

**The Importance of Neurorehabilitation and Lifelong Sports and
Activities That Enhance Quality of Life from the
Perspective of a Multiple Sclerosis (MS) Patient**
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“If MS wants to live with me,
must to do sports”
Zsuzsanna Szilárd

Background Multiplex sclerosis MS is an illness which makes life unpredictable for patients.

Most patients have problems with gross motor control and mobility. Physical power often decreases, which makes everyday tasks more difficult and negatively impacts on quality of life. Increasing amounts of research are highlighting the benefits of regular exercise and the importance of physical activity for MS patients. I have been living with MS for almost 30 years and it has affected my ability to walk. I was offered no treatments until 2018. In order to stay active, I choose to exercise regularly.

Material and methods I have studied research covering the impact of MS on quality of life, immobility, tiredness, inactive lifestyle, exercise and deliberately choosing (sport) activities.

In addition to this, I compared these to my own experiences.

Results Researchers highlight the positive benefits of exercise programs for MS patients including improved quality of life. However, the benefits of short term exercise programs decline after such programs finish. My personal case study shows the impacts of regular daily exercise on cognitive function and mobility. I have been engaging in sports since childhood. Now, I have no deformities, my sleeping, tiredness and depression levels are satisfactory and the relapses in my disease have been avoided in general. Since my symptoms appeared, physical activity has helped me to stay active and maintain my cognitive function.

Conclusion In this article I have written about my own experiences. Regular exercise has improved my quality of life and helped me to continue to be active and independent.

I have tried to find similarities between the literature and my own experiences and highlight differences, too. I am able to do it is as I am a PE teacher, swimmer, swimming coach, a mother of two and as a MS patient. With my work I would like to help other MS patients individually plan exercises to help to keep their optimal physical condition.

Multiple Sclerosis (MS)

Multiple sclerosis (MS) is the most common chronic progressive autoimmune neurological illness which affects the central nervous system. The disease causes inflammation, axon demyelination and neurodegeneration of the brain, spinal cord and optic nerve. Damage in the central nervous system can cause many sensory and cognitive symptoms, which are often irreversible. The majority of patients experience difficulties with motor control. Functional capacity is also reduced which negatively affects the quality of life. MS patients experience lower limb dysfunction with leg

muscles weakening sooner than in the upper limbs. Poorly innervated muscles, muscle wasting, reduced muscle strength and spasticity may contribute to an inactive lifestyle, but reduced activity may exacerbate these symptoms creating a vicious cycle. (1, 2, 3, 4). MS causes mental and physical symptoms particularly muscle weakness, abnormal gait, balance problems, ataxia, spasm, trembling, paralysis, fatigue, pain, cognitive damage, loss of sight, double vision, difficulty swallowing, speech impediment, bladder and bowel dysfunction and depression. MS patients often reduce their level of physical activities due to fears that symptoms may worsen (5, 6). After 15 years of suffering from the illness, 50% of patients use some near body (splints) or far from the body (walking stick) aids (7). There are many types of physical activity that patients with impaired mobility can participate in, encompassing basic rules of sport including warm up, rest, stretching and hydration. The WHO recommends that adults should do at least 180 minutes of exercise a week and declare that rehabilitation is a very important health strategy.

MS and me

My first neurological symptom presented itself in 1993 when I was diagnosed with optic neuritis which was treated with steroids. In 2009 areas of cerebral and spinal demyelination were discovered and my clinical status showed declining progression on my ability to walk, with ataxic gait and increased right sided pyramidal symptoms. I was diagnosed with Primary progressive MS (PPSM). 5 years ago my condition relapsed causing right sided AV plegia which was treated with steroids. My ability to walk has been continuously declining and to help with this I often use aids such as splints and walking sticks. I also attend rehabilitation and physical therapy sessions and according to medical tests I cooperate well with these. I was started on Ocrevus in 2019.

I swam competitively until 2017 and today I continue to swim recreationally as well as do other exercises to maintain my current level of function. I am a PE teacher and swimming coach and I have worked at András Pető Faculty of Semmelweis University for 20 years as a professor. I am committed to teach my students and disabled people, promote a healthy lifestyle and motivate them with my example.

MS and walking

The lower limbs play an exceptionally important role for walking which is essential in everyday life. Normal walking has two phases. One is the longer stance phase, the other is the shorter swinging phase. Walking is a natural movement and is automatic with normal function of the nervous system. Walking is a cyclical movement consisting of repetitive motions of step cycles. However, in MS patients there is often an imbalance of this symmetrical movement. Information transfer between nerves and muscles is weakened due to the damaged myelin sheath. This interrupts the normal continuity and cyclical motion of walking, and the movement is no longer automatic. Patients may experience changes to their walking, for example imperfect or missing foot take off and shortened pace. On the affected side the stance phase is shortened while the opposite limb swinging time and stride length changes which may result in a limp. Unnatural landing and joint movement is often characteristic

and disharmonic walking can cause wider deformities. Walking distance is shortened and patients may require several rest stops even when walking short distances. In many cases, decreased in function can be assisted with the use of aids such as walking sticks, crutches, zimmer frames and orthosis. Mobility can be improved with practice/repetition of walking movements. This is reliant on patient-teacher feedback, corrections and shadowing. For those patients whose mobility is significantly worsened because of MS, walking can be improved with the support of walking aids such as walking sticks, or through strengthening over cyclical movements using a bicycle or elliptic training.

In this case we compensate movement gaps caused by the brain function deficit or muscle fatigue caused by nerve tiredness (9).

MS movement barrier and exercise

Active MS makes patients inactive. Until the 1990s, doctors advised against physical activity in patients with MS as it was thought that the physical strain may make motor symptoms worse. However, since then, a study has shown worsening physical impairment in patients where physical activity was limited compared to those who had no restrictions (10, 11). Today, multiple studies support the idea that inactivity contributes to impaired motor function. Despite this, due to concern about worsening symptoms, some patients may still be physically inactive which is associated with increased mobility impairment, abnormal walking, lack of stability and poor quality of life (12, 13, 14). Current research suggests that in MS patients, personalised activity plans can significantly improve muscle function, flexibility, stability, fatigue, and respiratory function (15). In MS patients with moderate motor impediments, a study involving medium intensity exercise found this to be associated with improvements in movement, functional capacity, and fatigue levels (16). A third study concluded that to improve motor function, exercises need to replicate complex movements such as walking or running. Exercising one muscle group or joint in isolation is insufficient (17). Researchers investigating the effect of active sport in MS patients found that aerobic fitness is below average compared to healthy people but can be improved with exercise (18). Low or medium intensity aerobic exercise improved aerobic fitness and reduced fatigue in patients with mild, moderate and severe MS. Stretching and relaxation can help improve muscle pain and cramping which are a consequence of inactivity and shortened muscles caused by impaired nerve-muscle connections. Patients should consider that exercise can increase their body temperature (19). Tiredness is the common and significant symptom experienced by MS patients. Tiredness can worsen other symptoms of MS including pain, depression, anxiety, and cognitive dysfunction (20, 21, 22). Tiredness may also limit or withdraw participation in activities or result in long periods of recuperation following activities (23, 24, 25, 26). Research suggests that regular exercise is associated with reduced fatigue for most patients (27, 28). To assess level of physical activity, it is important to measure how active patients are in their home environment, the level of activity required for their routine daily tasks as well as other exercise in addition to this. Tiredness can be measured both objectively and subjectively. Subjective data is difficult to quantify as it is influenced by patient

reporting. Research has been conducted to collect information about physical activity levels, rehabilitation programmes and daily experiences with the aim of improving quality of life and optimising physical activity levels for patients. (ReSpAct). (29, 30). Researchers did not find any connection between tiredness and the amount of physical activities done at home (31). Data showed activity levels in the morning are significantly lower with minimal walking time. Peak activity levels appeared to be in the afternoon when more static activities (standing, sitting, lying) were low. Walking capacity tests showed no connection between evening tiredness and walking habits. Reduced physical activity levels may be a symptom of MS, like depression, muscle weakness, fatigue, spasm and ataxia (32). In a study by Marijke Jansen, researchers assessed active and inactive periods during the day and found they were dependent on many factors including living conditions, working habits, family, and free time. This helped researchers and patients integrate exercise into activities of everyday life and create exercise programs for the individuals (33). In their study, Ulric S Abonie and Co found that MS patients may consciously limit exercise to avoid more extreme tiredness. This study found a negative connection between fatigue and health related quality of life (34). Patients should be informed about possible individualised therapies, encouraged to do regular exercises, and live an active life (35). A further study points out that improvements in motor complex function can be achieved with exercises imitating walking running (36). Despite limited evidence supporting the effect of exercise on neurological changes in MS patients such as demyelination and neurodegeneration, many researchers suggest that patients should incorporate exercise programmes into their daily lives (37). Although ongoing research continues to seek the positive effects of regular exercises on neurological pathology in MS, there is currently no proven evidence of adopted mechanism's benefits (38).

MS and the possibilities of improving quality of life

There are many therapies available to treat MS which help reduce symptoms and stabilise quality of life. Health care professionals may offer multiple therapies including pharmacological and non-pharmacological such as walking aids and rehabilitation. Analgesics are commonly offered for pain relief, but evidence suggests that sessions with qualified physiotherapists or other professionals can also improve mental and physical wellbeing, which may also improve pain perception (39). Many aids can help patients mobilise and support exercise. Improved accessibility allows those with disabilities and mobility impairments to move around freely. Research and my own experiences demonstrate the positive effect regular exercise has on MS patients (40, 41). Despite evidence, the use of exercise in helping manage MS is not currently widely encouraged (42). Many studies have demonstrated that MS patients would like to be active. However, obstacles such as environment and lack of information may restrict patients from engaging with regular exercise or attending therapy sessions (43).

My experiences of sport and physical exercise as an MS patient

A key aim of physical exercise is to promote happiness. Regular exercise has been a part of my life since childhood, and since being diagnosed with MS, I have continued

exercising. My choice of sport is limited so I now have different aims and goals. I avoid activities which require large amounts of effort and concentration, like running and walking, but I attend physiotherapy and conductive sessions. I also attend walking improvement clinics where the movements of walking are practiced carefully. In my experience, time of day does not affect my ability to walk, but physical and mental strain during the day does. Using my expertise, I plan my daily exercises. I begin sessions with a thorough warm up, ensure exercises are executed accurately and finish with stretching exercises to promote the best outcome from the session. As I do exercises regularly, my body is used to the strain. However, I can't do the same amount of intensity or even more every day. I plan my exercises carefully, but I am not able to use programmes developed for elite athletes, and I must adapt programmes to my daily form. Some days, my body only allows me to do low intensity or short training. On these days, I prefer stretching exercises, small movements, breathing exercises or low intensity activities to stimulate my circulation and breathing. During the Covid-19 pandemic, leisure centres were closed which limited my ability to engage with these exercises. Despite this, I found other places to do exercise such as at home or outdoor gyms in parks. Medium intensity exercise makes me feel comfortably tired and slightly raises my temperature which does not concern me. I plan my training sessions to promote long time improvements in my strength, condition, endurance, balance, and coordination. Through stretching spastic muscles and increasing blood flow, I can increase the mobility in my joints and possibly delay pain and spasms. With this, I can maintain my physiological posture and improve my balance.

I try to avoid exercises that require significant effort and anaerobic exercises which encourage muscle pain and spasticity. I also avoid exercises which cause me to lose my balance and exercising in conditions which are too hot or cold. Low intensity exercises such as back exercises, yoga, or those supported in water (swimming water aerobic) are excellent in improving my muscle strength and tone. It is important for people to incorporate exercise into their daily routine. I tend to do my medium intensity exercises in the morning and get on with my day. Because of this regular consistency, the tiredness and pain caused by my MS are mild. In my experience, taking the first step to start doing exercise is often the hardest part, just like it is for everyone else. Whilst training might be hard, once I am past the first step, exercise is a joy to do and afterwards I feel much better and I am less tired. It is an excellent strategy to improve fatigue, help with everyday tasks and optimize general physical activity. I cannot participate in sports which require shifting movements, with the exception of swimming, where the water allows me to move pain and struggle free. Sports which don't require walking movements give me the greatest satisfaction and development. These include back exercises, yoga, strengthening and conditioning sessions in the gym, running movements in water, as well as machines that make cyclical movements, such as the cross trainer, bicycle, or outside gyms in the parks. I don't need external motivation to take part in these, my internal driving force makes me do exercise everyday. As well as this, I participate in physiotherapy, rehabilitation sessions, water exercise classes and conductive therapy sessions. To avoid physical deformities and joint problems which might be caused by mobility impairment and asymmetrical walking, I need to wear splints for support. I also

engage in regular, medium intensity exercises for 30 minutes a day which reduce my tiredness and pain. As a result of my impaired muscle innervations, I cannot achieve major muscle gains on my legs, but my upper limbs and torso muscles are very strong. I believe in strengthening core muscles as these form the base of all movements. I also cannot tolerate anaerobic activities but my body can cope with medium intensity movements for a long period. Whilst I feel tired after this, once I have recuperated my body seems to be working better. This helps me to independently complete daily activities including dressing, walking and lifting which improves my quality of life. I pay close attention to stretching exercises after training sessions as these help improve joint mobility and calm my body down. I also practice breathing exercises and eye exercises. Muscle activation patterns can only be effective if they are practiced in a safe environment.

Planning exercises for MS patients

Motor skill movements can be improved by regular, appropriately intense, personalised exercises (44). Exercise and physical rehabilitation is a safe and effective tool for managing both relapse remitting MS (Relapsing-remitting MS, RRMS) and primary progressive MS (Primary progressive MS, PPMS).

Methods of rehabilitation include creating a stress handling plan, conductive education, sports therapy, physiotherapy, hydrotherapy, massage, cognitive psychotherapy, dietitian advice, and alternative therapy (45, 46). The advice of a dedicated specialist such as a coach, PE teacher, rehabilitation expert or physiotherapies is needed.

There are general directions which can be followed when planning exercises for MS patients. These directions should be adapted to meet patients' needs, ability, and preferences (47). Regular medium aerobic exercises which improve quality of life can improve the general wellbeing of patients as well as promote relaxation and recuperate the body and soul. It is advisable to choose exercises which are possible with limited ability or potential mobility impairments. Before starting exercises it is important to talk to the patient. Goals have to be set and natural physical changes which occur during physical exercise such as sweating, increased breathing and circulation changes should be discussed.

It is important to test the patient's physical and mental state during an initial meeting, including breathing and circulation issues, metabolism, mobility, fitness, neuromuscular status and function competence.

Some of the most common symptoms of MS are balance and coordination issues, and this factor must be considered when choosing exercises. If exercises do not improve mood or are dangerous, they are unlikely to be effective. The quality and quantity of the daily exercises depend on the current physical and psychological-emotional status. The quality of the exercise determines the intensity and length of the activity. Exercises must be planned for the individual. Sometimes, extra hard sessions can be done. Some studies highlights the benefit of hard exercises for MS patients (48).

MS patients typically live inactive lives and experience increased lower limb weakness compared to upper limbs. Therefore, it is important to start with exercises

which are simple, and over time gradually increase difficulty whilst always keeping an eye on the patient's ability, emphasising lower limb strength, but not neglecting the upper limbs and the rest of the body. As a general rule, patients should initially focus on big muscle groups before moving onto the small muscle groups, and similarly multi joint exercises before single joint exercises. There are many studies that report the benefit of doing exercise programs for a few weeks or months (49). Choose exercises which are simple but effective. Simple muscle strengthening exercises such as arm lifts and leg lifts in sitting or laying position are easy to remember, short, can be done every day with little effort, and can be practiced by patients with mild, medium or even serious MS. Practicing simple exercises regularly can help MS patients engage in more complex routines such as using weights, Pilates, water exercises, cardio exercises and rowing. These movements help develop gross motor functions through improved coordination and conditioning. Through completing individually planned regular exercise, patients may feel less tired and their quality of life can improve. It is recommended that patients partake in medium intensity exercise that is adequate to their tolerance 2-5 times a week. To begin with, this may start as 10-30 minutes but can later be increased to 30-60 minutes as advised. Exercises improving balance and coordination may require more attention. These can include exercises on unstable surfaces, such as sitting on a fitness ball, using a balance board or cross trainer, vibration training, exercises in water, tai chi, and learning how to fall safely. Exercises which are done in a stable sitting position such as arm and leg exercises can be more secure and effective for MS patients with balance issues than doing exercises in a standing position using weights. Strengthening training using stretch bands, fitness or Pilates balls can also be effective in standing, sitting or lying positions. If necessary, help from an expert may be required to execute exercises safely where there are severe balance problems.

Over time, safe and independent training can be achieved. Through gradually increasing intensity of whole-body exercises, improving joint mobility and muscle symmetry, movements at low or medium intensity aerobic training can improve aerobic capacity and health related quality of life. These can improve mood in mild or medium MS patients. We must mention drawbacks which are based on individual impairment. MS patients tend to complain about exercise related tiredness, temperature intolerance, and loss of balance. Sometimes other problems occur like spasticity, neurological or cognitive deficit and incontinence which can disrupt the exercise program. Therefore, in these cases special measurements should be considered. Water is an excellent environment for those who are not afraid of it, as the body strain is different in the water. Cyclical, aerobic movements such as swimming and walking in the water can be done by MS patients. If such exercises are practiced consistently with the right intensity, and also alongside land-based activities where possible, these may contribute to improved cardiovascular health and improved neuromuscular interactions. The temperature rise due to exercises can cause worry for MS patients. Exercise induces Uhthoff syndrome cannot be seen as a counterproposal as the temporally temperature rise will not stay once exercising if finished. Tiredness is only a temporary reaction, not a neurological state. When choosing the exercises, we must consider the weather - too hot or too cold affects MS patients in an undesirable way. There are several advantages of exercises in the

water, as it is the one of the most optimal environments for improving muscle function and correcting movement. However the temperature of the water can influence the effectiveness of the session.

Studies have shown regular exercises do not increase the body temperature, normal heat control- sweating, peripheral vasodilation appears. It is important to consider and plan exercises carefully, for example choosing the right clothing, time of day, temperature, and rehydration.

Conclusion

MS patients often neglect to look after their impaired muscles and joints, yet the memory of fully functioning muscles remain, and, with right exercise, if needed with a specialist, we can get closer to the old experience, body functions and structures can be restored, pain can be eased or stopped. This study is to raise awareness as there is more and more evidence and my positive personal experiences that exercise, and physical rehabilitation can achieve a positive effect on MS patients Quality of Life (QoL). Results help to keep patients in optimal physical state with individually planned exercises. Most of the studies observed a short period of time, when patients did some physical exercises and proved physical exercise should have an important role for MS patients with mild, medium or serious disease severity. For this we must conquer social and physical obstacles. We must set out guidelines to meet patients' needs and can help to defeat the obstacles of physical activities which can help to live an active life, so Quality of Life (QoL) can improve. My own experience demonstrates that regular exercise can make one achieve, but it would be better to ask MS patient's own opinion and build them into programs. With my own experience I show regular function redeeming exercise daily for 30 minutes can be very effective for MS patients. In my case, despite my MS and due to my regular exercises I have no deformity, my level of sleeping, tiredness, and depression is satisfactory. Due to my regular exercises, since my first symptoms appeared, I am still able to keep my cognitive functions, work responsibly, do sports, relax, enjoy life, even if it is sometimes restricted.

Conscientiously planned daily routine, help from an expert, and my own experience reinforces professionals the best way to improve Quality of Life is to do regular daily exercises.

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