



Norwegian Directorate of Health

# Health Challenges, Ailments, and Disease Burden Among People with Brain Conditions

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# Summary

*Brain conditions encompass mental and neurological disorders, injuries, and substance use disorders. Approximately one in three people in Norway will develop a brain condition during their lifetime, and according to the global burden of disease study, brain conditions account for 36 percent of the burden of disease related to years lived with disability (YLD). This report provides new insights into the health challenges experienced by people with brain conditions. The report also examines challenges beyond health, such as self-esteem, participation in education and work, and social relationships.*

The report is based on data from the Global Burden of Disease (GBD) study, information from a survey of members of relevant patient organizations, and both a survey and interviews with employees of these organizations. In addition, we have obtained information from publicly available documents and statistics.

## A growing number of people are living with brain conditions

The incidence of brain conditions is increasing. As life expectancy increases, a larger and older population will lead to more cases of brain conditions.

## Fatigue is a symptom that recurs across many brain conditions

People living with brain conditions may have a range of health challenges that contribute to their burden of disease. These include mental, cognitive, and somatic challenges. The health challenges can be both visible and invisible. The responses from the survey among members of patient and user organizations provide insight into the health challenges experienced by people with brain conditions. 47 percent of respondents stated that tiredness or fatigue is one of the three symptoms they experience most in their daily lives, and respectively 30 and 23 percent stated the same for head and neck pain and brain fog.

## Anxiety disorders, depression, and migraines contribute most to the non-fatal health loss (YLD)

For diagnoses with a sufficient number of respondents, we estimated how health loss (YLD) is distributed across different health challenges for each brain condition (Figure 1-1, right). These diseases account for 70 percent of health loss related to brain diseases (Figure 1-1, left). Our estimates indicate that fatigue is the symptom that contributes most to total health loss.

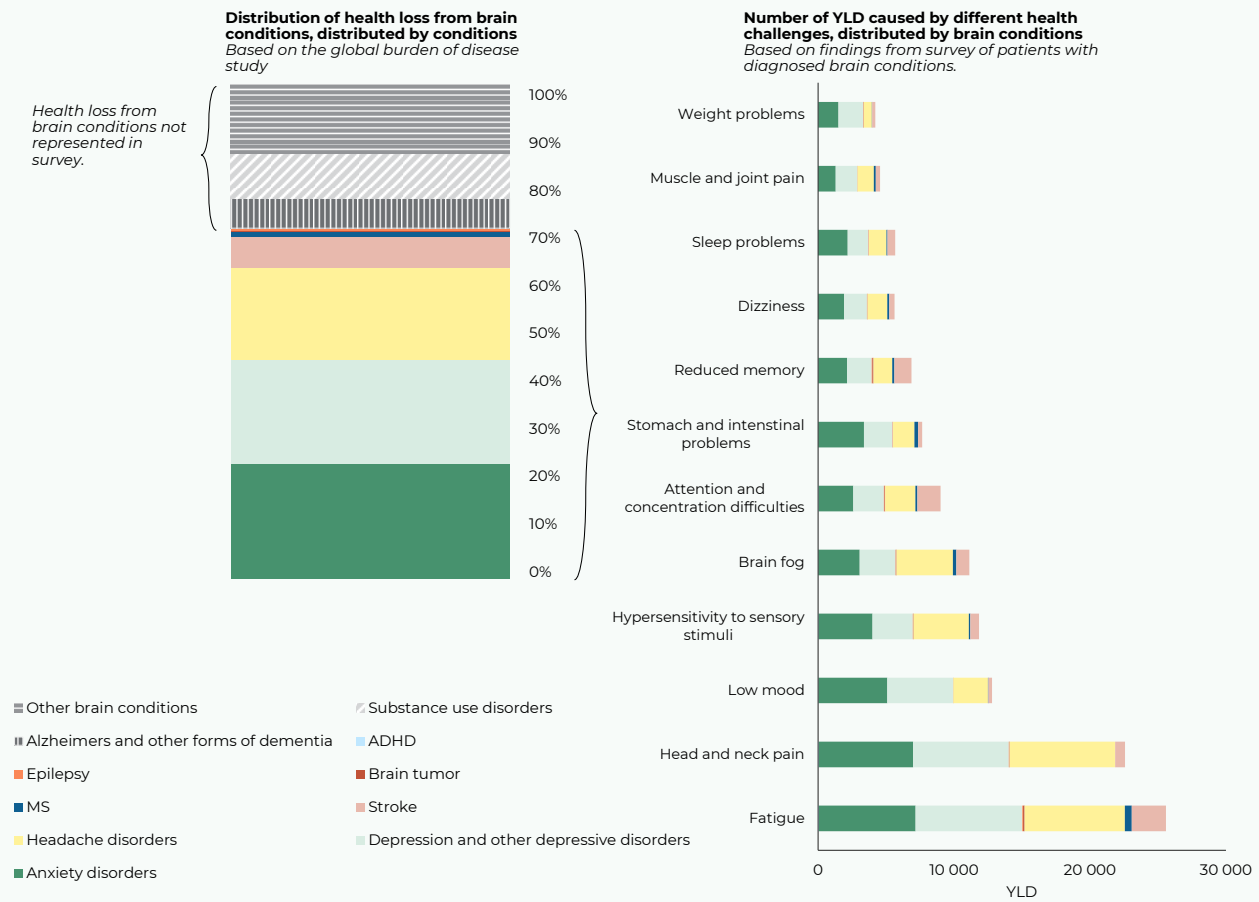
## Brain conditions also pose challenges that extend beyond the direct health impacts of the condition itself

A large proportion of those living with brain conditions experience significant challenges related to both personal and social aspects of life, as well as issues with work, education, and finances. Over 90 percent stated that they have significant or some degree of difficulty participating in social situations, and nearly 85 percent reported that they feel they are a significant or some degree of burden to those around them. 83 percent of respondents stated that they feel less like themselves, and 70 percent stated that they experience a feeling of shame to a large or some extent. This suggests that the disease not only affects physical and cognitive functions, but also personal identity.

## Further investigation may help to identify effective and targeted measures.

The findings of this report underscore the importance of continued collaboration between health authorities, health care services, patient organizations, and researchers to address the challenges associated with brain conditions. In addition, this knowledge may be valuable for other sectors, such as working life, education, and social planning, where an understanding of the health challenges associated with brain conditions can contribute to better facilitation, increased participation, and prevention of exclusion. To develop effective and coordinated measures, it is essential to identify the common challenges that exist across the various diagnoses. Further research and investigation of the symptoms and quality of life of people with brain conditions can facilitate the identification of measures that can contribute to a better life for people with brain conditions, thereby reducing the burden of disease.

Figure 1-1: What health challenges explain YLD (Years Lived with Disability)?



# 1. Background and methods

*Increased knowledge about the burden of brain diseases can provide a better understanding of what it is like to live with these diseases, and what are the key similarities and differences in challenges and burdens across the board. This provides a stronger basis for developing effective, joint measures that can reduce the burden of disease and improve the quality of life for many people living with brain conditions.*

## 1.1 A growing number of people are living with brain conditions

Brain conditions represent a significant public health challenge in Norway. Approximately one in three Norwegians will be affected by a brain condition during their lifetime, and the incidence is increasing. There are several reasons for this.

As life expectancy increases, a larger and older population will lead to more cases of brain conditions. Recent figures from the Global Burden of Disease Study (GBD) show that Norwegians are living longer, but that many are afflicted with disease during these additional life years.

Better diagnostics and treatment mean that more people survive and continue to live with their disease. At the same time, this means that an increasing number of people are living with the health challenges that result from their disease. Measures to improve patients' quality of life are therefore becoming increasingly important.

In this report, we use the term brain conditions as a collective term for mental and neurological disorders, conditions and injuries, as well as substance use disorders (see Box 2-1: *European Commission definition of brain conditions*).

### 1.1.1 Strategy for better brain health

Brain conditions impact many people, both those who are affected and their relatives. There is therefore a need for increased awareness and knowledge about brain health. This is an important reason why the Ministry of Health and Care Services launched the National Brain Health Strategy in 2017 (Helsedirektoratet, 2025), as the world's first political

strategy on brain health. The strategy aims to help both individuals and society to be better equipped to maintain brain health and prevent brain diseases. It also aims to ensure that people affected by brain diseases receive good follow-up care

To implement effective and targeted measures, it is essential to have a good understanding of brain health, brain diseases, and the burden of disease associated with these conditions. Brain conditions can have different causes, present different health challenges, have varying disease progression, and require different follow-up. People affected by brain conditions may therefore have very different needs. At the same time, many share common challenges that make it possible to develop measures that benefit several groups at the same time. By looking beyond individual diagnoses, we can gain a more comprehensive understanding of both the commonalities and variations in the burden of disease among people living with different brain conditions.

### 1.1.2 Large disease burden associated with brain conditions

Over the past 15 years, the burden of disease in Norway has increased by 11 percent (FHI, 2025). This increase is largely driven by a larger and older population, who live longer with chronic diseases. Cardiovascular diseases, cancer, and neurological diseases particularly contribute to the burden of disease among the elderly. Among the younger part of the population, anxiety disorders and depressive disorders are key contributors to the burden of disease.

Brain conditions encompass a wide range of conditions that affect the health and functioning of the brain. However, a common denominator is that brain conditions can give rise to a number of health challenges. These challenges can vary in complexity, severity, and duration—from transient and mild symptoms and ailments to conditions that occur episodically and complex, long-term, and serious conditions.

It is also not uncommon for people with brain conditions to experience comorbidity, i.e., several different brain conditions at the same time. For example, the degree of comorbidity between mental and neurological disorders is high (Demarin & Morovic, 2021) and between mental disorders and substance abuse disorders (Long, et al., 2017). Comorbid conditions increase the burden of

disease and can make it more challenging to provide effective treatment (Hesdorffer, 2016).

Health challenges can have a major impact on people's health-related quality of life and functional ability. Some people are born with functional impairments, while others experience a loss of function in areas such as movement, memory, language, and attention at a later stage in life. Functional impairment can make tasks that are simple and routine for many people difficult to perform. Furthermore, health challenges can affect self-esteem, participation in education and work, as well as relationships and social participation.

The main measure of disease burden is DALY (Disability-Adjusted Life Years), which indicates the number of healthy years lost in a population. DALY is the sum of years of healthy life lost due to disability (YLD) and years of life lost (YLL). According to the global burden of disease study, brain disease accounts for 36 percent of the disease burden related to years of healthy life lost (YLD). The fact that many of the symptoms and ailments are not visible to those around them can be perceived as an additional burden because others do not necessarily recognize or understand the consequences of the disease.

### 1.1.3 Limited knowledge about the prevalence of health challenges and their significance for the burden of disease

Although brain conditions account for a large proportion of the disease burden in Norway, there is limited knowledge about the health challenges faced by people with brain conditions and how these affect their functional ability and quality of life. In addition, different definitions of what constitutes a brain condition can make it difficult to compare figures across existing studies.

There is therefore a need for more systematic mapping of the prevalence of various health challenges associated with brain conditions and their impact on the burden of disease. Better knowledge helps us understand the extent and consequences of brain conditions and identify challenges across diagnoses. This is important in order to develop more coordinated and joint measures throughout the patient pathway for people with different brain conditions.

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<sup>1</sup> Data retrieved on October 20, 2025 from: <https://brainhealthatlas.org/data/brain-health/line>

## 1.2 Project overview

The purpose of this report is to provide comprehensive and up-to-date knowledge that highlights key challenges and consequences for adults living with brain conditions in Norway. The following issues are addressed in this report:

- How do brain conditions affect people's quality of life and functional ability?
- How do people with brain conditions experience living with disability (YLD)?
- Which visible and invisible symptoms and ailments contribute most to people with brain conditions living with reduced functional ability (YLD)?

## 1.3 Methods

In the following, we describe the methodological framework and the data used in our work with this report.

### 1.3.1 Data sources

To obtain information about the issues addressed in this report, a broad and thorough investigation is required. We achieve this by gathering information from several different sources. Below, we describe the most important types of sources we have used:

#### Statistics from the Global Burden of Disease Study

The Global Burden of Disease Study is an international initiative to research health loss and death related to diseases, injuries, and risk factors over time and across geographic areas. As part of the study, the burden of disease is quantified for over 350 diseases, including several brain conditions.

We have used data<sup>1</sup> showing the burden of disease for brain conditions as a whole and for a selection of specific brain conditions. The data show how the burden of disease is distributed between health loss (YLD) and mortality (YLL). We have extracted disease-specific data for a selection of brain conditions to illustrate how health loss and mortality are distributed among different brain conditions. For eight of these brain conditions, we also have survey data that allows us to break down the burden of disease by specific health challenges.

#### Survey among representatives from patient and user organizations

At the outset of the mapping process, we conducted a survey targeting representatives of

selected patient and user organizations. The purpose was to gain basic insight into the scope and diversity of health challenges and the burden of disease associated with brain conditions. This insight was then used to design and conduct a follow-up survey targeting people diagnosed with brain conditions.

The survey was distributed through The Norwegian Brain Council (Hjernerådet), which forwarded it to its member organizations. These organizations represent patients and users with various brain conditions. Mental Health Norway (Mental Helse Norge) and The Norwegian Council of Mental Health (Rådet for psykisk helse) also received the survey directly.

### Survey among members of patient and user organizations

People living with brain conditions have direct experience of the challenges these disorders entail and are therefore considered a key source of information. To gather their experiences, we have conducted a survey targeting members of relevant patient and user organizations.

### Interviews

Important segments of the target group for the survey have difficulty responding to a digital survey. This is believed to particularly apply to groups with limited digital skills, groups with extensive functional impairments, and the most seriously ill. To capture the experiences and challenges of these groups, we have conducted interviews with selected patient and user organizations.

We have interviewed representatives from the following organizations:

- Mental Health Norway (Mental Helse Norge)
- Norwegian Health Association (Nasjonalforeningen for folkehelsen)
- The Norwegian Parkinson Association (Norges Parkinsonforbund)
- The Norwegian Stroke Association (Norsk forening for slagrammede)
- A-larm (a nationwide organization for users and next of kin in the field of substance use)

In addition, we have conducted an interview with the National Center for Rare Diagnoses, Unit for Neurodevelopmental Disorders and Hypersomnia (Nasjonalt senter for sjeldne diagnoser, Enhet for nevroutviklingsforstyrrelser og hypersomnier).

### Previous reports and studies

We have also obtained and utilized knowledge from previous reports and studies. This includes research literature and reports from, among others,

the Norwegian Institute of Public Health (FHI) and the Norwegian Directorate of Health, which highlight issues related to brain condition and disease burden.

### 1.3.2 Analysis

Based on figures from the global burden of disease study, we analyze the prevalence of various brain diseases and the associated burden of disease. We mainly analyze health loss (YLD). We also estimate the average burden of disease per case of selected diseases.

Furthermore, we use the responses from the questionnaire to analyze five categories of health challenges:

- Nutrition and digestion challenges
- Neurological symptoms
- Cognitive challenges
- Mental and emotional symptoms
- Challenges with physical function and endurance

Each of the categories contain several health challenges. We take a closer look at which of these are most commonly experienced by people affected by brain diseases, and how these symptoms and ailments contribute to health loss. In addition, we analyze the differences across different disease groups. We then combine insights from the GDB estimates with findings from the survey to provide some simplified estimates of which health challenges contribute most to health loss.

Responses from the survey are also used to analyze challenges related to living with brain diseases. This includes how the disease and health challenges affect self-esteem and identity, participation in society, social life and relationships, sense of mastery, and lack of accommodation. We examine the prevalence of various challenges, both overall and broken down by different brain diseases. We also discuss how different challenges contribute to health loss.

### 1.3.3 Limitations and biases

A key limitation of the method we use in this analysis is that important parts of the target group cannot be expected to respond to a digital survey. This creates a risk that the experiences and challenges of certain groups will not be adequately captured, which may contribute to a skewed representation of the situation. We believe that there is a particular risk that groups with low digital literacy, groups with extensive functional impairments, and the most seriously ill are not represented. To counteract this bias, we have supplemented the information gathering with

other sources, such as interviews and reviews of publicly available documents and statistics.

Another possible source of bias is that members of patient and user organizations are not representative of the entire patient population that the association represents. Members may have more or less serious illnesses and/or health challenges than the average of the group they represent. On the one hand, it is conceivable that those most severely affected by health challenges are unable to be involved in a patient or user organization. On the other hand, it may also be the case that those who are only affected by mild illness are not as engaged and therefore cannot be reached through surveys distributed via patient and user organizations. This type of bias is more difficult to correct for.

The survey has more respondents with neurological disorders than with mental disorders, and particularly few with substance use or injuries. Nevertheless, the data make it possible to highlight the variation in challenges at the group level.

Another challenge is that respondents may have multiple comorbid conditions, making it difficult to distinguish between which health challenges are associated with which disease. However, this challenge is not specific to the chosen method but rather applies in general and places greater demands on the interpretation of the results.

Overall, the survey received many responses, but a longer implementation period and more time to involve patient and user organizations could probably have made the survey even more comprehensive.

#### 1.3.4 Implementation

The survey was conducted by Oslo Economics in the fall of 2025, in collaboration with Jonas Minet Kinge at the Department of Health Management and Health Economics at the University of Oslo. We would like to thank the Brain Council, the partnership for the brain health strategy, patient and user organizations, and everyone who responded to the surveys.

## 2. The impact of brain diseases on quality of life

*For many patients, brain diseases not only affect their health, but also have far-reaching consequences for their daily lives, including their ability to participate in education, work, or other activities. If we look at the burden of disease caused by non-fatal health loss, i.e., the consequences for patients while they are alive, brain diseases accounted for 36 percent of this burden of disease in Norway in 2021.*

### 2.1 Brain disease and brain health

Brain conditions include mental and neurological disorders, conditions, and injuries, as well as substance use disorders (Helse- og omsorgsdepartementet, 2017; Olesen, et al., 2011; Wang, et al., 2020). These diseases may have common features, but differ in terms of causal mechanisms, progression, and follow-up in the health service. Mental disorders often arise earlier in life and affect emotional and social functioning, while neurological diseases lead to a greater extent to motor and cognitive impairments. Other brain diseases, such as stroke and traumatic brain injury, can also cause similar types of health challenges. The differences between the disease groups are important for treatment, rehabilitation, and the need for long-term follow-up. Mental and physical illness are often closely related, and one can lead to the other and vice versa.

Brain conditions can occur as acute, gradually worsening, or chronic conditions (Helsedirektoratet, 2024). For some, their brain disease means that they have little or only periodical health challenges, while others live much of their lives with major health challenges and reduced quality of life.

#### Box 2-1: The European Commission's definition of brain disease

*"Brain conditions include neurodegenerative diseases such as Alzheimer's disease and Parkinson's disease, and other disorders like epilepsy, depression, stroke, migraine, sleep disorders, traumatic brain injury, pain syndromes and substance use."*

**Kilde: The European Commission**

Brain health is about the health of the brain from a life course perspective (Helsedirektoratet, 2024). It encompasses everything from caring for and developing the brain, to mental and neurological diseases, injuries, and conditions that affect the brain and other parts of the nervous system. In addition, brain health is about the conditions that enable people to promote their own brain health and cope with life with reduced function as a result of a brain disease.

#### 2.1.1 Mental disorders and substance use disorders

Within mental health, it is common to distinguish between mental health problems and mental disorders (FHI, 2023). Mental health problems are common variations in behavior and emotions, and can include problems such as anxiety, depression, and restlessness. Mental disorders is a collective term for illnesses and conditions that affect thoughts and emotions (Store medisinske leksikon, 2024). Unlike psychological distress, the burden of illness associated with mental disorders implies that the criteria for a clinical diagnosis are met and that this persists over time. In many cases, these disorders can lead to impaired functioning in everyday life and reduced quality of life.

Mental disorders can cause changes in behavior, but the term covers a wide range of conditions with varying degrees of severity and expression. The causes are usually complex and often result from an interaction between hereditary factors and environmental influences. In some cases, mental disorders can arise as a result of physical or psychological stress following illness or injury, particularly to the brain or central nervous system.

In the code system used for classifying diseases in the specialist health service in Norway (ICD-10), substance use disorders are classified in the chapter "Mental and behavioral disorders." Substance use disorders often occur together with other mental disorders (FHI, 2022).

#### 2.1.2 Neurological diseases

Neurological diseases are a broad group of diseases and conditions that affect the brain, spinal cord, and nerves that extend to the rest of the body. (Den norske legeforening, 2019). Many neurological diseases are chronic and involve a gradual deterioration in the patient's condition. Patients therefore often require long-term treatment and follow-up.

In the global burden of disease study, diseases and conditions of the nervous system are divided into many disease groups. The main group of neurological disorders includes Alzheimer's disease and other forms of dementia, Parkinson's disease, epilepsy, MS, motor neuron disease, headache disorders, and a residual category of other neurological disorders that among other things includes muscular dystrophy and Huntington's disease (FHI, 2018). Part of the disease burden that can be linked to neurological diseases is due to diseases classified in other groups in the global disease burden study (Steinmetz, Jaimie D et al., 2024). This includes stroke, encephalitis, tetanus, traumatic brain injury, spinal cord injury, cancer of the brain and central nervous system, and neurodevelopmental disorders.

## 2.2 Prevalence of brain disease

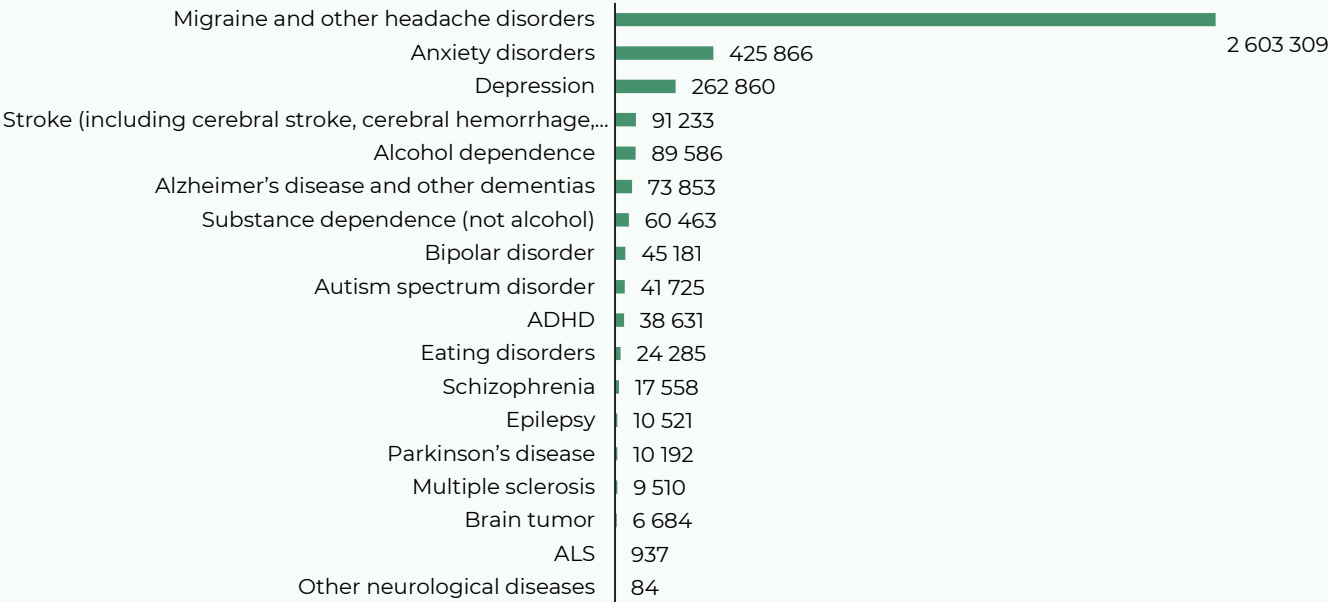
It is estimated that approximately one in three people in Norway will develop a brain disease during their lifetime (Regjeringen.no, 2023). The incidence<sup>2</sup> of brain diseases is increasing, and an increase of approximately 16 percent is expected

between 2021 and 2050 (Institute for Health Metrics and Evaluation (IHME), 2022). In addition to more people being affected by brain disease in the future, an increasing number of patients will live with one or more brain diseases for a longer period of time.

According to the IHME Brain Health Atlas, the total prevalence of brain conditions in Norway was 3,86 million in 2021 (Institute for Health Metrics and Evaluation (IHME), 2022).<sup>3</sup> This does not mean that 3,86 million people had a brain disorder in 2021, but rather that by the end of 2021, 3,86 million brain conditions had been registered in the population. One person may have several brain conditions at the same time, and many conditions occur as comorbidities. For example, depression often occurs in patients with Parkinson's disease (Dietrichs, 2003), while people with Tourette's syndrome may have additional conditions such as ADHD or anxiety (Eichele & Bakke, 2023).

The IHME Brain Health Atlas has compiled data from the global burden of disease study for diseases that they define as brain diseases. The selection differs somewhat from the selection of diagnoses in the Norwegian Directorate of Health's report *"Patients with brain disorders in specialist health*

Figure 2-1: Prevalence of brain conditions in 2021



Source: Information from IHME Brain Health Atlas. Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2021. Seattle, WA: IHME, 2022.

<sup>2</sup> Prevalence defined as point prevalence from the Global Burden of Disease Study 2021.

<sup>3</sup> Prevalence here refers to point prevalence, i.e., the proportion of people in the population who have a given

disease at a given time, as defined in the global burden of disease study.

services” (“Pasienter med hjernesykdommer i spesialisthelsetjenesten”) (Helsedirektoratet, 2024). The overview shows that there is considerable variation in the prevalence of different brain diseases (Figure 2-1). The most prevalent brain disease in Norway is migraine and other headache disorders. Migraine and other headache disorders alone account for 67 percent of all brain conditions, and almost 50 percent of the Norwegian population has migraine or other headache disorders, as defined by the IHME Brain Health Atlas. This is followed by anxiety disorders (11 percent) and depression (7 percent).

## 2.3 Impact of brain disease on quality of life and functional ability

Brain conditions can have far-reaching consequences for the daily lives and quality of life of those affected. Many experience a gradual loss of motor function, memory, language, and attention. This can make everyday activities difficult to perform. For many, brain disease also means a loss of ability to work, either due to reduced cognitive capacity, fatigue, or physical limitations. This, in turn, can have an impact on financial security and predictability.

Brain diseases can also affect social relationships and mental health. Some diseases can cause changes in personality, the ability to regulate emotions, and the ability to communicate. This can affect relationships with family, friends, and colleagues. For some, these changes can lead to social isolation and relationships changing or being lost. People with brain conditions may also experience prejudice as a result of their illness, and many choose to keep their condition hidden due to fear of stigmatization. In a survey of people with neurological disorders, 83 percent said they feel stigmatized because of their condition (The European Federation of Neurological Associations (EFNA), 2024).

Some brain conditions involve an increased risk of depression and anxiety. In addition, the burden on relatives can be considerable and lead to an increased risk of mental health problems (Helsebiblioteket/BMJ, 2024).

## 2.4 What is disease burden?

Burden of disease analyses shed light on public health in the population by showing how diseases, injuries, and risk factors contribute to premature death and reduced health (FHI, 2025). The method is used to calculate how many healthy years of life

are lost in the population, taking into account both diseases that lead to premature death and diseases that cause significant health loss without being fatal.

The Global Burden of Disease (GBD) study is an international initiative that quantifies the burden of disease for over 350 diseases and injuries, and approximately 90 risk factors. The project collects health data from around the world to create the most complete overview of public health possible, broken down by age, gender, geographical area, and time. Data from Norway is sourced from national health registries, population surveys, various questionnaires, sales data, and scientific studies.

The main measure of disease burden is DALY (Disability-Adjusted Life Years), which indicates the number of healthy years lost in a population. DALY is the sum of years lived with health loss (YLD) and

### Box 2-1: Calculation of disease burden

The calculation of the burden of disease is based on both the incidence and severity of diseases and injuries. To estimate health loss, the global burden of disease study collects data on incidence (new cases during a specific period) and prevalence (number of cases at a given point in time), as well as information on the extent to which health is reduced by various conditions. The data is obtained from registers, health surveys, and scientific studies, and is supplemented with models and assumptions when national data is lacking.

The severity of diseases is expressed through disability weights, which have been developed from population surveys in several countries. These weights rank health conditions on a scale from 0 (completely healthy) to 1 (equivalent to one lost year of life). For each disease, the number of people in each health condition is multiplied by the corresponding weight, and the sum gives the total health loss from the disease.

The health loss weights were developed by creating descriptions of health states of varying severity. A sample of representatives from nine countries, in addition to respondents in an open internet survey, were given descriptions of two health states and asked to rank which of the two they thought had the best health. Respondents were also asked to compare the benefits of interventions to save lives and prevent disease. Based on the responses, health loss was calculated for each of the diseases represented by the health conditions. The health loss weights are common to all countries, so that the burden of disease can be measured and compared globally.

Data from the Cause of Death Registry is used as the basis for calculating lost years of life for Norway.

**Source: (FHI, 2025)**

years of life lost (YLL). DALY is calculated in the same way regardless of gender, age, area, or time, and provides a common unit of measurement for diseases, injuries, and risk factors. This makes it possible to compare across areas.

## 2.5 Health loss related to brain conditions

Analysis of data from the global burden of disease study shows that brain conditions accounted for 29 percent of the total burden of disease (DALY) in Norway in 2021 (Helsedirektoratet, 2025). These diseases accounted for 22 percent of the loss associated with premature death (YLL) and 36 percent of the loss associated with years lived with health loss (YLD).

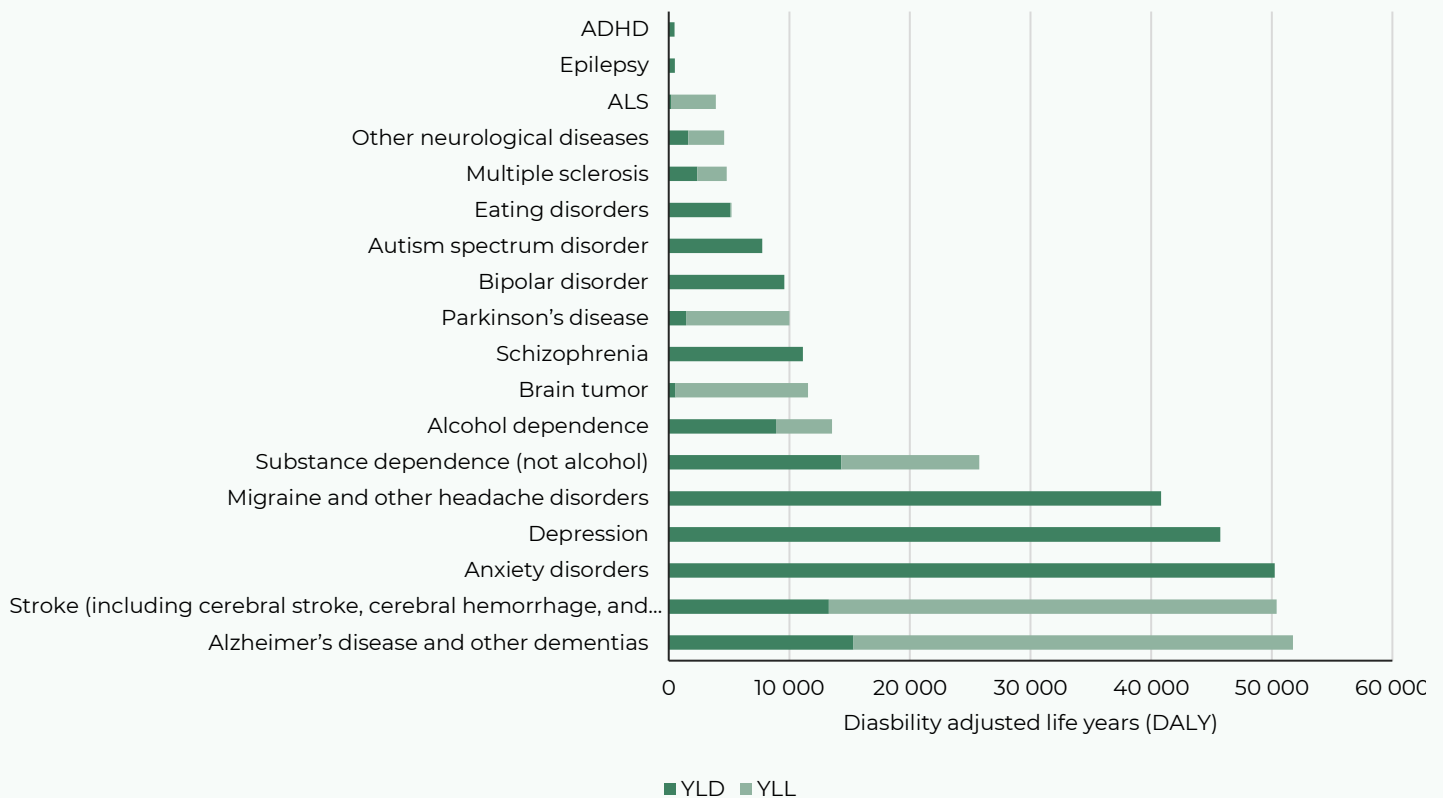
The diseases that contribute most to health loss in Norway are Alzheimer's disease and other forms of dementia, stroke, and anxiety disorders (Figure 2-2). However, the causes of health loss vary. While most of the health loss associated with Alzheimer's disease and other forms of dementia is due to

mortality, the health loss associated with anxiety disorders is due to many years of poor health.

For both mental disorders and neurological diseases, there has been an increase in the burden of disease (measured in DALYs) from 2010 to 2023 (FHI, 2025). For mental disorders, there has been a 42 percent increase in the burden of disease, while for neurological diseases there has been a 25 percent increase.

If we look at the change in the age-standardized rate (number of DALYs per 100,000 inhabitants adjusted for population growth and aging of the population), it is particularly the burden of disease associated with mental disorders that has increased (FHI, 2025). From 2010 to 2023, there has been a 28 percent increase in the age-standardized rate, and the increase is mainly due to health loss from anxiety disorders and depressive disorders. The increase is particularly evident among young people. For neurological diseases, there has been a 3 percent increase in the age-standardized rate of disease burden. The disease burden for these diseases is therefore particularly linked to a larger number of elderly people in the population.

Figure 2-2: Disease burden of brain conditions (DALY)



Source: Information from IHME Brain Health Atlas. Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2021. Seattle, WA: IHME, 2022.

# 3. Health challenges among individuals with brain conditions

Brain conditions can cause a wide range of health challenges that affect quality of life and functional ability. We find that a large proportion of patients with brain conditions struggle with tiredness and fatigue, and that these are important causes of the significant health loss associated with brain conditions. We estimate that tiredness and fatigue for eight selected brain conditions alone result in a health loss of over 25,000 YLD per year.

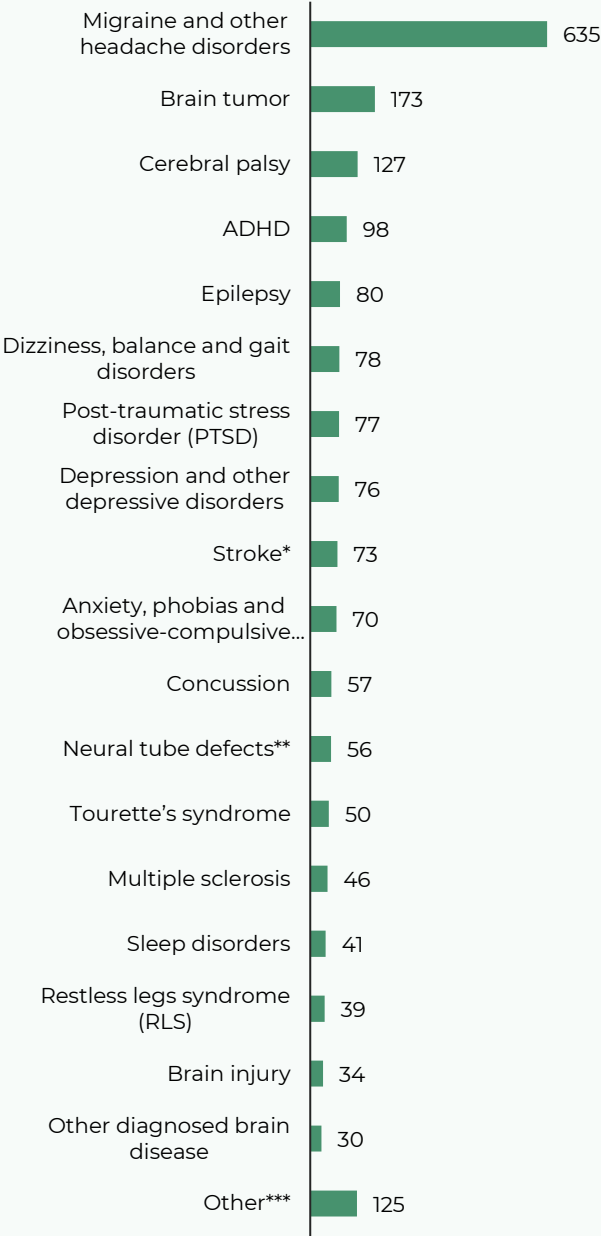
## 3.1 Brain diseases represented in the survey

This chapter is based on insights from a survey conducted by Oslo Economics among patients diagnosed with one or several brain conditions. The sample that responded to the survey is not representative of the distribution of brain conditions in the population. Certain disease groups are overrepresented in the survey sample, while others are underrepresented. For example, there are few respondents with dementia or other brain conditions that cause severe cognitive impairment, and there are also few with substance use disorders. These groups might face challenges in participating in this kind of survey. To capture their perspectives, we have therefore conducted interviews with relevant patient and user organizations.

The most common disease category among respondents in the survey was migraine and headache disorders (Figure 3-1). 53 percent of respondents reported having such disorders. Furthermore, approximately 15 percent of respondents stated that they have or have had a brain tumor, 11 percent stated that they have cerebral palsy, 8 percent stated that they have ADHD, and 7 percent stated that they have epilepsy. Several other brain conditions were represented among the respondents, but these accounted for a smaller proportion of the respondents.

Nevertheless, the survey provides insight into which health challenges people with brain conditions experience, and to what extent they are impaired

Figure 3-1: Number of respondents reporting various brain diseases



**N = 1192**  
**Note: It was possible to report more than one brain disease.**  
**Source: Survey conducted by Oslo Economics autumn 2025. The survey was sent to patient and member organizations in The Norwegian Brain Council (Hjernerådet), who were asked to distribute the survey to its members.**  
**\*Includes cerebral stroke, cerebral hemorrhage, and subarachnoid hemorrhage**  
**\*\*Includes spina bifida, hydrocephalus, and other diseases related to cerebrospinal fluid in the brain**  
**\*\*\*Other includes diseases reported by respondents fewer than 30 times (e.g., ME, eating disorders, autism spectrum disorder, other neurological diseases, bipolar disorder, spinal cord injury, Parkinson's disease, ALS, neuroborreliosis, Alzheimer's disease and other dementias, substance dependence)**

by the health challenges they experience. Using the respondents' answers to the questionnaire, it is also possible to examine, in general terms, whether the health challenges and the reported level of impairment from the health challenges differ between disease groups and in three overall disease categories: neurological diseases, mental disorders, and other brain conditions.

As it is possible to have more than one brain condition, respondents could report several brain conditions. It was specified that the brain condition reported should be diagnosed. 61 percent of respondents reported having one brain condition, while the rest reported having two or more brain conditions.

## 3.2 Health challenges

People living with brain conditions may have a range of health challenges. These include mental health problems as well as cognitive and somatic challenges.

Different brain conditions can cause common health challenges, but they can also cause very different challenges. For example, the symptoms of a person with ADHD and a person with Parkinson's disease will be very different, but it is also possible that both patient groups experience some of the same health challenges. Some brain conditions can cause a wide range of health challenges, while other brain conditions typically only cause a few health challenges.

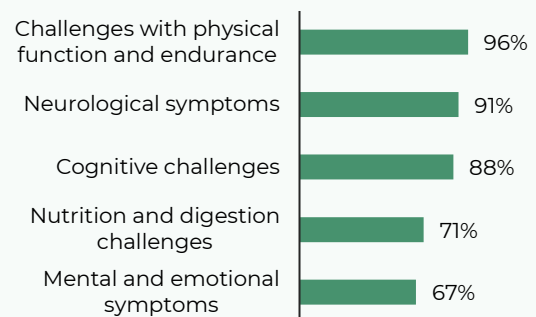
Based on the survey of patient organizations and background knowledge about brain conditions, we have identified five main groups that collectively summarize the most important symptoms and ailments of people diagnosed with brain conditions. These categories are:

- Nutrition and digestion challenges
- Neurological symptoms
- Cognitive challenges
- Mental and emotional symptoms
- Challenges with physical function and endurance

In the survey, most respondents stated that they have health challenges in several of the categories (Figure 2-2). Most respondents reported having health challenges in the symptom group "physical function and endurance," with over 96 percent of respondents struggling with challenges related to this. The fewest respondents reported having health challenges within the symptom group "mental and emotional symptoms" (67 percent) (Figure 3-2). Within each category, we have

identified symptoms based on previous research, dialogue with clinicians, and the survey of patient and user organizations. There is considerable variation in how common the symptoms are within each symptom category, and some of the included symptoms only occur in certain patient groups. The more specific symptoms are included because patient and user organizations have highlighted these symptoms as particularly defining for their patient group. The various symptoms and categories are described in Figure 3-2.

Figure 3-2: Proportion of respondents with health challenges in different categories



N = 1192

Source: Survey conducted by Oslo Economics autumn 2025. The survey was sent to patient and member organizations in The Norwegian Brain Council (Hjernerådet), who were asked to distribute the survey to its members.

## 3.3 Frequency and severity of various health challenges

The frequency and severity of health challenges among people with brain conditions vary considerably. In the survey of people diagnosed with brain conditions, we asked them to identify the three symptoms and ailments they "experience the most in their daily lives" (Figure 3-3). By limiting respondents to choosing only three health challenges, we capture the health challenges that individuals themselves experience as most burdensome.

The respondents reported fatigue as the most common symptom, with a total of 47 percent of respondents stating that this is one of the three symptoms they experience most in everyday life. The second most commonly reported symptoms were head and neck pain (31 percent) and brain fog (23 percent). This must be seen in light of the sample in the survey, where people with migraine

and headache disorders account for over half of the respondents. At the same time, migraine and headache disorders account for a large proportion of the total number of cases of brain conditions in Norway.

If we exclude respondents with migraine and headache disorders, only 10 percent of the remaining sample reported pain in the head and neck as one of the three symptoms they experience most. The symptom most frequently reported by respondents who do not have migraine and other forms of headache disorders is tiredness or fatigue (46 percent), followed by reduced memory (29 percent) and motor and muscular difficulties (29 percent).

The findings from the survey related to the frequency of health challenges will be influenced by the brain conditions of the respondents in the survey. The sample is not necessarily representative of all people with brain conditions. For example, there are few respondents with dementia and substance use disorders, while there are many respondents with migraine and headache disorders. The results must therefore be viewed in light of the brain conditions that the respondents have reported having, as described in section 3.1.

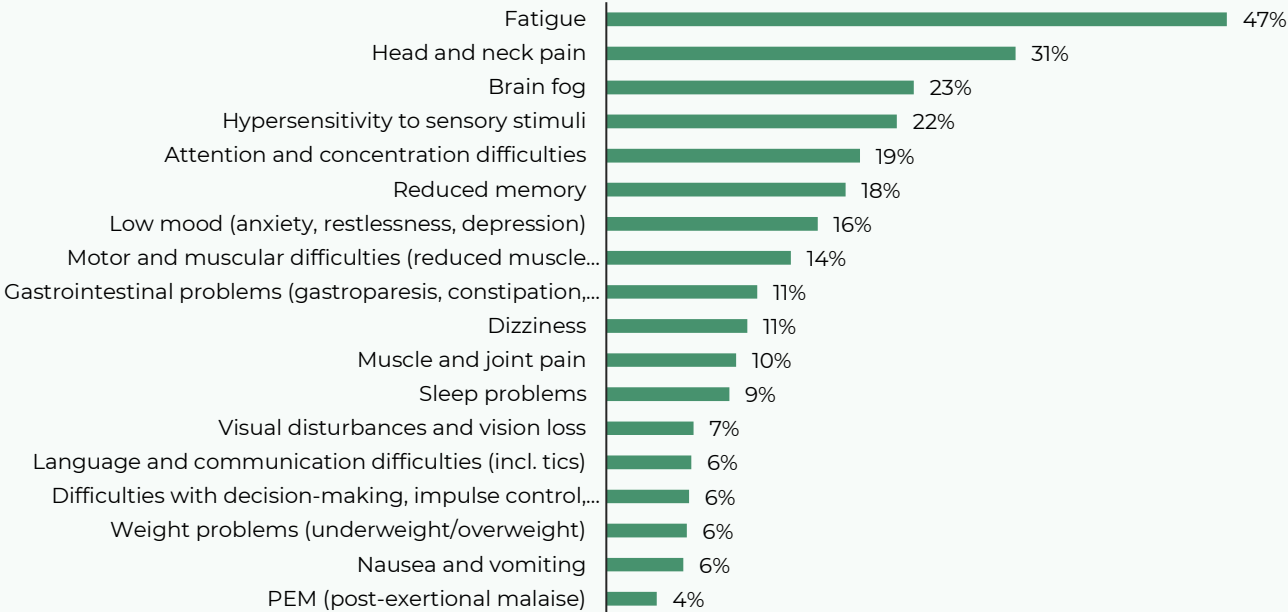
### 3.3.1 How troubled are the respondents who report the symptom?

Respondents in the survey were also asked to indicate how much discomfort they experienced from the three symptoms they chose to highlight. Respondents rated the pain on a scale from 1 to 5, where 1 was defined as "not uncomfortable" and 5 was "very uncomfortable."

For the entire sample, we see that the symptoms that are perceived as most troublesome on average are pain in the head and neck, with an average score of 4,5 (Figure 3-4). This was also the symptom that was highlighted most often for the entire sample.

After head and neck pain, PEM (post-exertional malaise) and sleep problems were the symptoms reported to be most troublesome. PEM is a key symptom of ME, among other conditions, and is characterized by the patient experiencing increased and prolonged fatigue, weakness, and/or pain after physical or mental activity because of exertion. In contrast to head and neck pain, relatively few people reported PEM as one of the three symptoms they experience most in their daily lives (Figure 3-4). Although PEM affects a small proportion of respondents, it is very troublesome for those who experience the symptom. Sleep problems were also highlighted by relatively few

Figure 3-3: Which health challenges do the respondents experience to the greatest extent?



**N = 1192**  
**Note:** Question: "Which three symptoms, among those you mentioned in the previous questions, do you experience the most in your daily life?"  
**Source:** Survey conducted by Oslo Economics autumn 2025. The survey was sent to patient and member organizations in The Norwegian Brain Council (Hjernerådet), who were asked to distribute the survey to its members.

respondents, but 110 respondents pointed out this as one of the three symptoms that most affect them in everyday life.

### 3.3.2 Differences between disease groups in terms of frequency and perceived burden of health challenges

The health challenges reported by respondents vary considerably between disease groups, both in terms of which health challenges occur and how troublesome they are perceived to be. We have therefore investigated the frequency by which a health challenge is reported and severity of the various symptoms for the different brain diseases.

Figure 3-5 shows a selection of health challenges experienced by a large proportion of the respondents. Each point corresponds to a brain disease, with brain diseases color-coded based on whether they are a neurological conditions, mental disorders, or in another category<sup>4</sup>. The Y-axis shows the percentage of people who reported the symptom, while the X-axis shows the average reported severity of the symptom for those in the group who experience the symptom.

### What is fatigue?

Fatigue is an abnormal and prolonged feeling of exhaustion. It can be described as a tiredness that does not go away with sleep or rest, where even enjoyable activities become challenging to perform.

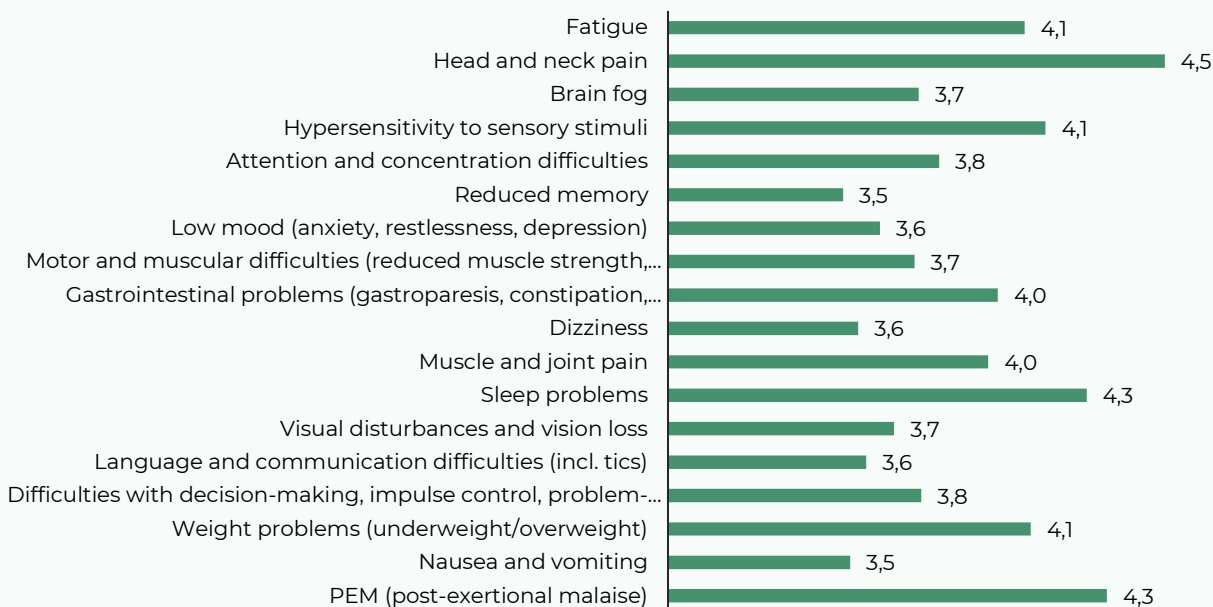
Fatigue can be both chronic and acute, and can vary greatly in severity. Common symptoms include lack of energy, difficulty concentrating, weakness, and feeling overwhelmed by even small tasks (Kreftforeningen, 2023).

### Fatigue

For a significant proportion of brain conditions, more than 40 percent of respondents stated that tiredness or fatigue is one of the three most troublesome symptoms (Figure 3-5 Panel A). This also corresponds with the information from the patient and user organizations we have been in dialogue with, where several pointed out that fatigue is something that a large proportion of their members suffer from.

MS, stroke, and migraine and other headache disorders (all of which are neurological diseases) are

Figure 3-4: How troubled are the respondents who experience different health challenges?



**N:** Fatigue = 554, head and neck pain = 366, brain fog = 275, hypersensitivity to sensory stimuli = 260, attention and concentration difficulties = 226, reduced memory = 214, low mood = 188, motor and muscular difficulties = 165, gastrointestinal problems = 135, dizziness = 127, muscle and joint pain = 116, sleep problems = 110, visual disturbances and vision loss = 78, language and communication difficulties = 76, difficulties with decision-making, impulse control, problem-solving = 74, weight problems = 72, nausea and vomiting = 69, PEM (post-exertional malaise) = 45.

**Note:** Question: "To what extent are you troubled by [the specified symptom]?" Scale from 1 to 5, where 1 is not troublesome and 5 is very troublesome.

**Source:** Survey conducted by Oslo Economics autumn 2025. The survey was sent to patient and member organizations in The Norwegian Brain Council (Hjernerådet), who were asked to distribute the survey to its members.

<sup>4</sup> The grouping of disorders is shown in Appendix A.

the three disease groups that most frequently reported being affected by tiredness or fatigue. Within these disease groups, more than half reported that they suffer from this symptom.

Although tiredness or fatigue is one of the most commonly reported symptoms across disease groups, the degree of discomfort experienced varies. Respondents with migraine, depression, and ADHD reported the highest average level of discomfort (around 4,5 on a scale of 1 to 5, where 1 is not uncomfortable and 5 is very uncomfortable), while people with brain tumors, cerebral palsy, and epilepsy reported lower levels of discomfort. Although a large proportion of respondents with brain tumors, cerebral palsy, and epilepsy experience fatigue or tiredness, the overall burden may be lower, as the perceived discomfort is lower.

### Head and neck pain

Head and neck pain has a different incidence and degree of severity than tiredness or fatigue (Figure 3-5, panel B). The proportion reporting this symptom varies between disease groups, but those who do report it indicate a high degree of severity. Across the various brain conditions, the average level of discomfort for those who experience head and neck pain is above 4, and for most brain conditions, the average level of discomfort was between 4,5 and 5.

There is considerable variation in how many people experience this symptom. While only 3 percent of respondents with brain damage and 7 percent of respondents with cerebral palsy reported experiencing pain in the head and neck, over 50 percent of those with concussion and migraine reported experiencing the same. The connection between head and neck pain and concussion and migraine is well known, and this type of pain is a core symptom of these conditions.

It is worth noting that high perceived discomfort does not necessarily correspond to a large share of the respondents reporting the health challenge. Respondents with stroke and sleep disorders reported a low incidence of head and neck pain, but very high perceived discomfort (average discomfort above 4,7). Both incidence and perceived discomfort must be considered when assessing the disease burden of the symptom for each individual brain disorder.

### Depression

The proportion who reported depression as one of the three most important symptoms was less than 40 percent for all disease groups (Figure 3-5, panel C). The share is highest among people with mental disorders, where the symptom is also perceived as

most burdensome. For four out of five defined mental disorders, the level of distress associated with depression is rated at over 4, with the exception of Tourette's syndrome, where the average distress was slightly lower.

For some somatic diseases, such as brain damage and dizziness, low mood is reported as very troublesome (average discomfort of 5). This may indicate that when depressive symptoms first occur in these groups, they can have a major impact on quality of life, even if the share of respondents reporting the symptom is low.

### Brain fog

There is some variation between disease groups in the proportion who reported experiencing brain fog, but for most disease groups, between 10 and 20 percent reported being bothered by brain fog (Figure 3-5, panel D).

The proportion who reported brain fog as one of the three most bothersome symptoms was highest among respondents with MS and migraine. 33 and 31 percent, respectively, reported that brain fog is one of the three symptoms they are most bothered by. The average score among respondents with migraine was 3,8, while respondents with MS reported a perceived severity of 3,3.

To an even greater extent than for the symptom of tiredness or fatigue, there was considerable variation in how troublesome brain fog was perceived to be for those who reported it as one of the three most troublesome symptoms. The average score among respondents with brain damage was 4,8, while respondents with MS had a lower average score despite a significantly higher share.

### Attention difficulties

Between 13 and 36 percent of respondents within various disease groups reported that attention difficulties are one of the symptoms that bother them most (Figure 3-5, panel E). There is relatively large variation in how much the different groups are bothered, but none of the groups had an average score of more than 4,5.

The average perceived severity is highest for respondents with anxiety and depression disorders, but relatively few of these reported this as one of the three symptoms that bother them most (12 and 13 percent of respondents with these diagnoses, respectively).

Among respondents with ADHD, 31 percent reported attention difficulties as one of the three symptoms that bother them the most. This reflects

the core problem of the disorder. One possible reason why the share of respondents is not higher in this group may be that respondents do not experience this as something that bothers them in everyday life. This may be because they do not experience attention difficulties, because they have received help to cope with this, or because they do not find it troublesome.

Furthermore, people who suffered a stroke (36 percent) and concussion (33 percent) reported a high share, which emphasizes that attention difficulties are also common in cases of acquired brain injury.

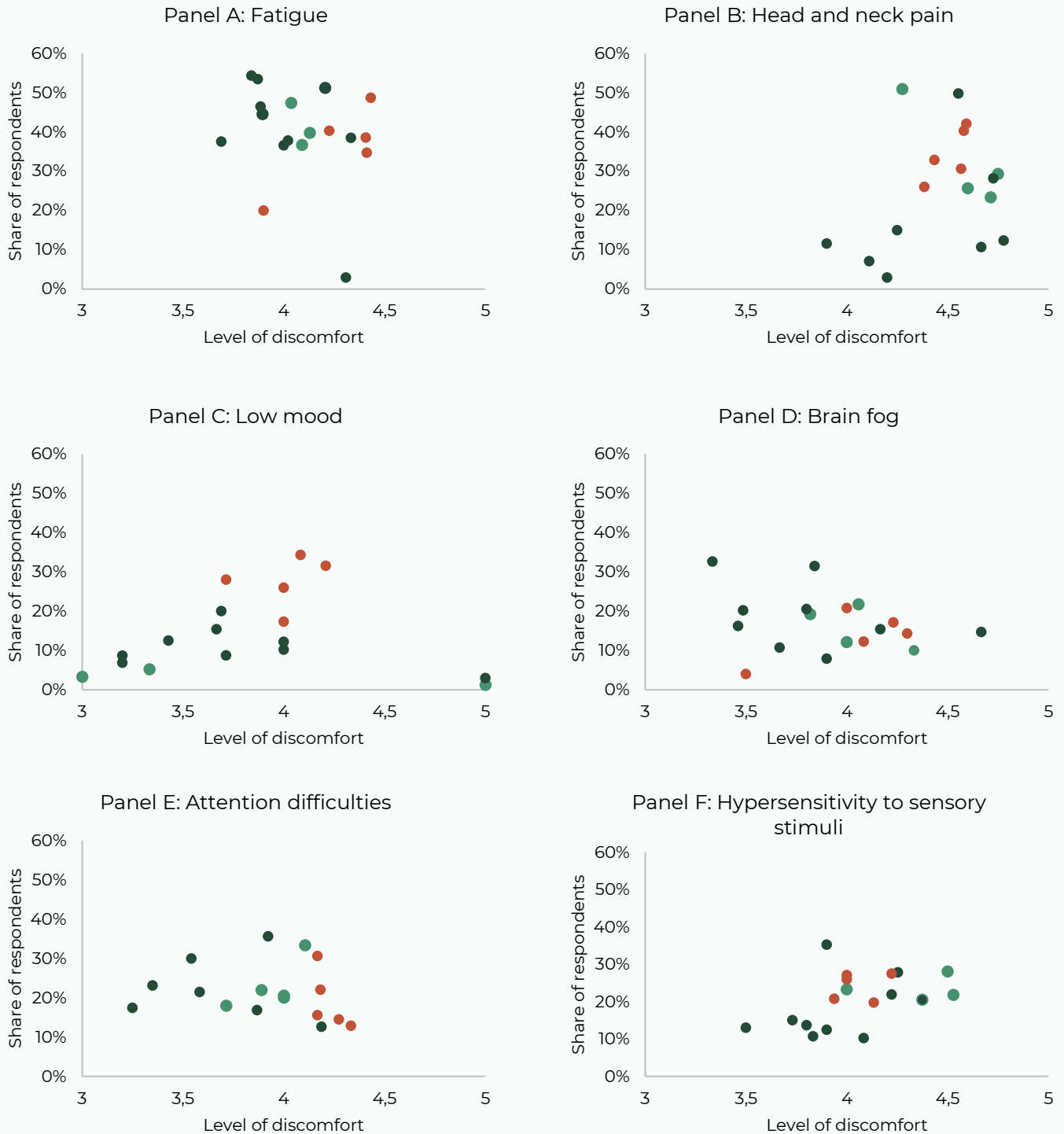
### Hypersensitivity to sensory stimuli

Compared with some other health challenges, hypersensitivity to sensory stimuli was highlighted to a lesser extent as one of the symptoms that respondents experience most (Figure 3-5, panel F).

Respondents with brain damage were the group that reported the highest incidence of hypersensitivity to sensory stimuli (35 percent). The symptom was reported by approximately 30 percent of respondents with concussion, migraine, and ADHD. For these three disease groups, those who reported the symptom are also more severely affected, with average scores of 4,5, 4,3 and 4,2, respectively.

Figure 3-5: Share reporting health challenge as one of the three most bothersome and average level of discomfort, per brain condition

- Neurological conditions
- Mental disorders
- Other brain conditions



**Source:** Survey conducted by Oslo Economics autumn 2025. The survey was sent to patient and member organizations in The Norwegian Brain Council (Hjernerådet), who were asked to distribute the survey to its members.  
**Note:** Level of discomfort calculated from question: "To what extent are you troubled by [the specified symptom]?" Scale from 1 to 5, where 1 is not troublesome and 5 is very troublesome. Share of respondents based on question: "Which three symptoms, among those you mentioned in the previous questions, do you experience the most in your daily life?"

### 3.3.3 Selected disease groups and health challenges

Although many health challenges are common to several brain diseases, there is also considerable variation between diseases in terms of the health challenges reported by patients. There is also variation in the extent to which the symptoms were reported to be a burden for the individual. To illustrate how different health challenges contribute to the burden of disease, we have taken a closer look at the three main disease categories: neurological conditions, mental disorders, and other brain diseases.

We base our findings on information from the survey of patients diagnosed with brain conditions. The categorization of disease groups from the survey into disease categories is described in Appendix C. In addition, we draw on information from interviews with employees of patient organizations.

Overall, a large proportion of respondents, both within the category of neurological conditions, mental disorders, and other brain diseases, reported suffering from fatigue and pain in the head and neck. Both of these symptoms are also perceived as very troublesome by the respondents who experience them, and thus probably contribute to a large proportion of the disease burden (Figure 3-6).

#### Neurological diseases

Neurological diseases include conditions that affect the functioning of the brain and nervous system and can cause a wide range of health challenges. Figure 3-6, panel A shows the proportion of respondents with neurological conditions who experience the various health challenges and the degree of discomfort they experience.

In our survey, people with neurological diseases reported that they most frequently experience tiredness or fatigue (48 percent), pain in the head and neck (32 percent), and brain fog (25 percent). Although fatigue is the most common symptom, pain in the head and neck is perceived as the most debilitating, with an average severity of 4.5 on a scale of 1–5. This means that for those who experience pain, the symptoms are very severe and have a significant impact on their daily lives. Fatigue has a level of discomfort of 4.1, which is also high, and because it affects a larger proportion of patients, represents a significant overall disease burden.

The survey does not cover all neurological diseases, but interviews with representatives of patient organizations have given us some insight into the health challenges that affect this patient group.

Dementia affects quality of life on many levels. In the early stages, loss of overview, difficulties with everyday tasks, and changes in social functioning can lead to uncertainty and frustration. Gradually, many people experience problems with basic functions such as personal hygiene, nutrition, and mobility. Anxiety, depression, restlessness, and sleep difficulties further exacerbate the burden of the disease. Many experience a loss of identity and social role, and the disease often involves shame, grief, and fear of the future.

#### Mental disorders

Mental disorders encompass conditions that affect thoughts, emotions, and behavior, and can cause both cognitive and somatic symptoms. In our survey, many people with mental disorders reported experiencing tiredness or fatigue (40 percent), head and neck pain (35 percent), and low mood (24 percent), see Figure 3-6, panel B. Fatigue is the symptom most commonly reported, and it is experienced as a significant burden with an average discomfort of 4,3 on a scale of 1–5. Head and neck pain was reported by a slightly smaller proportion but is the symptom that is perceived as most troublesome, with an average severity of 4,5.

Other recurring health challenges are hypersensitivity to sensory stimuli (24 percent) and attention and concentration difficulties (21 percent). These are also perceived as very distressing, with a discomfort level of 4,07 and 4,14, respectively. Depression occurs in almost a quarter of respondents and has a discomfort level of 3.9. This indicates that although it is less physically demanding than pain, it has a major impact on quality of life.

It is not surprising that fatigue and pain are perceived as most troublesome by a large proportion of respondents with mental disorders. Mental disorders is often associated with prolonged stress, sleep disturbances, and changes in the body's stress response, which can cause both physical pain and fatigue (Helsenorge, 2024).

Furthermore, hypersensitivity to sensory stimuli and concentration difficulties are typical health challenges associated with a number of mental disorders, including ADHD and autism. This can contribute to everyday situations being perceived as demanding. Depression is also a core symptom of many mental disorders.

In the survey, we did not receive responses from respondents with substance use disorders. From interviews, we have gained a general insight into the health challenges faced by people with substance use disorders. Substance use disorders

come in a wide range of severity, with the symptoms of the disorder depending on the form of substance use. In terms of health challenges, it is pointed out that a typical health challenge associated with long-term substance use is cognitive impairment. Furthermore, people with substance use disorders can develop several physical health problems, often as a result of their substance use. These can include wounds that do not heal, psychosis problems, and generally poorer overall health. Furthermore, it can be challenging to get help from the healthcare system due to the substance use, and it can be difficult to distinguish between problems arising from substance use and separate health problems. This can delay people with substance use disorders from receiving adequate treatment for other health problems.

### Other brain conditions

Other brain conditions identified in the survey include concussion, dizziness, balance and gait disorders, as well as certain other diagnosed conditions that do not naturally fall into the categories of neurological or mental disorders. This group is therefore complex and broad, and the disorders can cause both visible and invisible health challenges.

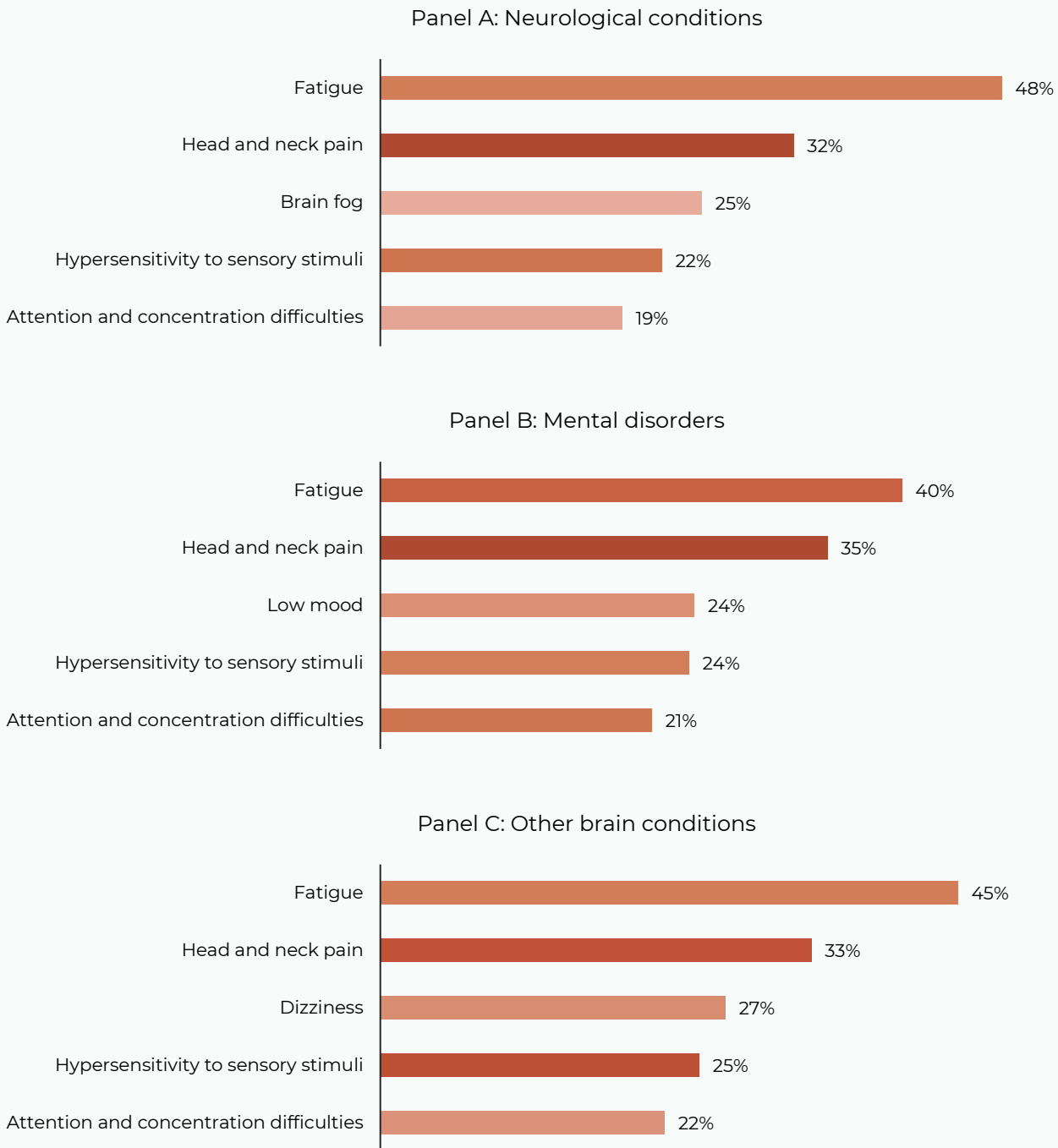
Fatigue is the symptom that most respondents in this group reported being bothered by. 45 percent

also reported fatigue as one of the three most burdensome symptoms, and the average discomfort is 4.1 on a scale of 1–5. This is at the same level as for respondents with neurological diseases. This indicates that tiredness or fatigue is a significant burden for those who experience it, even though the proportion affected is somewhat lower compared to respondents with neurological diseases.

Head and neck pain is the second most commonly reported symptom in this group and is perceived as the most troublesome, with an average discomfort of 4.4. Although fewer people experience this symptom compared to tiredness or fatigue, it is therefore more burdensome for those who experience it.

In addition, 27 percent reported dizziness, 25 percent hypersensitivity to sensory stimuli, and 22 percent attention and concentration difficulties. Dizziness and concentration difficulties are experienced as less troublesome than the other symptoms, while hypersensitivity to sensory stimuli has a level of discomfort of 4.4, similar to that for head and neck pain. This makes hypersensitivity one of the most burdensome symptoms in this group, despite the fact that it affects fewer people.

Figure 3-6: Share reporting health challenge as one of the three most bothersome and average level of discomfort, per group of brain condition



Gradient over average level of discomfort, on a scale from 1-5. Gradient from 3,5 to 5.



**Source:** Survey conducted by Oslo Economics autumn 2025. The survey was sent to patient and member organizations in The Norwegian Brain Council (Hjernerådet), who were asked to distribute the survey to its members.

**Note:** Level of discomfort calculated from question: "To what extent are you troubled by [the specified symptom]?" Scale from 1 to 5, where 1 is not troublesome and 5 is very troublesome. Share of respondents based on question: "Which three symptoms, among those you mentioned in the previous questions, do you experience the most in your daily life?" Neurological conditions N= 1070, Mental disorders N= 243, Other brain conditions N = 150.

### 3.4 Which health challenges account for the greatest health loss (YLD)?

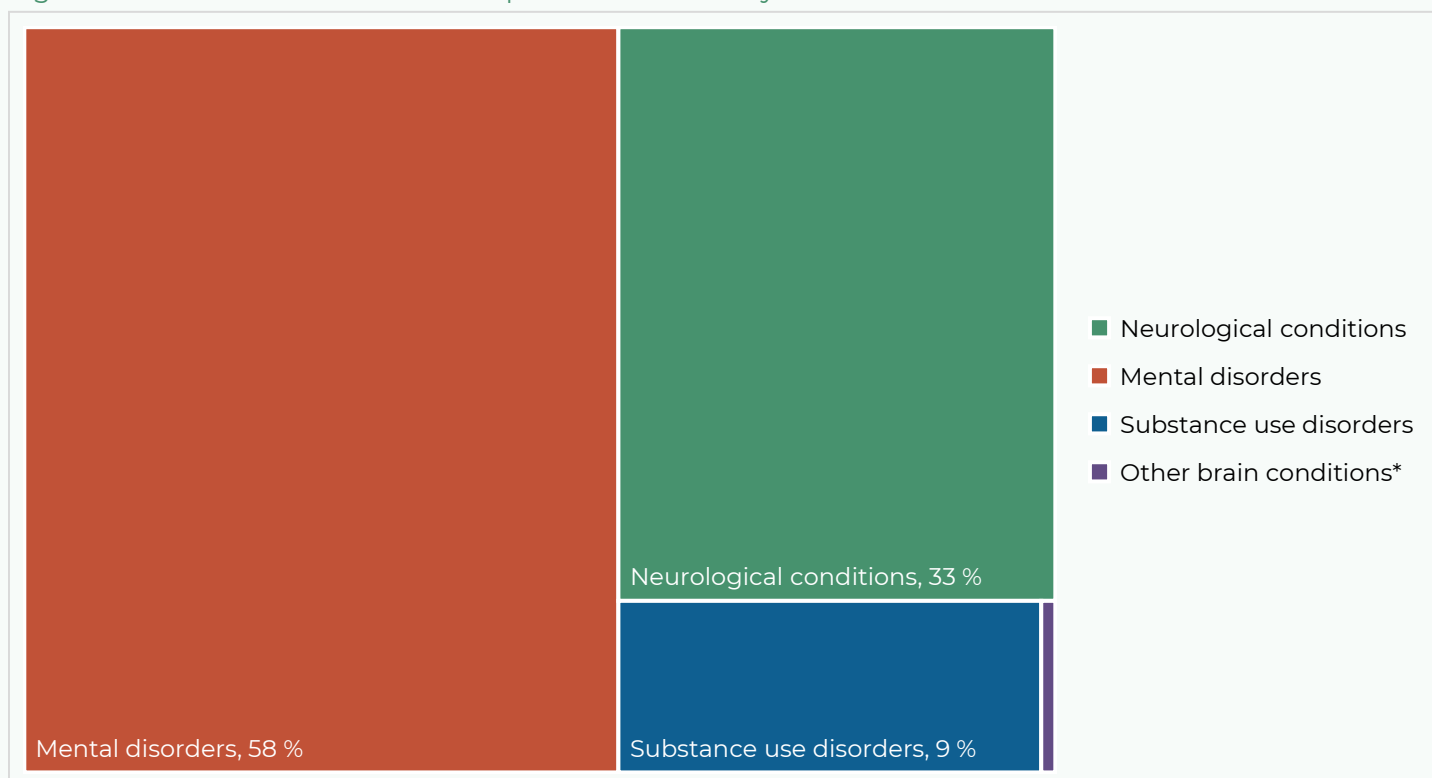
The various symptoms of brain disease contribute differently to the overall health loss in the population. The extent of this contribution depends on how widespread the symptom is among people with brain disease and the degree to which it affects functional ability and quality of life. A symptom that occurs frequently but with moderate severity can result in a large overall health loss, while less frequent health challenges with greater health loss can have a major impact on the individual.

Estimates from the global burden of disease study estimate that the health loss (YLD) from brain diseases totaled 245,660 health-adjusted life years in 2021 (Institute for Health Metrics and Evaluation (IHME), 2022). Health-adjusted life years are the number of years people live with disease or disability, adjusted for the severity of the health loss, to provide a measure of the total loss of good health

in the population. This means that people with brain diseases collectively experienced a health loss equivalent to 245,660 years of perfect health because they lived with brain disease in 2021. The global burden of disease study shows the health loss for both individual disease groups and overall disease categories, as illustrated in Figure 3-7. Mental disorders account for 58 percent of the total health loss, neurological diseases and disorders account for 33 percent, and substance use disorders account for 9 percent.

To estimate how health loss is distributed across different health challenges, we use data on the frequency and severity of health challenges from our survey, combined with established knowledge from the global disease study on health loss from various brain diseases. Since the frequency and severity of a symptom will depend on which brain disease a respondent has, we are only able to distribute the disease burden for brain diseases where there are sufficient respondents in the survey. We have set a minimum limit of 30 respondents who have reported a given brain disease in the survey. This means that we can

Figure 3-7: Which brain conditions explain YLD in Norway in 2021?



**Note:** Mental disorders include both mental disorders and self-harm. Neurological conditions include both neurological disorders and stroke. Other brain conditions include brain and nervous system cancer, encephalitis, and meningitis.  
**Source:** Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2021. Seattle, WA: IHME, 2022.

distribute health loss for the following eight brain diseases:

- Anxiety disorders
- Depression
- Migraine and other forms of headache disorders
- Stroke
- MS
- Brain tumor
- Epilepsy

Data from the global burden of disease study show that these brain diseases collectively account for approximately 70 percent of the total health loss due to brain diseases (Institute for Health Metrics and Evaluation (IHME), 2022). The remaining health loss comes from brain diseases for which we do not have sufficient data to distribute the health loss across different health challenges. For example, we do not have data to distribute the health loss from substance use disorders (9 percent of the total health loss from brain diseases) or Alzheimer's and other dementia diseases (6 percent of the total health loss from brain diseases) across different health challenges.

In the following, we link our findings on the share of respondents report a health challenge and the discomfort of various health challenges within different disease groups to estimate their impact on health loss (YLD). The procedure for the estimate is described in more detail in Box 3-2.

### 3.4.1 Which health challenges explain the health loss

Figure 3-8 shows estimates of how health loss (measured in YLD) is distributed among different health challenges across the identified brain diseases. The estimate of the distribution of health loss across health challenges does not apply to all brain diseases, but only to the eight diseases for which there has been sufficient data to distribute the disease burden across health challenges. As mentioned earlier, this means that 70 percent of the disease burden of brain diseases can be distributed among symptom groups, as the identified brain conditions in the study collectively account for 70 percent of the total disease burden.

Each symptom represents a total YLD burden in the population, while the colors in the bars show how much of this burden is assumed to come from the various brain conditions. The figure thus highlights the health challenges that are estimated to drive health loss to the greatest extent, and the diseases that contribute most to this.

### Box 3-1: Estimate of YLD-loss from different health challenges

To estimate what proportion of YLD loss can be attributed to different symptoms, a weighting has been made for each brain disease between how troublesome the symptom is perceived and the proportion who report having the symptom. The perceived severity of the symptom and the proportion reporting it are estimated based on Oslo Economics' survey of patients diagnosed with brain disease. Based on the weighted total burden, we have estimated the distribution of health loss between symptoms for each of the identified brain diseases.

YLD figures from the Global Burden of Disease (GBD) study are then used for each disease to calculate the number of health-adjusted life years (YLD) for each symptom. The health loss from symptoms for each disease is then aggregated across diseases, which provides an overall estimate of the health loss associated with each symptom for the identified brain diseases.

It should be noted that our estimate of YLD loss associated with various symptoms is based on patient-reported complaints. This is a different methodology than that used to calculate disability weights within the global burden of disease study. The results should therefore be understood as an illustrative distribution of patient-experienced symptom burden within the established YLD framework, and not as an alternative calculation of disability weights.

Overall, the brain conditions anxiety disorders, depression, and migraine contribute most to YLD loss within all symptom categories. This is because these are the disease groups that have the greatest total health loss.

Tiredness and fatigue are the symptoms that our estimates indicate contribute most to total health loss. The health loss due to tiredness or fatigue is estimated to amount to approximately 25,000 health loss-adjusted life years, which represents 17 percent of the total health loss that can be explained by these eight diseases. Tiredness or fatigue can thus explain 17 percent of 70 percent of the total health loss due to brain diseases. As discussed earlier in the report (see, for example, Figure 3-5), there is both a high incidence and a high level of discomfort associated with tiredness and fatigue in most disease groups. Tiredness and fatigue appear to account for a large proportion of the disease loss for all disease groups, and especially for stroke and MS.

Head and neck pain is the symptom that contributes second most to the total health loss from these eight brain diseases. Unlike tiredness or fatigue, the health loss from head and neck pain

comes almost exclusively from anxiety disorders, depression and other depressive disorders, and migraine, and to a certain extent from stroke. The total health loss from head and neck pain is 23,000 health-adjusted life years, which accounts for 15 percent of the health loss that can be explained by these eight diseases.

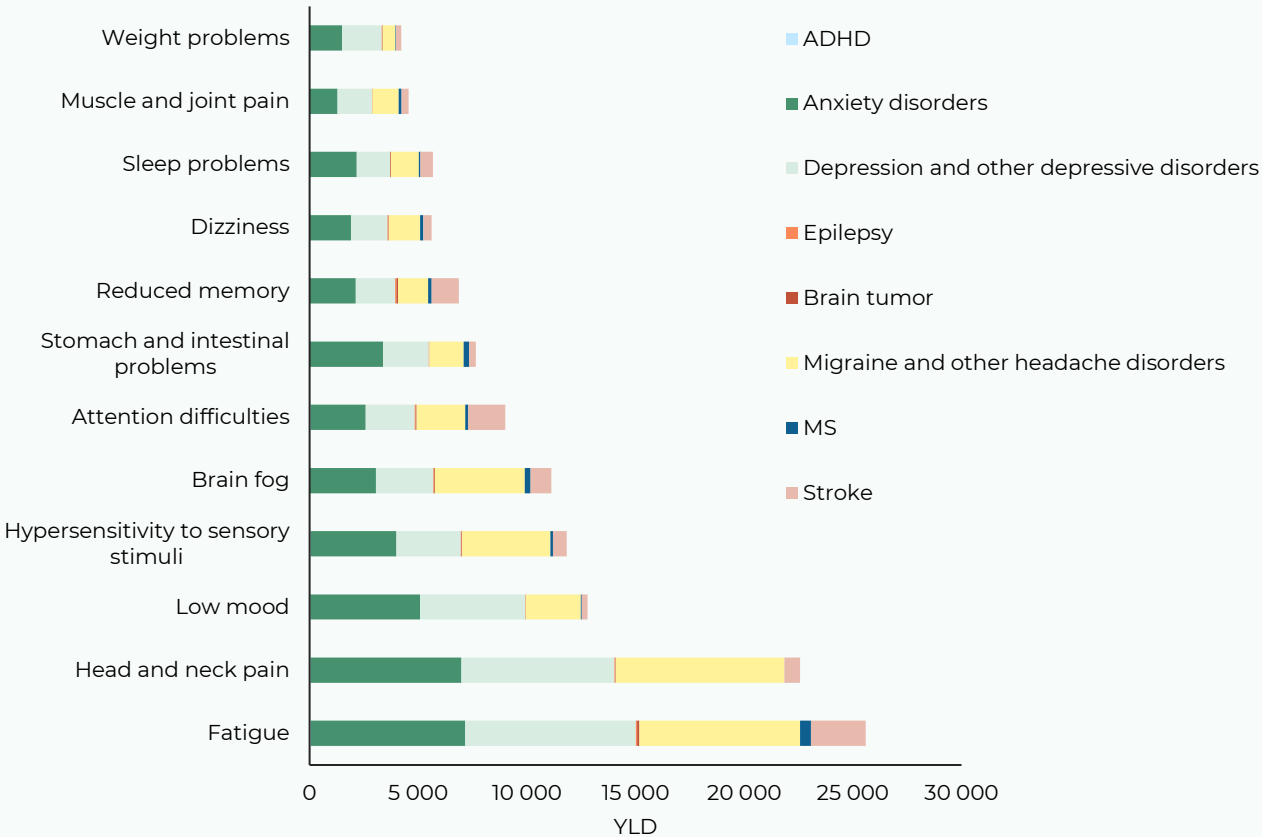
The symptom that contributes the third most to health loss is low mood. Low mood contributes less to health loss than head and neck pain and fatigue. This is somewhat surprising, as two of the diseases that contribute most to health loss, anxiety disorders and depression and other depressive disorders, have low mood as one of their core symptoms. For both of these disorders, low mood causes less health loss than both head and neck pain and fatigue. Overall, the health loss from low mood amounts to a total of 13,000 health loss-adjusted years of life, or 8 percent of the total health loss.

Hypersensitivity to sensory stimuli and brain fog are the symptoms that contribute to the fourth and fifth largest degree of health loss, respectively. Brain fog contributes to a slightly lesser extent than hypersensitivity to sensory stimuli to the health loss of those with anxiety disorders. Brain fog also accounts for a relatively large proportion of health loss for people who have had a stroke, compared to hypersensitivity to sensory stimuli and low mood.

Both brain fog and hypersensitivity to sensory stimuli account for a larger proportion of health loss for those with migraine and other headache disorders than low mood.

Overall, we estimate that the health loss from the five most common symptoms accounts for just over 55 percent of the total health loss that can be explained by the eight disease groups. The remaining health loss from these eight diseases is distributed across 26 minor health challenges, which contribute to health loss to a lesser extent.

Figure 3-8: Which symptoms explain YLD?



Source: Estimates calculated by Oslo Economics based on results from survey to patients with diagnosed brain conditions and estimated of total YLD-loss from Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2021. Seattle, WA: IHME, 2022. Note: See Box 3-2 for further details about calculations.

This indicates that health challenges affecting physical function, cognitive capacity, and mental health are the biggest drivers of the disease burden. Fatigue and pain in the head and neck limit the ability to perform daily activities and participate in working life, while brain fog and hypersensitivity to sensory stimuli can reduce concentration, attention, and social functioning. Low mood represents the psychological aspect of the burden of disease and exacerbates the other symptoms by affecting motivation, energy, and quality of life. Overall, this suggests that health loss is not only due to physical pain, but also to cognitive and emotional challenges that limit functional ability and participation in everyday life.

### 3.4.2 Health challenges and health loss for different diseases

The health challenges that contribute most to YLD loss are not identical across the disease groups for which we have data in the survey, reflecting both differences in symptom prevalence and symptom severity within each diagnosis.

For anxiety disorders, the total health loss is 50,000 health loss-adjusted life years, and of the eight disease groups we are able to distinguish, anxiety disorders are the disease that accounts for the largest share of health loss. Figure 3-9, Panel A shows our estimates for the distribution of health loss to different health challenges. Our calculations indicate that fatigue, head and neck pain, and low mood account for a large proportion of the health loss associated with anxiety disorders. Together, these symptoms account for approximately 38 percent of the estimated health loss. Overall, our estimates show that the six most common symptoms can explain approximately 59 percent of the total health loss associated with anxiety disorders.

Estimates for depression and other depressive disorders show roughly similar results to those for anxiety disorders (Figure 3-9 Panel B). Fatigue, head and neck pain, and low mood are the three symptoms that cause the greatest health loss in this group. For depression, we estimate that the health loss resulting from these symptoms is 17, 15, and 11 percent, respectively. Based on our estimates and assumptions, the six symptoms that we estimate account for the greatest degree of health loss can explain a total of 60 percent of the health loss associated with depression.

For migraine and other headache disorders, health loss appears to be particularly associated with head and neck pain and fatigue (Figure 3-9 Panel C). Our estimates indicate that 19 percent and 18 percent of the total health loss for migraine can be attributed

to these symptoms, respectively. This is consistent with established knowledge about migraine and headache disorders, where pain in the head and neck is one of the defining symptoms of the disease. It is therefore natural that this should account for a relatively large part of the disease burden. Furthermore, tiredness and fatigue are recognized symptoms of migraine.

Estimates of the distribution of health loss between health challenges for stroke indicate that fatigue accounts for a large proportion of the health loss for this group. In addition to fatigue, attention difficulties and reduced memory, we also find that the physical symptom of motor and muscular difficulties accounts for approximately 8 percent of the health loss due to stroke. A very common after-effect of stroke is motor and muscular difficulties, paralysis or similar, and it is natural that this should account for a proportion of the health loss. From interviews with patient organizations for stroke survivors, fatigue is also highlighted as one of the symptoms that most affects stroke survivors, and as a symptom that can be very debilitating in everyday life. Based on our estimates, the six most significant symptoms can explain 61 percent of the total health loss due to stroke.

The symptoms we estimate to contribute most to health loss for patients with MS are fatigue, brain fog, and stomach and intestinal problems. Fatigue stands out, accounting for one-fifth of health loss in MS based on our estimates. The proportion of health loss estimated to come from brain fog and gastrointestinal problems is 11 percent. Our estimates find that only 9 percent of health loss in MS comes from motor and muscular difficulties, which are common symptoms of MS.

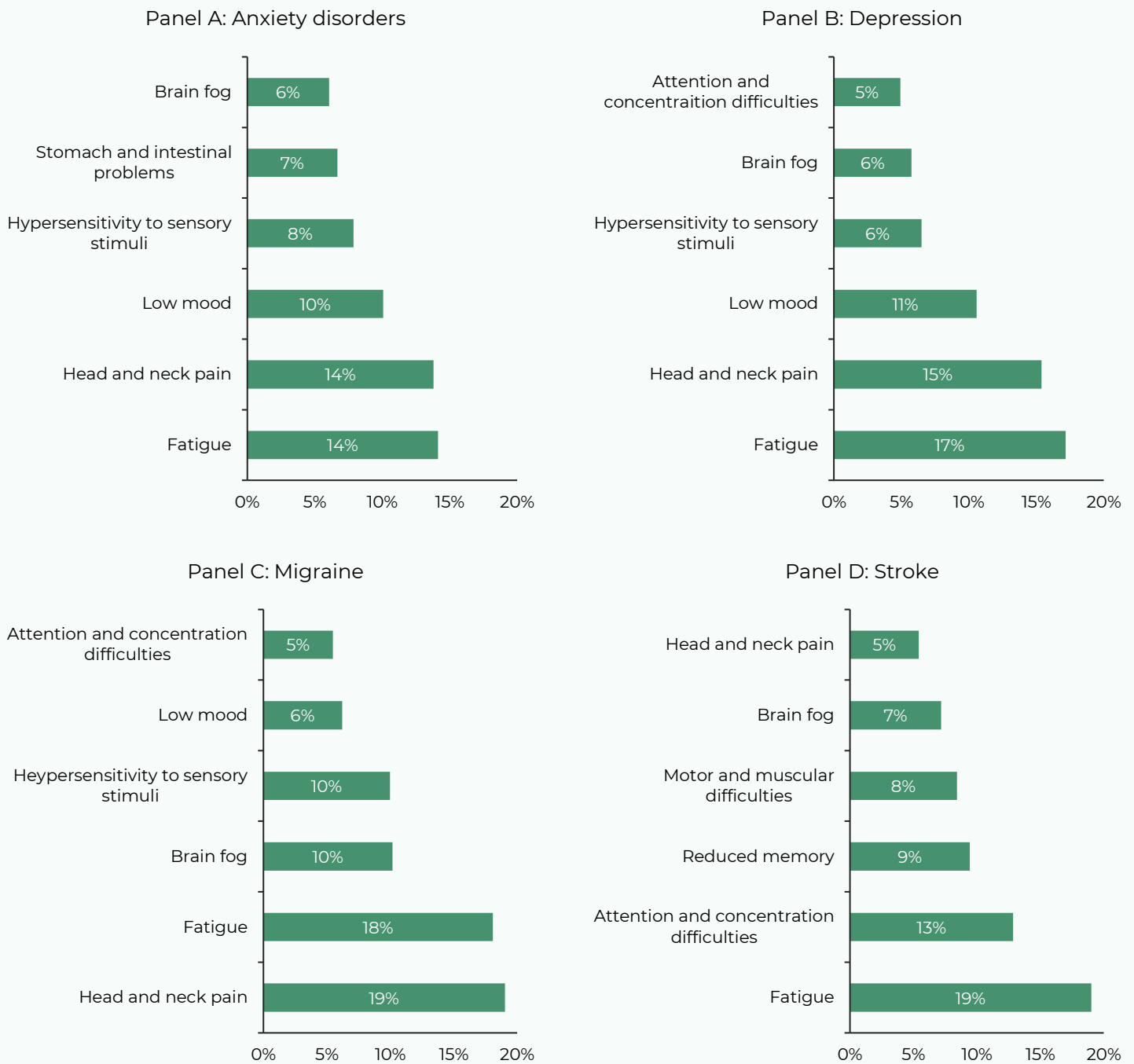
In the case of brain tumors, health loss appears to be mainly related to health challenges such as tiredness or fatigue (18 percent), reduced memory (15 percent), and attention difficulties (8 percent). These problems affect key cognitive functions and make it difficult to maintain awareness, concentration, and stamina in everyday life. Furthermore, we find that brain fog, hypersensitivity to sensory stimuli, and dizziness also contribute to health loss, but to a lesser extent. Overall, this may indicate that health loss in brain tumors is related to both cognitive and sensory challenges, which can limit independence, social participation, and work ability.

For people with epilepsy, the analyses suggest that the burden of disease is significantly related to fatigue (13 percent), motor and muscular difficulties (11 percent), as well as attention difficulties and reduced memory (both 10 percent). This

combination of physical and cognitive health challenges reflects how epilepsy affects several functional areas simultaneously. The health loss associated with epilepsy can to a lesser extent than for the other brain conditions be explained by the two or three most significant symptoms. Our results may therefore indicate that the health loss associated with epilepsy is more widespread, and that there is a greater diversity in the occurrence of health challenges and how burdensome they are perceived to be.

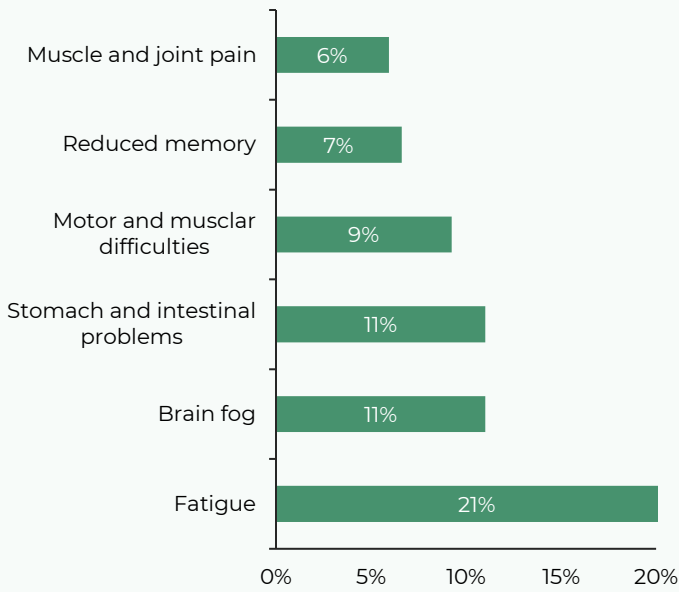
For ADHD, the calculations indicate that the health loss can mainly be linked to tiredness or fatigue (12 percent), head and neck pain (11 percent), and attention difficulties (10 percent). The symptom profile shows that health loss associated with ADHD is not only due to core challenges with attention and impulse control, but also secondary burdens such as exhaustion, emotional vulnerability, and physical discomfort. This underscores the complexity of the disease, in which multiple interacting health challenges reduce quality of life and functioning in school, work, and social life.

Figure 3-9: Estimates of distribution of YLD-loss on symptoms, by brain condition

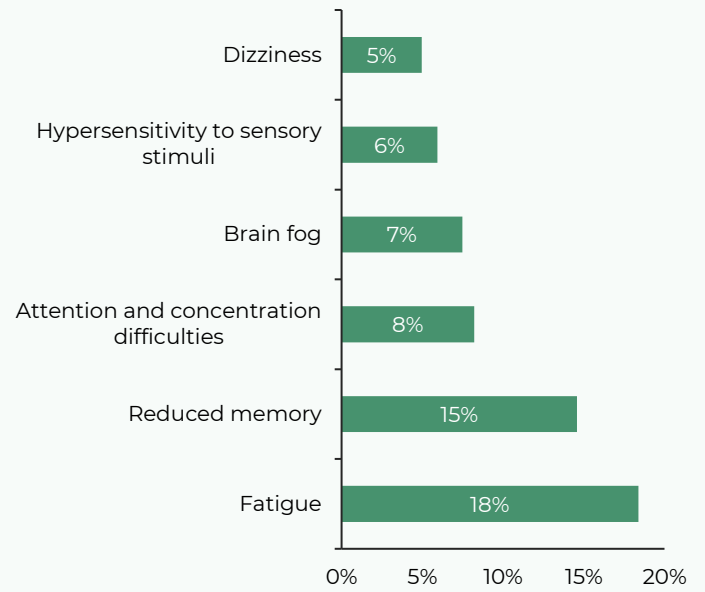


**Source:** Estimates calculated by Oslo Economics based on results from survey to patients with diagnosed brain conditions and estimated of total YLD-loss from Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2021. Seattle, WA: IHME, 2022. **Note:** See Box 3.3 for further details about calculations. Anxiety N= 153, Depression N = 76, Migraine N= 635, Stroke N= 73, MS N = 46, Brain tumor N= 127, Epilepsy N= 80, ADHD N= 98.

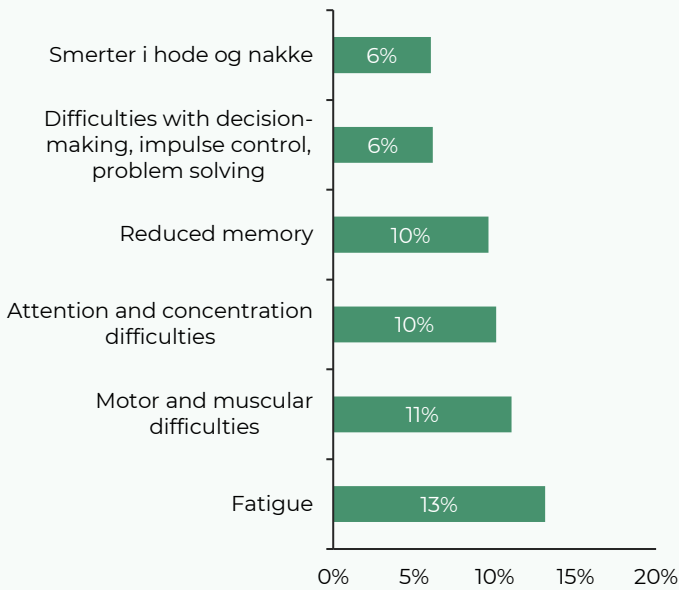
Panel E: MS



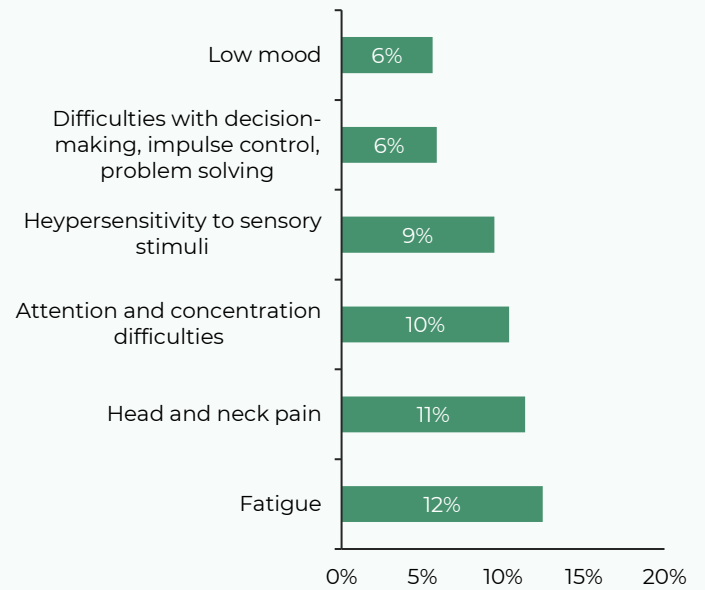
Panel F: Brain tumor



Panel G: Epilepsy



Panel H: ADHD



**Source:** Estimates calculated by Oslo Economics based on results from survey to patients with diagnosed brain conditions and estimated of total YLD-loss from Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Study 2021. Seattle, WA: IHME, 2022. **Note:** See Box 3.3 for further details about calculations. Anxiety N= 153, Depression N = 76, Migraine N= 635, Stroke N= 73, MS N = 46, Brain tumor N= 127, Epilepsy N= 80, ADHD N= 98.

## 4. Challenges associated with living with brain disease

*A large share of those living with brain conditions experience significant challenges related to both personal and social aspects of life, as well as issues related to work, education, and finances. Over 90 percent stated that they have some or significant challenges participating in social contexts, and nearly 85 percent reported that they feel they are a burden to those around them.*

### 4.1 What challenges do people with brain conditions face?

To gain a broad picture of what it is like to live with a brain condition, respondents in the survey were asked to respond to a number of statements relating to various aspects of everyday life. The statements cover both personal and social experiences, as well as issues related to work, education, and finances. Together, they provide insight into how brain conditions can affect self-esteem, relationships, the perception of understanding from others, and the ability to participate actively in society.

The results of the survey are shown in Figure 4-1. In summary, we find that people with brain conditions experience significant challenges in their everyday lives. It is difficult to determine which challenges contribute most to the loss of health, but certain areas stand out. The five most stressful challenges that respondents most often reported experiencing to a large extent are:

- Challenges participating in working life
- Challenges participating in social contexts
- Challenges with long-term planning
- Grief and frustration related to the situation
- Feeling less like oneself

The five challenges that were most frequently reported to a large or some extent largely correspond to the most stressful challenges and are as follows:

- Challenges with participating in social contexts
- Sadness and frustration related to the situation
- Feeling like a burden to the people around me

- Uncertainty and fear related to the course of my disease
- Challenges with long-term planning

The challenges affect a wide range of areas of life, from experiences related to self-esteem and identity to practical limitations and loss of coping skills, independence, and the ability to participate actively in society. Overall, they point to how brain diseases can have far-reaching consequences for both the individual's quality of life and the overall health loss in the population. These challenges are common across different disease groups, although the degree of burden varies.

#### Summary of Challenges

**91 percent** stated that they have difficulty participating in social situations.

**89 percent** stated that they experience frustration and sadness related to their situation

**85 percent** stated that they feel they are a burden to those around them.

**85 percent** stated that they experience uncertainty and fear related to the course of their illness

**84 percent** stated that they experience challenges with long-term planning

#### 4.1.1 Personal identity and sense of self

A large majority of respondents stated that their brain disease had affected their self-esteem. 83 percent of respondents stated that they felt less like themselves to a large or some extent, while 87 percent stated that they felt like a burden to those around them to a large or some extent.

It is noteworthy that a larger proportion stated that they feel less like themselves to a large extent (48 percent) than those who stated that they feel like a burden to the people around them to a large extent (28 percent). One possible reason for this is that the experience of being a burden can be perceived as more situational and temporary, while the feeling of feeling less like oneself is more fundamental and linked to one's identity. It can therefore be more difficult to grade the extent to which one feels less like oneself.

The experience of shame also occurs among respondents, with 70 percent of respondents stating that they experience a feeling of shame to a large or some extent. This suggests that the disease not only affects physical and cognitive functions, but also personal identity.

#### 4.1.2 Emotional strain

Frustration and sadness are among the most common emotional reactions. 88 percent of respondents reported experiencing these feelings to a large or some extent, and almost half experience them to a large extent. In addition, 84 percent reported uncertainty and fear related to the course of the disease.

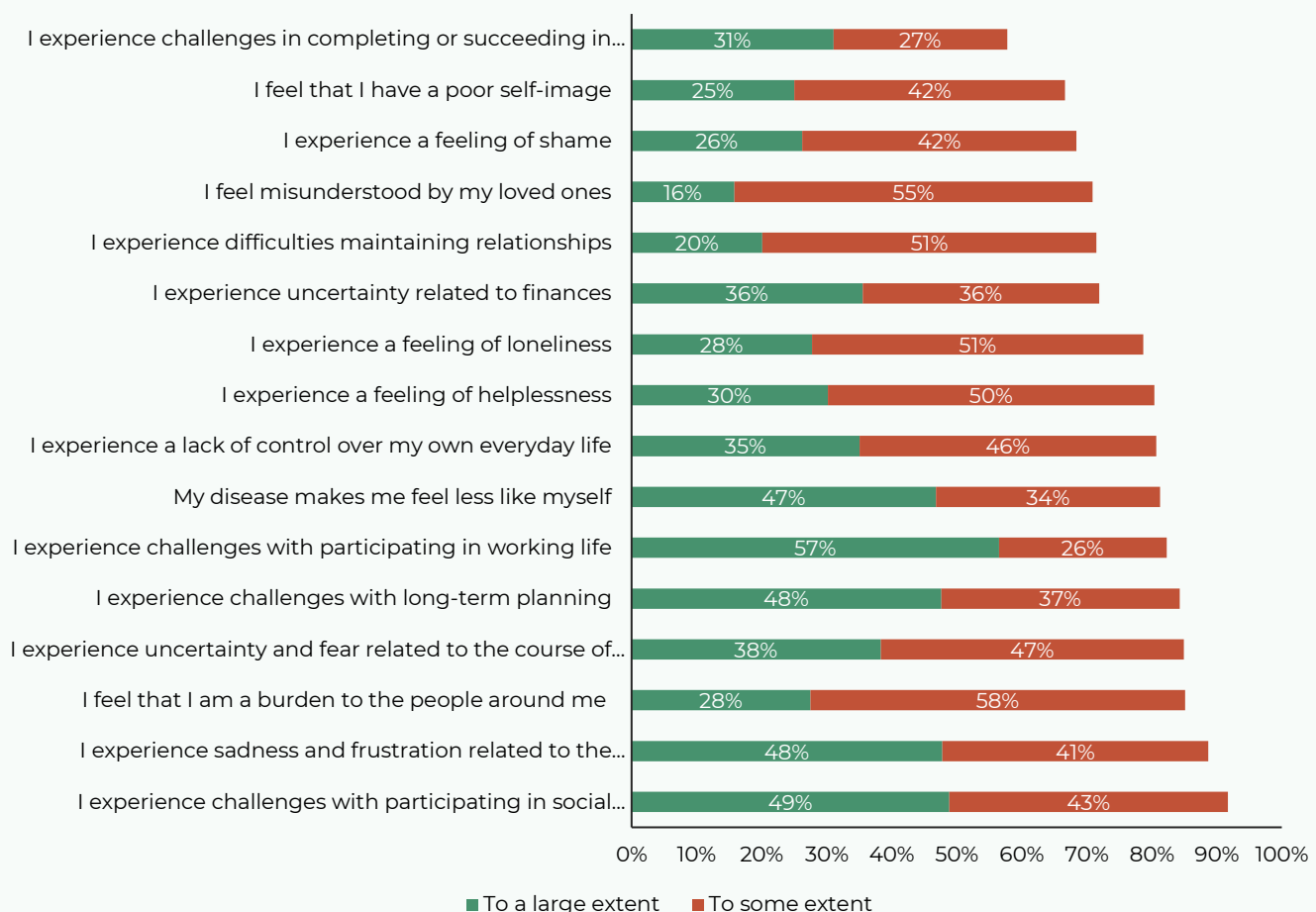
Feelings of frustration, sadness, uncertainty, and fear as a result of the course of the disease are to be expected. These feelings may be related to a loss of

quality of life, limited participation in activities, and a feeling that life has not turned out as one had imagined. Although such reactions are to be expected, it is important to recognize how widespread and stressful they are.

#### 4.1.3 Work, education, and finances

Challenges related to work and finances are very common. As many as 91 percent reported difficulties participating in working life, and 72 percent reported uncertainty related to finances. These findings must be viewed in context, where difficulties participating in working life will largely be linked to a perception of financial insecurity. In addition, 86 percent reported that they experience a lack of control over their own daily lives to a large or some extent, which can lead to a loss of independence and mastery. This shows that many

Figure 4-1: Share of respondents who to some or a large extent state that they experience the following challenges



Source: Survey conducted by Oslo Economics autumn 2025. The survey was sent to patient and member organizations in The Norwegian Brain Council (Hjernerådet), who were asked to distribute the survey to its members.  
 Note: Question «Which challenges do you experience related to your brain condition?». Share of respondents having answered to a large extent or to some extent.

feel that their illness limits their ability to manage and plan their own daily lives.

58 percent of respondents reported that they experience significant or some degree of difficulty in completing or mastering their education. This is the challenge that fewest respondents identify with<sup>5</sup>. Nevertheless, over 31 percent reported that they experience significant difficulties in completing or mastering education, which indicates that this challenge is significant for more than half of those who experience it.

#### 4.1.4 Challenges related to relationships and social life

Social isolation and loss of belonging are among the most common consequences of brain disease. Challenges with participating in social contexts is the challenge the most respondents reported having, and over 91 percent reported that they experience challenges with this to a large or some extent. In addition, 80 percent reported feeling lonely.

Furthermore, 70 percent reported difficulties maintaining relationships with family and friends. Although this is a high percentage, it is one of the challenges that respondents report the least. Only 16 percent reported that they to a large extent feel misunderstood by their loved ones, but over half reported experiencing this to some extent. This indicates that although few experience this as a major challenge, the majority still experience a

certain degree of lack of understanding from their loved ones. This suggests that the experience of misunderstanding and uncertainty may be widespread, but often not as stressful as the other challenges associated with living with brain disease.

In summary, the findings show that social isolation and loss of belonging are significant consequences of living with brain disease. Although the proportion reporting difficulties in maintaining relationships with friends and family is lower than for many other challenges, this should not be underestimated. The fact that a large majority of respondents experience this challenge emphasizes that this is a widespread and serious problem.

#### 4.1.5 Variation between disease groups

There is relatively little variation between disease groups in terms of the types of challenges that are perceived as most demanding. However, there is some variation between the burden of the various challenges, i.e., the proportion who report experiencing the challenge to a large extent and to some extent.

Across diagnoses, challenges related to participating in working life, participating in social contexts, and feeling inferior to oneself are recurring themes. This suggests that, to a large extent, the same issues are perceived as most burdensome regardless of illness, but that the proportion who experience them varies between disease groups.

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<sup>5</sup> It is conceivable that the percentage reflects the age composition of the sample to some extent, but we do not have the opportunity to map this with the available data.

## 5. Discussion of results

*This survey provides new insights into the health challenges experienced by people with brain conditions and how these challenges affect their everyday lives. Greater insight into the factors that contribute to health loss facilitates targeted measures and improved follow-up of care for people with brain conditions. Nevertheless, more knowledge is still needed to identify which measures will be most effective.*

### 5.1 Connection with the Global Burden of Disease Study

The survey and interviews in this report supplement the findings from the global burden of disease study by providing insight into patients' own experiences with brain conditions. The knowledge gathering also contributes to the national goal in the brain health strategy of good knowledge and quality through research and innovation.

The global burden of disease study highlights the burden of disease based on prevalence data and disability weights that indicate the average severity of different conditions. The weights are based on population surveys and do not necessarily reflect how people with the disease themselves experience living with brain diseases. The survey we conducted as part of the report highlights the health challenges that are perceived as most burdensome. This information can help to supplement the information from the global burden of disease study and provide a better basis for understanding the burden of brain disease in Norway.

We have highlighted how the health loss for each identified brain disease is distributed among different health challenges. In this way, we highlight which health challenges cause the greatest health loss. This provides more detailed knowledge about how health challenges affect functional ability, quality of life, and the need for health and care services. Increased insight into which health challenges drive health loss facilitates targeted measures and better prioritization in the follow-up of people with brain diseases.

### 5.2 Significance for everyday activities

Many of the health challenges associated with brain disease are invisible, and this can lead to challenges other than visible health challenges. Invisible health challenges include health challenges that are not immediately visible or that do not cause obvious physical symptoms, but which nevertheless have a major impact on quality of life, functional ability, and life expectancy. Invisible health challenges can make it difficult for those around the person to understand their limitations. Changes in, for example, energy levels, concentration, or memory are not visible to others. This can lead to misunderstandings and expectations that cannot be met.

Health challenges that reduce motor skills, cognitive impairment, tiredness or fatigue, and emotional changes can have a major impact on the ability to cope with everyday activities. Tasks such as personal care, cooking, using technology, managing finances, or participating in social contexts can become time-consuming and difficult to perform. Several of the symptoms associated with brain disease can mean that activities that are simple and routine for others require planning and support. For some, this means a need for assistive devices, adaptations in the home, or assistance from relatives and healthcare professionals.

For many people, the ability to participate in everyday activities is closely linked to their perceived quality of life and sense of mastery. Brain disease can lead to reduced independence, which can cause a feeling of loss of identity and belonging. Adaptations, follow-up, and rehabilitation can help maintain function and thus participation in activities.

### 5.3 Significance for participation in education and work life

Brain conditions can have significant consequences for a person's ability to participate in education and working life. Health challenges such as tiredness and fatigue, brain fog, attention and concentration difficulties, reduced memory, and difficulties with decision-making and impulse control can make it challenging to perform at the same level or maintain the same pace of work as people without these challenges. Because such health challenges

are invisible, they can be misunderstood as a lack of effort and lead to unrealistic demands and stress.

For young people, illness during their studies can mean that their studies take longer than expected, that their education is interrupted, or that they need special arrangements for teaching or other aspects of student life. Not being able to pursue the education one desires or ending up outside the labor market has a significant impact on the individual, both financially and socially. For many, this type of exclusion can lead to reduced self-esteem, social isolation, and a loss of structure in everyday life. The fact that some people are excluded from education or working life also has major consequences for society.

Flexible solutions such as graded work, the use of assistive devices, adapted training, and follow-up from employers and the Norwegian Labor and Welfare Administration (NAV) can help more people stay in work. Cooperation between health services and educational institutions or the workplace may be necessary to ensure adequate support for participation. This can also help to limit the social consequences of brain disease and maintain quality of life.

## 5.4 Measures to reduce the burden of disease

Several measures can help reduce the burden of disease for people with brain conditions – both in terms of prevention and living with the disease. At the same time, there are still gaps in our knowledge about which measures can most effectively improve the everyday lives of people with brain conditions, and more research is needed in this area.

### Prevention and early intervention

Measures that promote physical activity, a healthy diet, social participation, sleep, and good mental health have a documented effect on several neurological and mental disorders. Early identification of symptoms, especially in primary health care, can contribute to rapid referral, correct diagnosis, and treatment before the disease has a greater impact on function and quality of life.

### Need for a holistic approach

Although brain conditions encompass a wide range of diseases, there are many recurring health challenges. Many people need follow-up for their health challenges regardless of diagnosis, and a holistic approach can help address the needs of a larger group of people. Some brain diseases make it difficult for patients to make demands on the

services they receive or need, and it is therefore particularly important to ensure that these are of sufficient quality. Measures that contribute to comprehensive follow-up, where both follow-up in the health service and support for everyday activities are seen in context, can contribute to a good quality of life and a reduced burden of disease.

### Living with the disease

In the interviews, several of the patient organizations emphasized that it is important for their members to learn to live with the condition in the best possible way. Many brain conditions are long-term or chronic, and it is important that life is not put on hold because of the diagnosis. Many people can live good lives, and individually tailored treatment and follow-up can contribute to this.

Measures that promote good dialogue between patients, relatives, and healthcare professionals can help to promote independence and participation in education, work, and social activities, even in cases where the disease causes permanent functional changes. Follow-up that addresses medical, psychological, and social needs can make it possible to live a good life despite the condition.

### Increased knowledge among the general public

Increased knowledge among the general public and healthcare professionals about brain conditions and the symptoms and challenges they can cause can help reduce the burden on those affected by these disorders. People may have invisible health challenges without being aware of it, such as visual disturbances after a stroke.

Some may choose to cover up their health challenges because they are embarrassed or fear being excluded, and some may compensate with other skills to cover up the challenges.

Measures for training and increased competence can help reduce stigma and promote understanding that brain diseases often involve complex and invisible challenges. A public health perspective on brain health, anchored in national strategies and plans, will be crucial to meeting future needs and reducing the overall burden of disease.

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## Appendix A: Responses to the survey

	Number	Share
<i>I feel like a burden to the people around me</i>		
To a large extent	331	28 percent
To some extent	693	59 percent
Not at all	139	12 percent
Do not want to disclose	18	1 percent
<i>I find it challenging to participate in social situations.</i>		
To a large extent	588	50 percent
To some extent	515	44 percent
Not at all	75	6 percent
Do not want to disclose	2	0 percent
<i>I experience challenges in completing or succeeding in education</i>		
To a large extent	374	33 percent
To some extent	321	28 percent
Not at all	207	18 percent
Do not want to disclose	230	20 percent
<i>I experience challenges in participating in working life</i>		
To a large extent	680	58 percent
To some extent	310	26 percent
Not at all	94	8 percent
Do not want to disclose	88	8 percent
<i>I experience uncertainty related to finances</i>		
To a large extent	428	36 percent
To some extent	437	37 percent
Not at all	254	22 percent
Do not want to disclose	54	5 percent
<i>I experience uncertainty and fear related to the course of the disease</i>		
To a large extent	461	39 percent
To some extent	561	48 percent
Not at all	135	11 percent
Do not want to disclose	20	2 percent
<i>I feel a lack of control over my own everyday life</i>		
To a large extent	422	36 percent
To some extent	549	47 percent
Not at all	191	16 percent
Do not want to disclose	15	1 percent
<i>I feel a lack of control over my own everyday life</i>		
To a large extent	573	47 percent
To some extent	441	37 percent
Not at all	149	13 percent

Do not want to disclose	16	1 percent
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*I experience a feeling of shame*

To a large extent	316	27 percent
To some extent	507	43 percent
Not at all	326	28 percent
Do not want to disclose	29	2 percent

*I experience a feeling of loneliness*

To a large extent	334	28 percent
To some extent	613	52 percent
Not at all	212	18 percent
Do not want to disclose	20	2 percent

*I feel that my loved ones do not understand me*

To a large extent	190	16 percent
To some extent	693	57 percent
Not at all	312	26 percent
Do not want to disclose	13	1 percent

*I feel frustration and sadness about the situation*

To a large extent	575	49 percent
To some extent	492	42 percent
Not at all	100	8 percent
Do not want to disclose	14	1 percent

*I feel helpless*

To a large extent	363	31 percent
To some extent	604	51 percent
Not at all	189	16 percent
Do not want to disclose	21	2 percent

*I feel that I have a poor self-image*

To a large extent	301	26 percent
To some extent	571	49 percent
Not at all	275	23 percent
Do not want to disclose	28	2 percent

*I find it difficult to maintain relationships (family and friends)*

To a large extent	242	20 percent
To some extent	618	52 percent
Not at all	299	25 percent
Do not want to disclose	23	2 percent

*My illness makes me feel less like myself*

To a large extent	563	48 percent
To some extent	415	35 percent
Not at all	165	14 percent
Do not want to disclose	35	3 percent

## Appendix B: Health challenges in the survey of patients diagnosed with brain disease

The category nutrition and digestion includes the following symptoms:

- Swallowing difficulties
- Changes in appetite
- Nausea and vomiting
- Stomach and intestinal problems (gastroparesis, constipation, incontinence)
- Weight problems (underweight/overweight)

The category neurological symptoms includes the following symptoms:

- Language and communication difficulties (including tics)
- Motor and muscular difficulties (reduced muscle strength, spasticity, tremors, spasms, stiffness, paralysis)
- Fainting
- Dizziness
- Visual disturbances and vision loss
- Hearing loss
- Hypersensitivity to sensory stimuli

The cognitive challenges category includes the following symptoms:

- Reduced memory
- Brain fog
- Difficulties with decision-making, impulse control, problem-solving
- Aggression challenges
- Attention and concentration difficulties
- Compulsive behavior
- Difficulties interpreting social cues

The category of psychological and emotional symptoms includes the following symptoms:

- Low mood (anxiety, restlessness, depression)
- Suicidal thoughts
- Personality changes
- Confusion
- Hyperactivity

The category of physical function and endurance includes the following symptoms:

- Fatigue
- PEM (post-exertional malaise)
- Sleep problems
- Muscle and joint pain
- Head and neck pain
- Other pain
- Poor oxygen uptake
- Orthostatic intolerance

## Appendix C: Grouping of brain conditions

In Figure 3-5, we have grouped the brain conditions identified in our survey into three main categories: neurological disorders, mental disorders, and other brain conditions. We only illustrate group disorders where more than 30 respondents reported the brain disorder in the survey.

The grouping of brain conditions is shown below.

### **Neurological disorders**

- Migraine and other headache disorders
- Brain tumor
- Cerebral palsy
- Epilepsy
- Stroke (including cerebral stroke, cerebral hemorrhage, and subarachnoid hemorrhage)
- Neural tube defects (including spina bifida, hydrocephalus, and other diseases related to cerebrospinal fluid in the brain)
- MS
- Sleep disorders
- Restless legs syndrome (RLS)
- Brain damage

### **Mental disorders**

- ADHD
- Post-traumatic stress disorder (PTSD)
- Depression and other depressive disorders
- Anxiety, phobias and obsessive-compulsive disorder (OCD)
- Tourette's syndrome

### **Other brain conditions**

- Dizziness, balance and gait disorders
- Concussion
- Other diagnosed brain conditions

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