



Situation of PwMS in the EU:

- 1) A short snapshot of our campaigning**
- 2) A Swiss case study**

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A short look back to 2003

"There are hundreds of thousands of MS sufferers in the UK and across Europe who are finding life a lot harder than me but I am a strong person and fight hard to get what I should rightfully receive, while others are not in a position to be like this"



The fight of a courageous British young lady with MS insisting on her right as European citizen for the best possible therapy, found strong support from the EMSP, the Petition Committee of the European Parliament and finally of the European Parliament in total

Official presentation of the “First EU Report on MS”

18th December 2003, EU Parliament Straßbourg



- Presentation: Uma Aaltonen, MEP
- Discussion with MEP's

Results

Uptake of the MS Report by 240 MEP's in the European Parliament (Petition 842/2001) concerning the effects of discriminatory treatment towards persons with MS, within the European Union (2003/2173 (INI))

Structure of the “CODE of Good Practice” and its related European Guidelines/Consensus papers

A **political statement** reflecting “state of the art” practice outlined in the following **European Guidelines**:

- Disease modifying therapies (e.g. Interferons)
- Symptomatic treatments (e.g. against bladder problems)
- Rehabilitation
- Palliative Care
- Principles of Quality of Life (developed by MSIF)

http://ec.europa.eu/health/ph_information/dissemination/diseases/neuro_en.htm#monitoring

Supported by epidemiology facts and figures available on an interactive web database (www.europeanmapofms.org)

Letter in 2011 from Members of the European Parliament to all EU Health Ministers

- Was the Code of Good Practice used as a benchmarking tool?
- National initiatives or participation in MS related medical research activities?
- Patient empowerment and involvement?

Pocket Guide to the CODE

For dissemination

targeted to all suitable decision makers and multipliers in national health care- and social security bodies



Key Concerns for EU Patients

1. Unacceptable time delays for new therapies after market authorisation by EMA
2. Huge variations in access / reimbursement among & within Member States (“post code lottery”)
3. Rising costs of (innovative + personalised) treatments and healthcare services
4. High risk to loose employment in peak career time

Job retention for PwMS: Swiss Case Management Programme - External background

- MS is the most common neurological disease effecting young adults
- The development of MS still is unpredictable
- The social security systems continuously reduce coverage
- Employers are lacking qualified employees and yet are afraid of the costs an employee with MS might cause
- Insurances and pension insurances are facing high costs for younger people becoming unable to work (20.000 persons p.a. in Switzerland)

Background for people living with MS

- 80% diagnosed at the age between 20 and 40
- Diagnosis „MS“ hits in decisive phase of life (family, job...)
- Whole family system faces uncertainty and fear
- Public and neighborhood pressure against “lazy welfare cheaters” hits people with MS in specific (e.g. fatigue)
- Often humiliating quarrel with bureaucracy and institutions
- Problematic situation in the job forces people with MS to reduce workload or desperately quit job (fatigue, incontinence)
- Staying in the job in most cases has an very positive impact on the development of MS

Objectives

- **Persuade decision makers (i.e. employers and politicians) to support and implement an innovative care management programme based on the Swiss MS Society model**
 - Providing a wide range of services to enable people with MS to achieve the highest possible degree of independence and quality of life
 - Contribute evidence to the growing need for policy makers and employers to focus resources on ensuring PwMS find & stay employed
- **Highlight the importance of ensuring PwMS stay employed to improve QoL outcomes whilst also reducing costs to healthcare systems and society**
 - Build cost/business rational for ensuring investment and resources already invested in PwMS is maintained and enhanced
 - Showcase how reintegrating PwMS into the workforce can elevate pressure on national pension funds and invalidity insurance

Making It Happen

- **STAGE ONE:** Build case management programme based on Swiss MS Society model and work with local EMSP member organisations to roll out to a set percentage of registered members

SWISS MS SOCIETY: CASE MANAGEMENT PROGRAMME CONDITIONS

- A career plan is developed which includes career objectives, timeframe, and supporting resources
- A case manager is assigned, but other members are also involved in the career plan development which includes neurologist, employer, family member(s) and insurers
- Key considerations:
 - An individualised approach must be developed which takes into account disease progression and rehabilitation after a relapse
 - Must bring together the common interests of those involved without pushing the PwMS too much

Making It Happen

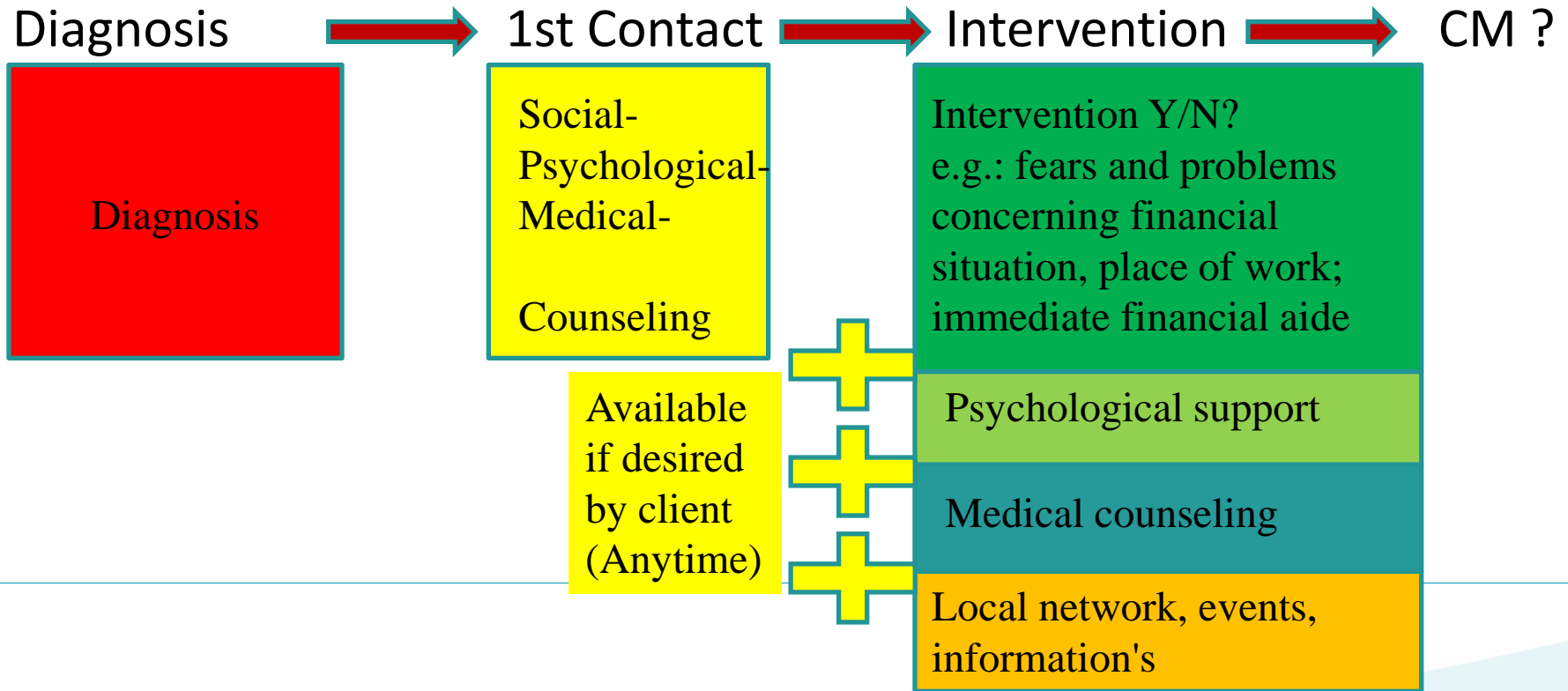
- **STAGE TWO:** Collate learnings from case management programmes implemented including those by industry (i.e. Novartis) and identify an opportunity for publication

PUBLICATION OPPORTUNITY:

- Provide brief summary of consolidated cost/benefit analysis: what continued and tailored employment offers to:
 - Society
 - People with MS and their carers
 - *Sources HE literature, MSIF summary review, recent and upcoming national analysis*
- Rebuilding the careers of PwMS
 - Care & case management programme
 - How the programme has been applied by local EMSP organisations including Swiss MS society and industry
- Publication opportunity yet to be identified - - publication manuscript to be available as a standalone document

Integrated Case Management

General process



Financial aspects: costs

Costs per client :

– Case Management approx. per case:	6.000 CHF
– Extra costs (time) neurologist:	1.750 CHF
– Retraining:	5.000 CHF
General costs per client in CM	12.750 CHF

With or without CM:

Cost for tools, modifications

Financial aspects: benefits (1)

Sample calculation:

Employer and daily benefits insurance:

1 employee can continue to work for 10 more years with an workload of 50%, income

80.000 CHF/p.a. incl. social benefits: *40.000*

CHF one year (1st) (no sick leave)

Financial aspects: benefits (2)

Sample calculation (Switzerland):

Employer indirect via pension insurance (company premium):

1 employee 10 years 50% pension (instead 100%)
with an yearly pension of 40.000 CHF: *200.000 CHF
in 10 years*

State pension insurance:

1 employee 10 years 50% state pension:
160.000 CHF in 10 years

e.g. the Swiss Case management tool : No miracles but results for about 50% PwMS

- Neurologists found that in general 50% people living with MS can benefit from participating in an CM
- Clear indication for an positive impact of CM on the general health status
- Improvement of the situation in the job, for employee as well as for employer and colleagues
- Personalized retraining kept know-how in the companies (60%) or in the general work-process (40%)
- A more stable and more predictive social situation is established

The need of “holistic budgeting” and higher priority of health in national budget decisions

“The cost of diagnosis and treatment of MS at the earliest possible stage (but definitely with -in the window of the first five years of the disease) can be offset by the reduction of societal costs in the long term, with considerable gains in the quality of life for PwMS at the same time.”



Dr. Gisela Kobelt at EMSP- MSID Conference Brussels, May 2007



*Thank you
for your attention!*

Time for Q&A?