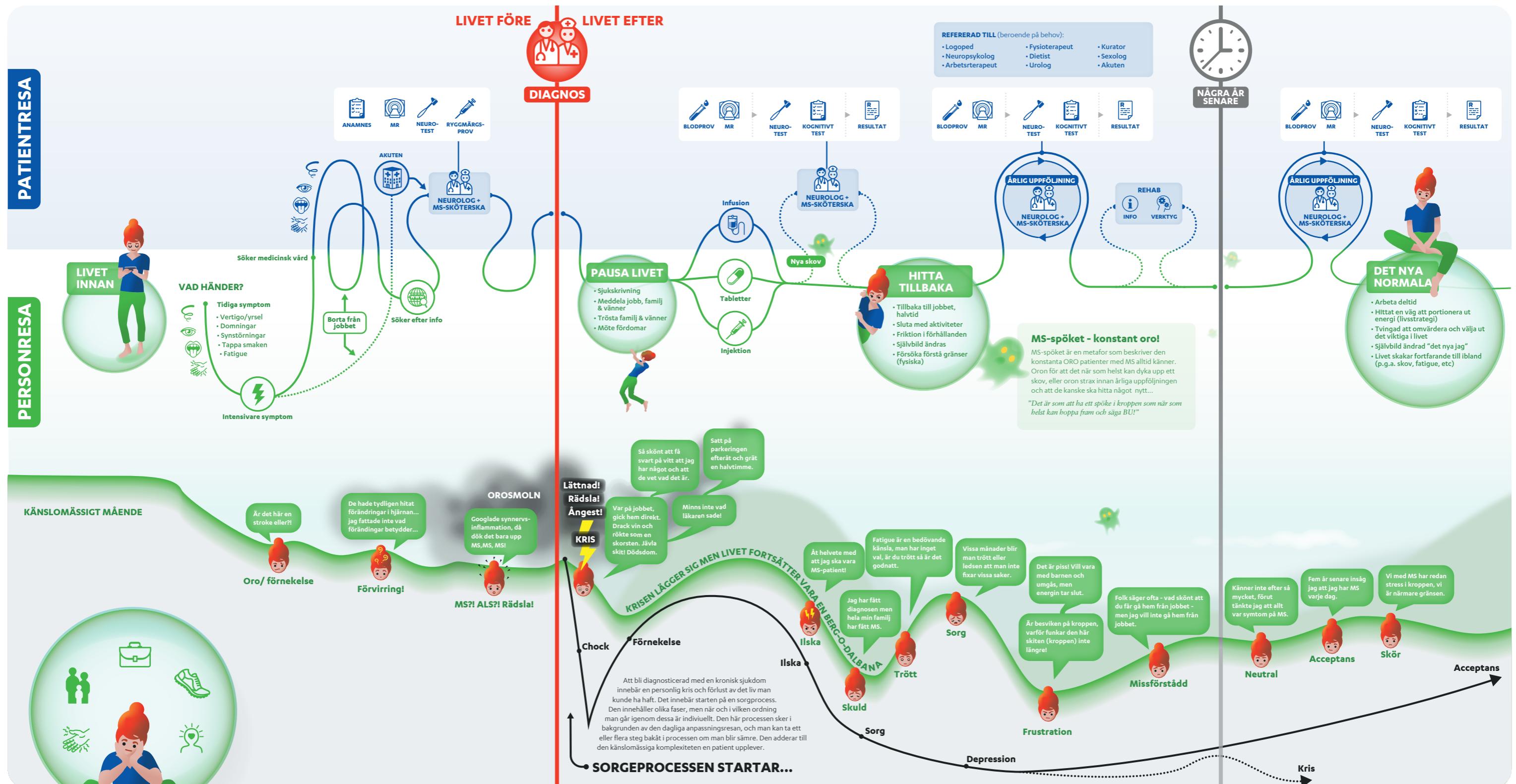


# **MS-RESAN** – EN ANPASSNINGSRESA



## HUR MS PÅVERKAR LIVET

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## Anhöriga

Familj och vänner behöver stöd, de drabbas också av sjukdomen men får ingen hjälp. Det faller ofta på patienten att informera och stötta.

- Pärfestande för relationer, för en närmre eller längre ifrån varandra och kan leda till separation.
  - Anhöriga drabbas också av MS - tar en stor roll i form av stöd och kontakt med värden.
  - Anhöriga får ingen eller begränsad hjälp, varken information eller hjälp att bearbeta det emotionella.
  - Många patienter har begränsat med energi för det sociala och tvingas prioritera.

1

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1

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LIVET MED MS

MS kommer ofta mitt i livet, när man är som mest aktiv med att forma sitt liv (karriär, familj, etc.). Det beskrivs ofta som en kris, där man tvingas lägga om sin livsplan på grund av MS. Många har svårigheter att hantera allt i livet. Dina relationer, ditt arbete, din livsstil och fritid. Ingen resa är den anden lik, dels pga att maskinskor hanterar sen sjukdom olika men också pga hur individuellt sjukdomen ter sig.

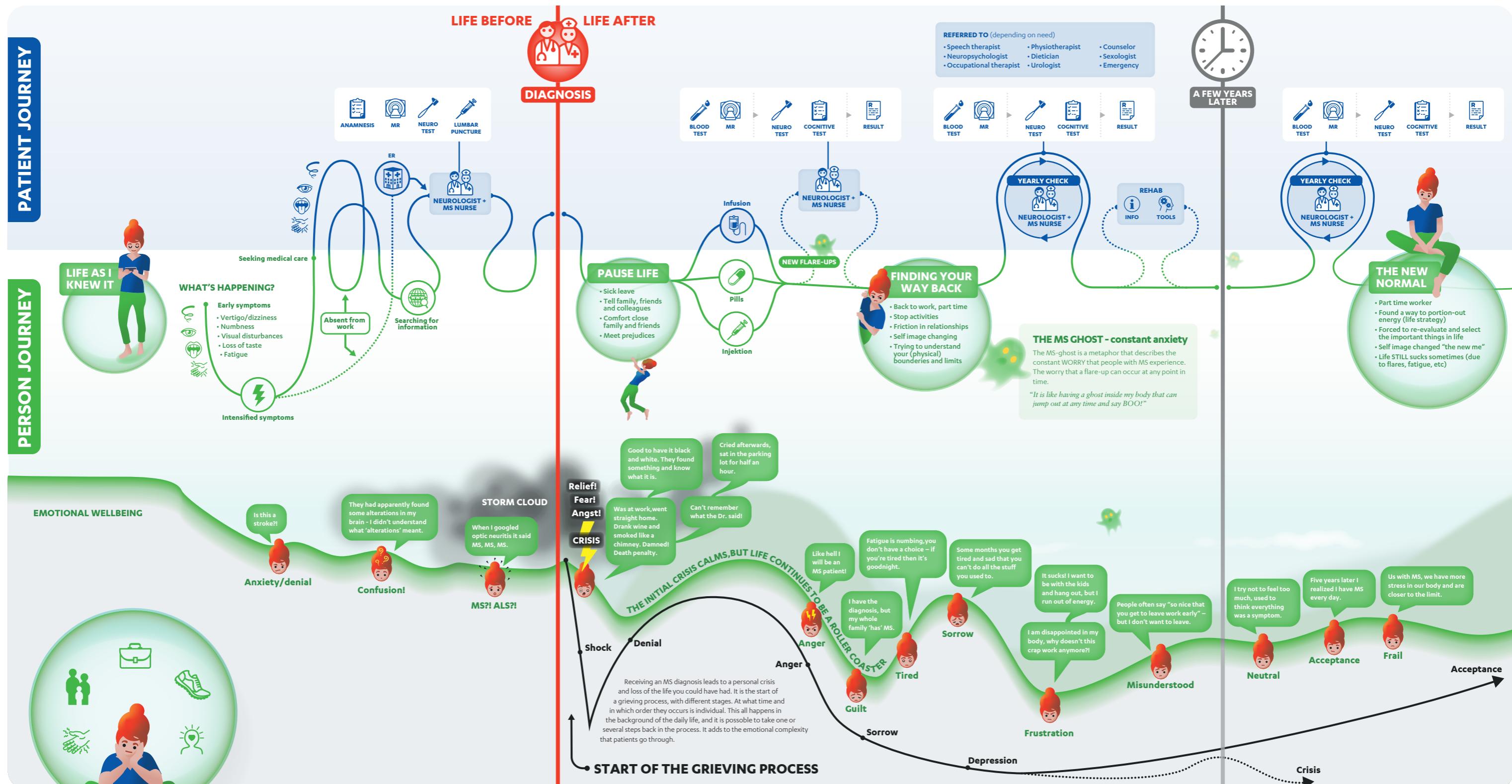
- MS-resan är mer en person- än en patientresa.
  - Livet med MS innebär att hantera alla delar av livet samtidigt som man hanterar sjukdomen.
  - Komplext känsoliv, mycket att hantera på olika nivåer.
  - Slitning mellan att ses som sjuk eller frisk, påfrestande för en själv och omgivningen. Även för självbilden.
  - En läranderesa och en anpassningsresa.

### Symtom – svåra att förstå

Första symtom kan vara svåra att förstå, de dyker upp i olika grad på olika ställen i kroppen och är svåra att koppla till någon specifik orsak eller sjukdom. MS är relativt okänt för de flesta och sjukdomens individuella karaktär gör det svårare att identifiera och förstå vad det är som händer. Symtom kopplas ofta till stress eller skjuts åt sidan då det är fullt upp med allt annat i livet. Ofta vill man inte förstå, man vill inte orsa sig i onöдан.



# THE MS JOURNEY – AN ADAPTATION JOURNEY



## Relatives

Family and friends need support, they are also afflicted by the disease but receive no help. It falls to the patients to inform and support.

- Strenuous on relationships, it brings you closer or apart and can lead to separation.
- Relatives are also afflicted by MS – carries a heavy burden when it comes to support and contact with healthcare.
- Relatives receive no or limited help, neither information nor support in processing their emotions.
- Many patients have limited energy for socialising and are forced to prioritise.

## HOW MS AFFECTS LIFE



## Work

Important for the self image and self esteem to continue working. Challenging communication – need understanding from colleagues without it affecting the value of one's work.

- Reduce hours or change jobs.
- Important for self image and wellbeing to come back to work.
- Worry around how the disease will affect work life, including colleagues' view of one's capability and how work life will affect the disease.
- Learning journey to find balance and know your limits.



## Lifestyle

Learning to use the energy you have is important for one's wellbeing. In order to learn, you must have started to accept the disease and acknowledged its impact on life.

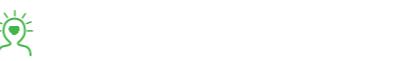
- Overall life is affected – how you travel, where you live, what activities you do etc.
- Many get to know their limits by exploring and testing them, others limit themselves.
- Physical workout is important to manage symptoms and for mental wellbeing.
- Might need to stop with a hobby because it is too demanding.



## Physical

The disease symptoms are individual and often invisible which makes them hard to understand both for yourself and your surroundings.

- Lasting symptoms, distinct or diffuse, such as pain, numbness or fatigue.
- Troubles with temporary pseudo-relapse.
- New flare-ups, distinct or diffuse, can be hard to recognise.
- Physical workout is important to manage symptoms and for mental wellbeing.
- Too much stimulus/sensory impression can be energy-draining.



## Mentally

Mental health is affected as much as the physical, and is harder to handle. There is a lack of support and training linked to coping with the disease, you are more frail than others.

- The diagnosis triggers a grieving process and affects the self image.
- Missing support and understanding from others, especially when symptoms are tough. This is made harder by the invisible character of the disease.
- Affected by others' view of oneself – do not want to be defined by the disease.
- Experience worry for flare-ups and the future, guilt linked to flare-ups and burdening others, shame of being weak, frustration over the body failing and being misunderstood.

## LIFE WITH MS

MS often shows up in the middle of life, when people are the most active in shaping their lives (career, family, etc.). Is often described as a crisis, where you have to adjust your life plan – at times fundamentally. MS affects all parts of life. Your relationships, your work, your lifestyle and spare time. No journey and another are alike, partly as people deal with the situation in different ways, but also due to the individuality of the disease.

Despite that most learn to deal with their disease and managing all of the components of life with time, many describe life as a roller coaster. New crisis or flare-ups can occur along the way, and treatment can improve the quality of life significantly, but you become better at dealing with changes in a better way.

It is a journey of adjustment as well as leaning. Learning in the sense of learning about the disease and what it means to you, getting to know your body and its limits as well as to recognise symptoms. Adjustment in the sense of how and what to change to best design your life given new circumstances and limitations.

## KEY INSIGHTS

- The MS-journey is more of a person than a patient journey.
- Life with MS means dealing with all parts of life at the same time as you are handling the disease.
- Complex emotional life, a lot to deal with on different levels.
- Conflict between being seen as sick or well, which is straining for oneself as well as the surrounding.
- A learning and adaptation journey.

# MS ONSET



## Symptoms – hard to understand

The first symptoms are hard to understand, as they occur in various places in the body. MS is relatively unknown to most people and the individuality of the disease makes it harder to grasp and identify what is happening. Symptoms are connected to stress or pushed aside, life is busy as it is. Often one does not want to understand, and worry for nothing.

Some symptoms are temporary and disappear before seeking care. -ups can occur that are not recognized until after diagnosis.

*"Was working out with a friend, and realized in the sauna that I couldn't extend my fingers. But it disappeared after 10 minutes."*

At the end, it becomes obvious that the symptoms are something beyond normal flaws, which leads to seeking care. Symptoms can be so severe they require admittance.

*"Is this a stroke?"*

*"I think I have experienced this before but connected it to stress and did not reflect on it much – now it has become a disturbance."*

## Diagnostics – misinterpreted and overlooked

The diagnostic journey can be long and cumbersome. On top of physical problems and anxiety, there is a struggle with healthcare and finding the right counterpart. Someone who believes you and can recognise the symptoms.

Many are misinterpreted and overlooked in primary care. If emergency admitted the process is normally significantly faster. The breaking point is contact with a neurologist.

On top of the symptoms stemming from MS, the test and process can bring additional physical stress.

*"After the lumbar puncture I got a headache way beyond normal, it was like carrying a magnetic helmet."*

It is a volatile phase, with varying symptoms and contact with different care instances – worry that something will be found, worry that nothing will be found. This is where most meet the term "MS" for the first time, and start to realize that it is a possibility.

*"When I looked at the staff I noticed their creased foreheads, it appeared to be serious."*

Flare-ups becomes a topic of mind, and many realize that there probably have been flare-ups in the past.

Many patients find it hard to grasp everything that is going on. Worrying takes over and can paralyse. Difficult terminology and poor or missing information from HCPs contributes to a false picture of the disease.

*"It landed when I came home that night, that this was not going away and that life was going to change. That was tough."*

## PATIENT JOURNEY LIFE WITH MS AS A PATIENT



### Contact with care – nonholistic

The contact with healthcare is important in dealing with the new life situation, especially initially at a time of crisis and questions, worry, uncertainty and angst. Many express that the neurologist is central, as the person who decides if the disease is under control or not. There is a longing for care that caters to the whole you, and a lack of mental support and training to help manage the disease. Many experience gaps in the type of information and support offered, as well as the timing.

The first meeting with a new HCP can be crucial, if it does not go well the trust in the system can be ruined for a long time.

*"Was offered a counsellor and a MS group, but did not feel like I needed it."*

*"I have not been receptive to information earlier."*

Rehab-classes of various kinds are appreciated by many – you get in touch with other similar patients, you get to know yourself you obtain tools to manage life with MS and you are offered some support for your family.

*"I had never seen a normal person with MS."*

*"My MS is my MS, but all share similar thoughts and feelings."*

Many are unhappy with their counselor meetings, often because they expected mental support and someone to talk to.

*"If you are not mortally ill you will not receive any help."*

Many 'maybes' and lack of prognosis amounts to a tough uncertainty about the future. It can be emotional to await and receive the MR results, especially if they are negative.

*"Feels like a death sentence every time I'm at the doctor."*

There is a lack of support outside of the clinical/medical.

*"I needed to get a new mental toolbox to deal with all the emotions."*



### Rehab – makes a difference

Rehab-classes are very appreciated, if given at the right time. They provide mental support (between patients), learnings of MS (through meeting experts) and help in developing strategies for dealing with life. The class seems to fill parts of the gap that many see in healthcare, when it comes to treating the whole you.

When you have first accepted the disease, you are ready to receive rehab support, by taking a class for example.

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### Treatment – the first step

The treatment is a saviour initially when you are in the middle of a crisis. The attitude to treatment over time is strongly connected to how well it works in preventing flare-ups and reducing symptoms. The medical treatment is at large placed in the hands of the neurologist. How much it affects life depends on type and frequency, if it is administered on your own or through healthcare. The treatment can disturb the daily life, but is accepted nonetheless.

With time side effects become more a topic of discussion, and are given more weight.

To medicate affects the self image and confirms that you are ill.

*"It is tough being one of those who medicate."*

*"I confirm my MS every time I take my medication."*

Life is on pause, finding a treatment is critical to be able to move on and not center life around the symptoms.

### Choice of treatment

Most have opinions on side effects, seek something established and wish to avoid injections, but leave the decision to the neurologist.

Neurologist follows guidelines and adapts to local competencies and traditions.

It is the neurologist who caters to most of the information. Many have a hard time to receive the information given, they are in a state of shock or denial.

*"Think I received material, but I threw it away – I did not need anything."*

There is knowledge that some treatments are stronger, which can be seen as positive due to higher efficacy but also as negative due to tougher side effects.

Some patients have read about connection between vitamin D and MS, when this has been brought up with HCPs it has been met with varying reactions – both prescription of supplements and contestations referring to lack of scientific proof.

Some have heard of stem cell transplantation, and also that it comes with risks.

### Living with treatment

Many are aware of side effects, and wish to limit them, but see them as a necessary evil.

*"I talked to the doctor about side effects, I can live with this – you get side effects from all the options."*

Infusion is seen as a relatively good type of treatment, even with side effects. It also gives an extra contact with HCPs as the treatment is administered by a nurse.

*"Infusion is so nice. A few hours lying there, eating something and listening to music – me time."*

*"The first time was boring, have a hard time sitting still. Felt ill before, but it was ascertained when going there sitting in a small group."*

Many know more of the disease and treatments when reaching a switch, and as such are able to partake a bit more in the discussion even though it is still the neurologist that decides.

*"I got to try the treatments my doctor recommended, one worked worse than the other, but I never questioned her choices."*

When switching, some are less risk averse and accept worse side effects, in the search for a treatment that works.

Pregnancy lowers the immune defence and enables a pause from the treatment. The pause can be very appreciated.

Decreases in frequency of infusions are not always understood by patients – they might think they get better or that it is too expensive.

*"I will now get it every ninth month as my tests looked good. Can't help but to get conspiracy minded – is it because it is too expensive? Is that why they are cutting my dosage?"*

There also those who stop totally with treatment.

*"The treatment stopped MS by 30%, had the disease been aggressive it would have flared up, so we stopped and followed up by MRs once a year."*

### Switching treatment

Changes normally occur due to lesions, flare-ups or severe side effects. Lighter side effects can hurry a switch along.

*"Went with the shots for 1.5 years, then they found new lesions. We switched to the pills which did not work well either, I also felt constantly nauseous. Just had one new lesion, they said could continue but I wanted to try something else."*

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## PERSON JOURNEY LIFE WITH MS AS A PERSON



### Relatives – they don't understand

MS does not just affect the individual, but also the people around you. This is especially tangible initially, but lasts over time. It is hard for the surrounding family and friends to understand what it is like to have MS, and they sometimes forget MS completely. The disease often does not show, which can be a good thing, but demands more in terms of communication – which adds to the list of do's for the patient.

Family and friends are also affected by the disease, but are not given sufficient or the right kind of support to enable this understanding. This becomes another frustration for the patient.

*"No information has been provided to my family, it has been up to me to inform them."*

*"I have to comfort others, they think I am going to die."*

The lack of visibility of the disease makes it hard to get the understanding needed. Patients need to remind and explain, especially the fatigue.

*"They don't understand. They say 'But you can watch YouTube on your mobile, why can't you empty the dishwasher?'*

Important that relatives understand how the disease affects, but that family and friends do not treat you differently.

*"Nice that my buddies still joke around and things are as normal."*

Some feel guilt and melancholy that they cannot live like they wished.

Parents can feel both worry and guilt, which harms rather than helps the patient.

*"Mom blamed herself, 'did I maybe smoke at some point?'*



### Work – important to come back

For many the disease affects the working life, leading to working part-time or changing jobs. On top of physical challenges linked to fatigue and cognitive problems, many experience stress around their capacity and ability to perform. As such, it varies to which extent the diagnosis is communicated to colleagues, some even skip this communication completely.

Some inform about the disease at work, as it can feel good that colleagues and bosses know and can have a chance to understand.

Some do not want to communicate at work, as it can create concerns around how you will be perceived, and you might miss out.

*"I was afraid that doors would close."*

Can be tough to work part-time if the colleagues do not understand why or forget the reason behind it.

*"Felt shame working 80%, but have accepted it now."*

Can be important to work, to not be isolated and keep a feeling of normality.

*"100% sick leave was not possible, I was cut off from society."*

Some are worried about their careers and that you no longer will be attractive in work-life. Confirmation of the opposite is important.

*"Nice that my buddies still joke around and things are as normal."*

Everyone runs into problems with the National Insurance Office, most count on this being a problem.

*"It is hard justifying absence from work, neurologists often get contradicted by the office."*



### Lifestyle – changes are necessary

For most the disease means changing your life also in the long term, after finding an effective treatment. It can be smaller changes like reducing activities or avoiding doing many things at once. It can also mean larger changes like stop doing something completely, move to another place or travel differently. The only way of doing this is by testing and getting to know your limits. It requires a certain amount of acceptance to start experimenting.

MS affects life and can demand a reactive adjustment. Some also adjust proactively to stop the disease.

*"Am sensitive to impressions. Am never in the city which is sad, love the pulse but it is too stressful and noisy."*

Adjustment can happen in different rounds, short term for temporary symptoms and long term for lasting symptoms. New flare-ups mean new adjustments, a new relationship or new job can also mean the need for new adjustment.

*"Everyday life does not work, how do I take care of household tasks?"*

Can be important to work, to not be isolated and keep a feeling of normality.

*"I am starting to realise where my limits are, I get tired."*

The disease can affect decisions around kids, travel, work, living and lead to changes in lifestyle related to exercise, diet, stopping smoking etc.

*"If I take on too much I become ill."*

Many believe stress is a contributing factor to the diagnosis and to flare-ups.

*"Those who have MS already have stress in our body, we are closer to the limit."*

Some escape