -16% odds of depression

*Grace D. Reilly et al (2017). International Differences in Multiple Sclerosis Health Outcomes and Associated Factors in a Cross-sectional Survey*

## Beyond Lifestyle: The Essential Role of Social Support

The study "*Unmet needs of patients feeling severely affected by multiple sclerosis in Germany*" (Garlushko M et al (2014)) reveals significant unmet needs among multiple sclerosis patients, emphasizing the challenges in social support, healthcare services, daily life management, and identity preservation.

**Social Support:** Many patients experience shrinking social circles, expressing a desire for increased family and friend contact and deeper understanding of their disabilities. Relationship breakdowns due to MS were reported as particularly painful, highlighting an emotional gap for these individuals.

**Healthcare Services:** The largest category of unmet needs, patients struggled with accessing services, finding competent doctors, and lacking timely, sensitive, and informed physician-patient interactions. Key desires included shorter waiting times, home visits, specialized transportation, and psychological counseling. Many felt a need for more honest communication and greater involvement in medical decisions.

**Daily Life Management:** Patients expressed needs in managing daily life, such as receiving help with housekeeping and adapting living spaces to physical limitations. The inability to continue working was especially difficult for those who viewed work as central to their identity, with patients also finding it challenging to replace pre-illness hobbies and leisure activities.

**Identity and Social Acceptance:** Coping with changes to self-identity due to physical limitations is a profound challenge, as patients grapple with feelings of stigma and exclusion. They voiced a desire for better public accessibility and societal acceptance, aiming to feel included rather than marginalized.

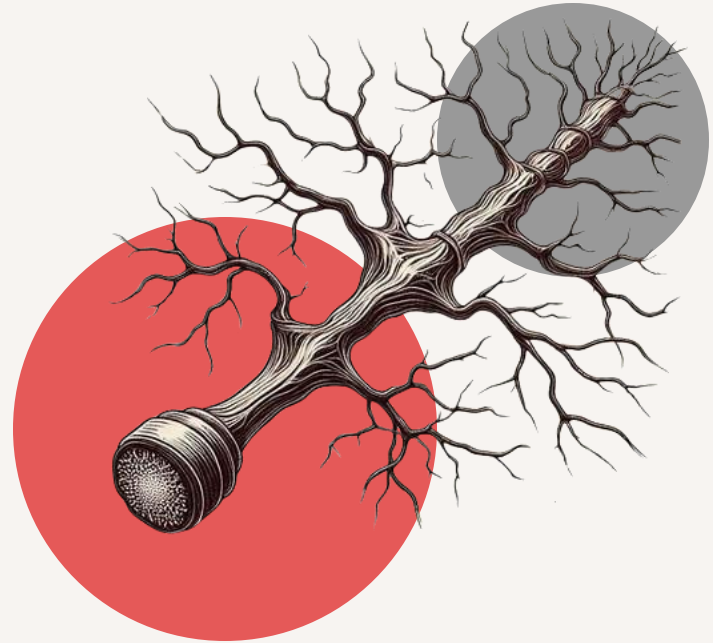
Addressing these needs requires enhanced psychological support, continuity in healthcare services, individualized caregiving, and a broader societal shift towards inclusivity for people with disabilities.

## Preventing Multiple Sclerosis Disease Through Lifestyle

Multiple Sclerosis is a complex disease influenced by a combination of lifestyle and environmental factors.

The data shows that certain behaviors, like smoking, being obese as a teenager, or low vitamin D levels, significantly raise the risk of MS, while others, like moderate alcohol consumption or high coffee intake, can reduce it.

Multiple sclerosis is not only about genetics—by promoting healthier lifestyles, such as staying active, getting enough sun, avoiding smoking, and maintaining a healthy weight, it's possible to lower the chances of developing MS in the future.



## Key Lifestyle Factors to Prevent Multiple Sclerosis

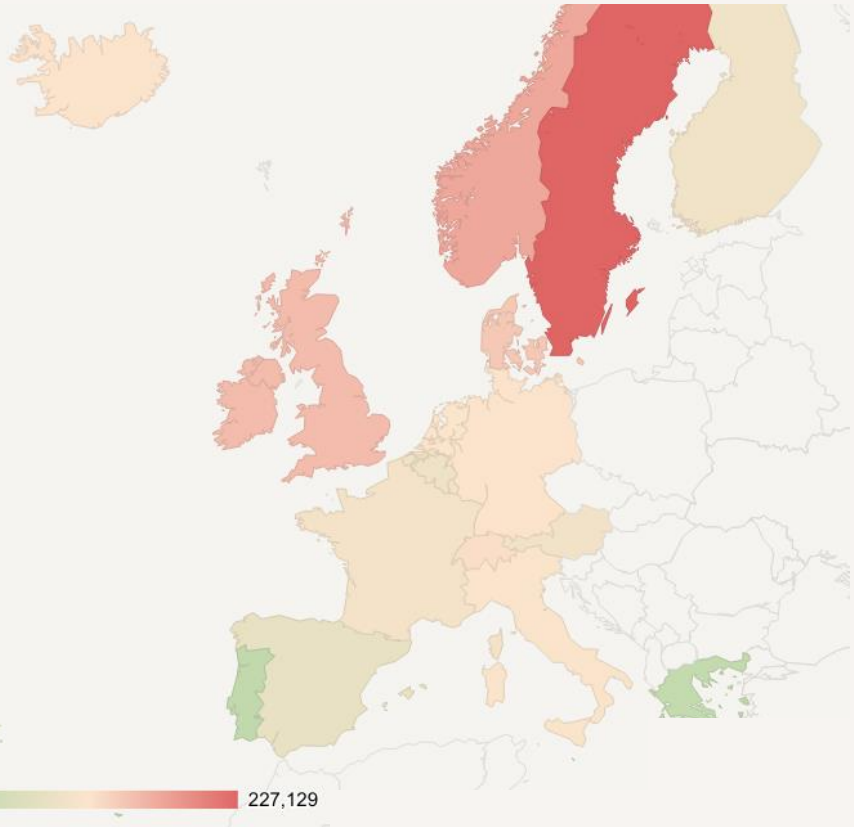
Lifestyle Factor	Probability of Developing MS	Explanation
Smoking	60%	Smoking leads to lung inflammation, triggering immune responses that increase MS risk.
Epstein-Barr Virus (EBV)	260%	EBV infection, especially in adolescence, triples the risk of developing MS by affecting immune regulation.
Vitamin D Deficiency	40%	Low levels of vitamin D, particularly due to limited sun exposure, impair the immune system.
Adolescent Obesity	100%	Obesity during adolescence alters immune regulation, promoting inflammation and increasing MS risk.
Night Shift Work	70%	Night shift work disrupts circadian rhythms, affecting immune functions and increasing MS risk.
Alcohol Consumption	-40%	Moderate alcohol consumption may reduce inflammation, contributing to a lower MS risk.
Passive Smoking	30%	Exposure to second-hand smoke also increases immune stress, similar to active smoking.
High Coffee Consumption	-30%	High coffee intake may have a neuroprotective effect, lowering the risk of developing MS.
Low Sun Exposure	100%	Reduced sun exposure limits vitamin D production, increasing the risk of MS.

## The Relationship Between Vitamin D and Multiple Sclerosis: A Geographical Challenge

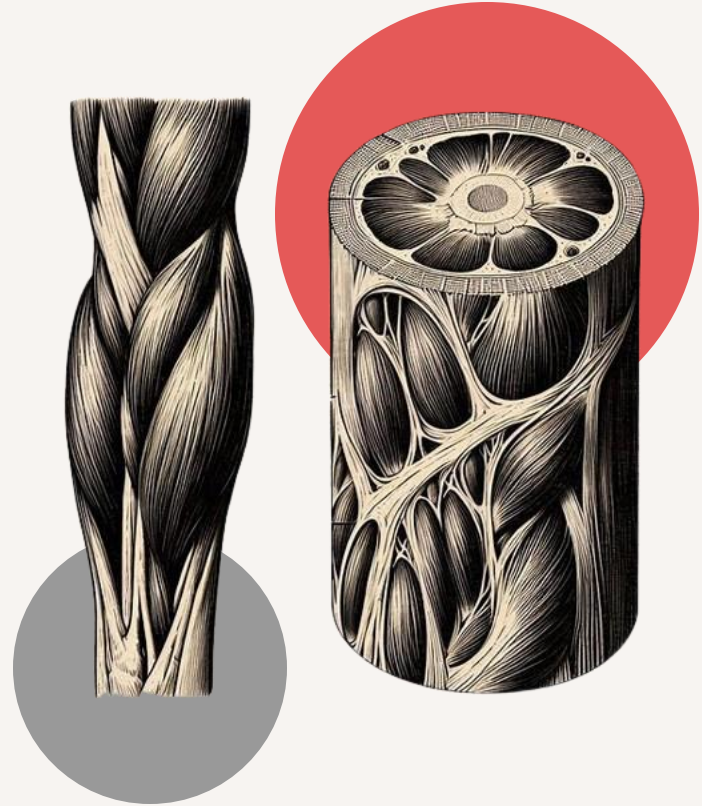
Data suggests that a deficiency in vitamin D is a significant factor that increases the likelihood of developing Multiple Sclerosis, a connection reflected in the geographical prevalence of the disease, as can be seen in this map.

In Nordic countries like Denmark or Sweden, MS prevalence ranges from 150 to 220 patients per 100,000 inhabitants, according to the Global Burden of Disease. In contrast, in Spain or Portugal, the prevalence is much lower, ranging from 40 to 100 per 100,000. To address this issue, patients and authorities in Nordic countries could promote strategies to increase vitamin D levels in the population, such as fortifying foods with vitamin D, encouraging safe sun exposure, or recommending vitamin D supplements, particularly during the winter months when natural sunlight is scarce.

31,118  227,129



# MUSCULAR DYSTROPHY

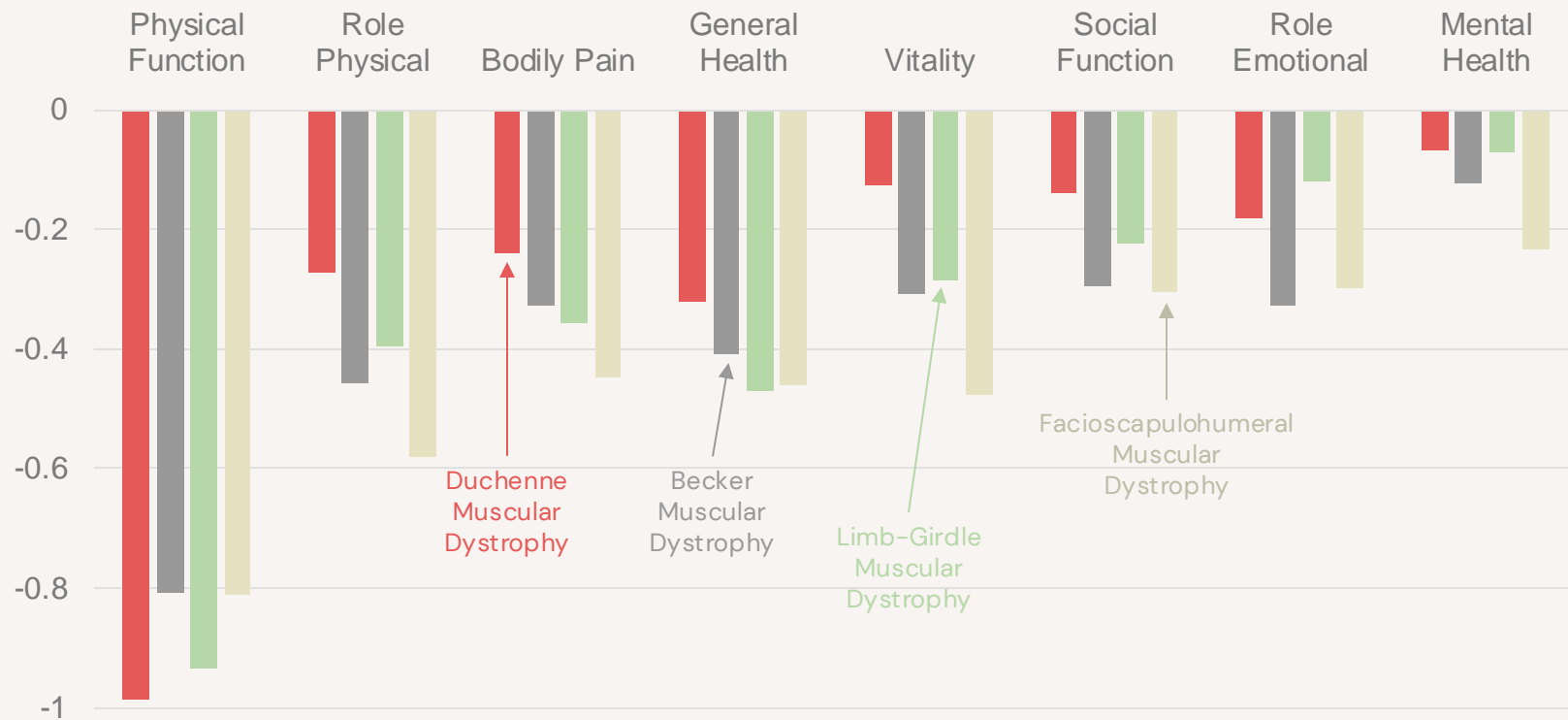


## Insights on Quality of Life for Adults with Muscular Dystrophy: Key Findings from the SF-36v2 Scores

The study “*Quality of life in adults with muscular dystrophy*” compares quality of life across different forms of Muscular Dystrophy (MD)—Duchenne Muscular Dystrophy (DMD), Becker Muscular Dystrophy (BMD), Limb-Girdle Muscular Dystrophy (LGMD), and Facioscapulohumeral Muscular Dystrophy (FSHD). As expected, all forms of MD display significantly lower physical health compared to controls (CTRL), with **DMD scoring lowest in Physical Function**. However, despite this drastic physical impairment, **DMD patients reported better-than-expected mental health**, scoring **79.0 ± 14.9** on Mental Health, which is surprisingly higher than FSHD's score of **65.0 ± 19.1**, and even approaching that of controls at **84.7 ± 8.5**. This suggests that **coping mechanisms and long-term adjustment** may contribute to the mental resilience observed in DMD patients, a chronic condition from early life. Put another way, when someone is born with a disease, it doesn't affect them as much emotionally, because they have nothing to compare it to. In the case of FSHD, since it usually appears later, in adolescence or adulthood, the impact on mental health is worse..

Interestingly, FSHD patients exhibited **substantial losses in vitality** compared to DMD patients. This highlights the **more severe impact on energy levels in FSHD**, perhaps due to its later onset and more localized muscular involvement, which may affect psychosocial wellbeing more acutely.

Overall, the study reveals nuanced differences between the types of MD, emphasizing that although **physical limitations are profound across all forms**, their mental and emotional impacts vary significantly, likely depending on factors like **disease onset, coping strategies, and social support networks**. These findings suggest that managing fatigue and promoting mental health support should be prioritized differently across MD classifications to improve overall QoL.



Percentage loss relative to the controls. "Quality of life in adults with muscular dystrophy". Matthew Jaques et al (2019)

The study "Association between health-related quality of life and motor function in ambulant and non-ambulant Duchenne muscular dystrophy patients" (Gocheva et al., 2019) analyzed the impact of the disease on the health-related quality of life (HRQoL) of children around 11 years old. In addition to asking the children, the researchers also surveyed the parents about the issues they believed their children were facing. For both parents and children, the biggest challenge was loss of mobility, followed by social functioning.

The researchers highlight that social functioning issues could largely stem from the difficulties these patients face in adjusting their facial expressions during social interactions. Awareness campaigns in classrooms with children who have muscular dystrophy could help their peers understand the communication challenges these children face, potentially easing the stigma they experience due to these differences.

“

We can't expect an educator to be well versed in many different disabilities. We have to educate them and work with them. The more we do that, the more willing teachers are to work with our children.

C.L. Webb 2005. Parent's perspectives on coping with Duchenne Muscular Dystrophy



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## Muscular Dystrophy: Irreversibility and Focus on Managing Symptoms

Muscular Dystrophy is primarily a genetic disorder, meaning that lifestyle factors are less influential in preventing its onset compared to diseases like Parkinson's or Multiple Sclerosis. MD is caused by mutations in specific genes that affect muscle function, and currently, there is no known way to prevent the genetic mutation from occurring or being passed on.

However, while MD itself cannot be prevented through lifestyle changes, there are factors that can significantly improve the quality of life. These include:

1. **Regular physical therapy and exercise:** Engaging in tailored physical activities can help maintain muscle function and flexibility, delaying muscle deterioration.
2. **Healthy diet:** Maintaining a balanced diet can support overall health and energy levels, which is important for those managing the disease's impact on muscle strength.
3. **Respiratory care:** Since MD affects muscles involved in breathing, interventions such as respiratory therapy can prevent complications that arise from weakened respiratory muscles.

Though no lifestyle factors can prevent Muscular Dystrophy from developing, these measures can mitigate its impact, improving both life expectancy and quality of life for individuals living with the condition. For this reason, proactive management through lifestyle modifications remains crucial in MD care.

## SUMMARY

### PROTECTIVE FACTORS

The analysis of protective and lifestyle factors that can improve patients' lives shows us that, while these diseases may not yet have a cure, there are many ways to make life significantly better for those affected. From the more obvious factors like regular exercise, a healthy diet, or quitting smoking, to the less commonly discussed challenges, such as the embarrassment Parkinson's patients may feel from spilling food or the difficulties with facial expressions faced by muscular dystrophy patients—a skill so essential for emotional expression.

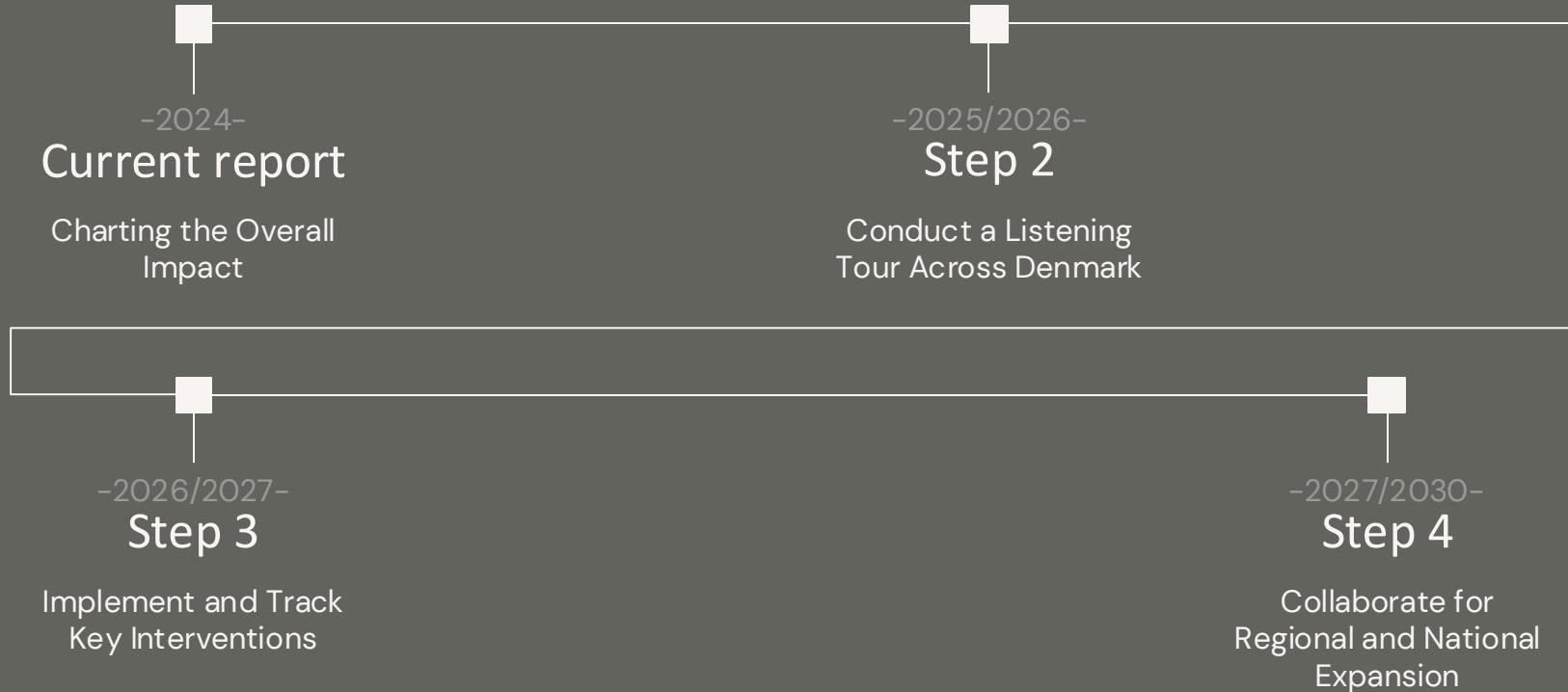
As we've highlighted throughout this portfolio, the ability to connect with others is one of the biggest issues patients face. There is much both they and society can do to address this. Group therapy with peers facing similar conditions, environments with communal spaces or raising awareness about MD in schools are some simple steps that can greatly enhance the quality of life for these patients.

In this section, we also explored lifestyle choices that can decrease the likelihood of developing these diseases across the population. For Parkinson's, reducing alcohol and tobacco consumption can lower the risk by 29% and 35%, respectively. In the case of multiple sclerosis, eradicating the Epstein-Barr virus appears to be the most crucial factor to address. From a public health perspective, promoting healthy lifestyle habits across society emerges as a smart strategy to prevent the onset of these conditions. Given the significant impact of MS on public wellbeing—nearly double the effect of divorce across Denmark—closer monitoring of the spread of the Epstein-Barr virus should be promoted by the Danish Infectious Disease Center to reduce the population's risk of developing MS.

Next steps:  
Turning Insights into  
Action

In this report, we have mapped the impact of three neurodegenerative diseases on the wellbeing of the Danish and broader European populations. This initial exploration serves as a foundation for understanding and quantifying the elusive nature of suffering, sparking a much-needed social conversation about those who are often unheard in our society. Moving forward, we recommend a series of concrete steps to build on the insights gathered here.

# FROM DATA TO CHANGE



## Step 2: Conduct a Listening Tour Across Denmark.

Conduct a listening tour across Denmark, involving patients, their partners, and parents of those affected by these diseases. Develop a comprehensive questionnaire that delves into the most pressing issues, such as key socialization barriers, the circumstances of those who feel most isolated, and practical ways to support them (2025-2026)

### Step 3: Implement and Track Key Interventions.

Roll out targeted interventions identified as impactful, and monitor their effects on wellbeing. For example, a school-based awareness campaign aimed at educating both students and teachers about the unique needs of students with Muscular Dystrophy. Tracking these schools, alongside those without such programs, could provide clear, actionable insights to present to policymakers (2026–2027)

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#### Step 4: Collaborate for Regional and National Expansion.

Work with patients and local authorities to scale up successful interventions at the regional or national level, with ongoing monitoring of their impact on quality of life (2027–2030)

Initiative	Objective	2024	2025	2026	2027	2028	2029
1. Current report	Gain a comprehensive understanding of how neurodegenerative diseases affect wellbeing and quality of life.						
2. Conduct a listening tour across Denmark	Engage deeply with patients, families, and caregivers to identify key challenges and needs.						
3. Implement and track key interventions	Introduce impactful initiatives and measure their effects on wellbeing over time.						
4. Collaborate for regional and national expansion	Present and communicate the results. Engage in public debate.						
	Build consensus with key institutions. Collaborate with healthcare providers, patient advocacy groups, government bodies, and other stakeholders to develop a unified, actionable national plan to support patients and their families.						
	Implement measures regionally and nationally						