

RETHINKINGMS IN DENMARK

A policy brief



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About RETHINKING MS

RETHINKING MS is a research-driven project which offers tangible policy changes to improve the lives of people living with MS across Europe, building on the 2017 Value of Treatment report from the European Brain Council. The RETHINKING MS series includes *RETHINKING MS in Europe* – a policy report providing an analysis of unmet MS care and support needs across Europe, and practical and sustainable policy recommendations – and a series of reports providing an in-depth analysis of policy, care and support available for people with MS in Denmark, Italy, Romania and Spain.

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About the European Brain Council

The European Brain Council (EBC) is a non-profit organisation that aims to improve the lives of those living with brain disorders by advancing the understanding of the healthy and diseased brain through bringing together science and society.

About The Health Policy Partnership

The Health Policy Partnership (HPP) is an independent research consultancy, working with partners across the health spectrum to drive the policy and system changes that will improve people's health.

For more information on RETHINKING MS, please visit:

www.braincouncil.eu/RethinkingMS



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Multiple sclerosis (MS) is a complex and progressive disease of the central nervous system, where the immune system destroys brain, optic nerve and spinal cord tissue.¹⁻³

What is happening in Denmark?

There are approximately 16,000–16,500 people with MS in Denmark ^{4 5}
Prevalence of MS is 250 per 100,000 ⁶
Average age at diagnosis ranges from 36–38 ^{5 7}
Approximately two thirds of the MS population are women ⁴

What are the costs of MS in Denmark?^{8*}

	Mild	Moderate	Severe
Direct costs for healthcare (DKK)	114,007	119,459	67,488
Direct costs for services and informal care (DKK)	8,028	32,674	294,617
Indirect costs for short- and long-term absence from work and early retirement (DKK)	74,000	135,170	171,145
Combined direct and indirect costs (DKK)	196,000	287,000	533,000

*Average costs per person, per year. Data were collected in 2015. Costs were calculated in Danish Krone (DKK); combined costs are rounded to the nearest 100. The Expanded Disability Status Scale (EDSS) classes MS severity with a score of 0–9: a score of 0–3 is mild, 4–6.5 is moderate and 7–9 is severe. For more information on the different types of MS, see the appendix.

WHAT IS MISSING FROM MS CARE IN DENMARK?

To better understand unmet needs in Denmark, interviews were conducted with experts in MS. In order to improve MS care, interviewees recommended that Danish policymakers and decision-makers should look to:

- establish and resource specialist interdisciplinary MS care units
- ensure that people with progressive MS have their needs met for symptom management and psychosocial support during annual reviews at specialised MS clinics
- ensure sufficient social and primary care for people with MS and their families, and improve integration and communication between the different care providers.





COUNTRY CONTEXT

Denmark is a country with comparatively high wellbeing and equity. Its small population of around 5.8 million inhabitants⁹ has a relatively high level of social equality and health equity compared to the rest of Europe.¹⁰ Denmark consistently performs well on measures of health, wellbeing and employment standards in comparison with other countries.¹⁰

Public funding means healthcare services are widely accessible. Healthcare spending accounts for 10.2% of GDP, which is higher than the Organisation for Economic Co-operation and Development (OECD) average.¹⁰ Healthcare services are typically free at the point of use; approximately 84% of healthcare expenditure is publicly financed and 16% is financed primarily through individual co-payments.¹¹ However, there are various exemptions to these co-payments based on individual circumstance or need.

Integration and communication between healthcare providers at the state, regional and municipal levels can be variable,¹⁰ but efforts are underway to address this. The state holds the regulatory and supervisory functions, while hospital and psychiatric care are organised at the regional level.¹¹ The 98 municipalities organise primary care, home nurses, social care and other services. To tackle the variation across services, since 2007 Danish regions and municipalities must develop health agreements to ensure coordinated, collaborative and high-quality care across all patient pathways.⁶

Denmark is committed to monitoring and improving its healthcare system. It has long been a leader in institutional reform and quality-improvement initiatives.^{10 12} The Danish Healthcare Quality Programme was recently launched to further improve the quality of care, in line with overarching government goals in Denmark (*Figure 1*).¹¹

An extensive variety of registries allows for unique insights into population health. Denmark has a significant number of national and regional registries collecting data on aspects such as health, education, income and employment.¹³⁻¹⁵ Each resident is provided with a unique civil identification number that allows linkages and analysis between different registries. As such, the Danish registries are a useful resource at a national and international level.

Digitisation is a hallmark of the Danish healthcare system, facilitating efficiency and integration. Digital communication and use of technology in the public sector are extremely high in Denmark.¹⁰ In the healthcare sector, all referrals to medical specialists and psychologists are made electronically and 99% of all prescriptions are sent electronically to pharmacies.¹¹ There are plans underway to further enhance the use of technology and data, including:¹¹

- 2012 National Telemedicine Action Plan, with four large-scale projects
- 2019 use of patient-reported outcomes in daily clinical practice for prostate cancer, breast cancer and epilepsy.

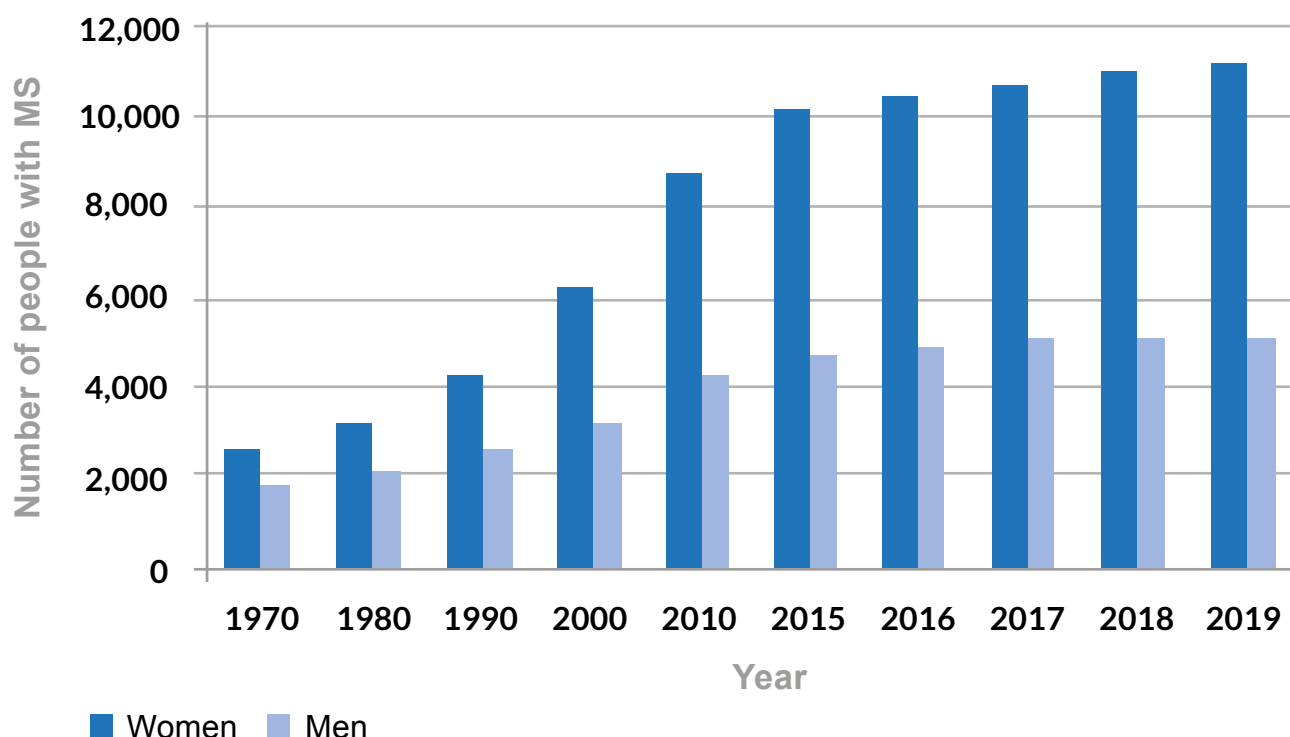
Figure 1. National objectives for healthcare¹¹



MS POLICY LANDSCAPE

Prevalence of MS in Denmark is increasing, partly due to more accurate diagnosis and improved treatment options.^{6 16 17} This increase is seen in both men and women, and Denmark follows the global trend of higher prevalence of MS in women (*Figure 2*).¹⁶ The increase in survival has been seen for many years, even before the development of disease-modifying therapies (DMTs) or the adoption of the McDonald criteria for the diagnosis of MS.¹⁸

Figure 2. The number of people with MS in Denmark on 1 January each year since 1970¹⁶



Due to DMTs and innovative treatment, life expectancy for people with MS in Denmark is only 8–10 years shorter than for people without MS.⁶ In line with the ageing general population, there is an increasing number of older people with MS,¹⁶ which brings additional challenges in care and support.

The breadth of data available in Denmark allows for important insights into the epidemiology and impact of MS. The Danish MS Registry was established in 1956 as an epidemiological register,¹³ drawing information from neurology departments, private neurologists and the national patient registry.²¹ It now also incorporates the Danish MS Treatment Register, which was established in 1996 to follow people with MS on DMTs.²⁰ These registries have provided interesting insights, including the following:

- Familial cases of MS are diagnosed faster than sporadic cases.²¹
- At age 11, children with a mother who has MS do not demonstrate mental health issues more than their peers.²²
- At age 30, people who have a parent with MS are less likely to be employed or more likely to have a lower income than their peers with similar educational achievements.²³

The Danish MS Society plays a significant supportive role in the lives of people with MS. The organisation was founded in 1957 and currently has over 12,000 members diagnosed with MS.²⁴ It has a broad role in funding research and the Danish MS Registry, and also provides support, information and advocacy for people with MS through a team of social workers, counsellors and psychologists.

What policies exist for MS in Denmark?

Inclusion of MS in the national non-communicable disease or chronic disease plan	Yes
Neurological disorders plan	No
Inclusion of MS in neurological disorders plan	N/A
National strategy on MS	Yes
National clinical guidelines	Guidelines exist for treatment of MS. ²⁵ There are multiple historical guidelines, ²⁶ guidelines for physiotherapy and occupational therapy ²⁷ and for clinically isolated syndrome. ²⁸ The Medicine Council is also developing 'Joint regional treatment guidance for multiple sclerosis', and a new Specialist Committee for MS has been established to support this initiative ²⁹
National MS registry	Yes



ORGANISATION OF CARE

‘All too often, people with MS have to be their own advocates across the different health and social care providers, which can be extremely challenging.’

Anders Skjerbaek, the Danish MS Hospitals

Highly specialised and integrated care is the cornerstone of MS care in Denmark.

People with suspected MS are diagnosed in specialist MS clinics and, in many cases, they proceed to be cared for on an outpatient basis in these centres.⁶ DMTs and other treatments are only allowed to be prescribed in MS clinics, and these hospitals are accredited and outlined in documents by the Ministry of Health (Sundhedsstyrelsens).³⁰ There are two MS Hospitals, in Ry and Haslev, which offer highly specialised rehabilitation and treatment for all people with MS. The MS Hospitals are overseen by the Danish Health Authority,³¹ and this centralisation of specialised care is seen as essential in the drive to provide high-quality and coordinated care while using resources efficiently.

Specialist neurologists typically lead MS treatment and coordinate the interdisciplinary team as needed. However, the makeup of interdisciplinary teams and the services they offer can vary as they are organised by different providers across Denmark (*Figure 3*).⁶ It is also worth noting that the heterogeneity of trajectories in MS means that each person's experience will vary depending on their individual needs.

Rehabilitation is essential, but specialist programmes are not consistently available.

Rehabilitation supports people to maintain functionality and quality of life.³²⁻³⁴ It is an essential component of care, especially for people with progressive forms of MS.

Neurologists are required to assess rehabilitation needs as part of discharge planning,⁶ but the local municipality is responsible for providing appropriate services.^{6 11} However, some municipalities have struggled to provide adequate services and do not meet the 14-day waiting target for rehabilitation,³⁵ partly due to difficulty in finding suitable rehabilitation professionals with expertise in MS.³⁶

In addition to municipal rehabilitation, a neurologist may also refer people to the MS Hospitals for personalised inpatient rehabilitation.^{6 31} There are many highly personalised interdisciplinary rehabilitation programmes at the MS Hospitals, including those for newly diagnosed people, young people or people with complex needs.³⁶ However, capacity at these hospitals is limited, meaning that only a small proportion of the Danish MS population receive care at the hospitals each year.³⁶

Figure 3. Healthcare providers and interactions associated with MS care in Denmark



Timely diagnosis and personalised treatment

Although awareness of MS among general practitioners (GPs) can be variable, once MS is suspected the diagnosis pathways usually enable a timely diagnosis. People may present with MS symptoms to various healthcare professionals, but most commonly to a GP.⁶ GPs' awareness of MS symptoms can vary,^{36 37} potentially delaying symptom recognition and timely referral. Furthermore, comorbidities such as cerebrovascular, cardiovascular and lung and other conditions can challenge symptom recognition and delay diagnosis.³⁸ However, upon identification of the symptoms, the person with suspected MS is referred to a neurological department and MS clinic for tests and diagnosis.^{6 39} The pathway from initial contact with the healthcare system to MS diagnosis takes approximately 12 weeks.⁵ Experts agree that this pathway is generally smooth in Denmark and there is reasonable availability of diagnostic procedures.⁴⁰

Despite best efforts of healthcare professionals, many people with MS face unmet needs regarding information on MS at the point of diagnosis. Receiving a diagnosis of MS is life-changing. Having access to adequate information at diagnosis can make a real difference to people with MS and their families, and help them adapt to life with MS.^{41 42} One study noted that Danish patients had a lack of information at diagnosis, mostly regarding symptom management and the availability of support in the community.⁴³

'I don't think there is enough education for people with MS and their families. The MS Hospitals are really good at educating people about MS, and they help teach the family of the person with MS too. But they just don't have the capacity to help everyone who needs it.'

Dr Peder Olesgaard, MS carer and retired GP

Pharmacological management of MS

‘I think one of the biggest challenges is to find the right treatment for the right person at the right time. It can take considerable time and resources to get to the right choice.’

Professor Melinda Magyari, Danish Multiple Sclerosis Center

There have been rapid improvements in DMT use in Denmark, but restrictions remain.

Prompt initiation of DMTs is essential to prevent potentially irreversible disability.^{3 44} Anyone on DMTs is followed closely on the MS Treatment Register.^{6 20} Earlier use of therapies, and greater number of available therapies, have meant that the number of people on DMTs has steadily grown from 25% in 2013⁴⁵ to 52% in 2014⁴⁶ and 61% in 2018.⁵ One 2015 survey estimated that 77% of people with MS in Denmark are on DMTs and/or symptomatic treatment.⁸ However, there are restrictions on which hospitals can provide DMTs; for example, just 11 hospitals are able to provide second-line DMTs.³⁰ Other restrictions are driven by the Danish Medical Council.³⁶

Cost-containment strategies limit initial choice of DMT, but switching and escalation are common.

In Denmark, all people with MS eligible for DMTs are required to start on one of two oral DMTs.^{39 40} Should they have a suboptimal response, they are then able to choose an alternative DMT that may be more effective. Intolerable side effects or presence of neutralising antibodies are sufficient reasons to change treatment in Denmark,⁴⁰ which is not the case in all European countries.²⁸ At this point, the choice of DMT is shared between the neurologist and person with MS; both patients and specialist MS neurologists consider such shared decision-making to be effective.^{39 43}

Widespread access to scans facilitates treatment escalation. Treatment can be escalated based on evidence from magnetic resonance imaging (MRI) alone.⁴⁰ Given that many people with MS in Denmark have the opportunity for routine MRI scans every 6 or 12 months, there are more opportunities to escalate therapy than in other countries.²⁸

Symptomatic therapies are helpful, but access can be challenging. MS symptoms significantly affect quality of life, and adequate symptomatic treatment can be hugely beneficial for people with MS.⁴⁷ However, one survey found that 22% of people with MS are on a symptomatic therapy, most frequently for spasticity, walking and pain.⁸ Drivers of low use of symptomatic therapies include capacity issues and short consultation times at MS clinics.⁴⁰

What pharmacological treatments are available in Denmark?

Availability of symptomatic therapies	Many symptomatic treatments are available in Denmark, ^{6 48} including medical marijuana in specific cases ⁴⁹
Availability of DMTs	All approved by EU ^{25 29}
DMT reimbursement	100% reimbursement ⁵⁰

Interdisciplinary and coordinated care

‘One of the biggest challenges in MS is ensuring that all people have access to specialist interdisciplinary care in dedicated MS clinics and MS Hospitals.’

Professor Per Soelberg Sørensen, Danish Multiple Sclerosis Center

The limited number of specialist MS neurologists is a challenge to provision of care. Typically, the specialist MS neurologist oversees the care and management of all people with MS – and there are about 35 specialist MS neurologists in Denmark.⁴⁵ Combined with the high demands of safety monitoring for people on DMTs, this means that many people with progressive MS are not seen regularly by a specialist MS neurologist.^{36 39 40 51} The MS Society estimates that approximately 4,500 people with progressive MS were not seen by a specialist MS neurologist in the past year.³⁶ This may lead to many unmet needs, including fewer referrals to rehabilitation or other interdisciplinary support.^{51 52}

Greater use of a community- and hospital-based interdisciplinary team may help reduce capacity issues. Interdisciplinary teams can help transfer some of the burden of care and management from neurologists to other healthcare and allied health professionals.^{36 40} For example, nurses have become a central point of contact for people with MS in Denmark^{32 39 51} and 64% of people with MS go to their MS nurse for information and education.⁵³ With further training and support, specialist roles such as nurses or physiotherapists could provide check-ups and more detailed information and support for many people with MS.^{36 40 51}

Access to certain interdisciplinary roles may be limited depending on location. Around 50% of people with MS live within 20km of an MS clinic and interdisciplinary team.⁴⁰ However, depending on the MS clinic, there are variations in access to different interdisciplinary roles. For example, key members of the interdisciplinary team not frequently seen by people in Denmark include speech therapists, occupational therapists, psychiatrists and counsellors.⁸

Rehabilitation is a high priority in Denmark but access to specialised care depends on the level of disability. All people with MS are able to access exercise therapy at the municipal level; however, as symptoms develop, people are offered increasingly individualised physiotherapy and occupational therapy.⁵¹ Interdisciplinary rehabilitation has been shown to improve fitness, help inform people about their MS and improve quality of life.⁵⁴ However, many people with MS experience delays in starting rehabilitation.⁵¹ There are differences in the type and quality of physiotherapy services available depending on geographic location⁵⁵ and access to specialists. For example:

- The quality of generalised rehabilitation at the municipal level may depend on the physiotherapist's knowledge or awareness of MS.⁵¹
- For people with advanced MS, rehabilitation is much more personalised and specialised. However, access can be challenging, due to the limited capacity of the MS Hospitals.³⁶

How many specialist interdisciplinary services for MS are available in Denmark?

Number of interdisciplinary MS clinics	13 MS clinics
Number of specialist rehabilitation services	2 (1 in each of the MS Hospitals)
Number of neurologists and MS specialist neurologists	Approximately 240 neurologists Approximately 35 MS specialist neurologists ⁴⁵
Number of specialist nurses	Approximately 50 MS specialist nurses ⁴⁵



Monitoring and long-term follow-up

‘There is a need for a much more comprehensive and holistic approach for people with MS in Denmark. Current treatment is too focused on the hospital and clinic.’

Professor Per Soelberg Sørensen, Danish Multiple Sclerosis Center

Access to follow-up care varies depending on an individual’s disease progression and treatment. For people on DMTs, side-effect monitoring requires a visit to a neurologist three months after initiation or change of treatment, and then every six months thereafter.²⁰ This typically occurs as an outpatient in a neurological department or MS Hospital.⁶

Some people with MS are at risk of ‘falling through the gaps’ in care. People with progressive forms of MS and those who are not on DMTs do not tend to see a neurologist regularly.^{39 40 43 52} Even an annual appointment can be challenging to achieve. This impacts the person with MS and their family because without contact with neurologists – in addition to any potential health-related unmet needs⁴³ – it is more difficult to access social workers, rehabilitation and benefits.⁵²

GPs are a key point of contact for people with MS in Denmark, but they need to be better supported. For people with progressive MS and those living in rural areas, GPs play an enhanced role in long-term MS management and care.^{6 37} However, GP knowledge of MS can be relatively low, meaning they may not provide optimal care and support.^{36 37 39 51} To improve GP support, the MS Hospitals provide voluntary MS training programmes for GPs.⁵¹ It is important to further prioritise, incentivise and fund such continuing medical education on a larger scale.

Integration between community- and hospital-based teams needs improvement. People with MS are left to be their own advocates across multiple care providers, and care can be very fragmented with poor communication between the GP, hospital and municipality.^{36 37 40 51} A personal health coordinator has been identified as a helpful role in the interdisciplinary team.⁴³ This role could help improve coordination and integration of care across many providers and reduce some of the administrative burden from the healthcare team and the person with MS.



Adaptable support in daily life

‘The social care system in Denmark is not reflective of the variability and unpredictability of MS, and many of the symptoms of MS are invisible to some of the assessment tests.’

Nadia Buchard, Danish Multiple Sclerosis Association

Denmark has a wide range of social care and practical home support available, which can relieve pressure on family members caring for people with MS. MS affects the whole household;⁴³ in Denmark, 75% of people with MS live with their families and, of these, 40% require practical support from their families.⁸ To better support people with chronic illnesses, municipalities provide nursing and practical help at home free of charge.¹¹ Support can include commuting allowances and transport support, assistive devices and help with specific tasks such as grocery shopping and other aspects of daily living.⁵⁶ Services are frequently used by people with MS⁵² and are required more regularly by those with increasing levels of disability.⁸ However, people may experience issues in accessing disability pensions or specific types of familial support.^{36 52}

Disability assessment varies across municipalities, impacting the level of support on offer. In order to determine the types of social, practical or financial support that a person with MS might receive, the neurologist refers them for disability assessment. The EDSS scale is typically part of the assessment; however, this metric has many limitations and may not always reflect the reality of living with MS.⁵⁵ There is significant diversity across municipalities in the way that MS and disability are assessed, meaning that people may receive different types of care and support depending on where in Denmark they live.^{36 52} Furthermore, social workers in the municipalities may not have knowledge about the variability or unpredictability of MS.⁵⁵ This means assessment outcomes may also vary within a region, depending on the social worker.

Despite overarching equity within the health and social care system,^{12 57} there remain some inequalities. People with MS who do not see a specialist neurologist on a regular basis are at risk of being overlooked for regular disability assessments and may not have access to help that is available to them and their family.⁵² Notably, people with lower educational levels or financial resources, or those experiencing cognitive difficulties as part of their MS, may be less able to navigate the health and social care systems and may have more unmet needs.³⁷

Political prioritisation of employment has greatly improved employment prospects for people with MS. Denmark has one of the highest employment rates in Europe,¹¹ and the government has actively prioritised labour-market inclusivity for people with disabilities.¹⁰ This has led to numerous disability and equal opportunities policies, such as financial support for reduced working hours provided by the municipalities.⁵² The MS Society supports people with MS in all facets of their lives, and has particular services to help support people with MS to remain in employment.^{36 52} As a result, people with MS are increasingly present in the labour market.⁵²

Despite political prioritisation, issues persist. People with MS have a lower employment rate, lower overall income and higher social transfer rate compared with the general population.^{8 58} Of those with MS who work, most work part-time.⁸ Many people with MS are apprehensive about disclosing their condition to their employers,⁵² fearing stigma. Furthermore, organising suitable workplace adaptations can be extremely challenging, as the person with MS must lead any adaptations, coordinating the municipality, employer, social worker and other actors.³⁶

What patient groups exist in Denmark?

National patient groups	Danish MS Society www.scleroseforeningen.dk
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Case study 1

Enhanced support and education for people newly diagnosed with MS^{51 59}

Receiving a diagnosis of MS can be overwhelming, and people may feel lost and have many questions. To better support people at this critical moment, the MS Hospitals in Ry and Haslev run two-week inpatient programmes for people with a recent MS diagnosis. The programme involves interdisciplinary rehabilitation and support, goal setting, education activities including training on MS, and support to manage MS symptoms. There are also opportunities for individualised physiotherapy, occupational therapy, coaching and counselling with a psychologist or social worker. Rehabilitation specialists describe the value of these programmes for people with MS in terms of both the tangible skills learnt and the important opportunity for peer-to-peer communication and support.

Case study 2

Supporting effective navigation through the healthcare system⁶⁰

Many people with MS are unsure how to navigate the healthcare system and receive the care and support to which they are entitled. The Danish MS Society has developed the patienthåndbogen (Patient Handbook) to help people with MS understand what care and services they should receive, and how to complain when care does not meet these standards. Linking directly to Danish health legislation, it clearly outlines expectations and rights around treatment choice, informed consent, second opinions, rehabilitation, interdisciplinary care and other aspects. It is updated as legislation changes, and is freely available on the MS Society website. It is hoped that this resource can better support people to advocate for the care and support that they need.



Case study 3

Strengthening cooperation between the MS hospitals and municipalities⁶¹

Consistency of rehabilitation, care transitions and communication between different rehabilitation providers in Denmark can be variable. Furthermore, services offered and knowledge of MS in the municipalities can be limited. The National Board of Health is running a pilot project to improve collaboration and communication between the MS Hospitals and the municipalities of Kalundborg, Morsø and Vejen. The project aims to:

- improve the consistency of the rehabilitation process for each person with MS
- increase contact and cooperation between the MS Hospitals and municipalities
- improve the understanding of municipal services available for people with MS and their families
- improve MS knowledge for municipality workers and improve knowledge of the municipalities for MS Hospital staff
- uncover barriers in collaboration between the MS Hospitals and municipalities and develop initiatives to overcome them.

There are approximately 18 models underway, including knowledge-sharing seminars between MS Hospitals and municipal employees, and competence training in MS. More than 250 people have so far undergone training on MS, including staff from nursing homes, job centres and other locations. Over time, the pilot will expand and all municipalities will utilise optimal models for communication and collaboration.



APPENDIX: ABOUT MS

MS is a complex and progressive disease of the central nervous system, where the immune system destroys brain, optic nerve and spinal cord tissue.¹⁻³ As a result, people with MS develop irreversible motor-disability and cognitive impairment over time.^{1 32 62} MS affects almost every aspect of day-to-day life,^{63 64} and its personal and economic impacts grow significantly as the condition progresses and disability worsens.^{3 44 65}

There are four main types of MS:

- **Clinically isolated syndrome (CIS)** is the first clinical presentation of inflammation or lesions.⁶⁶ However, many people with CIS will not go on to develop MS.⁶⁷ If CIS becomes clinically active and fulfils the current diagnostic criteria, it can be reclassified as relapsing and remitting MS.⁶⁶
- **Relapsing and remitting MS (RRMS)** is characterised by intermittent ‘relapses’ (sudden onset of MS symptoms and disability), followed by remission periods where symptoms abate.^{68 69} Approximately 85–90% of people with MS have RRMS at diagnosis.^{2 68}
- **Secondary progressive MS (SPMS)** is characterised by progressive accumulation of disability after an initial relapsing course. There are no clear criteria to mark the transition between RRMS and SPMS, and often SPMS is only diagnosed retrospectively.⁶⁶
- **Primary progressive MS (PPMS)** is where disability accumulates without relapses from the outset.⁶⁶

MS can be a challenging condition to manage, due to its unpredictability and each individual’s changing healthcare needs.⁷⁰ Management strategies aim to reduce disease activity and development of disability, but must be tailored to each person. They typically fall into three categories:

- DMTs
- Symptomatic therapies and rehabilitation
- Lifestyle interventions.



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