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Readjustment: A Personal Revolution Young People's Conference 2016, Oslo



By Emma Rogan.

Readjustment

“If you can develop this ability to see what you look at, to understand its meaning, to readjust your knowledge to this new information, you can continue to learn and to grow as long as you live and you’ll have a wonderful time doing it.”

— Eleanor Roosevelt, *You Learn by Living: Eleven Keys for a More Fulfilling Life*

In May 2016, young people from across Europe travelled to Oslo to take part in the EMSP Spring Conference and join a two-day session with EMSP’s Young People’s Network (YPN).

It was an energetic in-depth exploration of the situation for young people with multiple sclerosis (MS) in Europe. The EMSP Young People’s Network serves primarily to include the voice of the young people in EMSP’s activities and ensure that EMSP represents the MS population while taking into account the diverse needs of diverse communities.

Using a phrase that encapsulated the vision for the Young People’s Network, the *Readjustment* event was an opportunity to learn from one another, share experiences and take strategic steps so that people can have access to the information they need. Information and knowledge allow them to prepare for the changes MS may bring.



Day 1: Starting the session

There was no hesitation from those in attendance - being with other young people with MS is an energising experience. The breadth of information gathered during these meetings improves their level of knowledge allowing for better informed decision-making and in turn, better health. The reality of their situations outside of the conference and the daily experiences of young people vary greatly in Europe. Breaking into groups people discussed the high standards of care in Norway (support in education, employment, social care and rehabilitation), the limited access to treatment in the Republic of Moldova and low levels of awareness of the condition in Romania. A Europe-wide perspective: the challenges include cultural misunderstanding of MS; difficulty building and maintaining young people’s groups; how to focus on achievable outcomes; expectation management of what a local YPN can provide for young people with MS and

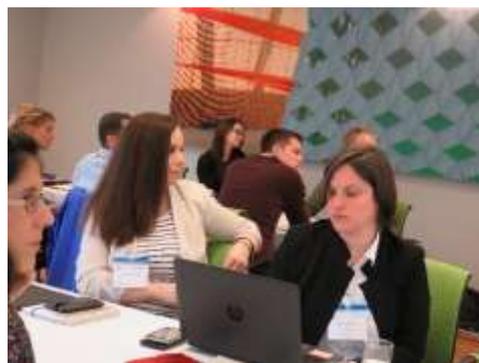
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ensuring we maintain communication with other people in the YPN in the months ahead. Despite these challenges, the network will work to overcome at least some of the issues identified using strategies that include:

- Local social groups for young people with MS
- Awareness-raising campaigns for the different countries to break the stigma and taboos in some cultures
- Online resource bank of recommended resources localised for every country
- A specific section for young people in the EMSP newsletter



What does Readjustment mean?

Readjustment is a way of dealing with the impact of diagnosis. This theme inspired conversations that delved deep into the psychological effects of chronic illness on the life experience of a young adult and the methods people use to recover. Not only are there specific MS medical implications, there are the psychosocial impacts that transcended national boundaries. No matter their origins the commonalities in the group were profound.

Habits for Health

A list of recommendations for young people with MS:

- Have a good relationship with yourself: do what you have to do to be healthy in mind and body
- Optimise wellbeing on a daily basis as part of staying ready and prepared for future events
- REACH OUT: support from your community is important – whether from family, friends or society in general
- Train yourself to overcome fear by creating healthy habits
- Well informed decisions and a positive and realistic approach to what you do will make a positive difference to your life
- Use your passion to contribute by making connections, meeting new people and learning from others
- If you are struggling with self-doubt, practical information will get you back on track
- Everything will pass and things will get better- don't give up
- Negative thinking negatively affects our life experiences.
- Invest in yourself by doing things you enjoy

BE POSITIVE

PLAN &
PRIORITISE

GET THE RIGHT
INFORMATION

One of the best ways to approach challenges is to adopt a positive attitude- this not only means “thinking positive” but actually doing things that influence a good life. Nothing can compare to being surrounded with positive people, but at the same time it is useful to keep oneself always realistic. Loving relatives, partners and friends can be some of the most important figures in a patient’s life, but they must go alongside the choice of a good, reliable and helpful neurologist/health care team.

Anticipation, adaptation and acceptance are key words to approach a life affected by MS: if you’re living life in a way that enhances your wellbeing while also anticipating moments where you would feel down and also possible relapses, you’re living a healthy lifestyle.

In any case, preparation can only be thorough if accompanied by an **adaptation** (of both brain and body) to the idea that physical functions and overall body health are destined to regress in time. Accept this with the fiercest attitude and a renewed will to live life day by day.

Stay Ready!

Maintaining a healthy life extends beyond what you do for yourself. The group reflected on the best ways to put in practice healthy habits in the daily life routine. Their advice includes being prepared to ensure that, whatever comes your way, you will be as well-equipped as possible to make the best of your abilities and resources you have access to. To be prepared is a process of living *with purpose*. When a problem arises, you know to go within and use those skills that allow you to change.

Daily habits to stay ready:

- Review what you eat- is it good for you? How you exercise- if you don’t, start an activity and consider supplements (including Vitamin D)
- Use conscious presence, get stronger by rediscovering yourself and connecting with other people
- Be willing to try new things today. Start now
- Plan and prioritise your actions
- Your mental health is your strength- speak with a therapist/professional if you’re struggling. It is possible to rebuild your mental health.
- Adopt a positive approach (use gratitude techniques, keeping a diary, meditation etc.) and seek support where you need it
- Knowledge is a powerful tool for living a good life. However, you must filter what is useful and discern what is best for you on your terms



Moving forward with the Young People's Network

We have an abundance of brilliant ideas and innovative approaches to improve the life experience of any young European diagnosed with MS. The members of EMSP Young People's Network have experienced the good, the bad, the downright horrific and the best of European healthcare and support. The work of this network is to influence change in every place where there is a member, sending the message out in ways that empower, equip and inspire young people who want to be part of the change.

We will succeed by doing the following:

- Advertising campaign- educate and dismantle the stigma
- MS- **Fact not the Fiction!** Information sheets
- Employment resources to stay in work and be financially independent
- Online resource database hosted on the EMSP website
- Use the stories and concrete plans to lobby politicians and decision makers
- Develop a personal strategy tool

