EUROPEAN MULTIPLE SCLEROSIS PLATFORM
ANNUAL CONFERENCE
1-4 MAY 2003, MALTA

POST CONGRESS PAPERS

WEBSITE CONTACTS

EM SP

European Multiple Sclerosis Platform

www.ms-in-europe.org

multiple sclerosis
international federation

Multiple Sclerosis International Federation

www.msif.org

European Neurological Society

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ABOUT THE EUROPEAN MS PLATFORM

European Multiple Sclerosis Platform Annual Conference

Quality of Life for Persons with Multiple Sclerosis
What Rehabilitation Can Really Do

The European Multiple Sclerosis Platform (EMSP) was formed in 1991 and has five main aims:

- *To promote actively the interests of people affected by MS on an European level*
- *To act as a focal point of liaison with relevant EU bodies*
- *To facilitate joint programmes and skill shares between MS societies*
- *To procure and disseminate information being of interest for our members*
- *To encourage research related to MS both in medical and non-medical areas*

We currently have members from 29 MS societies all over Europe – from Greece in the South to Iceland in the North – from Ireland in the West to Latvia in the East.

The conference this year focuses on rehabilitation and how it affects the quality of lives of persons with MS.

Its aim is to target people with MS and their spouses, carers (both professional and volunteers), MS nurses, social workers and other health care professionals from the MS Societies and MS centres (RIMS), medical experts (neurologists, psychologists and others).

To get in touch with us about any aspect of our work, please contact the President, Peter Kauffeldt or the Secretary General, Christoph Thalheim, at:

Christoph Thalheim
Secretary General
European MS Platform
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BELGIUM
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Pharmacoeconomics of Disease Modifying Drugs in MS in the Czech Republic

Delegate List

CONGRESS PROGRAMME

Thursday 1st May 2003

16.00-17.0	Pharmacoeconomics of disease modifying drugs in MS in Czech Republic	Eva Havrdova
17.00-18.30	Examples of “best practice” – How MS Rehabilitation Centres were set up in Estonia, Slovenia	Mateja de Reya Katrin Gross
19:00	Welcome Reception	

Friday 2nd May 2003

Topic of the Morning: What Rehabilitation in MS Really Means
Chair:
Jurg Kesselring

09:45-10:00	Welcome and Official Opening Introduction to the European Year of People with Disabilities	Peter Kauffeldt Leslie Agius Ray Busuttil
10:00-11:00	What is Rehabilitation – How to Measure its Success	Jurg Kesselring
11:00-11:45	Different stages of MS – What are the appropriate rehabilitation measures for “in-patients”, “out-patients” and and at home	Pierre Ketelaer

12:00-12:30	A new way for young “newly diagnosed” people in Denmark – Empowerment instead of despair	Brita Loevendal
12:30-12.45	Introduction to parallel workshops	Alan Cook

Topic of the afternoon: Practical Aspects of Rehabilitation

14:30-16.00			
	1.	Managing Fatigue	Marijke Duportail Belgium
	2.	MS and Emotional Problems: How to cope with These – What Kind of Support is Useful?	Marianne Bache Denmark
	3.	Telecommunication as Means for self-help in MS	Pierre Ketelaer Belgium
	4.	Communication Limitations: How to Detect and Fight Them	Guy Ganty Belgium
	5.	“Uro-Rehabilitation” An important tool to treat urinary dysfunction	Maria Lopes de Carvalho Italy
	6.	Innovative models for Physiotherapy in the UK	Jill Anderson Tracey Mifflin U.K.

17:30-18:30	How to make a workshop report lively and interesting for the plenary session – tips and hints for “rapporteurs”	Alan Cook
19.30	Gala Dinner	

Saturday 3rd May 2003

Topic of the Morning:	Report from the Workshops	Chair: Alan Cook
09:00-09.20	Report from Russia	Yan Vlasov Igor Stolyarov
09.20 – 10.15	Reports from Workshop 1, 2 and 3 Plenary Discussion	
10:45-12.00	Reports from Workshop 4, 5 and 6 Plenary Discussion	
12.00 – 12.30	Summary of results of the Workshops “Take home messages”	
12:45- 14.30	*Lunch break – Kon Tiki Restaurant – 1st Floor*	
14.30-16.30	Further developments in the Field Of rehabilitation in Europe – what Persons with MS can expect from RIMS and EMSP on a political level	Pierre Ketelaer Peter Kauffeldt Frans Nijhuis
17:30	Discover Malta tour	

Sunday 4th May 2003
Departure Day

CONTACT DETAILS OF SPEAKERS AND FACILITATORS

Jill Anderson
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Jill has been working for the MS Society since August 2001. Prior to that she was working as a physiotherapist in a community neurological team. Jill qualified as a physiotherapist in 1986 and has been working in neurology for the past 10 years. She is responsible for managing the MS Society physiotherapy service development programme.

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Marianne is head of the Counselling Department of the Danish MS Society, consisting of 20 professionals and around 50 volunteer advisors. The department offers support for members and their families with respect to medical, psychological and social issues. Marianne is a psychologist specialised in organisational psychology and also works as a counsellor for persons with MS and their relatives.

Alan Cook
Facilitator
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Alan Cook runs Collaborate, which specialises in working creatively with people in organisations through dynamic and interactive approaches to training, coaching, teambuilding, facilitation and consulting. He also works for Edgecumbe Consulting Group and the TUC's Partnership Institute as an associate, offering assessment and training in the areas of appraisal, management development, leadership, partnership working and business research. Prior to SDL Alan worked as an organisational development consultant within the NHS and other public sector areas, responsible for many years for top level management development programmes.

Mateja De Reya
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In 1996 Mateja De Reya was appointed as Secretary General of the Slovenian MS Society. As a legal adviser by education, her responsibilities as a senior fulltime staff member include execution of diverse social services for PwMS provided by the Slovenian MSS, management of rehabilitation for all PwMS regardless of their membership in the Slovenian MSS, management of human resources (employees and volunteers), preparation of plans and reports for diverse governmental and non - governmental Institutions who fund the Slovenian MSS.

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Marijke is currently Head of the Occupational Therapy Department in the rehabilitation department of The National MS Centre. She is specialised in home adaptations, adapted devices and energy conservation and has an advisory role to newly diagnosed persons with MS on these issues.

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Guy has been Head of the Speech Therapy Department at the National MS Centre since 1976. He is Chairman of the Clinical Care Committee on Communication and Swallowing Disorders for RIMS.

Katrin Gross-Paju
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Katrin is currently the head of the Estonian MS Centre. She was one of the founders of the Estonian MS Society in 1990 and also the founder of the Estonian MS Clinic in 1997 and MS Centre in Tallinn in 1999. She is especially interested in bladder dysfunction and depression in MS and of course, as a neurologist in new DMT in MS.

Katharina Grössing
European Volunteer
From Vienna, Austria.
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Katharina is a politics and theatre (film,media) student from Vienna. In the summer of 2002 she took a time-out from university and applied for an EVS volunteer project. On the 20th of July 2002 she started working for the EMSP-project of cybercafès in european MS-centres. Her project is situated in Italy in a hotel for PwMS, run by the Italian MS society, AISM. At her work place with Nia Sullivan (another volunteer) she instructs the guests how to use the internet, how to stay/build up social contacts (e-mail, chat) and to take advantage of Internet as a form of entertainment without barriers.

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After studying Neurology at Charles University, Prague, Eva Havrdova is now Head of the MS Centre there since 1996 and teaches Neurology and research work. She introduced DMDs to the Czech Republic.

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Peter has been CEO of the Danish MS Society since 1994. He was educated in shipping and industry including studies at Insead in France. The Danish MS Society enjoys the support of more than 50 000 members and regular donors. Main purposes are research, care and counselling for persons with MS and public information. The society manages two rehabilitation clinics for MS and a very accessible holiday centre.

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Professor Jürg Kesselring is the Head of the Department of Neurology at the Rehabilitation Centre in Valens, Switzerland. He received his MD from University in Berne, Switzerland, after training in St. Gallen, Lübeck, Banbury, Oxford and Berlin. Professor Kesselring stayed several times as Senior Honorary Research Fellow at the Institute of Neurology, Queen Square, London. He is Chairman of the International Medical and Scientific Board (IMSB) of Multiple Sclerosis International Federation (MSIF) and of the WHO Working Group on Multiple Sclerosis and Vice-President of the Swiss MS Society after having been President of its Medical Advisory Board for 20 years. In 1999 he was awarded with the „Goldene Ehrennadel für Internationale Verdienste" by the German MS Society.

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Pierre Ketelaer is the former Medical Director of the Rehabilitation Centre of The National MS Centre. He is specialised in neurology and rehabilitation and has been for the last 34 years active full-time in the field of MS Rehabilitation. He is, with Mario Battaglia, the co-founder of RIMS, the network of European MS Centres.

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Brita has since august 2002 been Director of the two Danish MS-hospitals. Before that she worked as counselling manager in the Danish MS-Society. Her professional background is Cultural Sociology (1978), Social Work (1982) and Social Science (1995). Keywords of interest are management, users influence, empowerment, organizational development and learning.

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Maria is a physiatrist (rehabilitation doctor) and has founded an uro-rehabilitation service in AISM Rehabilitation Centre of Genoa.

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Tracey is Superintendent 2 and is responsible for all general medical and neurological physiotherapy services in West Cumbria Primary Care Trust. Tracey qualified as a physiotherapist in 1986 and has specialised in neurological physiotherapy for the past 14 years. She is responsible for submitting the original proposal to develop the MS physiotherapy services in West Cumbria under the MS Society physiotherapy service development programme.

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Professor Dr. Frans J N Nijhuis is a Professor at the University of Maastricht in The Netherlands. He specialises in psychology of work and health with special attention to vocational rehabilitation. He is also Director of the Hoensbroeck Center for Vocational Rehabilitation.

Igor Stolyarov
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Professor Dr Igor Stolyarov has been Head of the Neuroimmunology Laboratory at the Institute of the Human Brain in St Petersburg, Russia since 1991. He is a member of the Board of Directors of the All-Russian Human Society of Disabled People and a member of the Board of Directors of the Federal Scientific Centre of Multiple Sclerosis.

Nia Rhiannon Sullivan
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Nia is a Business Studies student from Wales. Currently on a year out from her studies she is working as an EVS volunteer on the European project "Cyber Cafès for PwMS" in a hotel of the Italian MS society in Tuscany. She teaches the guests at the hotel how to use the internet and take advantage of the opportunities internet can offer.

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Yan is director general of All Russian Public Organization of invalids with Multiple Sclerosis. He is a faculty member of neurology and neurosurgery chair, Samara State Medical University. His primary work approach is complex rehabilitation of Multiple Sclerosis patients and creation and development of rehabilitation programs and target groups of people.

SPONSOR ACKNOWLEDGEMENTS

We are delighted to acknowledge the sponsors for this year's European Multiple Sclerosis Platform Congress.

The EMSP welcomes and is grateful towards all our Sponsors for their financial support. Without it this event would not be possible. However, this does not imply a preferential recommendation for any products which our sponsors may produce or distribute. The EMSP is not able to make any judgement or recommendation for treatment. Such recommendations can only be made by members of the Medical profession on an individual patient basis. Our sponsors accept and recognise this situation.

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PHARMACOECONOMICS OF DISEASE MODIFYING DRUGS IN MS IN CZECH REPUBLIC

Eva Havrdova

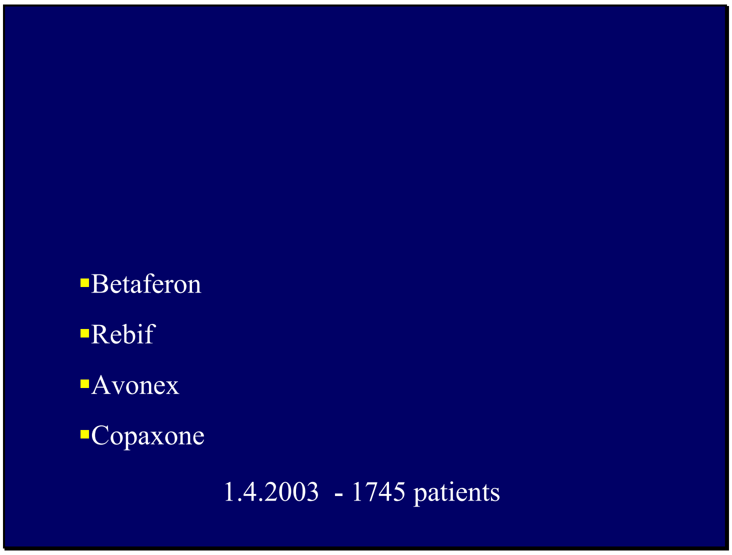
Slide 1

First pharmaco-economic data
on treatment with disease modifying drugs
in the Czech Republic

Eva Havrdova
& co-workers from Czech MS Centres

Charles University, Praha,
Palacký University, Olomouc

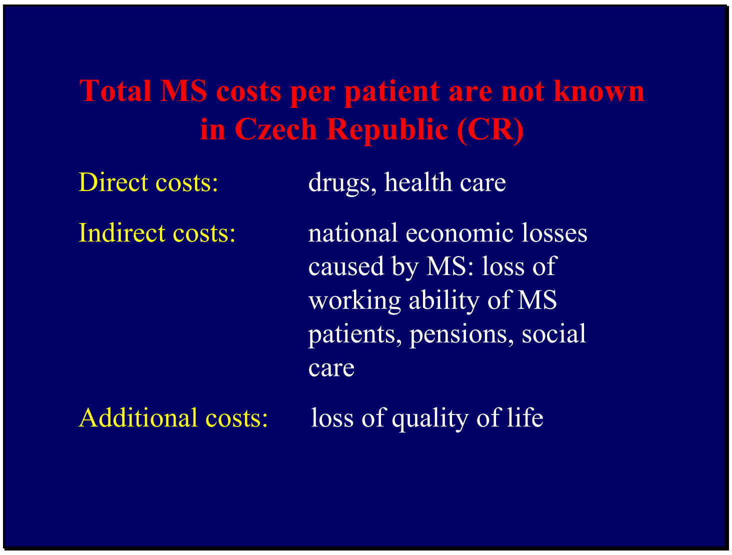
Slide 2



- Betaferon
- Rebif
- Avonex
- Copaxone

1.4.2003 - 1745 patients

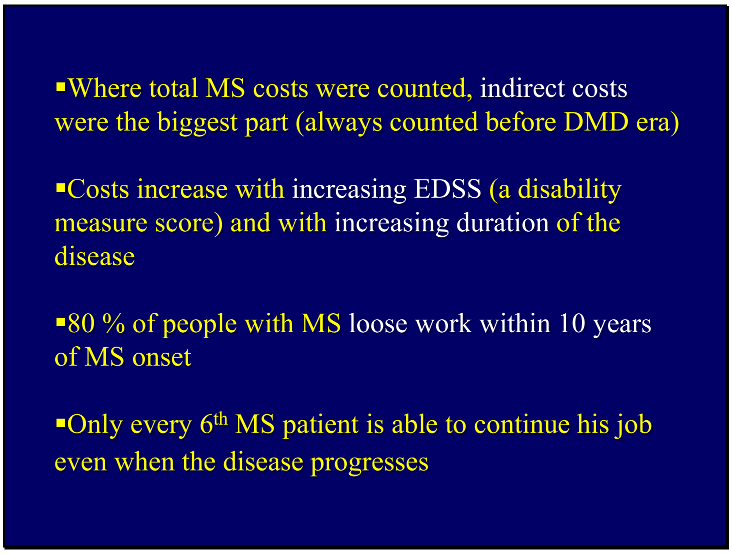
Slide 3



Total MS costs per patient are not known in Czech Republic (CR)

Direct costs:	drugs, health care
Indirect costs:	national economic losses caused by MS: loss of working ability of MS patients, pensions, social care
Additional costs:	loss of quality of life

Slide 4



- Where total MS costs were counted, indirect costs were the biggest part (always counted before DMD era)
- Costs increase with increasing EDSS (a disability measure score) and with increasing duration of the disease
- 80 % of people with MS loose work within 10 years of MS onset
- Only every 6th MS patient is able to continue his job even when the disease progresses

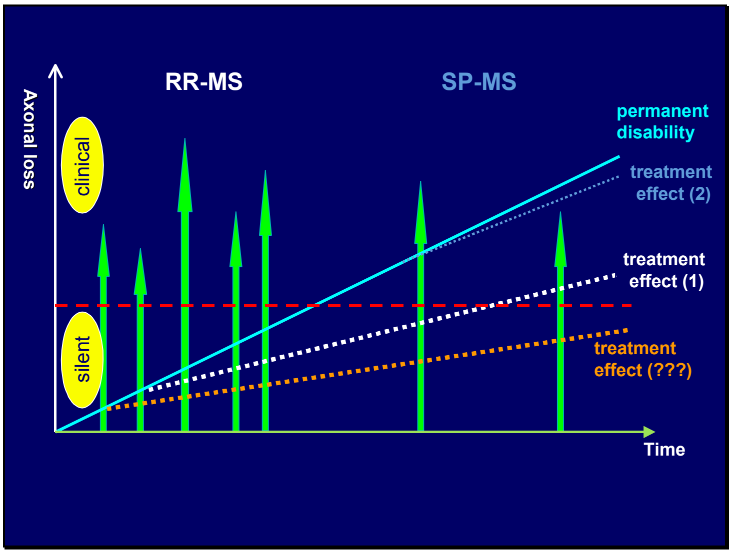
Slide 5

Criteria of Czech Neurological Society for introducing DMD therapy and reimbursement

- Definite diagnosis of MS, relapsing type
  McDonald´s criteria 2001 (diagnosis may be made after one relapse)
- High activity of the disease
  2 attacks / year or 3 attacks / 2 years
- Relatively good clinical status
  EDSS ≤ 4.5

EDSS scale
0 = no disability 7.5 = Wheelchair bound

Slide 6



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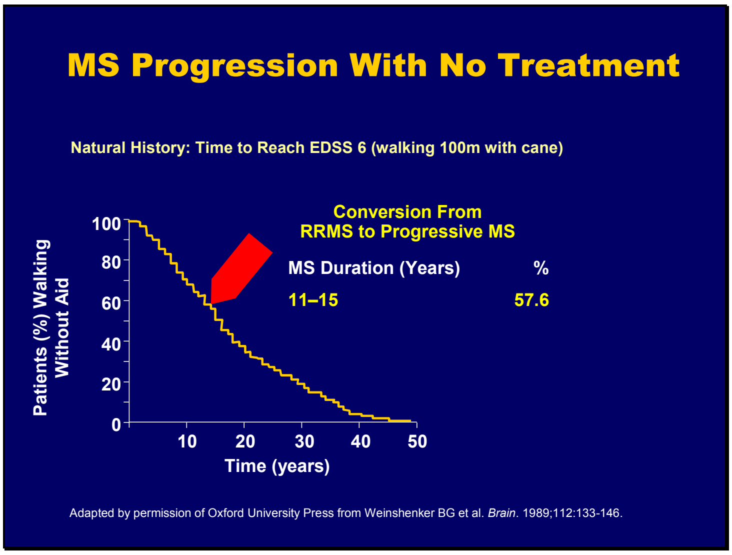


MS Progression With No Treatment

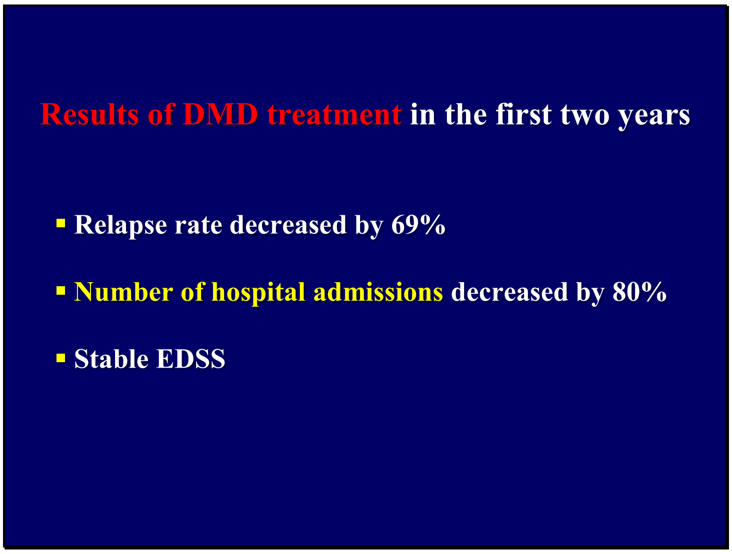
Natural History: Time to Reach EDSS 6 (walking 100m with cane)

Conversion From
RRMS to Progressive MS

MS Duration (Years)	%
11–15	57.6

Adapted by permission of Oxford University Press from Weinshenker BG et al. *Brain*. 1989;112:133-146.

Slide 8



Results of DMD treatment in the first two years

- Relapse rate decreased by 69%
- Number of hospital admissions decreased by 80%
- Stable EDSS

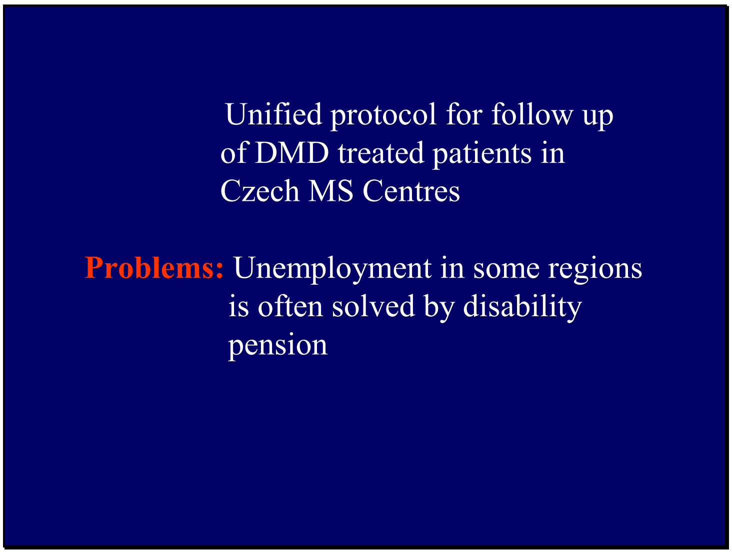
Slide 9

We need to prove not only medical but also pharmaco-economic efficacy of DMD treatment for the whole society

Collection of data from MS patients treated > 3 years by DMDs in Czech MS Centres:

- Follow up of clinical status
- Follow up of disease activity
  (attacks and hospitalisations due to MS)
- Follow up of working ability and disability development

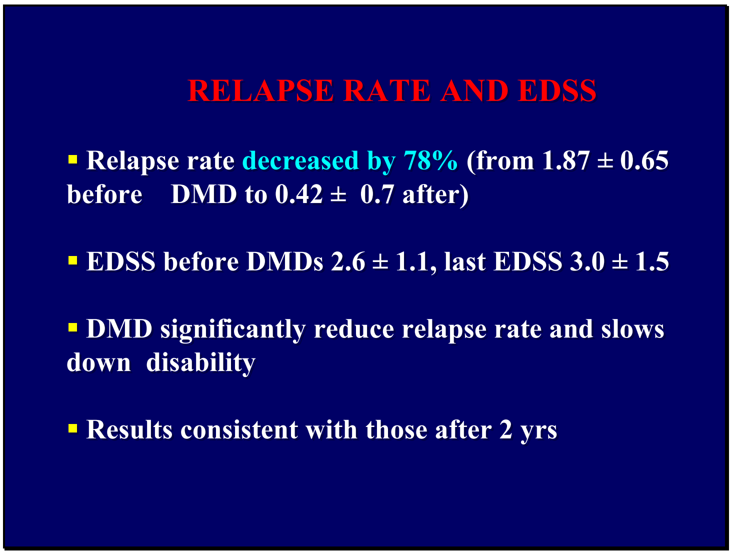
Slide 10



Unified protocol for follow up of DMD treated patients in Czech MS Centres

Problems: Unemployment in some regions is often solved by disability pension

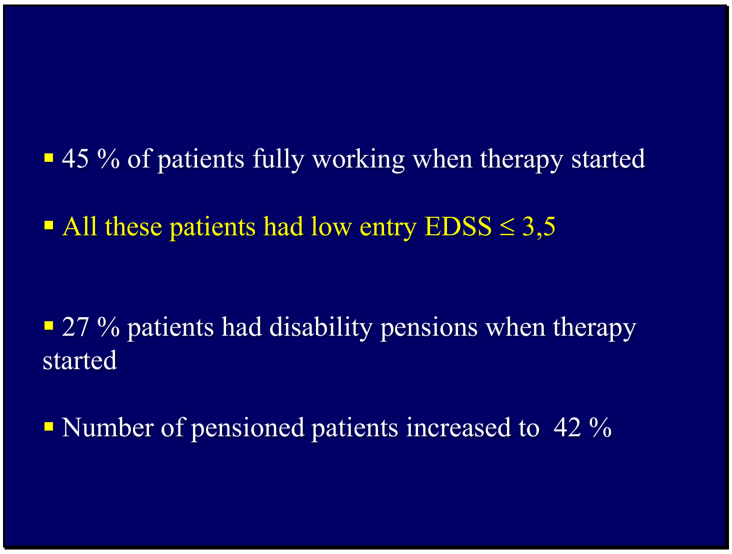
Slide 11



RELAPSE RATE AND EDSS

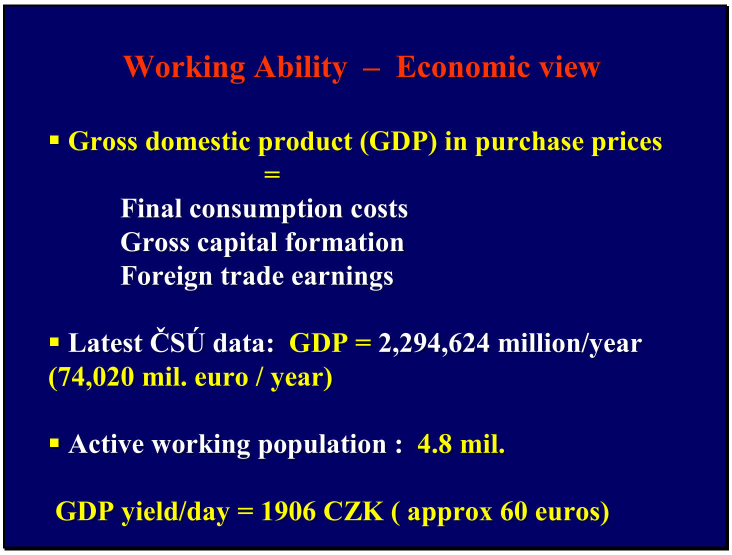
- Relapse rate decreased by 78% (from 1.87 ± 0.65 before DMD to 0.42 ± 0.7 after)
- EDSS before DMDs 2.6 ± 1.1, last EDSS 3.0 ± 1.5
- DMD significantly reduce relapse rate and slows down disability
- Results consistent with those after 2 yrs

Slide 12



- 45 % of patients fully working when therapy started
- All these patients had low entry EDSS ≤ 3,5
- 27 % patients had disability pensions when therapy started
- Number of pensioned patients increased to 42 %

Slide 13



Working Ability – Economic view

- **Gross domestic product (GDP) in purchase prices**

  =

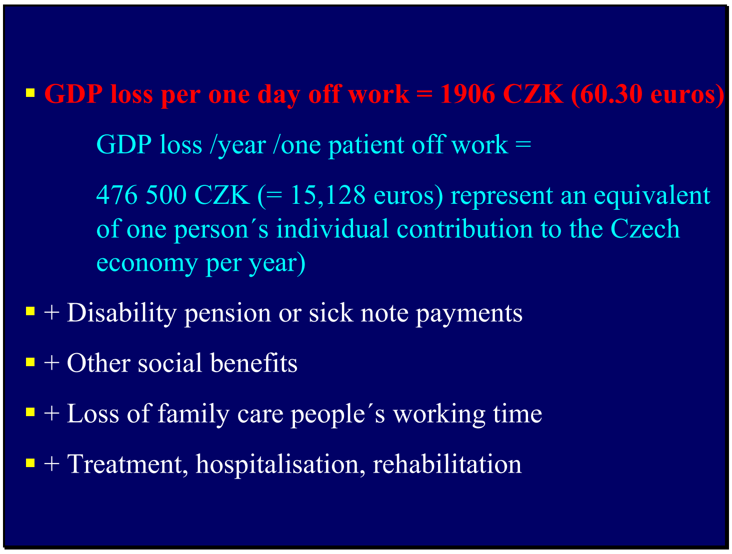
  Final consumption costs
  Gross capital formation
  Foreign trade earnings

- **Latest ČSÚ data: GDP = 2,294,624 million/year (74,020 mil. euro / year)**

- **Active working population : 4.8 mil.**

GDP yield/day = 1906 CZK (approx 60 euros)

Slide 14



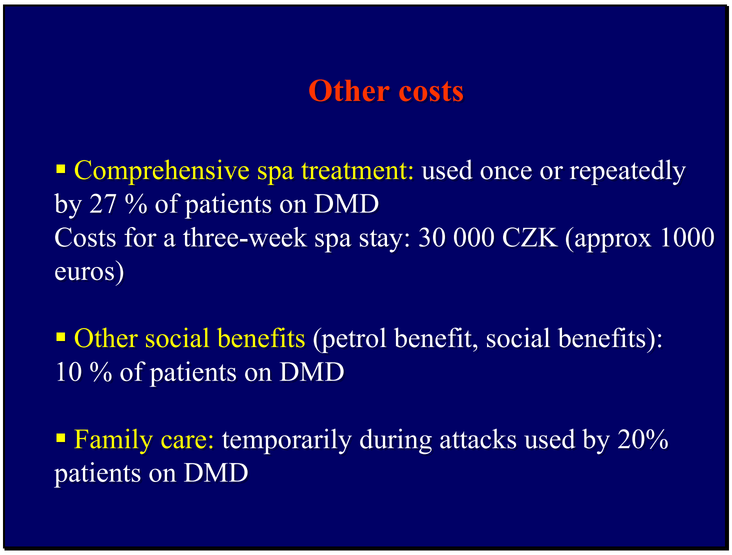
- **GDP loss per one day off work = 1906 CZK (60.30 euros)**

  GDP loss /year /one patient off work =

  476 500 CZK (= 15,128 euros) represent an equivalent of one person´s individual contribution to the Czech economy per year)

- \+ Disability pension or sick note payments
- \+ Other social benefits
- \+ Loss of family care people´s working time
- \+ Treatment, hospitalisation, rehabilitation

Slide 15



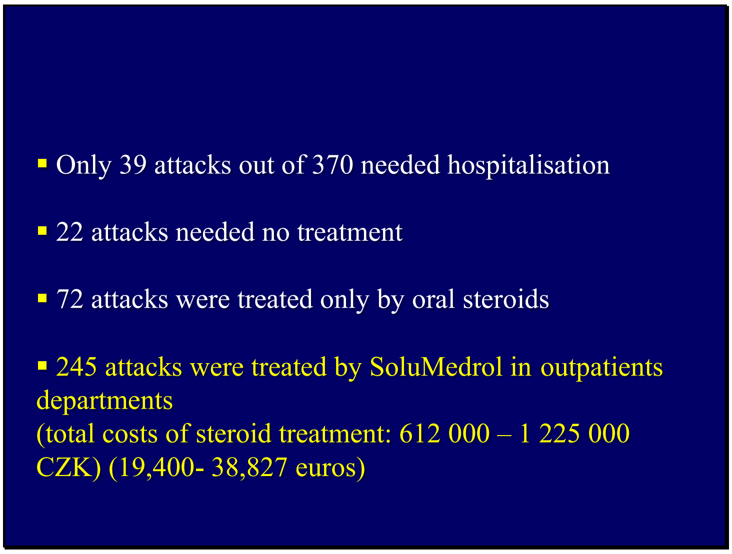
Other costs

- Comprehensive spa treatment: used once or repeatedly by 27 % of patients on DMD
Costs for a three-week spa stay: 30 000 CZK (approx 1000 euros)

- Other social benefits (petrol benefit, social benefits): 10 % of patients on DMD

- Family care: temporarily during attacks used by 20% patients on DMD

Slide 16



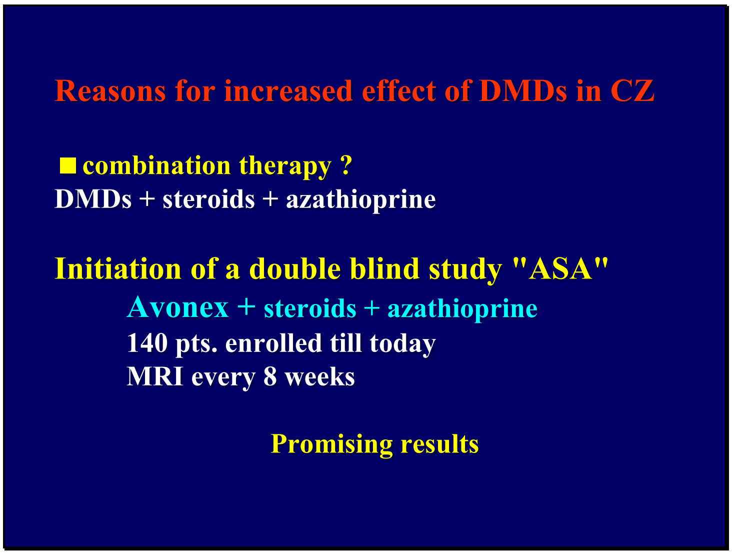
- Only 39 attacks out of 370 needed hospitalisation

- 22 attacks needed no treatment

- 72 attacks were treated only by oral steroids

- 245 attacks were treated by SoluMedrol in outpatients departments
(total costs of steroid treatment: 612 000 – 1 225 000 CZK) (19,400- 38,827 euros)

Slide 17



Reasons for increased effect of DMDs in CZ

- ■ combination therapy ?

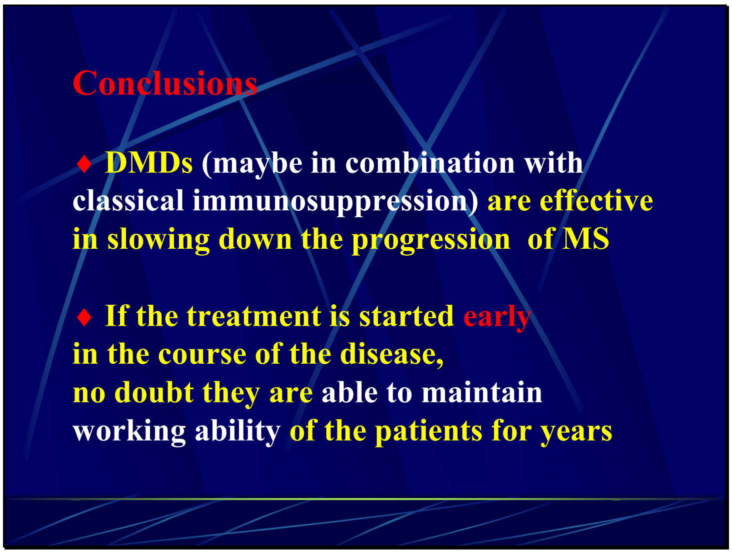
DMDs + steroids + azathioprine

Initiation of a double blind study "ASA"

Avonex + steroids + azathioprine
140 pts. enrolled till today
MRI every 8 weeks

Promising results

Slide 18

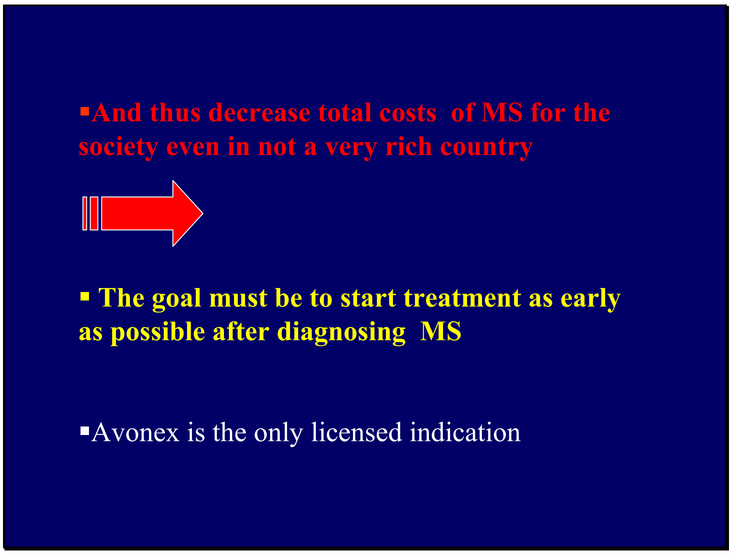


Conclusions

♦ DMDs (maybe in combination with classical immunosuppression) are effective in slowing down the progression of MS

♦ If the treatment is started early in the course of the disease, no doubt they are able to maintain working ability of the patients for years

Slide 19

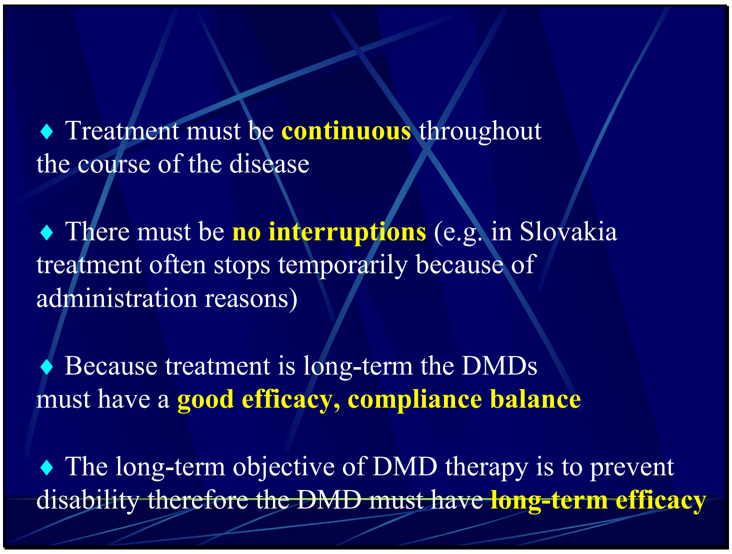


- **And thus decrease total costs of MS for the society even in not a very rich country**

- **The goal must be to start treatment as early as possible after diagnosing MS**

- Avonex is the only licensed indication

Slide 20



♦ Treatment must be **continuous** throughout the course of the disease

♦ There must be **no interruptions** (e.g. in Slovakia treatment often stops temporarily because of administration reasons)

♦ Because treatment is long-term the DMDs must have a **good efficacy, compliance balance**

♦ The long-term objective of DMD therapy is to prevent disability therefore the DMD must have **long-term efficacy**

EXAMPLES OF “BEST PRACTICE” – HOW MS REHABILITATION CENTRES WERE SET UP IN ESTONIA AND SLOVENIA

Mateja de Reya

Please look at the following websites for further information:

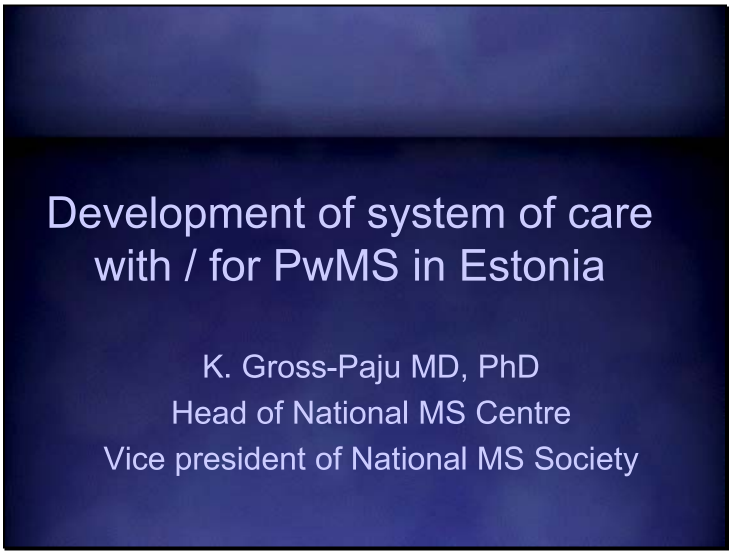
For Reha Centre La¹ko http://www.zdravilisce-lasko.si/eset.htm
For Reha Centre Topol¹ica http://www.t-topolsica.si/eng/inf.htm and for Mladika the actual MS Centre http://www.t-topolsica.si/cms.htm


15 6 '02

EXAMPLES OF "BEST PRACTICE" – HOW MS REHABILITATION CENTRES WERE SET UP IN ESTONIA AND SLOVENIA

Katrin Gross

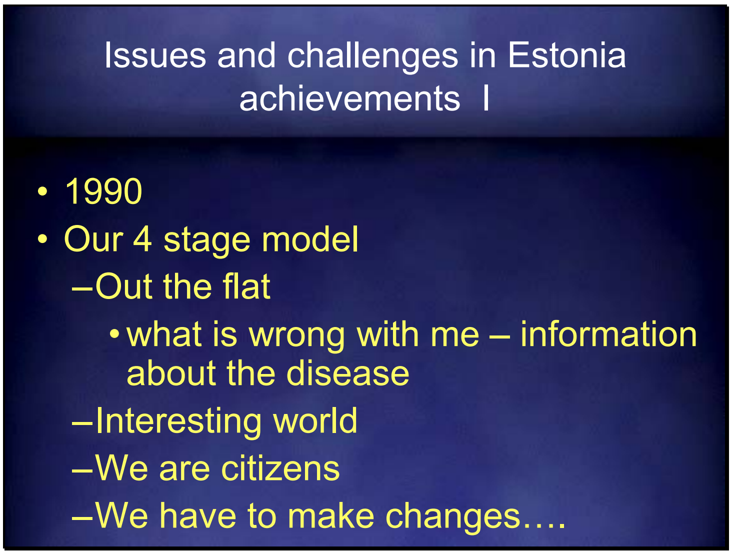
Slide 1



Development of system of care with / for PwMS in Estonia

K. Gross-Paju MD, PhD
Head of National MS Centre
Vice president of National MS Society

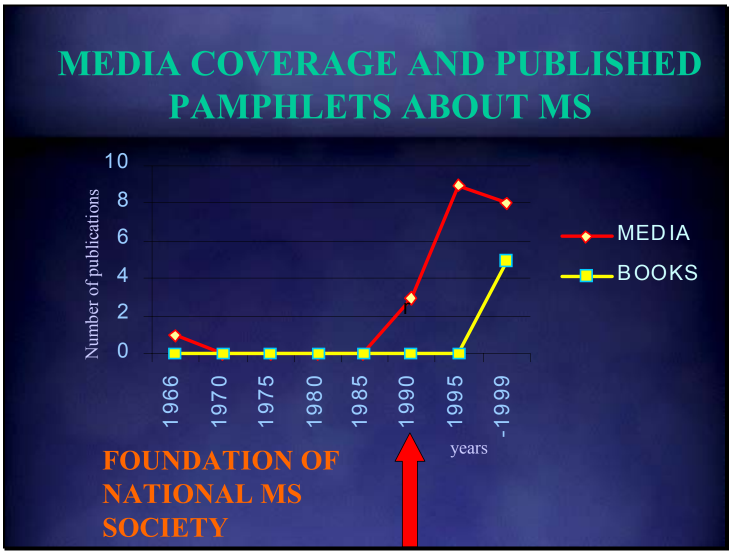
Slide 2



Issues and challenges in Estonia achievements I

- 1990
- Our 4 stage model
  - –Out the flat
    - what is wrong with me – information about the disease
  - –Interesting world
  - –We are citizens
  - –We have to make changes….

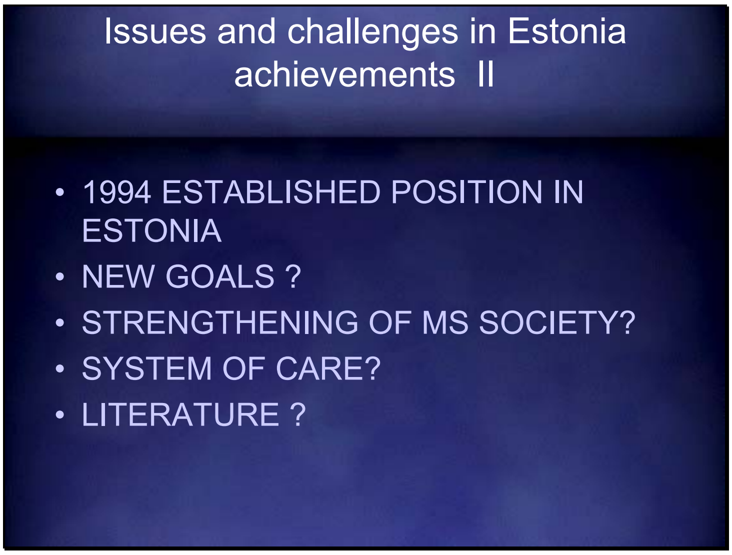
Slide 3



MEDIA COVERAGE AND PUBLISHED PAMPHLETS ABOUT MS

FOUNDATION OF NATIONAL MS SOCIETY

Slide 4



Issues and challenges in Estonia achievements II

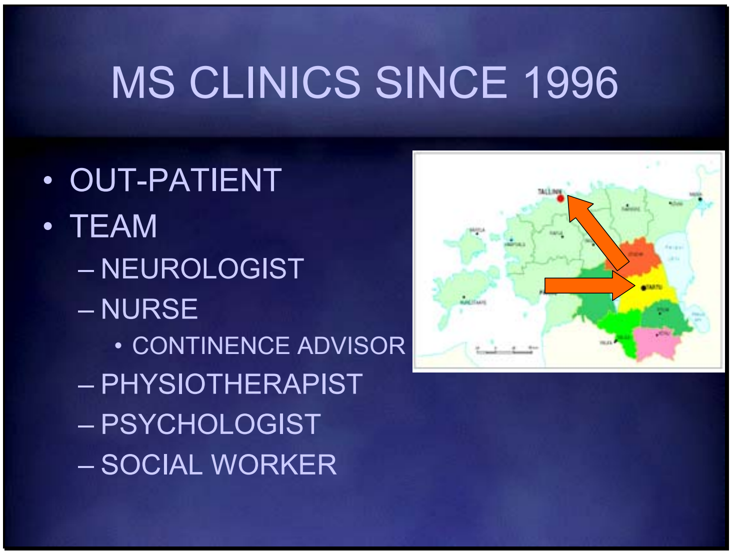
- 1994 ESTABLISHED POSITION IN ESTONIA
- NEW GOALS ?
- STRENGTHENING OF MS SOCIETY?
- SYSTEM OF CARE?
- LITERATURE ?

Slide 5

SYSTEM OF COMPREHENSIVE CARE

- 1995 PECO-MARCH
  - IDEA
    - COMPREHENSIVE CARE
    - TEAM WORK
- 1997 OPEN SOCIETY FOUNDATION
  - STRENGTHENING OF SOCIETY
  - CREATION OF MS CLINIC
  - CREATION OF MULTIDISCIPLINARY TEAM
- 1998 PHARE WITH FINNISH MS SOCIETY
- 2000 WEB PAGE

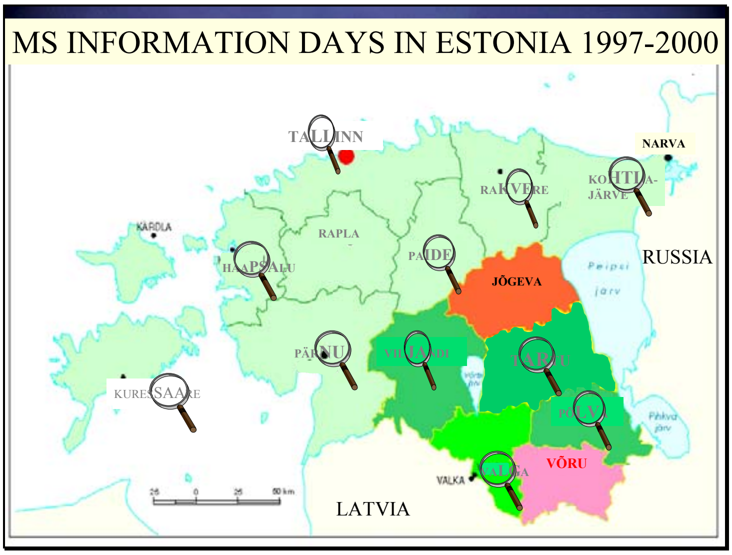
Slide 6



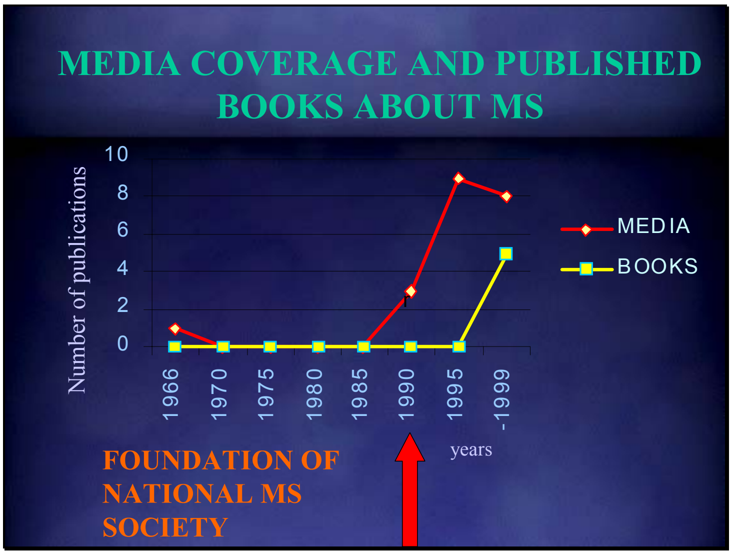
MS CLINICS SINCE 1996

- OUT-PATIENT
- TEAM
  - NEUROLOGIST
  - NURSE
    - CONTINENCE ADVISOR
  - PHYSIOTHERAPIST
  - PSYCHOLOGIST
  - SOCIAL WORKER

Slide 7


MS INFORMATION DAYS IN ESTONIA 1997-2000

Slide 8


MEDIA COVERAGE AND PUBLISHED BOOKS ABOUT MS

FOUNDATION OF NATIONAL MS SOCIETY

Slide 9

SCLEROSIS MULTIPLEX-i KESKUS

RAAMATUD

Vene keeles on ilmunud SM ja põiehäired

MINUL ON SM - TÄHTSAT TEAVET HAIGESTUNULE

Juhani Ruutiainen

ASJADEST, MIDA MA OLEKSIN TAHTNUD, ET KEEGI OLEKS MULLE RÄÄKINUD väljatrükkimiseks (pdf formaadis)

Suzanne Rogers

KOGNITIIVSED PROBLEEMID JA *SCLEROSIS MULTIPLEX* väljatrükkimiseks (pdf formaadis)

KUI MINU VANEMAL ON SCLEROSIS MULTIPLEX väljatrükkimiseks (pdf formaadis)

Pamela Cavallo, Martha Jablow

SEKS JA SPASTILISUS 1 väljatrükkimiseks (pdf formaadis)
SEKS JA SPASTILISUS 2 väljatrükkimiseks (pdf formaadis)
Eesti Sclerosis Multiplex'i Ühing

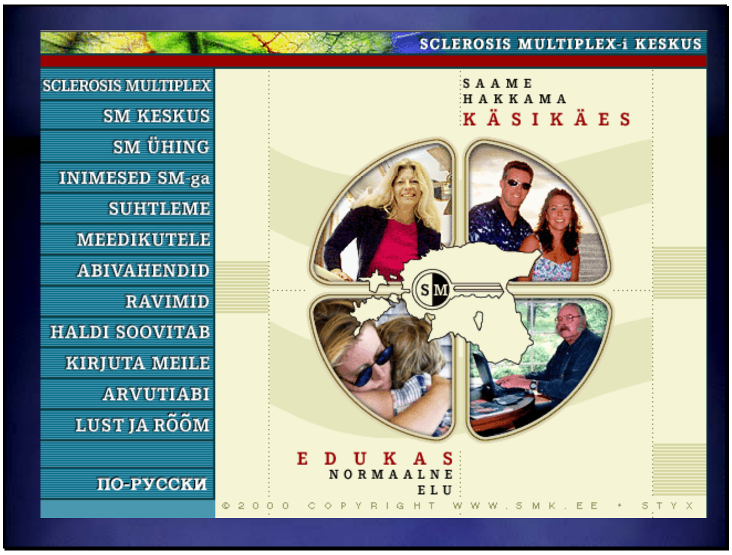
Slide 10

Нанси Дж. Голланд
Мишель Г. Мадонна

МОЧЕВОЙ ПУЗЫРЬ И РАССЕЯННЫЙ СКЛЕРОЗ

Эстонское Общество Рассеянного Склероза

Slide 11



SCLEROSIS MULTIPLEX-i KESKUS

- SCLEROSIS MULTIPLEX
- SM KESKUS
- SM ÜHING
- INIMESED SM-ga
- SUHTLEME
- MEEDIKUTELE
- ABIVAHENDID
- RAVIMID
- HALDI SOOVITAB
- KIRJUTA MEILE
- ARVUTIABI
- LUST JA RÕÕM
- ПО-РУССКИ

SAAME
HAKKAMA
KÄSIKÄES

EDUKAS
NORMAALNE
ELU

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Slide 12

MS MANAGEMENT IN ESTONIA SINCE 1999

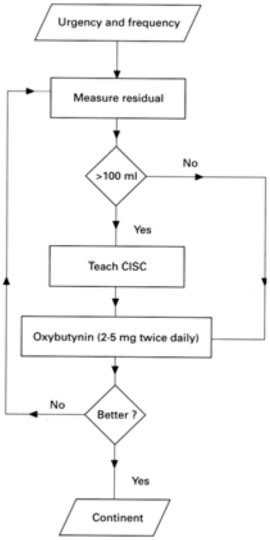
Slide 13

TEAM

- NEUROLOGIST
- NURSE-CONTINENCE ADVISOR
- PSYCHOLOGIST/NEUROPSYCHOLOGIST
- PHYSIOTHERAPISTS
- SOCIAL WORKER
- OUR NURSES/ASSISTANT NURSES
  - SKIN CARE, PRESSURE SORES
  - NUTRITION, SWALLOWING

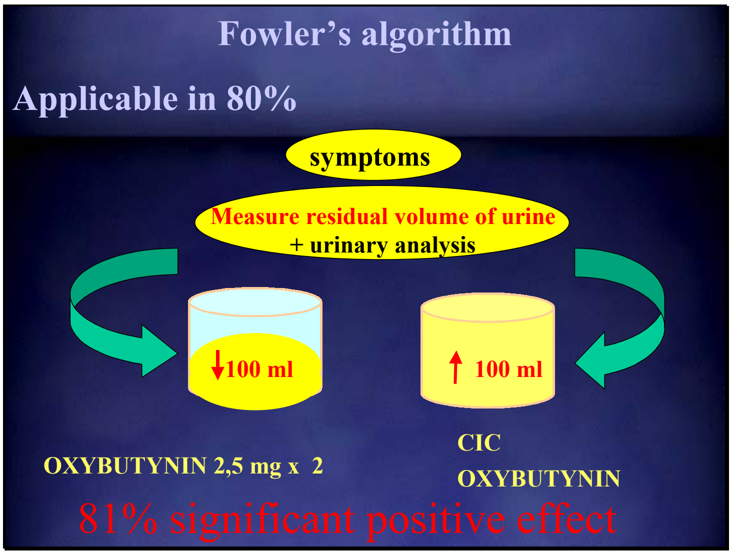
Slide 14

Fowler’s algorithm



From: Fowler: J Neurol Neurosurg Psychiatry, Volume 60(1).January 1996.6-13

Slide 15



Fowler's algorithm

Applicable in 80%

symptoms

Measure residual volume of urine
+ urinary analysis

↓100 ml

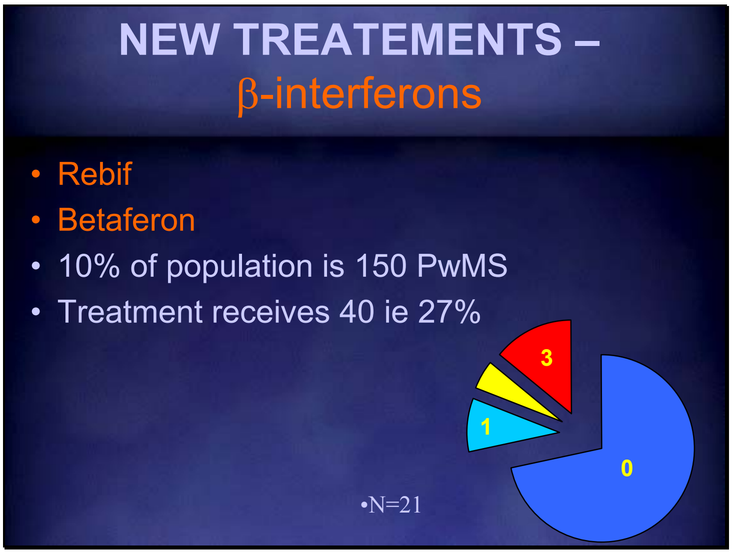
↑ 100 ml

OXYBUTYNIN 2,5 mg x 2

CIC
OXYBUTYNIN

81% significant positive effect

Slide 16

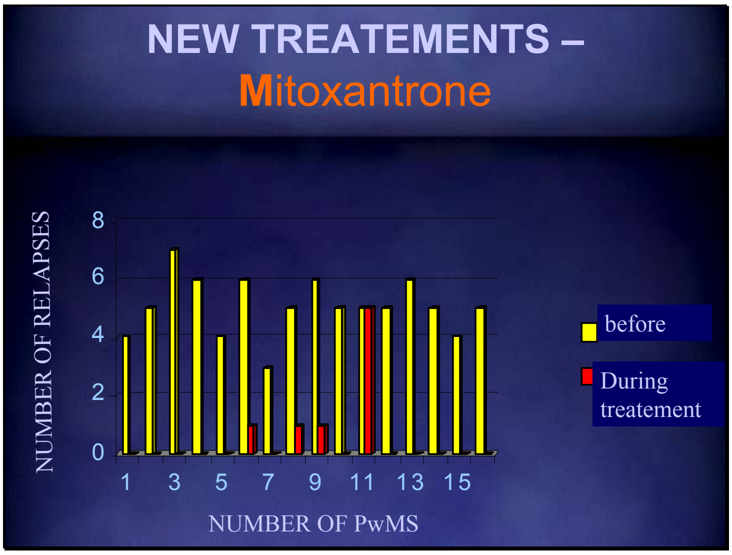


NEW TREATEMENTS – β-interferons

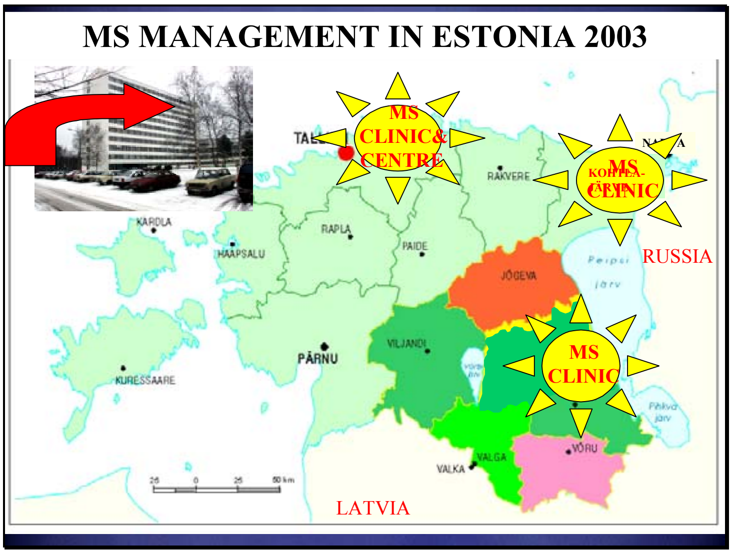
- Rebif
- Betaferon
- 10% of population is 150 PwMS
- Treatment receives 40 ie 27%

•N=21

Slide 17


NEW TREATEMENTS – Mitoxantrone

Slide 18


MS MANAGEMENT IN ESTONIA 2003

WELCOME AND OFFICIAL OPENING

Leslie Agius

It gives me great pleasure to welcome all our distinguished guests from overseas to this EMSP Congress.

It is also an honour for us to have with us today Dr. Ray Busuttil the Director-General of Health. H. E. The President of the Republic would have wished to be with us this morning but a very heavy schedule unfortunately prevents him from doing so. Nevertheless he has made a very special effort to find the time to receive a small EMSP delegation later this morning. The Minister of Health too was planning to come and give a welcome address but as is bound to happen in the health sector, he felt unwell these past few days and is taking a rest. He had already written his speech which he has asked Dr. Busuttil to read on his behalf.

The holding of this Congress in Malta is significant for a number of reasons:

- firstly, this is the first European conference being held in Malta following Malta's formal accession to the European Union only three weeks ago;

- secondly, this is the first time that our young Maltese MS Society, founded in 1997, plays host to an international MS conference

- thirdly, this meeting takes place during 2003, the European Year of the Disabled Persons.

I will start with this last point first.

It is very appropriate that Europe has dedicated this year to the Disabled Persons because Europe needs to focus in a more holistic manner on the needs of such persons.

We in Malta consider ourselves lucky in having a very active focal point for disability issues. This is the National Commission Persons with Disability, locally known by its Maltese initials, KNPD, which is under the able chairmanship of Mr. Joe Camilleri who would have liked to be with us but who has to travel.

Since its inception in 1987, KNPD has been at the forefront of the struggle for the rights of Maltese disabled persons and has registered progress in various important areas, such as:

- putting disabled persons at the forefront of all decision-making processes;
- the introduction of anti-discriminatory legislation, namely the Equal Opportunities (Persons with Disability) Act of 2000;
- the introduction of the Social Model of Disability into all areas of activity related to this sector;
- changing the language used in relation to Disability and disabled persons from a language based on the Charity model, to language focused on civil rights and equal opportunities;
- the introduction of a national inclusive education policy;
- the vetting of new building projects and major modifications from the point of view of Design-for-All Guidelines;
- changing public attitudes regarding disabled persons especially by educating Maltese youngsters about various aspects of disability and
- research and publication of various reports and booklets relating to disability.

For this year of the Disabled Persons KNPD has laid on an impressive and all-encompassing programme of activities which range from awareness-building to political lobbying, catering to disabled persons' spiritual needs, education and research, empowerment of young people and women with disability, employment, and physical access to buildings. It would take me the best part of this morning to describe even briefly what each activity entails and I have no intention of doing that. I will just highlight the principal aims of these activities which are:

(a) firstly, so that all members of Maltese society have a clear idea of what disability entails;

(b) secondly, the message that disabled persons can make a useful contribution to Society and;

(c) finally, that there is the need for a national action plan which should be realised and implemented with the full participation of disabled persons.

From the foregoing you will understand why Malta is so proud of its KNPD and why our Society treasures the advice and support received by KNPD and from Mr. Camilleri personally.

The MS Society of Malta is one of the youngest MS Societies in the world and probably also the smallest. This is because MS is not a high-incidence condition in our country. As we all know MS is generally more closely associated with climates colder than those enjoyed in the Mediterranean area.

Having said that we are witnessing an increasing number of MS cases in Malta. This is due to two factors : better diagnostic facilities particularly MRI and more neurology experts with specialisation in MS.

Although small our Society prides itself in being very active. Hardly a month passes by that we do not organise an activity, be it of a medical or a social nature, for our members. The participation rate at these meetings is high and is a source of great encouragement to us.

Our work is made considerably easier by the help we receive from various sources. The welfare state in Malta is highly developed and provides a solid safety net for persons who encounter serious health problems. The system provides not only free medical testing and hospital care but also free medicines and other assistance, some of it means-tested, other not. Through KNPD persons with disability can have regular home help, the services of a handyman when required, assistance to install a stair lift, blue stickers for parking, free car road licence. Even the ferry crossing to the sister island Gozo is offered free of charge to persons with disability.

In cases where the government safety net cannot provide the necessary support the community at large steps in to fill in the void. The Community Chest Fund is the biggest charity in Malta and is headed by the President of the Republic, Prof. De Marco, ably assisted by the indefatigable Mrs. De Marco. Together they work unstintingly to raise funds, to identify needs among the community and to help persons in need in whatever way the can.

It is natural for a small association in a small island to look beyond its shores for international linkages which will help it develop. This is what we have done in the few years we have been in existence and this is why EMSP is here today. EMSP has been most supportive towards us and I should like to thanks Peter Kauffeldt and Christoph Thalheim for their support. We are sure that the presence of so many distinguished personalities from so many countries will help us establish contacts and friendships which will prove beneficial to our membership. Now that

Malta will shortly be a full member of the European Union we intend to be more active members, especially insofar as European programmes are concerned. I am pleased to note here that we will be making a start within the next couple of months when through the invitation made to us by EMSP to participate in a European volunteer programme, we shall be receiving volunteers from Europe who will set up a Cybercafe project to help not only persons with MS but also other persons with a disability who may wish to be involved. We shall be setting up this Cybercafe facility at the Park of Friendship Malta's leading facility for disabled persons whose management we thank for their cooperation.

This is but a start.

We are confident that in the months and years ahead there will many other projects – hopefully also medical research projects – in which we could collaborate with EMSP. All I can say is that we shall spare no effort to making our collaboration a very successful one.

The theme of this year's conference ' Rehabilitation' is one of great interest to all those interested in MS. Rehabilitation has a special interest to us in Malta since this is the area that we are concentrating on. Already for the past two years we have been offering our members a subsidised physiotherapy service at home and we have just started a group psychotherapy service both for persons with MS and for their carers. We look forward to getting some new ideas from this conference about new approaches and additional services that we may offer our members.

May I conclude by saying how grateful I am to Christoph Thalheim and to Rebecca Jestico for making my task in Malta a lot easier through their professional help and advice and by expressing our delight that you have made it to Malta. We hope that we will live up to your expectations, and that the quality of the interventions and debate at the conference will in the tradition of EMSP, be of the highest quality. May I also express the hope that you will visit us again some time in the future you will always we welcome. Thank you.

OPENING SPEECH FROM DIRECTOR OF HEALTH OF MALTA

Ray Busuttil

Ladies and Gentlemen: it is indeed my great pleasure to welcome you all to Malta and to this meeting on "Quality of Life for People with Multiple Sclerosis – what Rehabilitation can do" which is being held in Malta under the auspices of the European Multiple Sclerosis Platform.

Though Multiple Sclerosis has a worldwide distribution and in the European scene it is especially common in Northern Europe, in Malta it has always been recognized that the disease had a low prevalence. Indeed as a medical student I very well remember the late Professor Walter Ganado, who was Professor of Medicine and the first Maltese physician to have a special interest in Neurolgy, claiming that the disease was uncommon and that during his practice of over 30 years, he had seen only around 15 cases of MS and all of these were cases of progressive disease which led to chronic disability. This low prevalence in Malta is borne out by a recent study published in the September 2002 issue of the journal of neurology, neurosurgery and psychiatry by Geoffrey Dean and all the Maltese neurologists. This study reports a prevalence of 13.2/100,000 of clinically definite cases, even lower than surrounding Mediterranean countries. However since the introduction of MRI, an earlier diagnosis and a number of milder cases who live self-sufficient and productive lives is being diagnosed. As you know the distressing fact about MS is that there is no curative treatment though the present medication may hopefully reduce the relapse rate. However I understand that there may be some light at the end of the tunnel. I was intrigued by a paper in the April 2003 issue of the prestigious journal Nature where researchers from the San Raffaele Institute in Milan reported that in mice, the injection of adult brain stem cells could achieve significant clinical benefit in multiple sclerosis syndromes; indeed they went on to suggest that their research opened new opportunities for the clinical use of stem-cell based therapies to treat hitherto incurable diseases in humans.

Looking at your programme, it is obvious that you are dealing with the situation of MS as it presents now. In the next two days, you will be concentrating on issues of rehabilitation and how these could greatly benefit those sufferers of MS who had progressed to chronic disability. These are the patients who greatly benefit from the support of the appropriate multi-disciplinary team made up of neurologists, nurses, physiotherapists, occupational therapists and social workers. As in other chronic conditions, these teams have to liaise with patients and their carers. The activities of support groups such as NGOs are of immense value and I am delighted that in Malta, we have such a group represented by the Malta Multiple Sclerosis Society. I can assure you that the NGOs in the healthcare field can count on the support of my Ministry and the Government.

This multidisciplinary approach to management is very much the basis of modern medical practice. We in Malta are very conscious and proud of our long tradition of service in the health care field. Though we are a small island nation, which on the 1st of May 2004 will become a full member of the European Union, we have had a Medical School since 1676. This dates back to the time when the first Chair of Anatomy and Surgery was established at the Sacra Infermeria during the reign of Grandmaster Nicola Cottoner. At that time, the Sacra Infermeria was one of the top hospitals in Europe. Just over 300 years later, since the present Government was elected for first time in 1987, my Government has embarked on an on-going reform of the Health sector. The objectives of our reforms are to decentralize and devolve the provision of services at both the community and hospital level. We want to provide and improve the quality of services; services that are responsive to patients' requirements. As part of this exercise, over the last 5 years, we have been constructing a new 825 bedded hospital, the Mater Dei Hospital, with state of the art facilities. This new teaching hospital will cater for the needs of our population and we intend to make it a centre of excellence in the Mediterranean region. This is our aim and this is our mission.

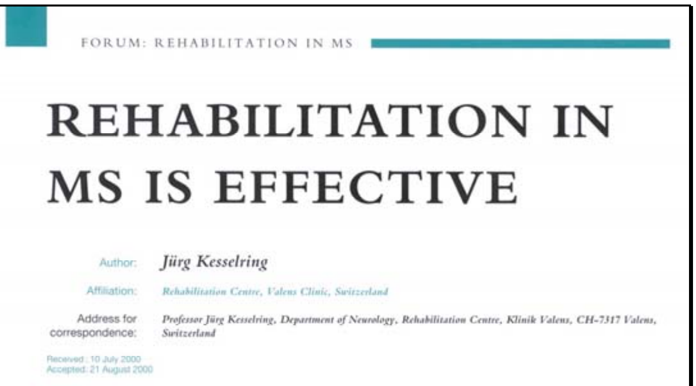
Finally, ladies and gentlemen, I would like to congratulate the Organizing Committee for holding this meeting in Malta. The outcome of your deliberations will result in an improvement in the quality of life of those who suffer from the disabling effects of multiple sclerosis. On my own personal behalf and on behalf of the Maltese Government, I wish you all a very successful meeting. I also wish our overseas guests a very pleasant stay in Malta.

Thank you.

WHAT IS REHABILITATION – HOW TO MEASURE ITS SUCCESS

Jurg Kesselring

Slide 1



FORUM: REHABILITATION IN MS

REHABILITATION IN MS IS EFFECTIVE

Author: *Jürg Kesselring*

Affiliation: *Rehabilitation Centre, Valens Clinic, Switzerland*

Address for correspondence: *Professor Jürg Kesselring, Department of Neurology, Rehabilitation Centre, Klinik Valens, CH-7317 Valens, Switzerland*

Received: 10 July 2000
Accepted: 21 August 2000

Int MS J 2001; 8: 68 - 71

Slide 2

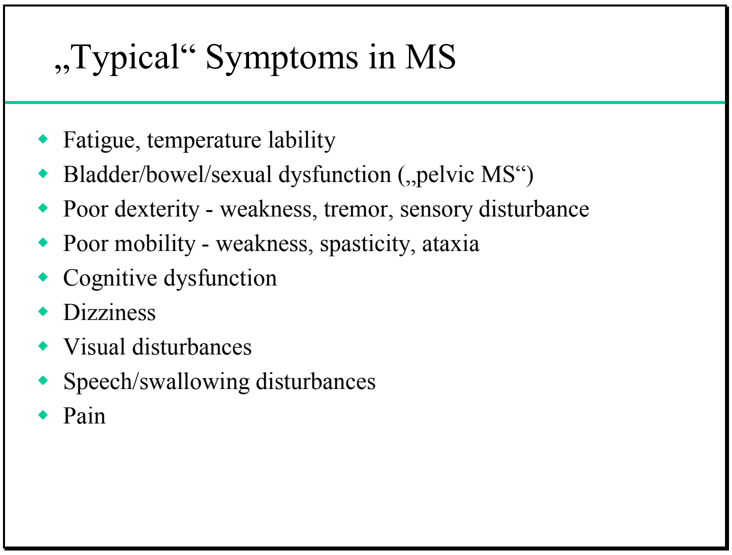
Rehabilitation: definition

- an active process of education and enablement
- focused on the proper management of disability
- and the minimisation of handicap
- with the goal to achieve a full recovery

or when a full recovery is not possible (as in MS):

- *realise the optimal physical, mental and social potential*
- *in order to remain (or become) integrated into the most appropriate environment.*

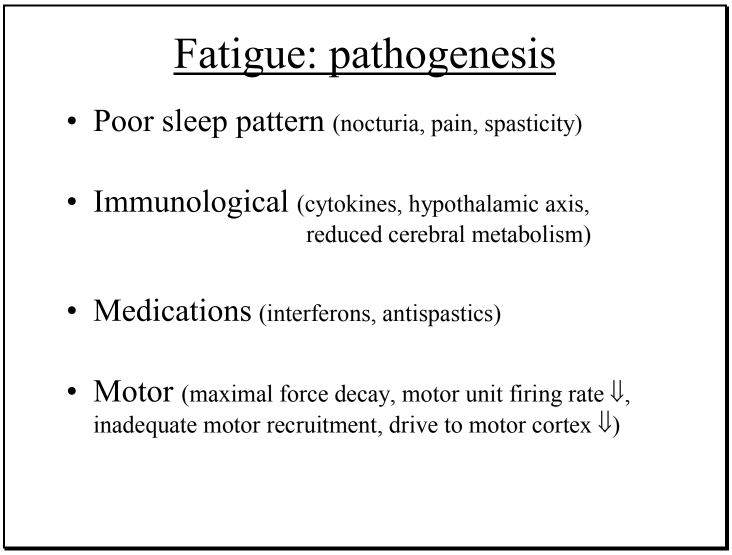
Slide 3



„Typical“ Symptoms in MS

- Fatigue, temperature lability
- Bladder/bowel/sexual dysfunction („pelvic MS“)
- Poor dexterity - weakness, tremor, sensory disturbance
- Poor mobility - weakness, spasticity, ataxia
- Cognitive dysfunction
- Dizziness
- Visual disturbances
- Speech/swallowing disturbances
- Pain

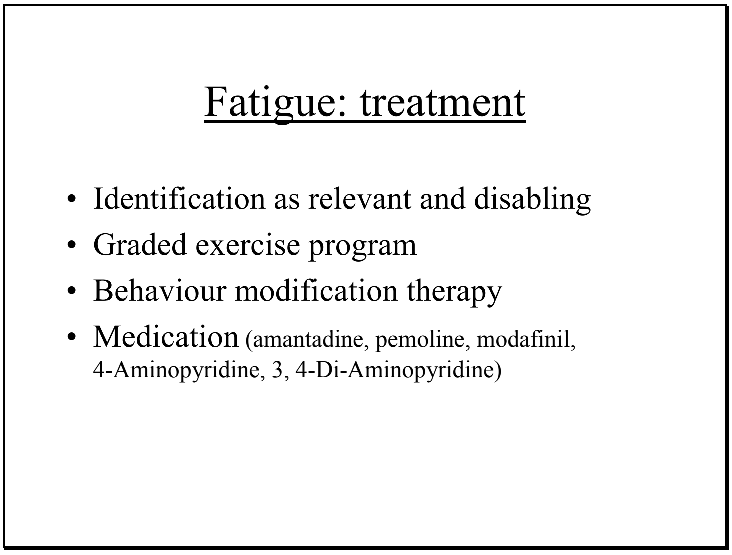
Slide 4



Fatigue: pathogenesis

- Poor sleep pattern (nocturia, pain, spasticity)
- Immunological (cytokines, hypothalamic axis, reduced cerebral metabolism)
- Medications (interferons, antispastics)
- Motor (maximal force decay, motor unit firing rate ⇓, inadequate motor recruitment, drive to motor cortex ⇓)

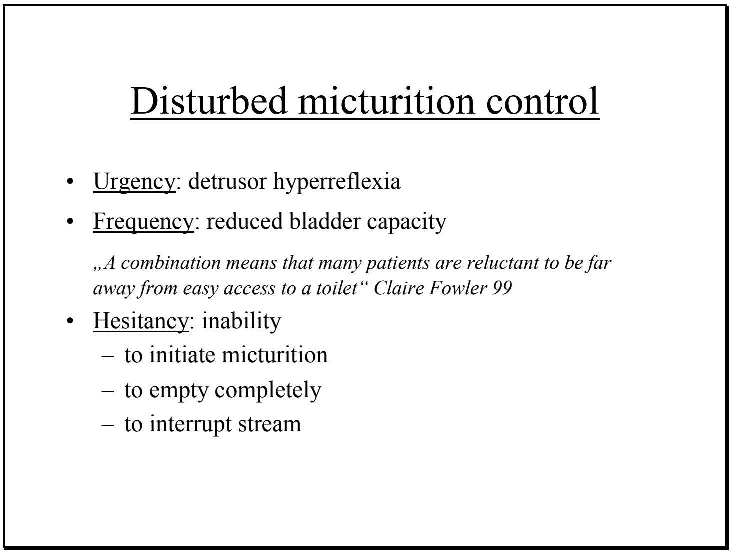
Slide 5



Fatigue: treatment

- Identification as relevant and disabling
- Graded exercise program
- Behaviour modification therapy
- Medication (amantadine, pemoline, modafinil, 4-Aminopyridine, 3, 4-Di-Aminopyridine)

Slide 6

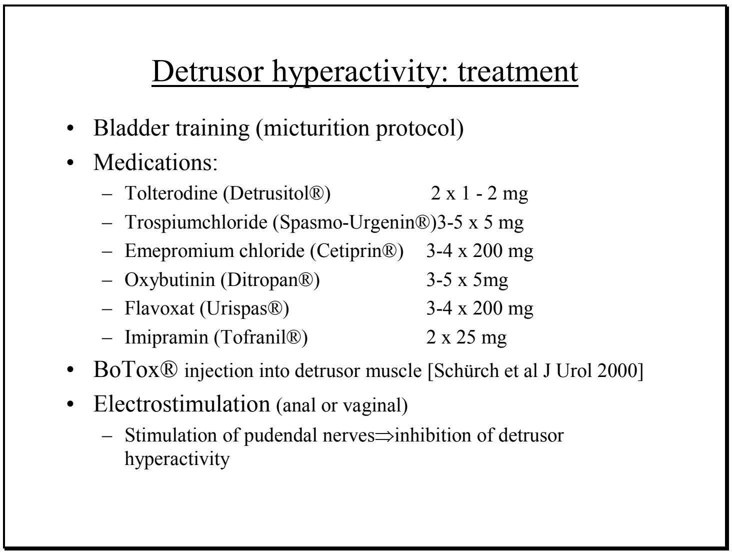


Disturbed micturition control

- Urgency: detrusor hyperreflexia
- Frequency: reduced bladder capacity

  „A combination means that many patients are reluctant to be far away from easy access to a toilet“ Claire Fowler 99
- Hesitancy: inability
  - to initiate micturition
  - to empty completely
  - to interrupt stream

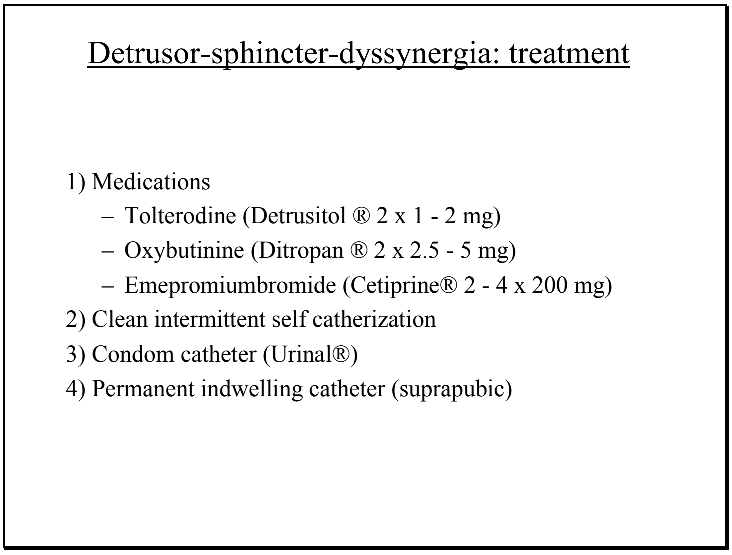
Slide 7



Detrusor hyperactivity: treatment

- Bladder training (micturition protocol)
- Medications:
  - Tolterodine (Detrusitol®) 2 x 1 - 2 mg
  - Trospiumchloride (Spasmo-Urgenin®)3-5 x 5 mg
  - Emepromium chloride (Cetiprin®) 3-4 x 200 mg
  - Oxybutinin (Ditropan®) 3-5 x 5mg
  - Flavoxat (Urispas®) 3-4 x 200 mg
  - Imipramin (Tofranil®) 2 x 25 mg
- BoTox® injection into detrusor muscle [Schürch et al J Urol 2000]
- Electrostimulation (anal or vaginal)
  - Stimulation of pudendal nerves⇒inhibition of detrusor hyperactivity

Slide 8

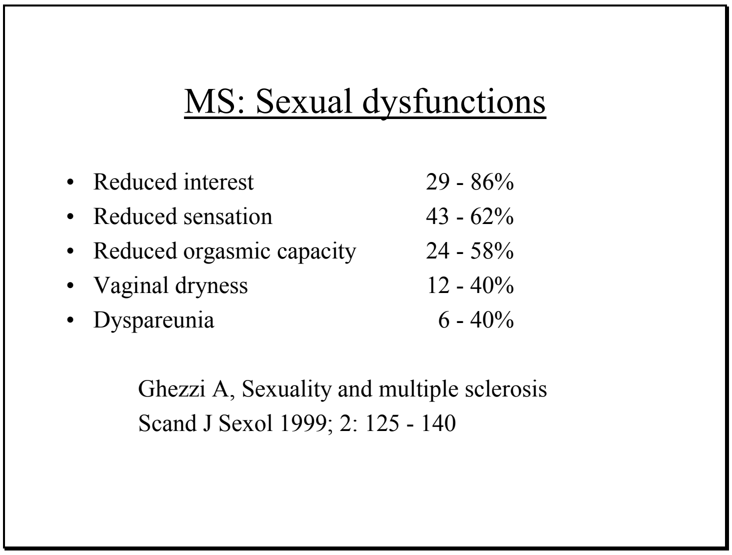


Detrusor-sphincter-dyssynergia: treatment

1) Medications
  - Tolterodine (Detrusitol ® 2 x 1 - 2 mg)
  - Oxybutinine (Ditropan ® 2 x 2.5 - 5 mg)
  - Emepromiumbromide (Cetiprine® 2 - 4 x 200 mg)

2) Clean intermittent self catherization
3) Condom catheter (Urinal®)
4) Permanent indwelling catheter (suprapubic)

Slide 9

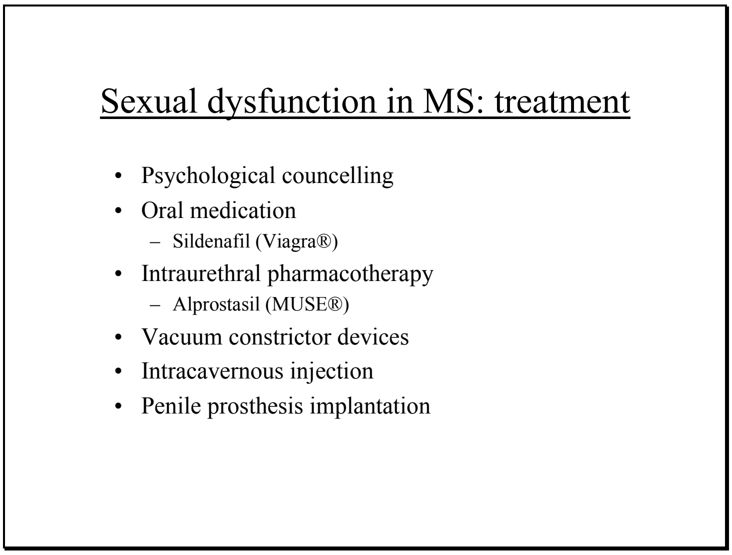


MS: Sexual dysfunctions

• Reduced interest	29 - 86%
• Reduced sensation	43 - 62%
• Reduced orgasmic capacity	24 - 58%
• Vaginal dryness	12 - 40%
• Dyspareunia	6 - 40%

Ghezzi A, Sexuality and multiple sclerosis
Scand J Sexol 1999; 2: 125 - 140

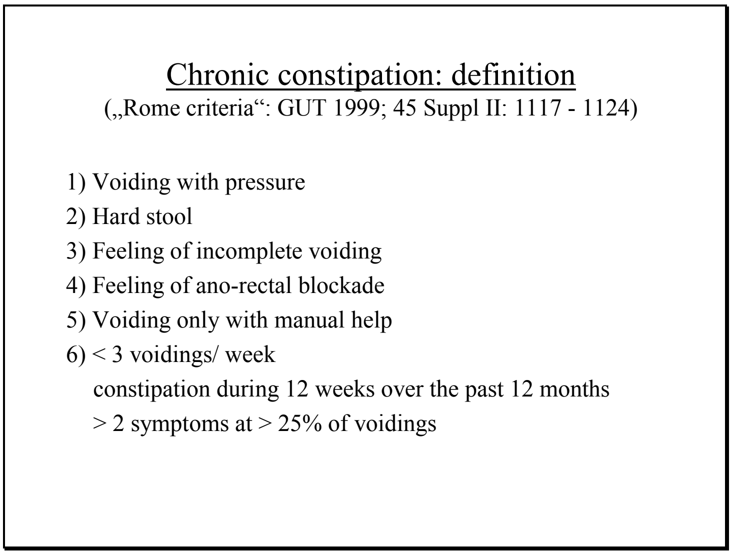
Slide 10



Sexual dysfunction in MS: treatment

- Psychological councelling
- Oral medication
  - Sildenafil (Viagra®)
- Intraurethral pharmacotherapy
  - Alprostasil (MUSE®)
- Vacuum constrictor devices
- Intracavernous injection
- Penile prosthesis implantation

Slide 11

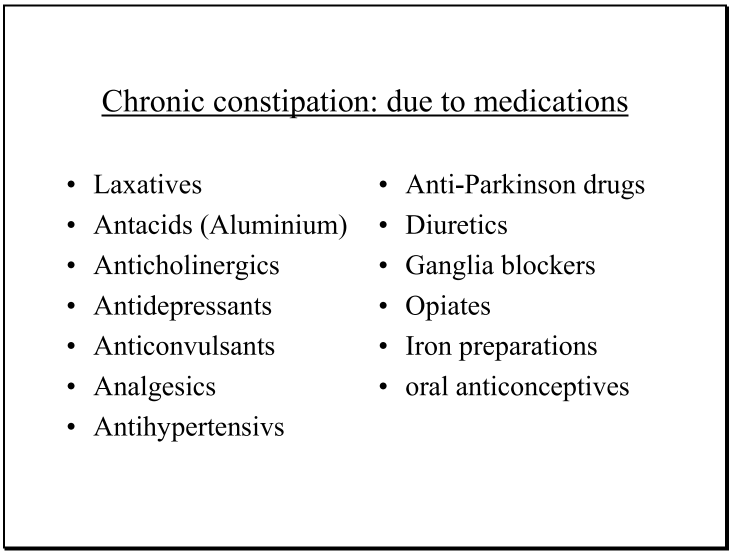


Chronic constipation: definition

(„Rome criteria“: GUT 1999; 45 Suppl II: 1117 - 1124)

1) Voiding with pressure
2) Hard stool
3) Feeling of incomplete voiding
4) Feeling of ano-rectal blockade
5) Voiding only with manual help
6) < 3 voidings/ week
   constipation during 12 weeks over the past 12 months
   > 2 symptoms at > 25% of voidings

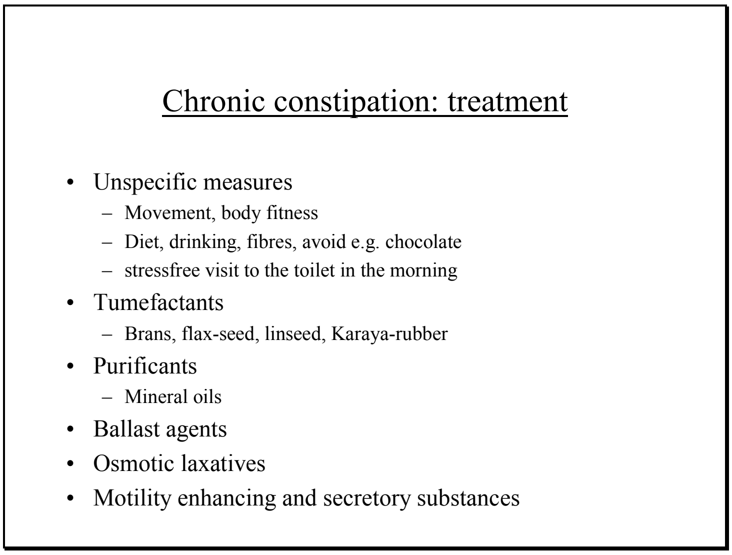
Slide 12



Chronic constipation: due to medications

- Laxatives
- Antacids (Aluminium)
- Anticholinergics
- Antidepressants
- Anticonvulsants
- Analgesics
- Antihypertensivs
- Anti-Parkinson drugs
- Diuretics
- Ganglia blockers
- Opiates
- Iron preparations
- oral anticonceptives

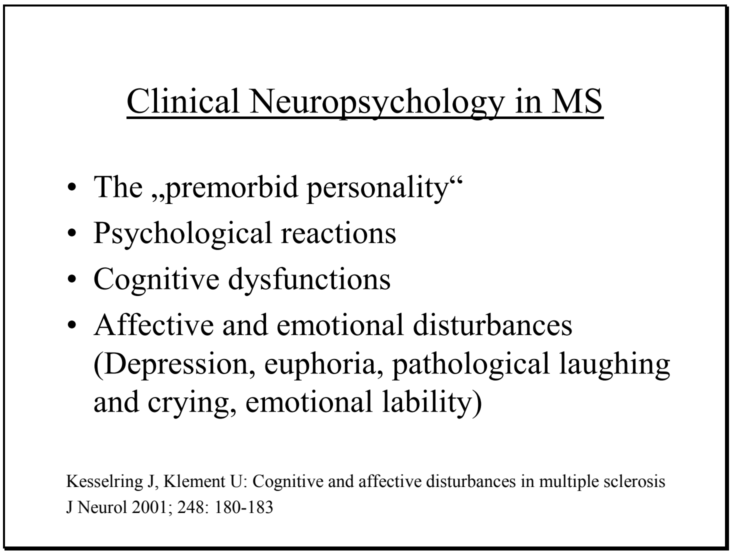
Slide 13



Chronic constipation: treatment

- Unspecific measures
  - Movement, body fitness
  - Diet, drinking, fibres, avoid e.g. chocolate
  - stressfree visit to the toilet in the morning
- Tumefactants
  - Brans, flax-seed, linseed, Karaya-rubber
- Purificants
  - Mineral oils
- Ballast agents
- Osmotic laxatives
- Motility enhancing and secretory substances

Slide 14

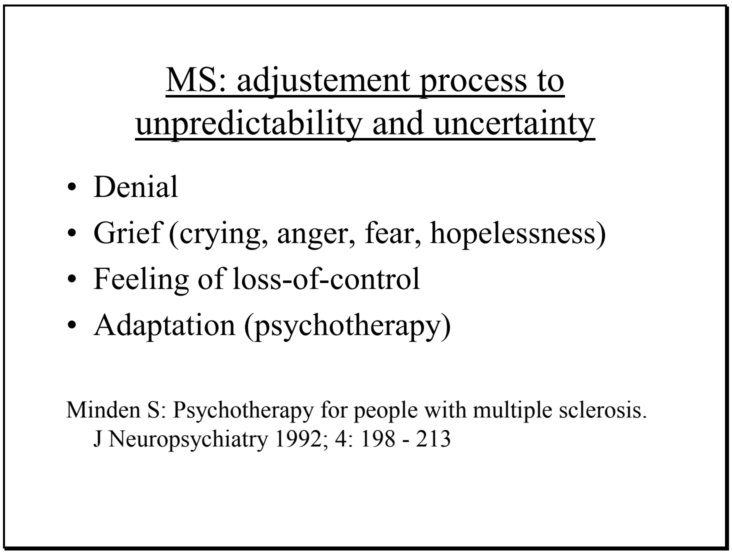


Clinical Neuropsychology in MS

- The „premorbid personality“
- Psychological reactions
- Cognitive dysfunctions
- Affective and emotional disturbances (Depression, euphoria, pathological laughing and crying, emotional lability)

Kesselring J, Klement U: Cognitive and affective disturbances in multiple sclerosis
J Neurol 2001; 248: 180-183

Slide 15

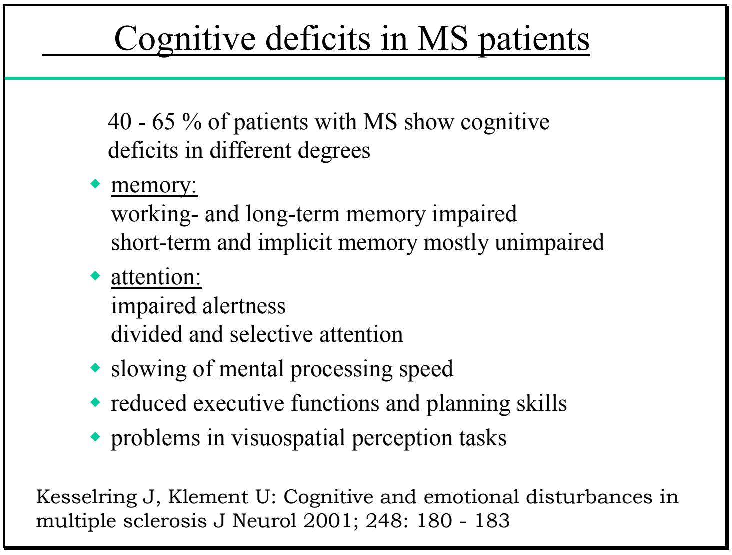


MS: adjustement process to unpredictability and uncertainty

- Denial
- Grief (crying, anger, fear, hopelessness)
- Feeling of loss-of-control
- Adaptation (psychotherapy)

Minden S: Psychotherapy for people with multiple sclerosis. J Neuropsychiatry 1992; 4: 198 - 213

Slide 16



Cognitive deficits in MS patients

40 - 65 % of patients with MS show cognitive deficits in different degrees

- memory:
  working- and long-term memory impaired
  short-term and implicit memory mostly unimpaired
- attention:
  impaired alertness
  divided and selective attention
- slowing of mental processing speed
- reduced executive functions and planning skills
- problems in visuospatial perception tasks

Kesselring J, Klement U: Cognitive and emotional disturbances in multiple sclerosis J Neurol 2001; 248: 180 - 183

Slide 17

MS and depression: prevalence and association to disease duration

- Lifetime prevalence 25 - 50% (= 3 times more than in general population) [Feinstein A 1999]
- 73% difficulties controlling emotions, irritability 57% , crying 40%, sadness 36%, major depression 17%, low mood 64%, anger 64% [Feinstein&Feinstein 2001]
- Positive association between depression and physical disability [Whitlock & Siskind 1980, McIvor et al 1984]
- No relationship between depression [Minden et al 1987] and emotional dysfunction [Rabins et al 1986, Ron & Logsdail 1987]

Slide 18

MS - emotional lability

- 10 % of MS patients
- no family history or mental illness
- no gender prevalence
- longstanding disease (> 10 years)
- progressive disability
- uncontrollable crying more common than laughing

Feinstein et al: The prevalence of neurobehavioral correlates of pathological laughing and crying in multiple sclerosis Arch Neurol 1997; 54: 1116 - 21

Slide 19

Spasticity: treatment

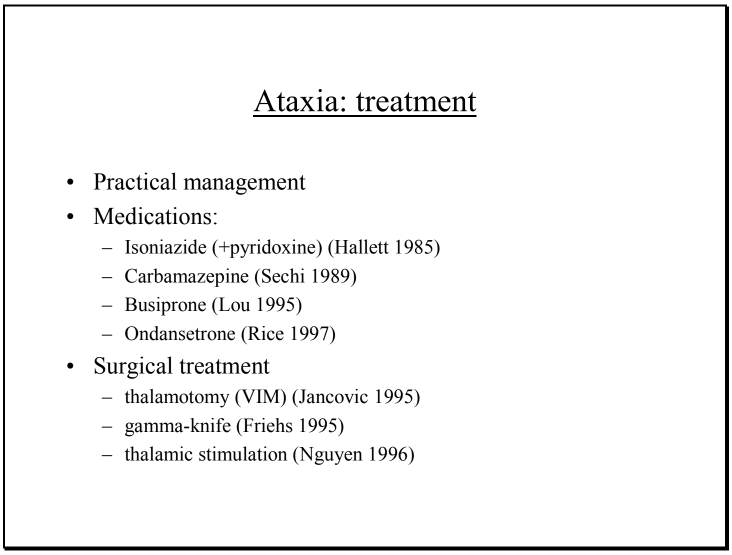
- Oral drugs
  - Tizanidine (MR)
  - Baclofen
  - (Diazepam)
  - (Dantrolene)
- Intrathecal baclofen (Medtronic™-pump)

Slide 20

Pain

- directly disease-related
  - Trigeminal neuralgia (1% of MS over time, 1% of TN due to MS)
  - Tonic seizures
  - Paroxysmal pain syndromes
- indirectly disease-related
  - Flexor spasms
  - Contractures
- related to disability and treatment
  - Neck pain in wheelchair users
  - Osteoporosis
  - Peripheral nerve lesions

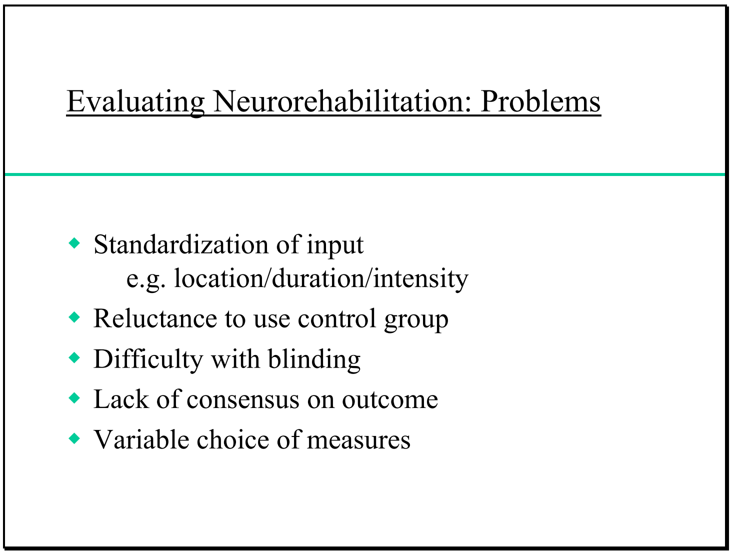
Slide 21



Ataxia: treatment

- Practical management
- Medications:
  - Isoniazide (+pyridoxine) (Hallett 1985)
  - Carbamazepine (Sechi 1989)
  - Busiprone (Lou 1995)
  - Ondansetrone (Rice 1997)
- Surgical treatment
  - thalamotomy (VIM) (Jancovic 1995)
  - gamma-knife (Friehs 1995)
  - thalamic stimulation (Nguyen 1996)

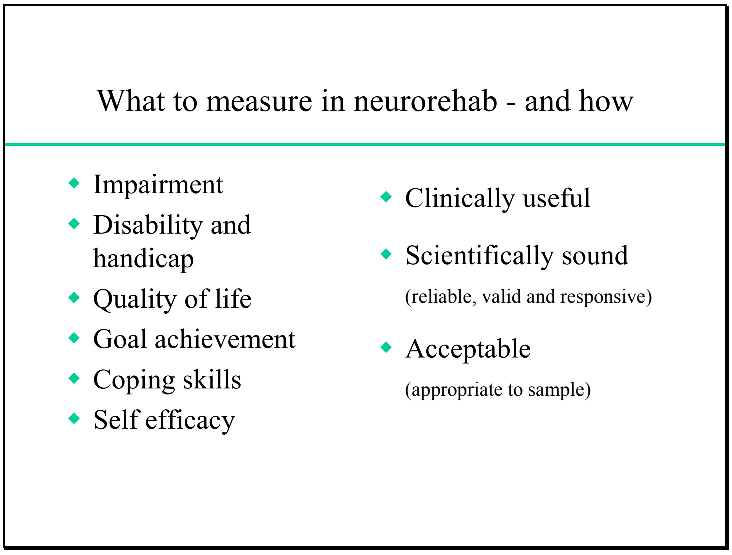
Slide 22



Evaluating Neurorehabilitation: Problems

- Standardization of input
  e.g. location/duration/intensity
- Reluctance to use control group
- Difficulty with blinding
- Lack of consensus on outcome
- Variable choice of measures

Slide 23

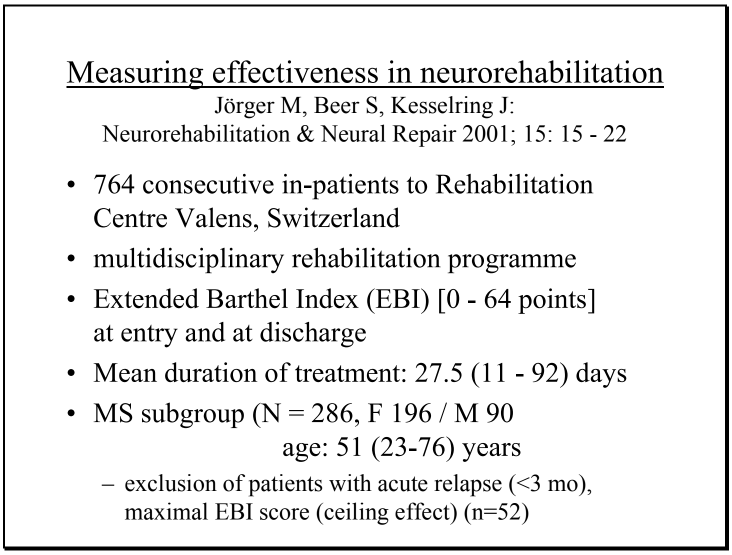


What to measure in neurorehab - and how

- Impairment
- Disability and handicap
- Quality of life
- Goal achievement
- Coping skills
- Self efficacy

- Clinically useful
- Scientifically sound
  (reliable, valid and responsive)
- Acceptable
  (appropriate to sample)

Slide 24

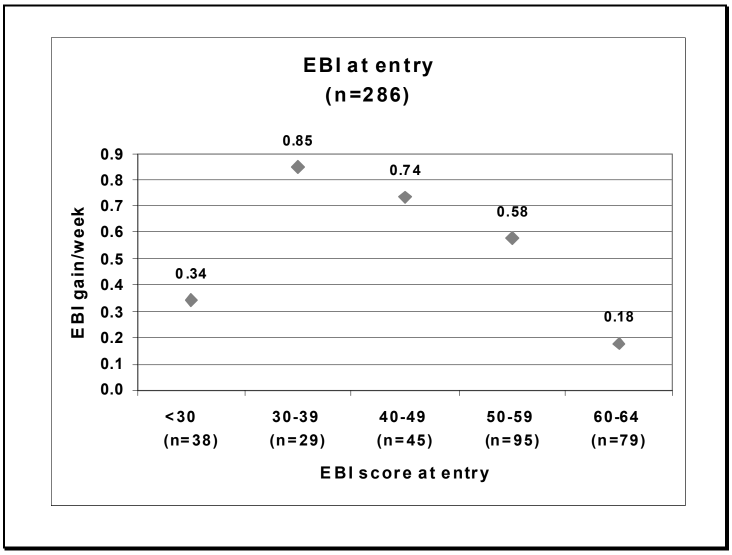


Measuring effectiveness in neurorehabilitation

Jörger M, Beer S, Kesselring J:
Neurorehabilitation & Neural Repair 2001; 15: 15 - 22

- 764 consecutive in-patients to Rehabilitation Centre Valens, Switzerland
- multidisciplinary rehabilitation programme
- Extended Barthel Index (EBI) [0 - 64 points] at entry and at discharge
- Mean duration of treatment: 27.5 (11 - 92) days
- MS subgroup (N = 286, F 196 / M 90
  age: 51 (23-76) years
  - exclusion of patients with acute relapse (<3 mo), maximal EBI score (ceiling effect) (n=52)

Slide 25



Slide 26

Stefan Mostert, Jürg Kesselring

Effects of a short term exercise training program on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis.

Multiple Sclerosis 2002;8: 161 - 168

- 37 MS patients, 5*30 min sessions per week of bicycle exercise with individualised intensity. Graded maximal exercise test with measurement of gas exchange and a lung function test before and after 4 weeks of aerobic exercise training,

- Results:
  - significant rightward placement of the aerobic threshold (VO_2 +13%; work rate +11%)
  - improvement of health perception (vitality +46%; social interaction +36%)
  - increase of activity level (+17%)
  - tendency to less fatigue.

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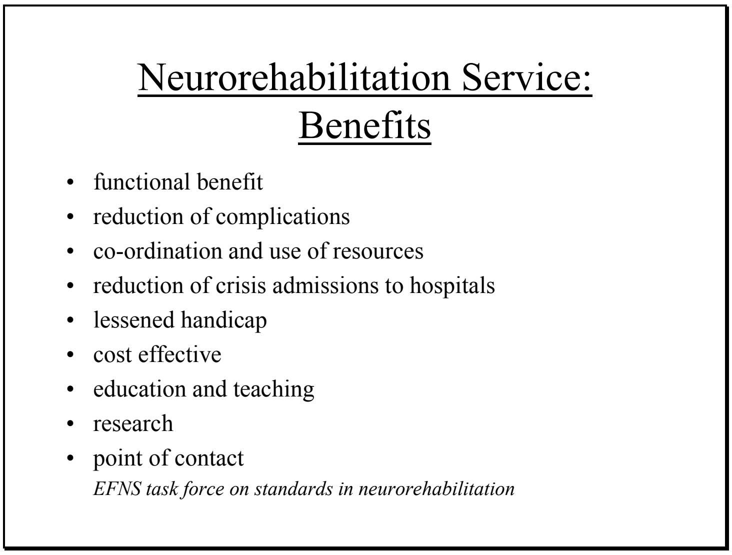
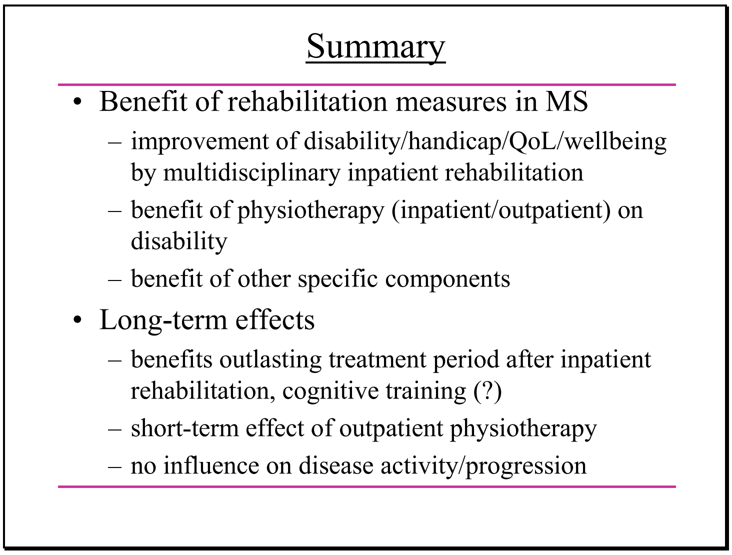


Neurorehabilitation Service: Benefits

- functional benefit
- reduction of complications
- co-ordination and use of resources
- reduction of crisis admissions to hospitals
- lessened handicap
- cost effective
- education and teaching
- research
- point of contact

EFNS task force on standards in neurorehabilitation

Slide 28



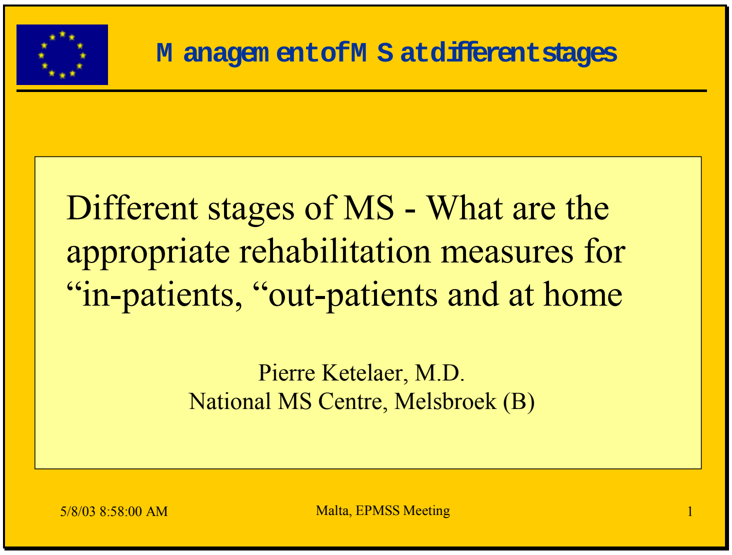
Summary

- Benefit of rehabilitation measures in MS
  - improvement of disability/handicap/QoL/wellbeing by multidisciplinary inpatient rehabilitation
  - benefit of physiotherapy (inpatient/outpatient) on disability
  - benefit of other specific components
- Long-term effects
  - benefits outlasting treatment period after inpatient rehabilitation, cognitive training (?)
  - short-term effect of outpatient physiotherapy
  - no influence on disease activity/progression

DIFFERENT STAGES OF MS – WHAT ARE THE APPROPRIATE REHABILITATION MEASURES FOR “IN-PATIENTS”, “OUT-PATIENTS” AND AT HOME

Pierre Ketelaer

Slide 1



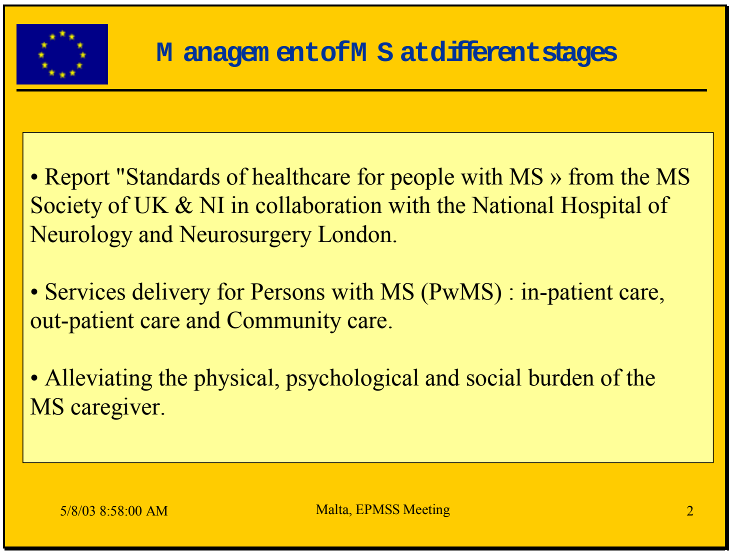
Management of MS at different stages

Different stages of MS - What are the appropriate rehabilitation measures for “in-patients, “out-patients and at home

Pierre Ketelaer, M.D.
National MS Centre, Melsbroek (B)

5/8/03 8:58:00 AM Malta, EPMSS Meeting 1

Slide 2



Management of MS at different stages

- Report "Standards of healthcare for people with MS » from the MS Society of UK & NI in collaboration with the National Hospital of Neurology and Neurosurgery London.
- Services delivery for Persons with MS (PwMS) : in-patient care, out-patient care and Community care.
- Alleviating the physical, psychological and social burden of the MS caregiver.

5/8/03 8:58:00 AM Malta, EPMSS Meeting 2

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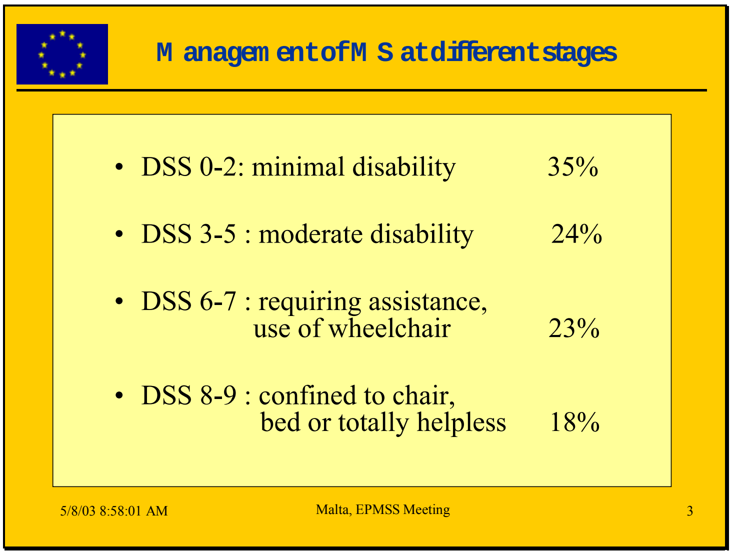
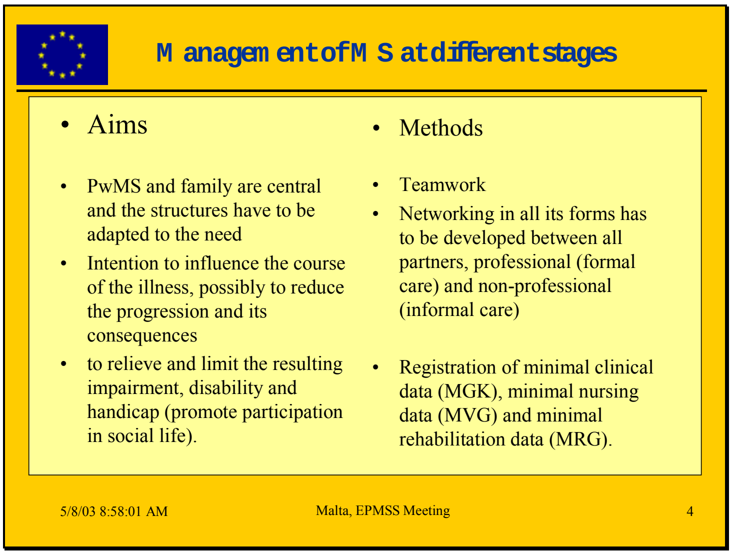


Management of MS at different stages

- DSS 0-2: minimal disability 35%
- DSS 3-5 : moderate disability 24%
- DSS 6-7 : requiring assistance, use of wheelchair 23%
- DSS 8-9 : confined to chair, bed or totally helpless 18%

5/8/03 8:58:01 AM Malta, EPMSS Meeting 3

Slide 4



Management of MS at different stages

- Aims
  - PwMS and family are central and the structures have to be adapted to the need
  - Intention to influence the course of the illness, possibly to reduce the progression and its consequences
  - to relieve and limit the resulting impairment, disability and handicap (promote participation in social life).
- Methods
  - Teamwork
  - Networking in all its forms has to be developed between all partners, professional (formal care) and non-professional (informal care)
  - Registration of minimal clinical data (MGK), minimal nursing data (MVG) and minimal rehabilitation data (MRG).

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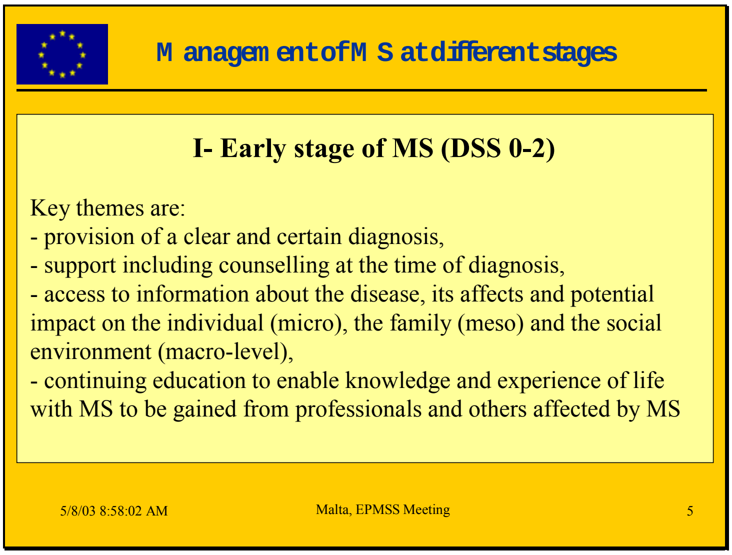

Management of MS at different stages

I- Early stage of MS (DSS 0-2)

Key themes are:
- provision of a clear and certain diagnosis,
- support including counselling at the time of diagnosis,
- access to information about the disease, its affects and potential impact on the individual (micro), the family (meso) and the social environment (macro-level),
- continuing education to enable knowledge and experience of life with MS to be gained from professionals and others affected by MS

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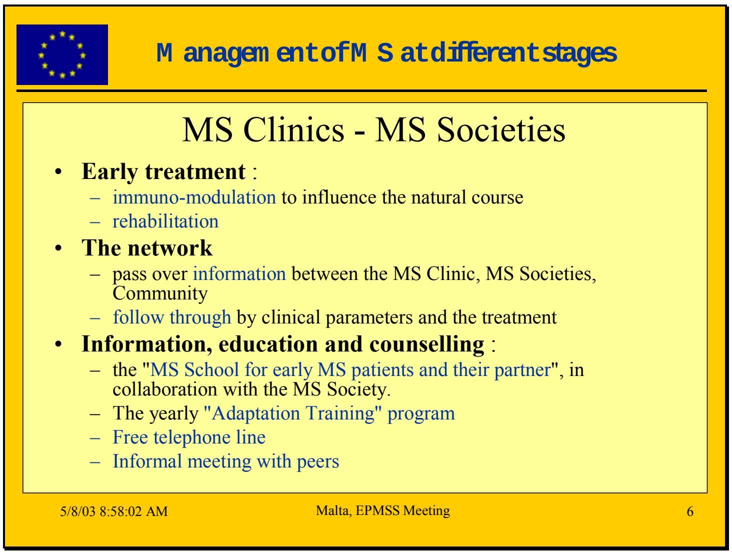

Management of MS at different stages

MS Clinics - MS Societies

- **Early treatment** :
  - immuno-modulation to influence the natural course
  - rehabilitation
- **The network**
  - pass over information between the MS Clinic, MS Societies, Community
  - follow through by clinical parameters and the treatment
- **Information, education and counselling** :
  - the "MS School for early MS patients and their partner", in collaboration with the MS Society.
  - The yearly "Adaptation Training" program
  - Free telephone line
  - Informal meeting with peers

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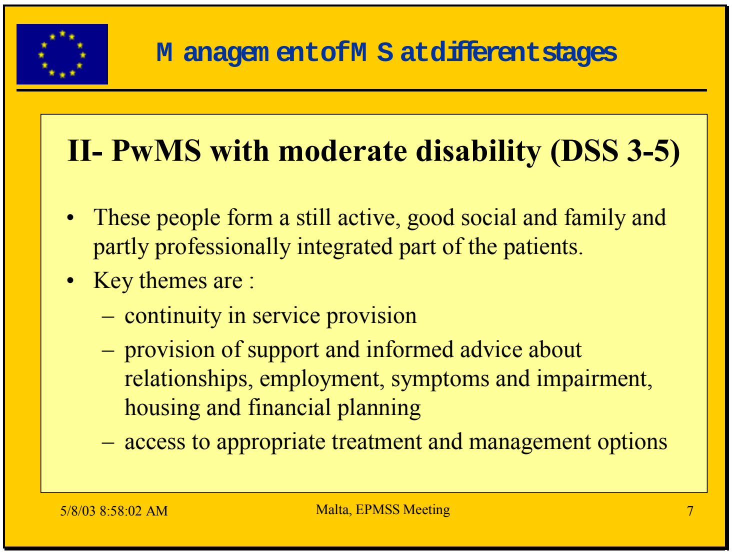

Management of MS at different stages

II- PwMS with moderate disability (DSS 3-5)

- These people form a still active, good social and family and partly professionally integrated part of the patients.
- Key themes are :
  - continuity in service provision
  - provision of support and informed advice about relationships, employment, symptoms and impairment, housing and financial planning
  - access to appropriate treatment and management options

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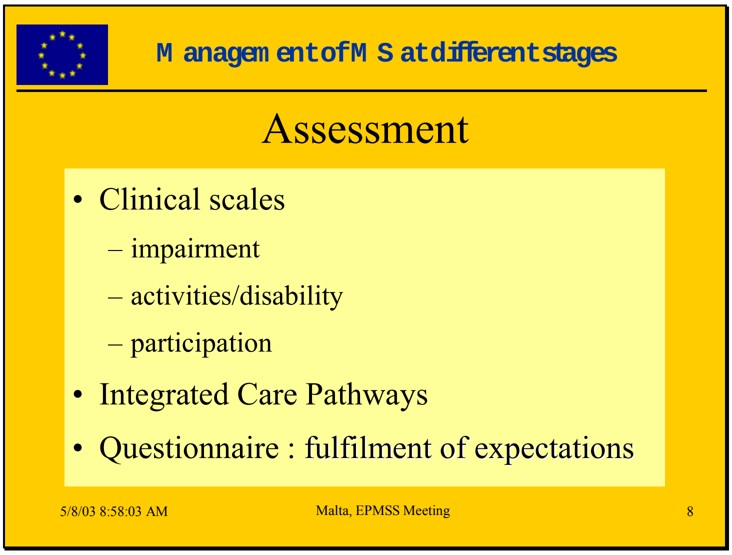

Management of MS at different stages

Assessment

- Clinical scales
  - impairment
  - activities/disability
  - participation
- Integrated Care Pathways
- Questionnaire : fulfilment of expectations

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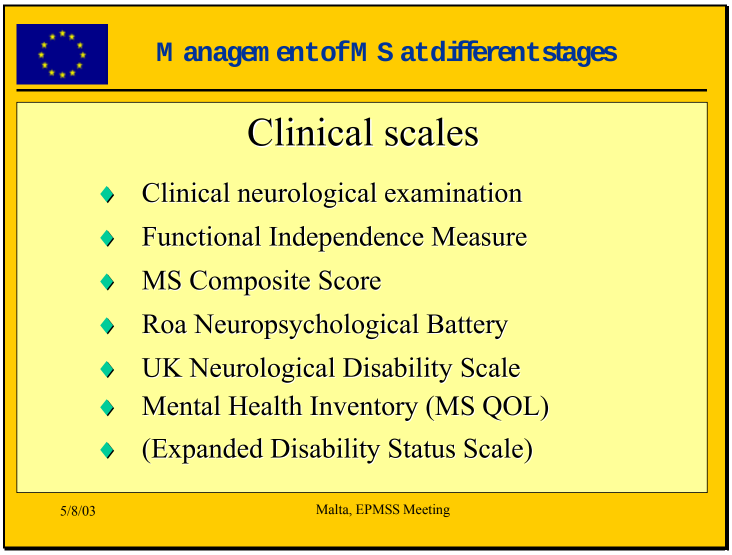

Management of MS at different stages

Clinical scales

- Clinical neurological examination
- Functional Independence Measure
- MS Composite Score
- Roa Neuropsychological Battery
- UK Neurological Disability Scale
- Mental Health Inventory (MS QOL)
- (Expanded Disability Status Scale)

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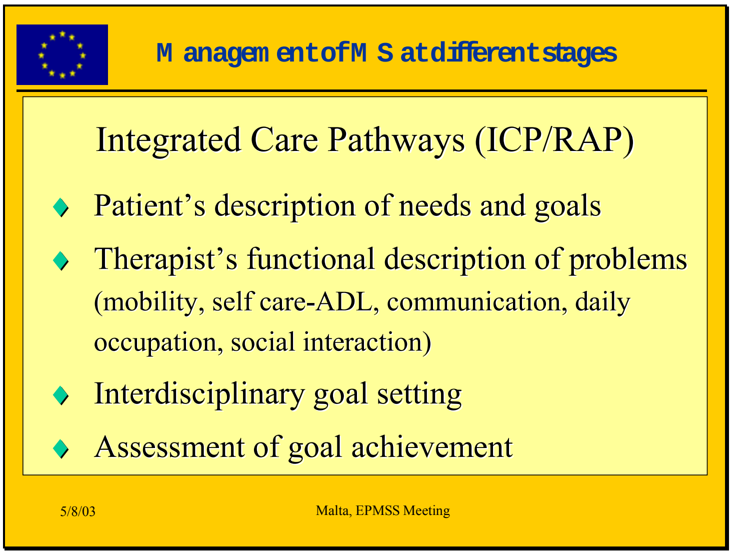

Management of MS at different stages

Integrated Care Pathways (ICP/RAP)

- Patient’s description of needs and goals
- Therapist’s functional description of problems (mobility, self care-ADL, communication, daily occupation, social interaction)
- Interdisciplinary goal setting
- Assessment of goal achievement

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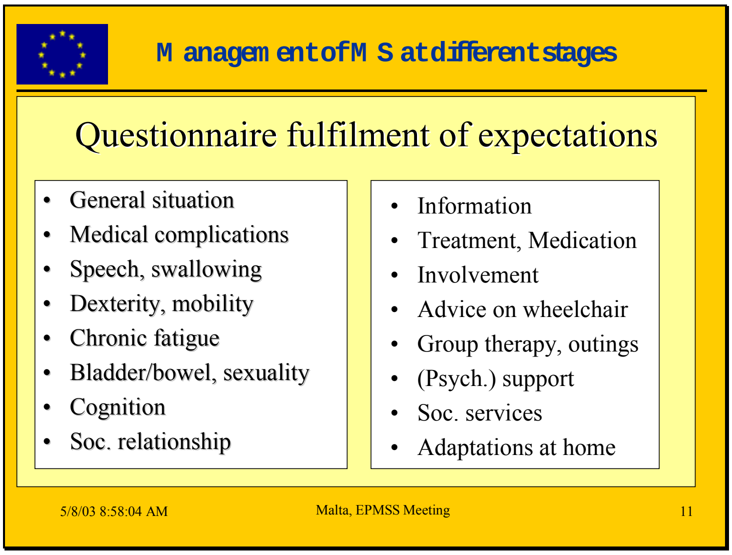

Management of MS at different stages

Questionnaire fulfilment of expectations

- General situation
- Medical complications
- Speech, swallowing
- Dexterity, mobility
- Chronic fatigue
- Bladder/bowel, sexuality
- Cognition
- Soc. relationship

- Information
- Treatment, Medication
- Involvement
- Advice on wheelchair
- Group therapy, outings
- (Psych.) support
- Soc. services
- Adaptations at home

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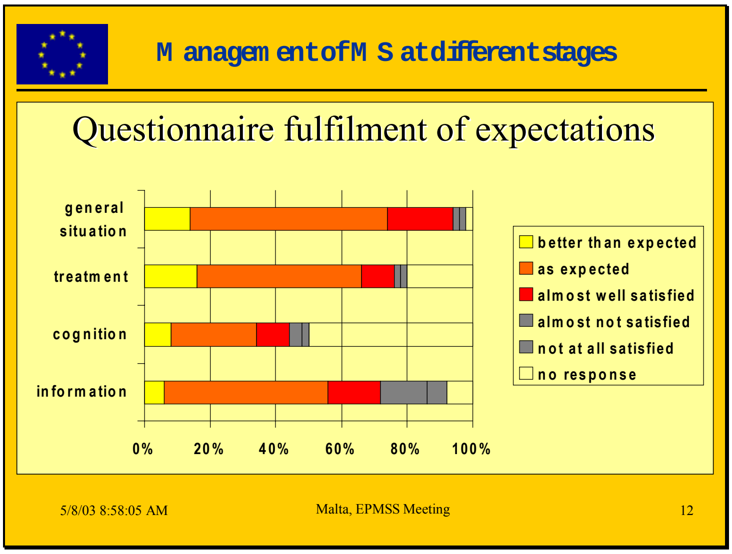

Management of MS at different stages

Questionnaire fulfilment of expectations

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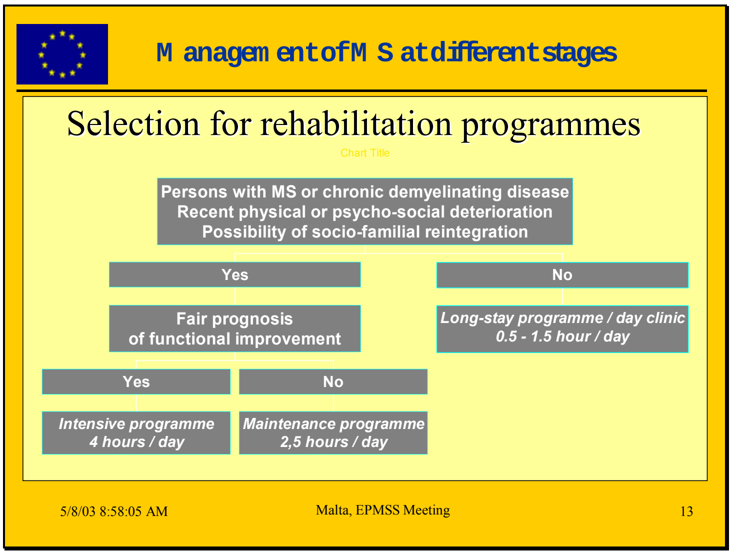
Slide 13



Management of MS at different stages

Selection for rehabilitation programmes

Chart Title

Persons with MS or chronic demyelinating disease
Recent physical or psycho-social deterioration
Possibility of socio-familial reintegration

Yes

Fair prognosis
of functional improvement

Yes

Intensive programme
4 hours / day

No

Maintenance programme
2,5 hours / day

No

Long-stay programme / day clinic
0.5 - 1.5 hour / day

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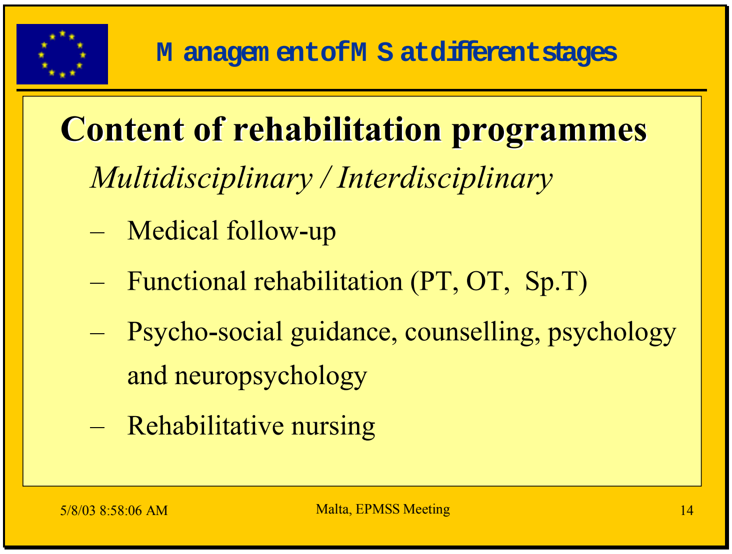

Management of MS at different stages

Content of rehabilitation programmes

Multidisciplinary / Interdisciplinary

- Medical follow-up
- Functional rehabilitation (PT, OT, Sp.T)
- Psycho-social guidance, counselling, psychology and neuropsychology
- Rehabilitative nursing

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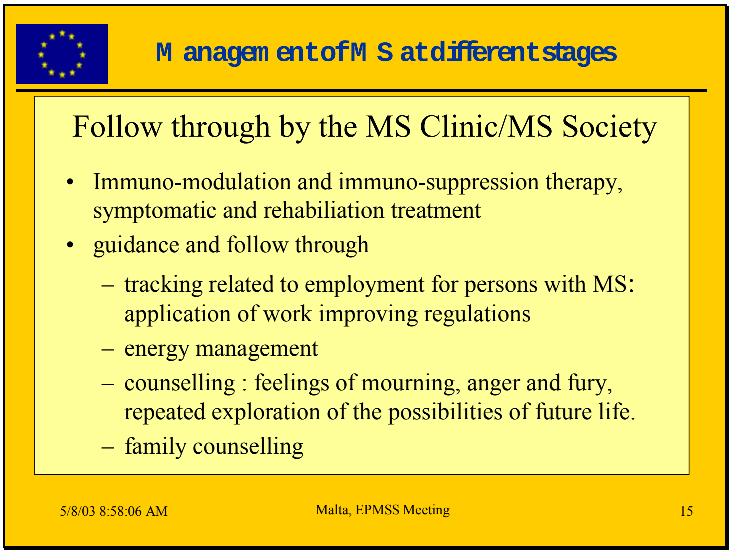

Management of MS at different stages

Follow through by the MS Clinic/MS Society

- Immuno-modulation and immuno-suppression therapy, symptomatic and rehabilitation treatment
- guidance and follow through
  - tracking related to employment for persons with MS: application of work improving regulations
  - energy management
  - counselling : feelings of mourning, anger and fury, repeated exploration of the possibilities of future life.
  - family counselling

5/8/03 8:58:06 AM Malta, EPMSS Meeting 15

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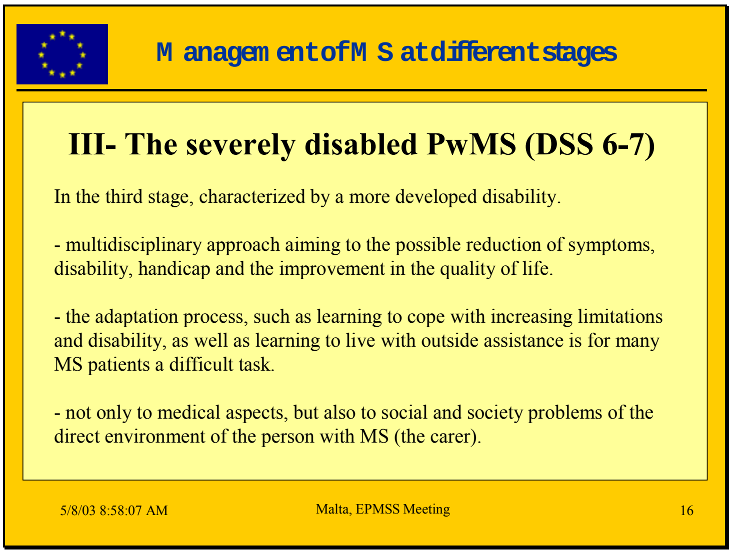

Management of MS at different stages

III- The severely disabled PwMS (DSS 6-7)

In the third stage, characterized by a more developed disability.

- multidisciplinary approach aiming to the possible reduction of symptoms, disability, handicap and the improvement in the quality of life.

- the adaptation process, such as learning to cope with increasing limitations and disability, as well as learning to live with outside assistance is for many MS patients a difficult task.

- not only to medical aspects, but also to social and society problems of the direct environment of the person with MS (the carer).

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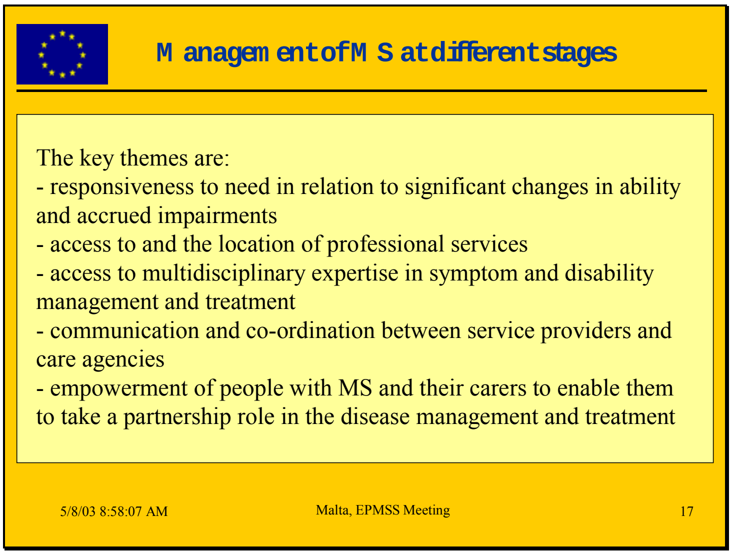

Management of MS at different stages

The key themes are:
- responsiveness to need in relation to significant changes in ability and accrued impairments
- access to and the location of professional services
- access to multidisciplinary expertise in symptom and disability management and treatment
- communication and co-ordination between service providers and care agencies
- empowerment of people with MS and their carers to enable them to take a partnership role in the disease management and treatment

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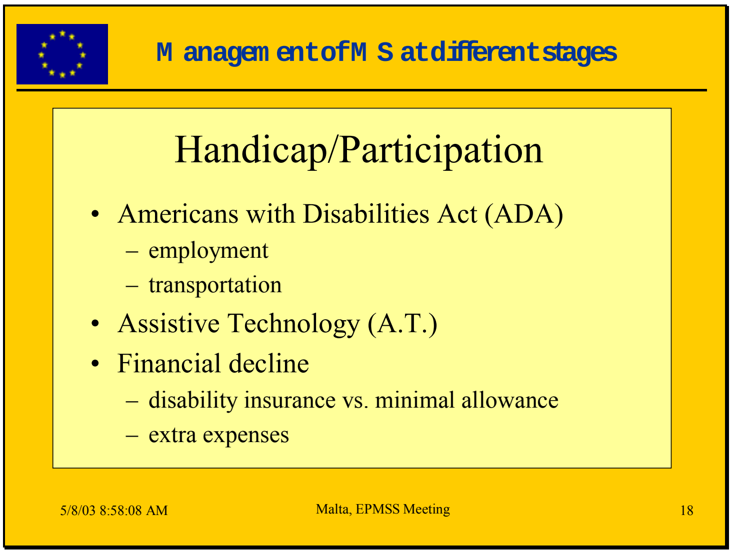

Management of MS at different stages

Handicap/Participation

- Americans with Disabilities Act (ADA)
  - employment
  - transportation
- Assistive Technology (A.T.)
- Financial decline
  - disability insurance vs. minimal allowance
  - extra expenses

5/8/03 8:58:08 AM Malta, EPMSS Meeting 18

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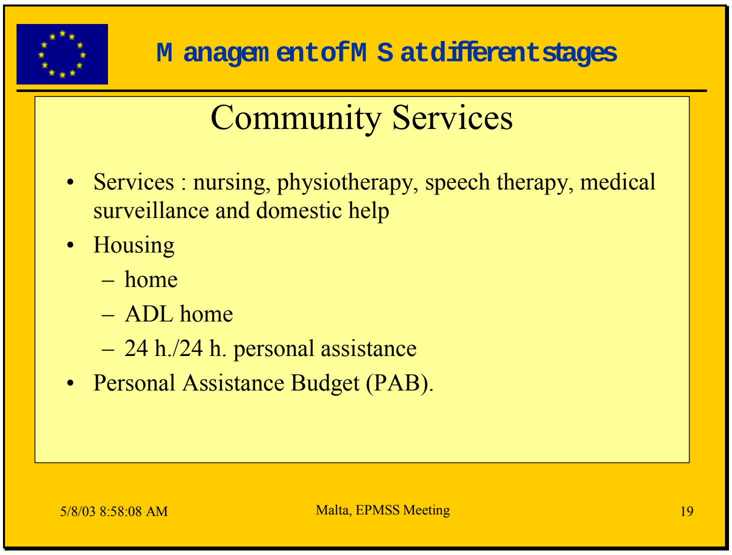

Management of MS at different stages

Community Services

- Services : nursing, physiotherapy, speech therapy, medical surveillance and domestic help
- Housing
  - home
  - ADL home
  - 24 h./24 h. personal assistance
- Personal Assistance Budget (PAB).

5/8/03 8:58:08 AM Malta, EPMSS Meeting 19

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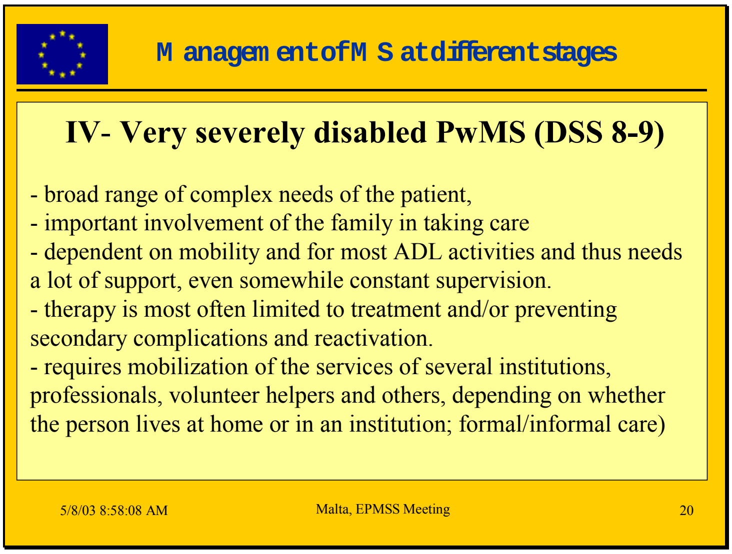

Management of MS at different stages

IV- Very severely disabled PwMS (DSS 8-9)

- broad range of complex needs of the patient,
- important involvement of the family in taking care
- dependent on mobility and for most ADL activities and thus needs a lot of support, even somewhile constant supervision.
- therapy is most often limited to treatment and/or preventing secondary complications and reactivation.
- requires mobilization of the services of several institutions, professionals, volunteer helpers and others, depending on whether the person lives at home or in an institution; formal/informal care)

5/8/03 8:58:08 AM Malta, EPMSS Meeting 20

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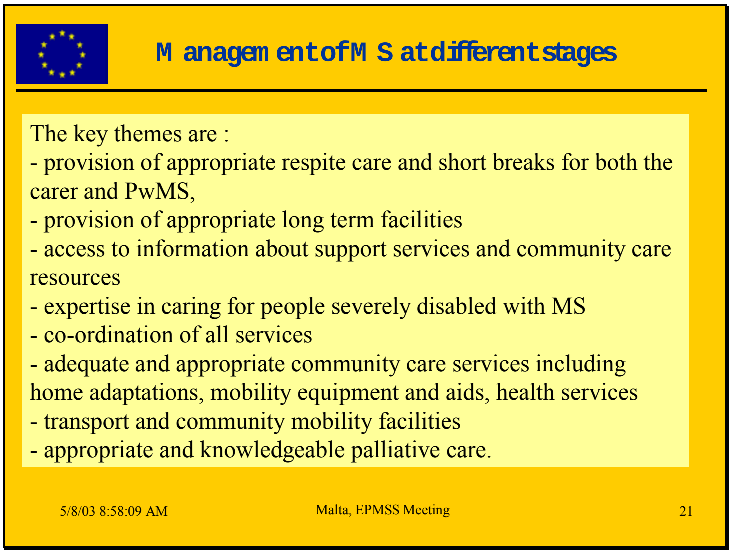

Management of MS at different stages

The key themes are :
- provision of appropriate respite care and short breaks for both the carer and PwMS,
- provision of appropriate long term facilities
- access to information about support services and community care resources
- expertise in caring for people severely disabled with MS
- co-ordination of all services
- adequate and appropriate community care services including home adaptations, mobility equipment and aids, health services
- transport and community mobility facilities
- appropriate and knowledgeable palliative care.

5/8/03 8:58:09 AM Malta, EPMSS Meeting 21

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Management of MS at different stages

Community Care

- Formal care : nursing, G.P, physiotherapy, occupational therapy, speech therapy, social services
- Need of household help, care and nursing.
- > 80% is being done by volunteer carers.
  - can not have a personal life
  - become dependent on help constant care
  - some relations can also break down

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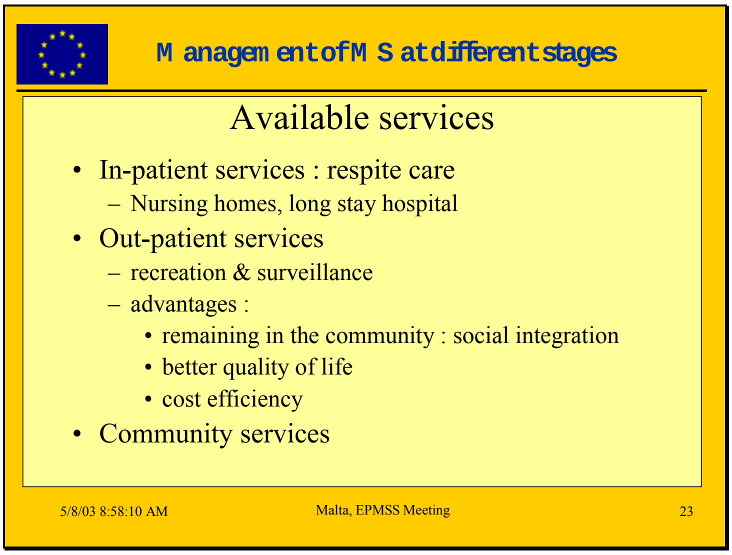

Management of MS at different stages

Available services

- In-patient services : respite care
  - Nursing homes, long stay hospital
- Out-patient services
  - recreation & surveillance
  - advantages :
    - remaining in the community : social integration
    - better quality of life
    - cost efficiency
- Community services

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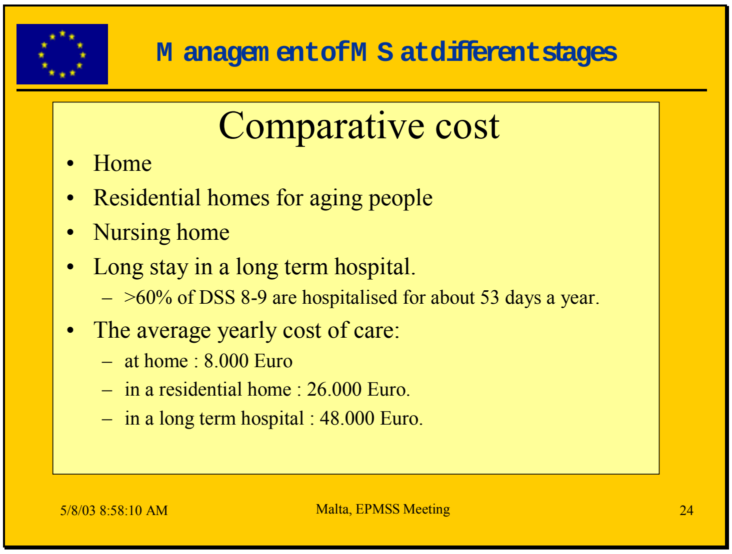

Management of MS at different stages

Comparative cost

- Home
- Residential homes for aging people
- Nursing home
- Long stay in a long term hospital.
  - >60% of DSS 8-9 are hospitalised for about 53 days a year.
- The average yearly cost of care:
  - at home : 8.000 Euro
  - in a residential home : 26.000 Euro.
  - in a long term hospital : 48.000 Euro.

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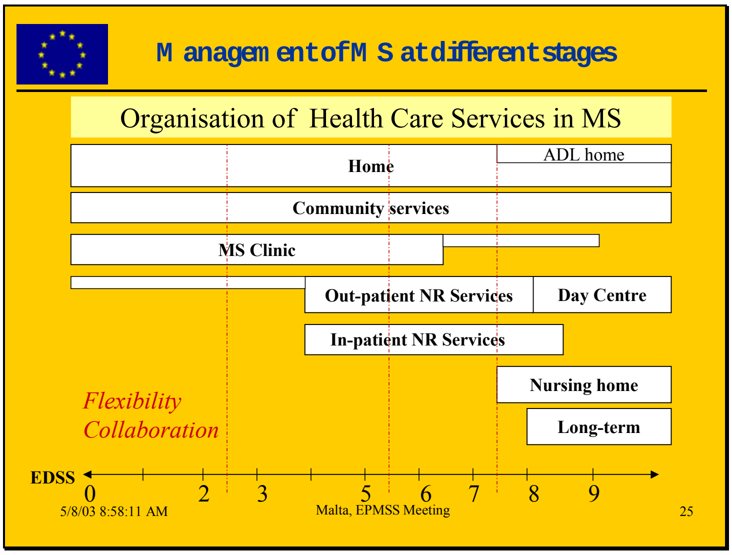

Management of MS at different stages

Organisation of Health Care Services in MS

Home

ADL home

Community services

MS Clinic

Out-patient NR Services

Day Centre

In-patient NR Services

Nursing home

Long-term

Flexibility
Collaboration

EDSS 0 2 3 5 6 7 8 9

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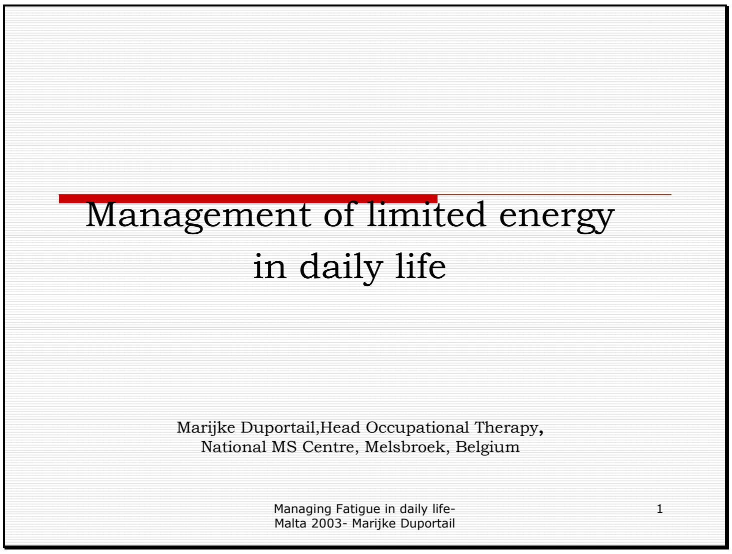
Malta, EPMSS Meeting

25

WORKSHOP 1
MANAGING FATIGUE

Marijke Duportail

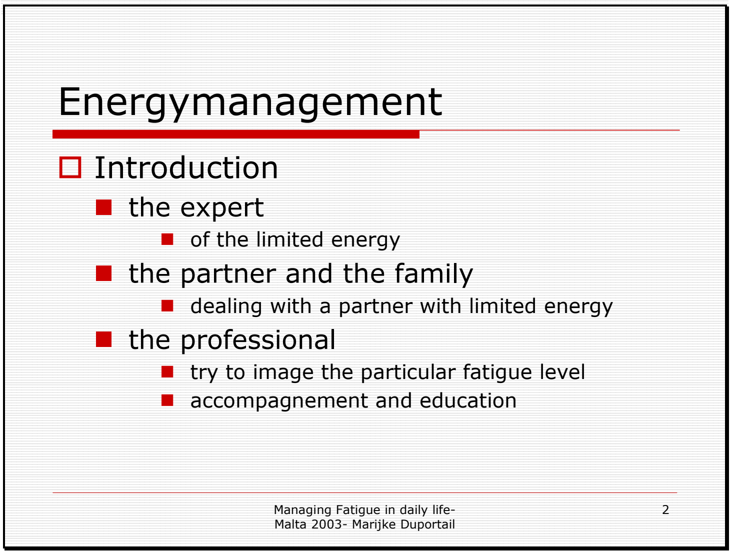
Slide 1



Management of limited energy in daily life

Marijke Duportail,Head Occupational Therapy,
National MS Centre, Melsbroek, Belgium

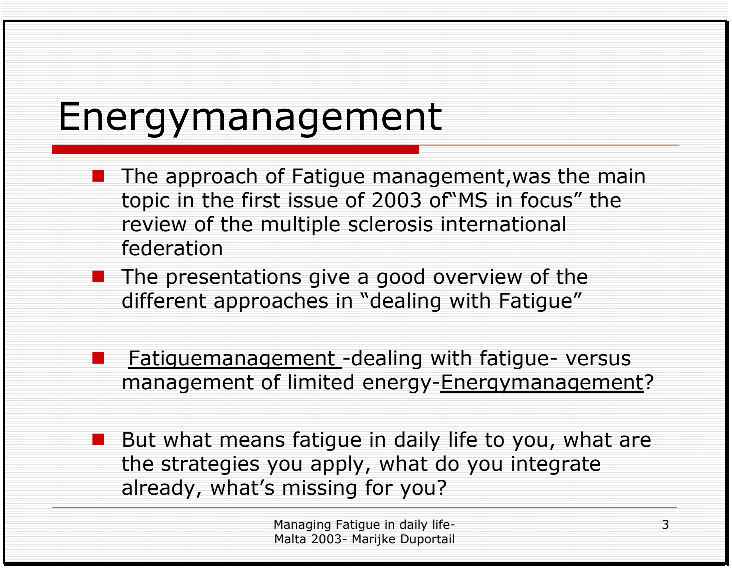
Slide 2



Energymanagement

☐ Introduction
- the expert
  - of the limited energy
- the partner and the family
  - dealing with a partner with limited energy
- the professional
  - try to image the particular fatigue level
  - accompagnement and education

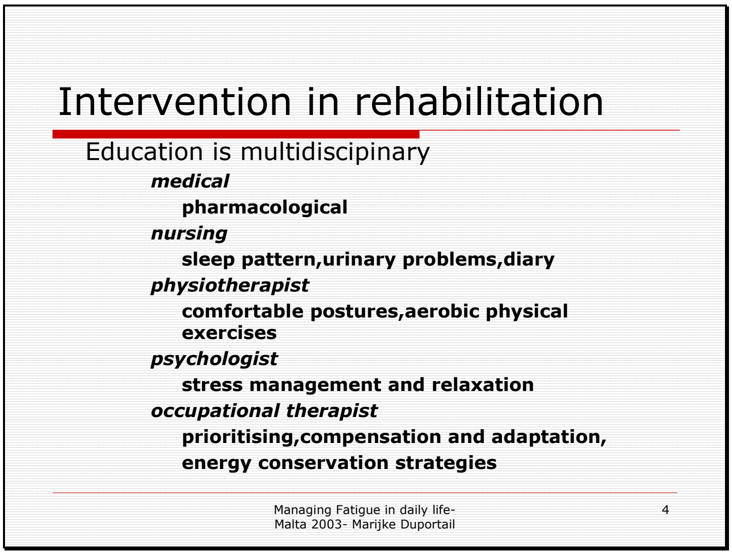
Slide 3



Energymanagement

- The approach of Fatigue management,was the main topic in the first issue of 2003 of“MS in focus” the review of the multiple sclerosis international federation
- The presentations give a good overview of the different approaches in “dealing with Fatigue”
- Fatiguemanagement -dealing with fatigue- versus management of limited energy-Energymanagement?
- But what means fatigue in daily life to you, what are the strategies you apply, what do you integrate already, what’s missing for you?

Slide 4

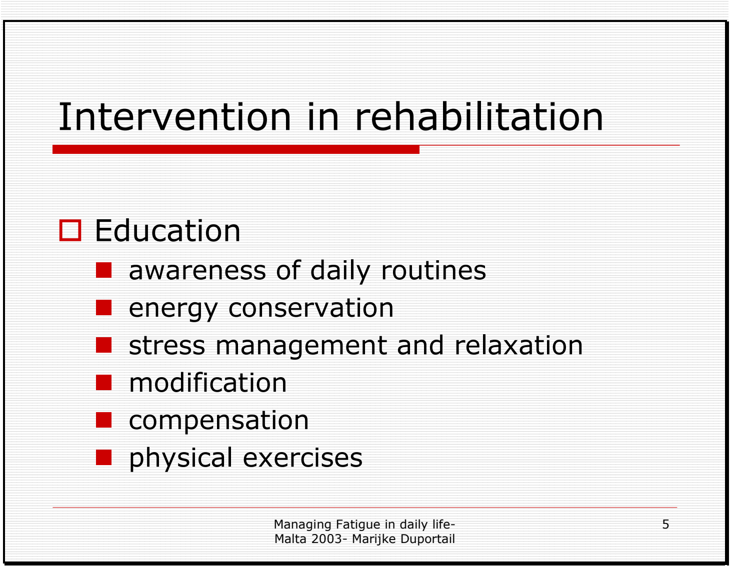


Intervention in rehabilitation

Education is multidisciplinary

- ***medical***
  - **pharmacological**
- ***nursing***
  - **sleep pattern,urinary problems,diary**
- ***physiotherapist***
  - **comfortable postures,aerobic physical exercises**
- ***psychologist***
  - **stress management and relaxation**
- ***occupational therapist***
  - **prioritising,compensation and adaptation, energy conservation strategies**

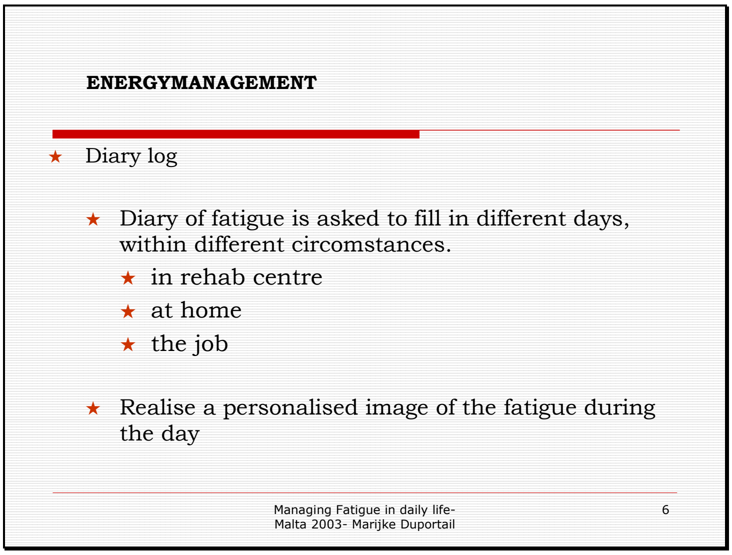
Slide 5



Intervention in rehabilitation

- ☐ Education
  - awareness of daily routines
  - energy conservation
  - stress management and relaxation
  - modification
  - compensation
  - physical exercises

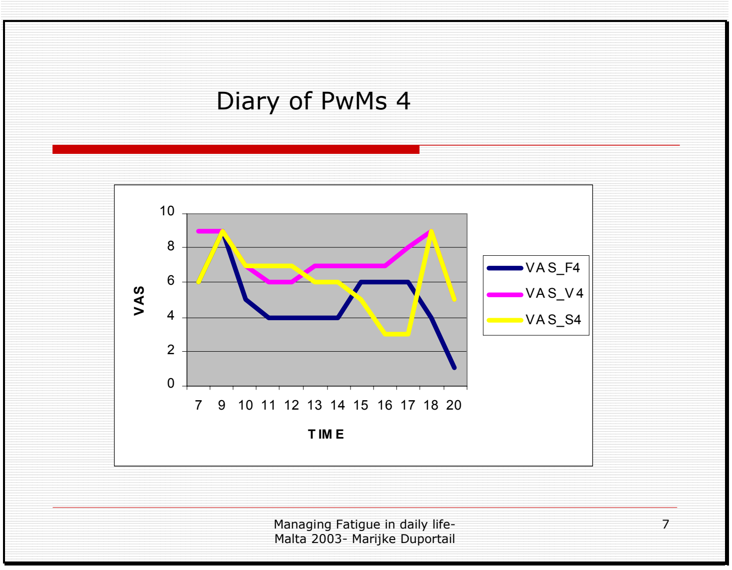
Slide 6



ENERGYMANAGEMENT

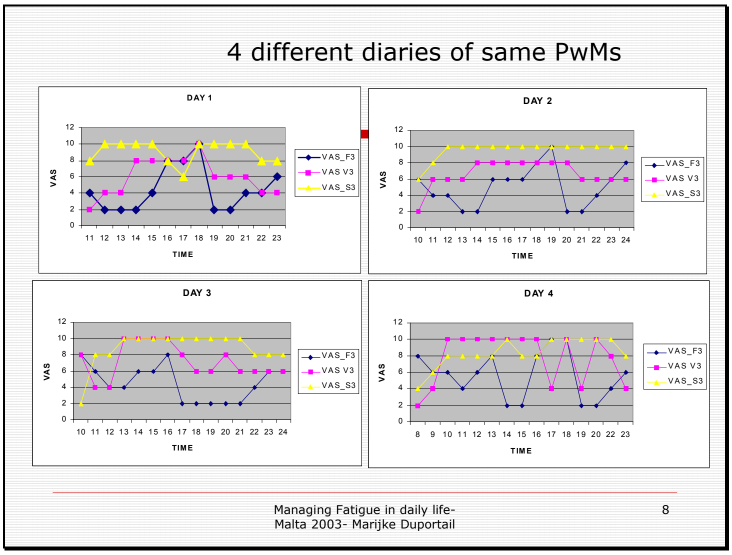
- ★ Diary log
  - ★ Diary of fatigue is asked to fill in different days, within different circomstances.
    - ★ in rehab centre
    - ★ at home
    - ★ the job
  - ★ Realise a personalised image of the fatigue during the day

Slide 7



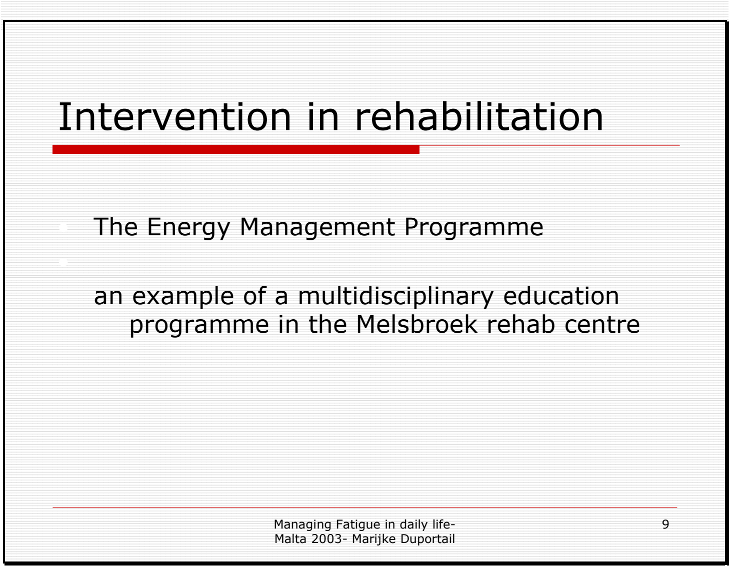
Diary of PwMs 4

Slide 8



4 different diaries of same PwMs

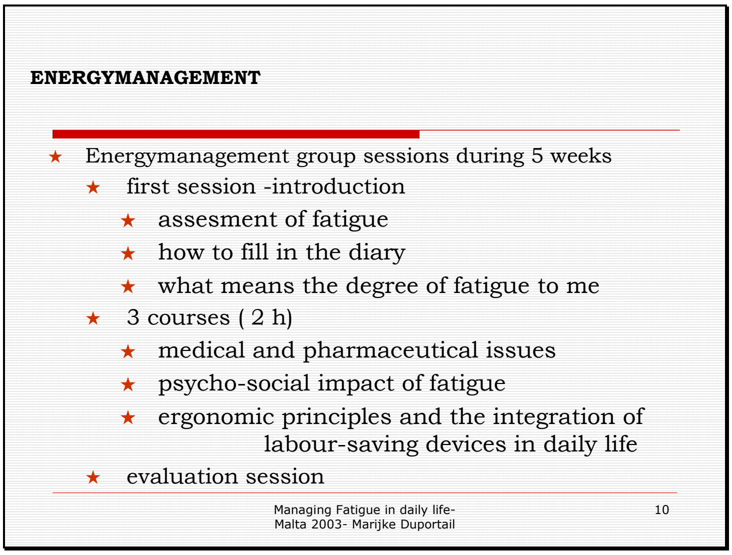
Slide 9



Intervention in rehabilitation

- The Energy Management Programme
- an example of a multidisciplinary education programme in the Melsbroek rehab centre

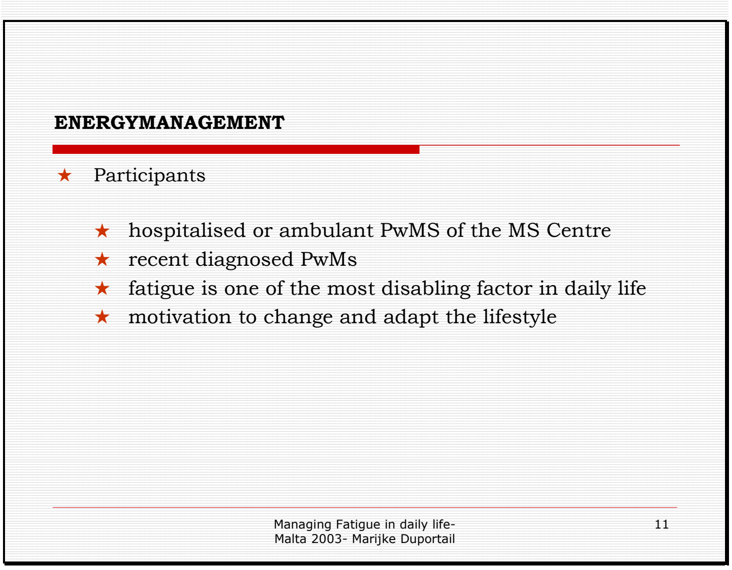
Slide 10



ENERGYMANAGEMENT

- ★ Energymanagement group sessions during 5 weeks
  - ★ first session -introduction
    - ★ assesment of fatigue
    - ★ how to fill in the diary
    - ★ what means the degree of fatigue to me
  - ★ 3 courses (2 h)
    - ★ medical and pharmaceutical issues
    - ★ psycho-social impact of fatigue
    - ★ ergonomic principles and the integration of labour-saving devices in daily life
  - ★ evaluation session

Slide 11



ENERGYMANAGEMENT

- Participants
  - hospitalised or ambulant PwMS of the MS Centre
  - recent diagnosed PwMs
  - fatigue is one of the most disabling factor in daily life
  - motivation to change and adapt the lifestyle

Managing Fatigue in daily life-
Malta 2003- Marijke Duportail

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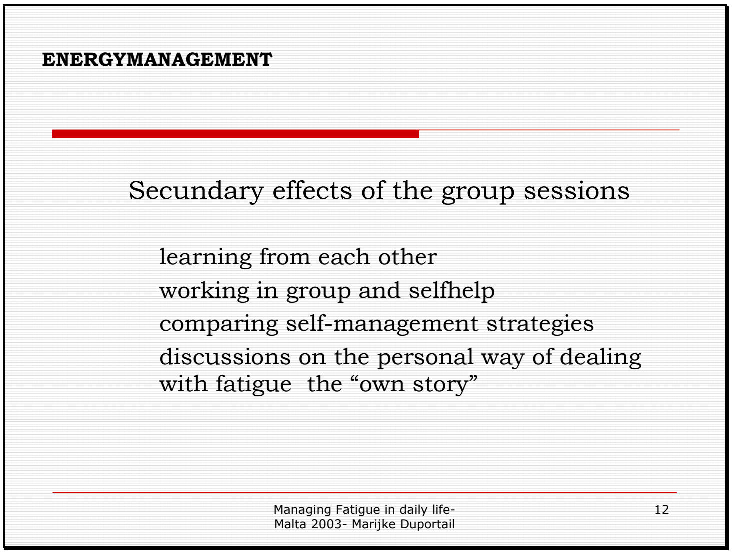
Slide 12



ENERGYMANAGEMENT

Secundary effects of the group sessions

learning from each other
working in group and selfhelp
comparing self-management strategies
discussions on the personal way of dealing with fatigue the “own story”

Managing Fatigue in daily life-
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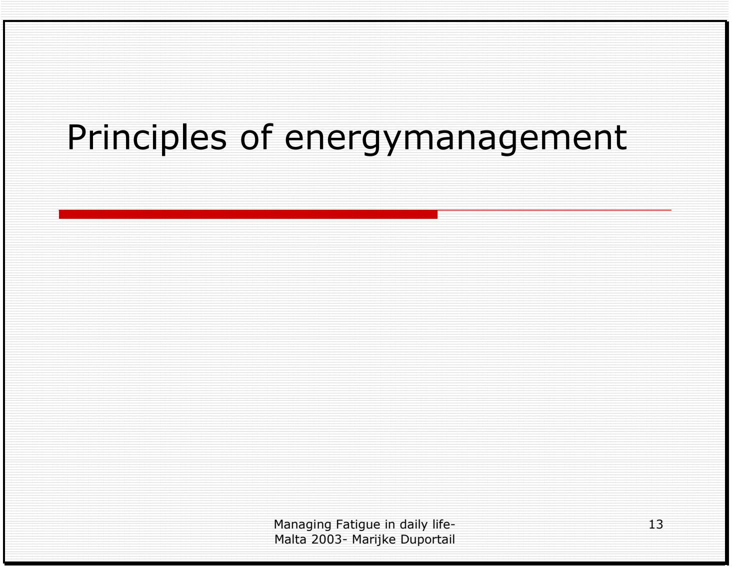
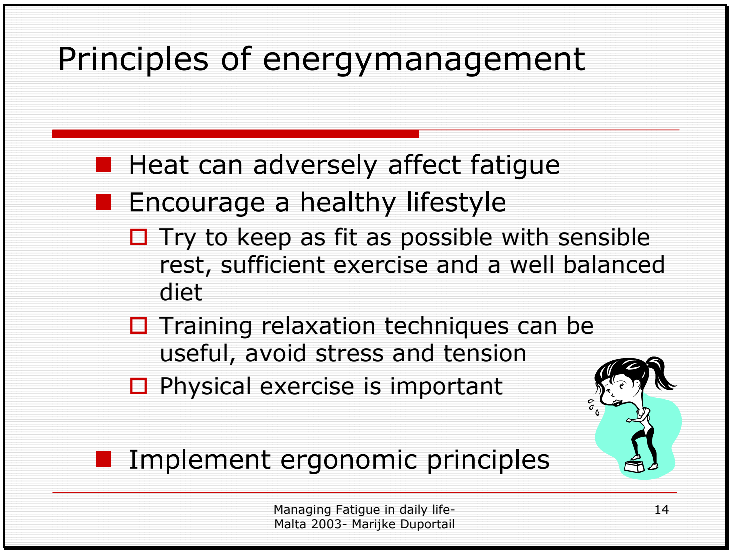
Slide 13



Principles of energymanagement

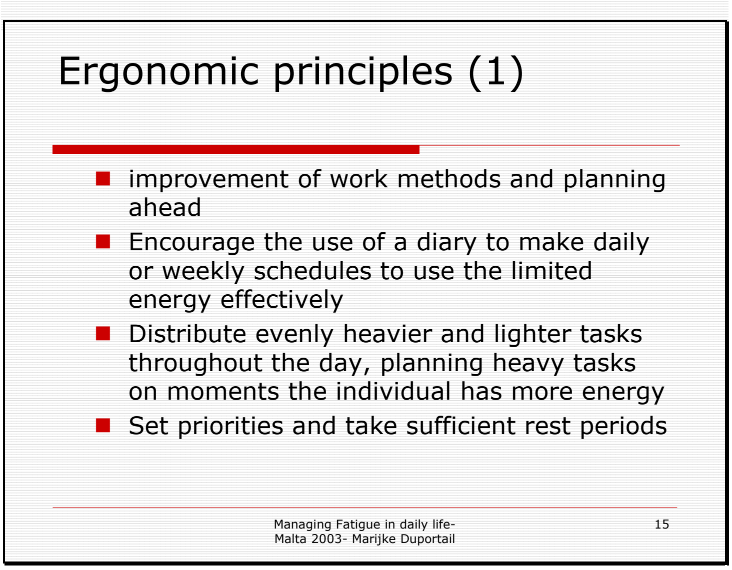
Slide 14



Principles of energymanagement

- Heat can adversely affect fatigue
- Encourage a healthy lifestyle
  - ☐ Try to keep as fit as possible with sensible rest, sufficient exercise and a well balanced diet
  - ☐ Training relaxation techniques can be useful, avoid stress and tension
  - ☐ Physical exercise is important
- Implement ergonomic principles

Slide 15



Ergonomic principles (1)

- improvement of work methods and planning ahead
- Encourage the use of a diary to make daily or weekly schedules to use the limited energy effectively
- Distribute evenly heavier and lighter tasks throughout the day, planning heavy tasks on moments the individual has more energy
- Set priorities and take sufficient rest periods

Managing Fatigue in daily life-
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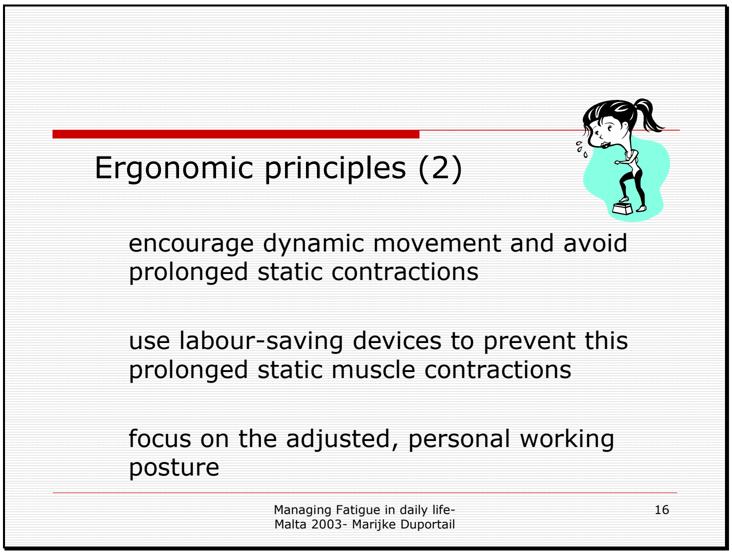
Slide 16



Ergonomic principles (2)

encourage dynamic movement and avoid prolonged static contractions

use labour-saving devices to prevent this prolonged static muscle contractions

focus on the adjusted, personal working posture

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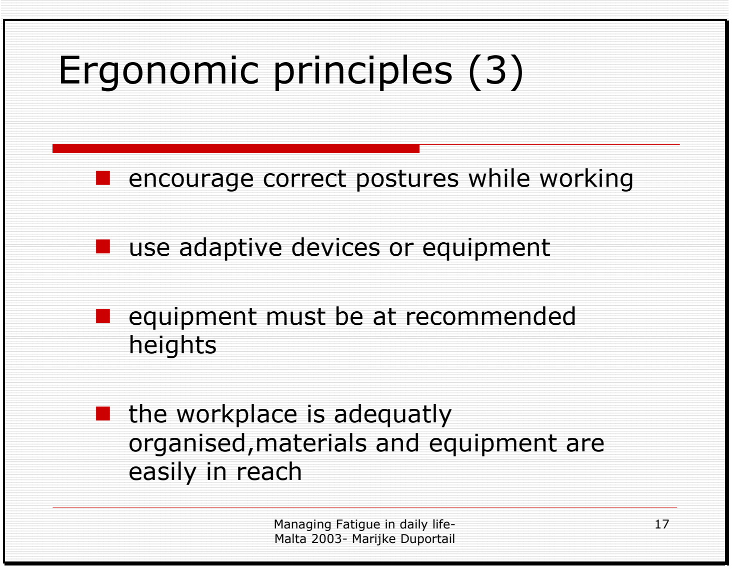
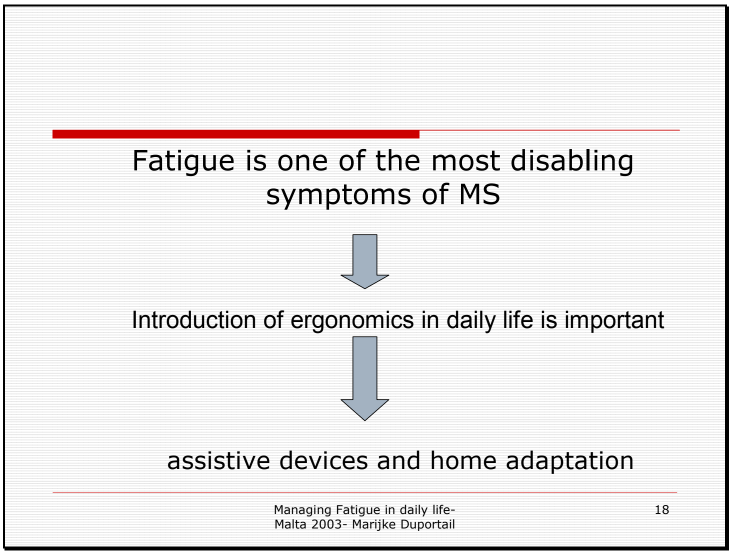
Slide 17



Ergonomic principles (3)

- encourage correct postures while working
- use adaptive devices or equipment
- equipment must be at recommended heights
- the workplace is adequatly organised,materials and equipment are easily in reach

Slide 18



Fatigue is one of the most disabling symptoms of MS

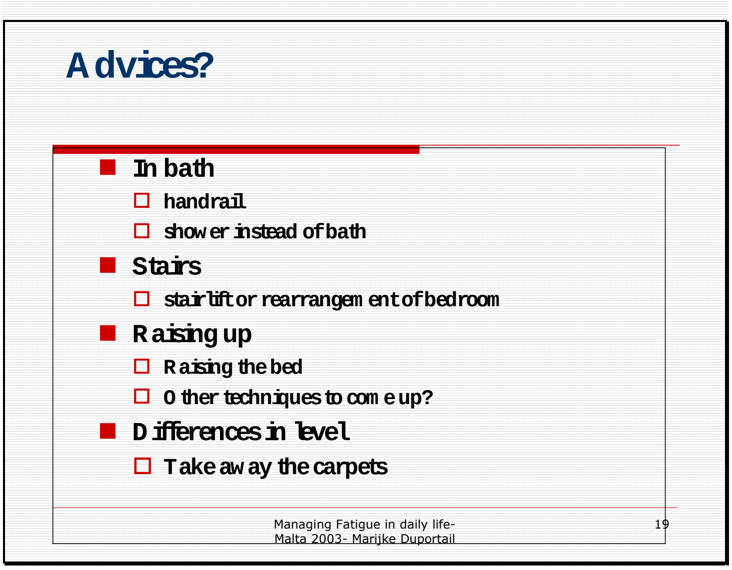
↓

Introduction of ergonomics in daily life is important

↓

assistive devices and home adaptation

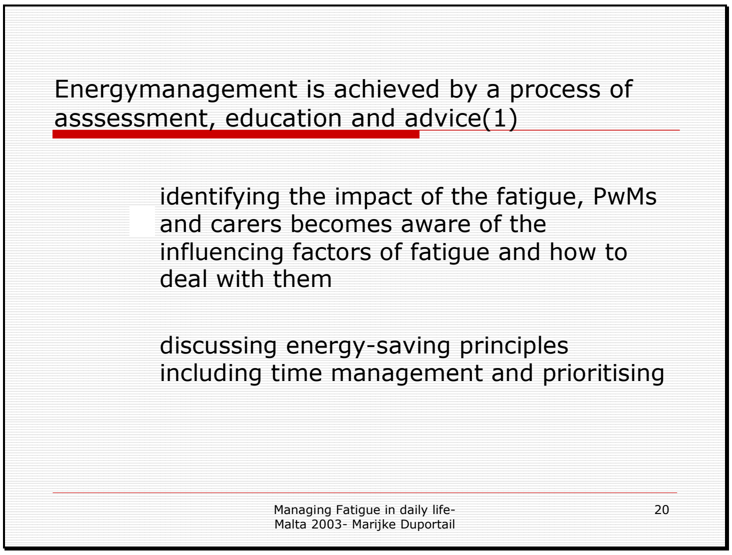
Slide 19



Advices?

- In bath
  - handrail
  - shower instead of bath
- Stairs
  - stairlift or rearrangement of bedroom
- Raising up
  - Raising the bed
  - Other techniques to come up?
- Differences in level
  - Take away the carpets

Slide 20

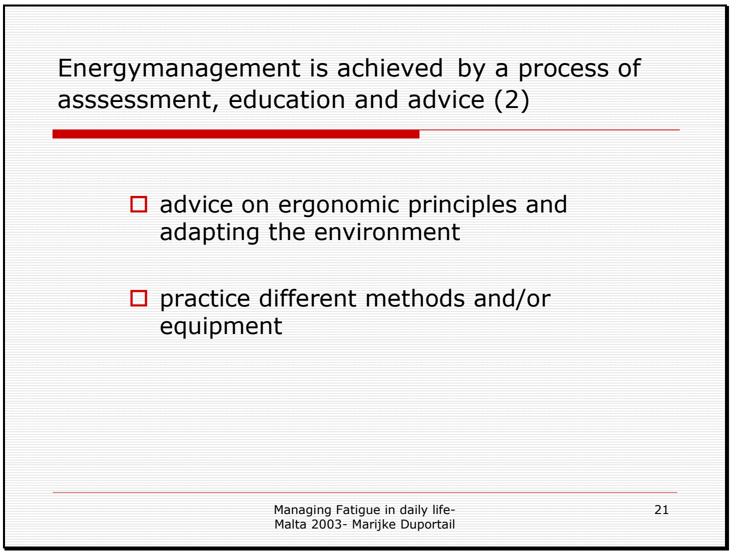


Energymanagement is achieved by a process of asssessment, education and advice(1)

identifying the impact of the fatigue, PwMs and carers becomes aware of the influencing factors of fatigue and how to deal with them

discussing energy-saving principles including time management and prioritising

Slide 21



Energymanagement is achieved by a process of asssessment, education and advice (2)

- advice on ergonomic principles and adapting the environment
- practice different methods and/or equipment

WORKSHOP 2 AND REPORT
MANAGING FATIGUE

Marianne Bache

1. What are the most common emotional problems for PwMS?
   - brainstorm – suggestions from the participants

2. Summary of common emotional problems

You can divide them into:

a) EP related to getting the diagnosis and living with af chronical and progressive disease

General problems **(also other similar diseases)**

- ***grieving*** **the loss**
  - **of being a healthy person, loosing one's good health of invulnerability**
  - **of control over one's life**
  - **of the planned / projected future – the dreams and life perspective is shattered**

  grieving a loss is a complex and highly individual process – time is needed to come to terms with the losses – "holding on" and "letting go" as part of this – ***denial /acceptance of the disease*** **- the importance of respecting the individual's own pace with the disease must be balanced with the preventing effect of early support.**

- ***anger*** **(can transform into bitterness)**
  - **at fate, God, for being hit by this, "this is not fair"**
  - **at the healthy persons**
  - **at being dependent**

- ***anxiety*** **– about one's future life**

- ***searching for meaning*** **– why did this happen to me? If I can only find a reason, a meaning I may be able to control it / the future**

- ***searching for regaining control*** **of the disease, of the future – "bargaining" – trying to live as normally as possible, denying the disease**

- ***searching for a new identity*** **– who am I now? Who is this person who is ill? Changing one's story about one-self.**

These three items are not feelings/emotions. They are a kind of "tasks", problems that the PwMS is trying to solve and find answers to. They create *confusion, tension, pain, changing moods, malaise.* A kind of "emotional rollercoaster".

- ***feelings of meaninglessness and hopelessness***
  - depression, suicidal thoughts

Specific problems due to the nature of MS

- ***uncertainty and unpredictability***

- ***grieving repeated losses*** **as the disease worsen**

- ***anxiety of being affected intellectually or of changing as a person***

It is not possible to present figures for the extent of these emotional problems. Most PwMS will experience some of them.

b) EP related to the impact of the disease – in the form of plaques – in certain centres of the brain

- ***Depression***
  - **sadness, despair**
  - **diminished interest in activities**
  - **changes in appetite**
  - **sleep disturbances**
  - **restlessness**
  - **fatigue, loss of energy**
  - **feelings of worthlessness and guilt**
  - **thought of death, suicide**

  50 % experience depression at some point, the prevalence of depression is estimated to be 25-55 %

Studies document that antidepressant drugs and psychotherapy have a positive effect on depression

- ***Emotional outbursts, ”short fuse”, increased irritability***

- ***Emotional lability,***
  - ***changing moods***
  - ***laughing and crying without apparent reason***
    medication may have an effect
  - ***euphoria***
    cheerfulness, optimism

It is difficult to distinguish precisely whether emotional problems are psychological or caused by damages in CNS.

Emotional problems are not necessarily related to duration of disease or degree of disability.

Emotional problems may be a result of or worsened by other symptoms of MS, for instance fatigue, pain, the fact that daily life activities are energy consuming

3. How to deal with emotional problems related to MS in the best way?

Personal reflection:

- **List 3 things that have been useful for you / the PwMS in dealing with emotional problems.**

Small group discussion:

- **Interview each other about the ways of coping with EP that you have found useful. Take turns**

  For instance ask for each of the problems:
  - **For what kind of EP was it helpful?**
  - **What did you do?**
  - **Who was involved in the process?**
  - **Why do you think this was helpful?**
  - **Would it be helpful for others too?**
  - **Looking at it today, would you have done anything differently? If so, what and how?**

4. Plenary:

The suggested means for coping with emotional problems were shared, and the following day they were summarised by two rapporteurs:

Rolande Cutner gave a personal and breathtaking presentation and live demonstration of some of the emotional problems that the group had discussed: Rage and anger, grief, depression, mood swings, envy, isolation, helplessness and feeling useless.

Janos Nadaban summarised the plenary discussion of ways to deal with EP:

"We had to list 3 things that we found useful for dealing with EPs and then discuss our opinions in groups of 3 or 4. This was a great idea and I found this small team-work very effective and useful. Presenting our conclusions afterwards in the plenary resulted in findings of great value:

First in the long list was to think positive **instead of negative. Try to find new ways of doing things and try to find new things to do and delete the expression: "I AM NOT ABLE" from our dictionary! Having MS changes the life of people showing new directions to go which are not necessarily worse than those before, but sometimes only different. Because of this change you yourselves need some change which will surely help finding new alternatives.**

It was indeed very astonishing for me to hear a gentleman tell that his wheelchair meant that he gotten new friends, because he met people he would never have met, if he had not been forced to use a wheelchair. This was another great example of seeing the bright side of life and thus thinking positively.

The second point is maybe even more important and that is communication. **It is of high importance to find somebody to talk to, who, however, should not be anyone, but someone who cares and knows what MS means. So, in other words, you must make sure you are** talking to the right person. **At this point a lady from Britain added that sometimes this person will not be the one closest to you (so s/he might not in all instances be your wife/husband). It does not always seem enough to find the right person to talk to, it is also a key thing to find the appropriate time and place for talking.**

We also found that dedicating ourselves to something helps and that we all - and not only PwMS or with any other chronical disease! - should do things that bring us joy and pleasure**, neutralising the bad effects we encounter. Now here the ladies of our workshop suggested - I think - the most expensive kind of treatment in history which was retail-therapy. Being a simple man, I cannot explain the philosophy and the source of joy behind mere shopping. I do apologise for that!**

Talking about different EPs, we also found - based on individual experiences - that for example in the case of long-lasting and deep depression only proper medication **can help. So that is the point where health professionals enter the scene with their help.**

One group came up with a fairly unexpected structure as the group consisted of 3 people with 3 different aspects:
1. One was patient-to-patient advice **on what could help coping with EPs containing:**

- **Gathering all the available information on MS, to know EXACTLY what one must face**
- **Achieving the acceptance of the family, one of the most important (if not the most important) part of our lives**
- **Using the MS societies of which a newly diagnosed should learn as soon as possible, since those are the places where they can get help and where they can belong and thus feel useful and important.**

2. The other one was the friend-to-patient-level advice **where communication, the need for a change in the environment (holidays, recreation etc.) and appropriate professional therapy were stressed.**

3. Finally, a new problem-solution-structure arose when we got to the level of self-help**:**
Problem1: Anxiety of loosing intellectual capability
Solution1: Keep the brain active and work with it!
Problem2: Feeling isolated
Solution2: Be nice and friendly to others and they will be nice to you too. Smile and the world will smile back at you!
Problem3: Managing difficulties
Solution3: Do not hesitate to call for help! People are usually willing to help, but know not how to do it. Tell them exactly what you need and they will be glad to help you. However, - as an advice from a strong-hearted lady in a wheelchair - if no one helps, do it yourself!

Despite talking about EPs for hours we still kept in mind that there is a time for everything in our lives, and so there is a time for feeling blue and for wanting to be alone with all our thoughts circling around in our minds. It is humane to feel down at times, but not for longer than natural and not in deeper grief. And, unfortunately PwMS tend to be in a bad mood more often than they should be.
One of the reasons for this - as I have said before - is the feeling of uselessness and having a depression. Again a woman from the group presented a good method: every morning she writes down all the things (even the tiny ones), she has to do that day and crosses out those she has done. And in the end of the day she sees with delight that she has done many, many things, which IS a very good feeling for everyone!

Against depression Rolande provided her solution which was going straight away to her hairdresser and setting her hair in flames. As she would put is: she needed some action**, to do something crazy and to do that NOW!**

Those of you who had such great endurance that they could stand the temptation of falling asleep might have noticed that I have not yet spoken about the role of the MS Societies in helping to cope with EPs. There are indeed many ways that a society can help its members, such as: a help-line, psychotherapist, support groups, workshops on different aspects of the problem, personal assistance and of course education.

In my point of view, we did find valuable things, but - as one of the participants keen-eyed observed - each and every person in the room was the fighting-type and not by any chance someone who would give in. And finishing off, I would like to say that it is a great and admirable thing! Keep up the good spirit!"

WORKSHOP 3
TELECOMMUNICATION AS A MEANS FOR SELF-HELP IN MS

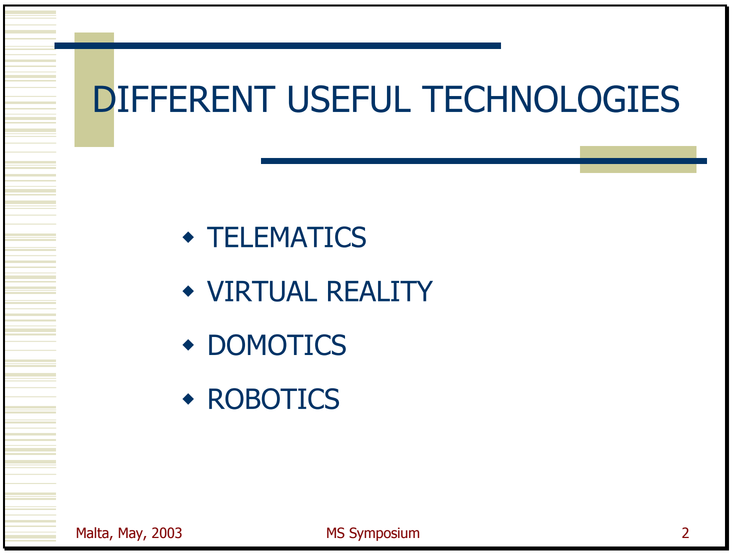
Pierre Ketelaer

Slide 1

Workshop: applications of telecommunication in MS

Pierre Ketelaer M.D.
Luc De Wolf Eng. PhD.
National Multiple Sclerosis Centre, Melsbroek, Belgium
Institute of Technology, Leuven, Belgium

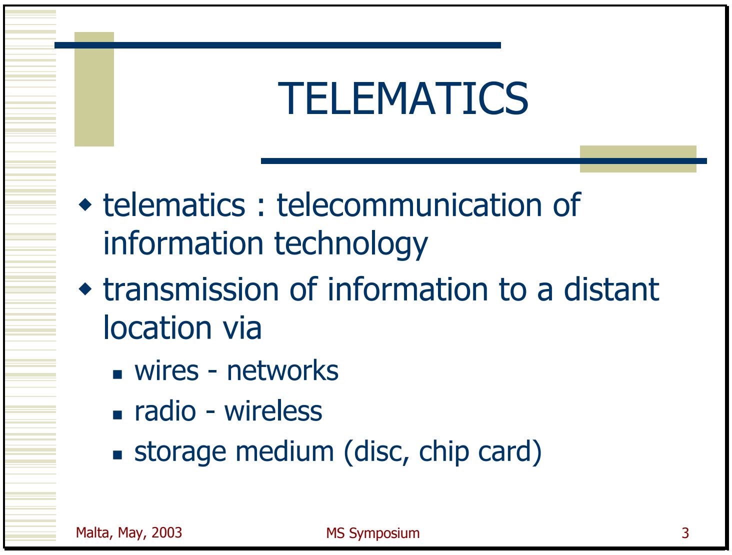
Slide 2



DIFFERENT USEFUL TECHNOLOGIES

- TELEMATICS
- VIRTUAL REALITY
- DOMOTICS
- ROBOTICS

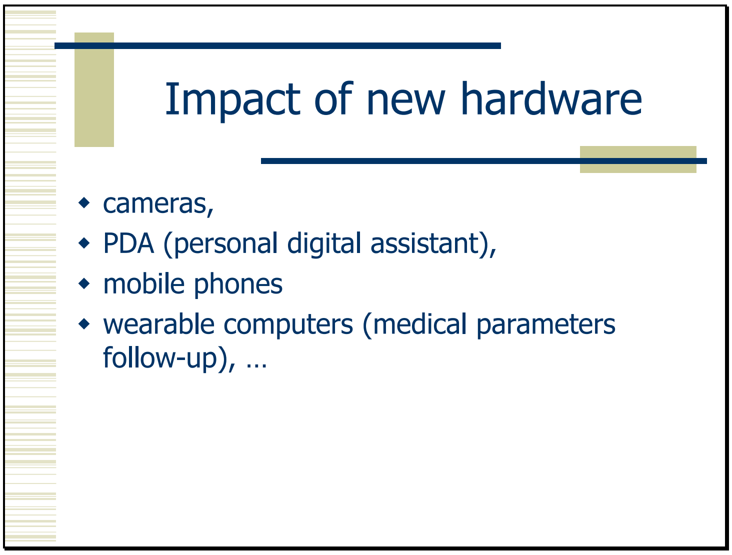
Slide 3



TELEMATICS

- telematics : telecommunication of information technology
- transmission of information to a distant location via
  - wires - networks
  - radio - wireless
  - storage medium (disc, chip card)

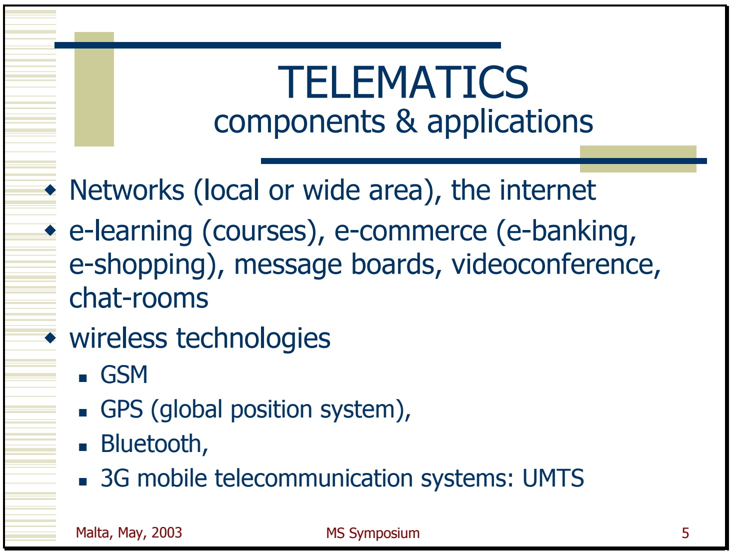
Slide 4



Impact of new hardware

- cameras,
- PDA (personal digital assistant),
- mobile phones
- wearable computers (medical parameters follow-up), …

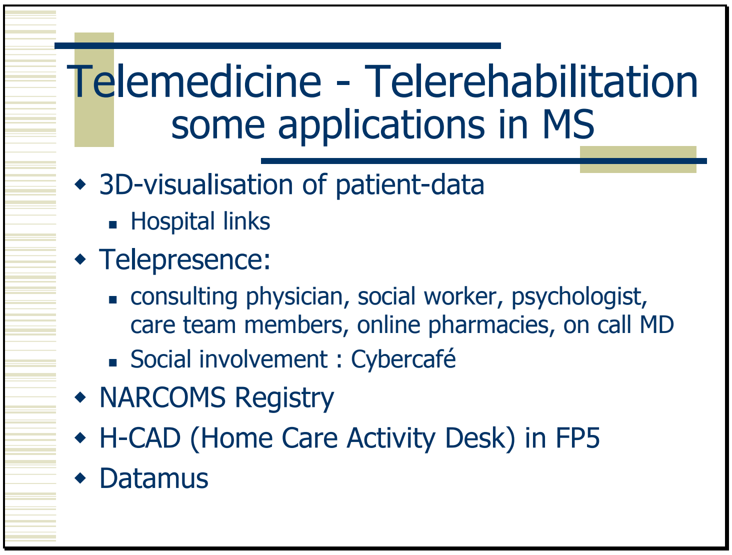
Slide 5



TELEMATICS
components & applications

- Networks (local or wide area), the internet
- e-learning (courses), e-commerce (e-banking, e-shopping), message boards, videoconference, chat-rooms
- wireless technologies
  - GSM
  - GPS (global position system),
  - Bluetooth,
  - 3G mobile telecommunication systems: UMTS

Slide 6



Telemedicine - Telerehabilitation
some applications in MS

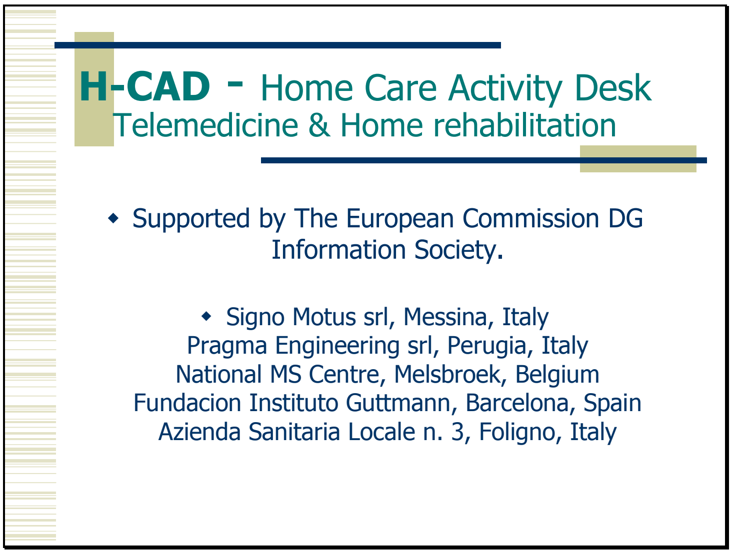
- 3D-visualisation of patient-data
  - Hospital links
- Telepresence:
  - consulting physician, social worker, psychologist, care team members, online pharmacies, on call MD
  - Social involvement : Cybercafé
- NARCOMS Registry
- H-CAD (Home Care Activity Desk) in FP5
- Datamus

Slide 7

Telepresence

- Inquiry at the National MS Centre (NMSC)
- e-communication PwMS-NMSC
- Cybercafé in Melsbroek
- Research projects

Slide 8

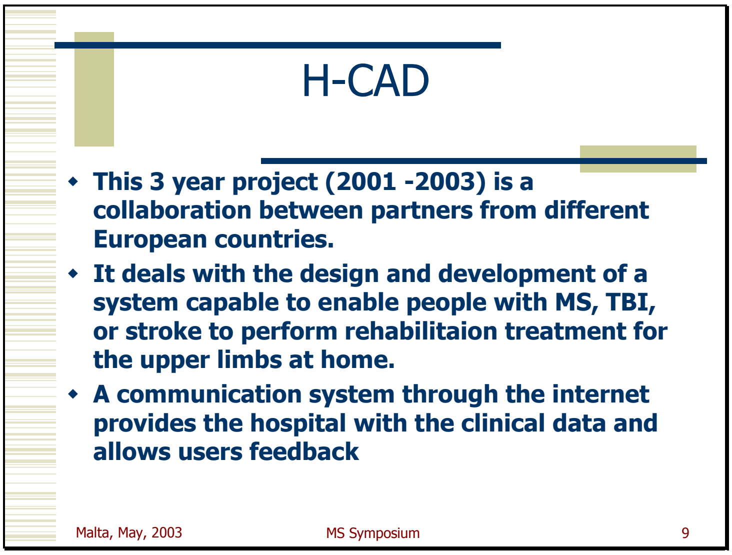


H-CAD - Home Care Activity Desk
Telemedicine & Home rehabilitation

- Supported by The European Commission DG Information Society.

- Signo Motus srl, Messina, Italy
  Pragma Engineering srl, Perugia, Italy
  National MS Centre, Melsbroek, Belgium
  Fundacion Instituto Guttmann, Barcelona, Spain
  Azienda Sanitaria Locale n. 3, Foligno, Italy

Slide 9

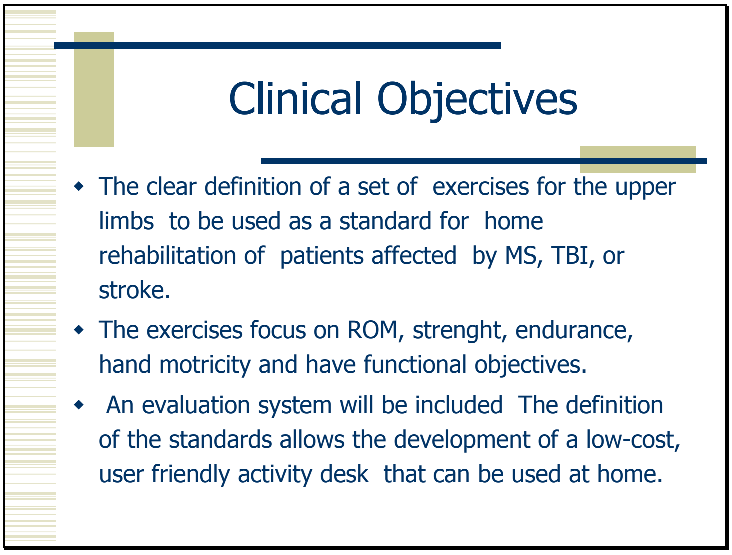


H-CAD

- **This 3 year project (2001 -2003) is a collaboration between partners from different European countries.**
- **It deals with the design and development of a system capable to enable people with MS, TBI, or stroke to perform rehabilitaion treatment for the upper limbs at home.**
- **A communication system through the internet provides the hospital with the clinical data and allows users feedback**

Malta, May, 2003 MS Symposium 9

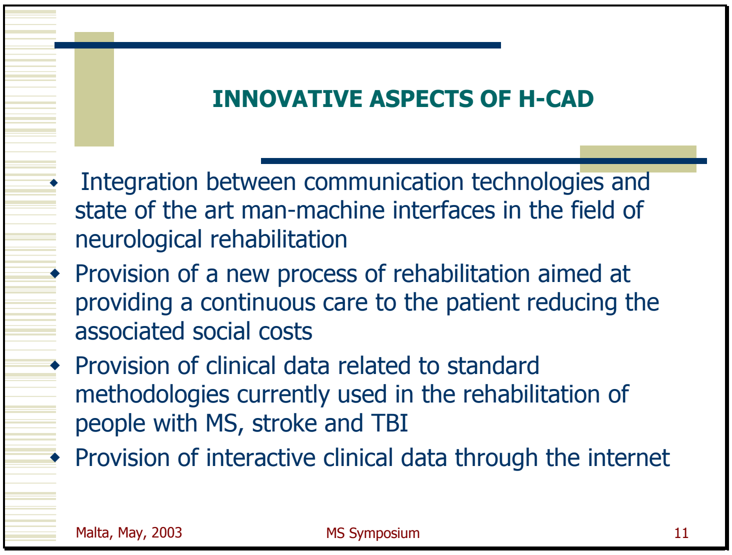
Slide 10



Clinical Objectives

- The clear definition of a set of exercises for the upper limbs to be used as a standard for home rehabilitation of patients affected by MS, TBI, or stroke.
- The exercises focus on ROM, strenght, endurance, hand motricity and have functional objectives.
- An evaluation system will be included The definition of the standards allows the development of a low-cost, user friendly activity desk that can be used at home.

Slide 11



INNOVATIVE ASPECTS OF H-CAD

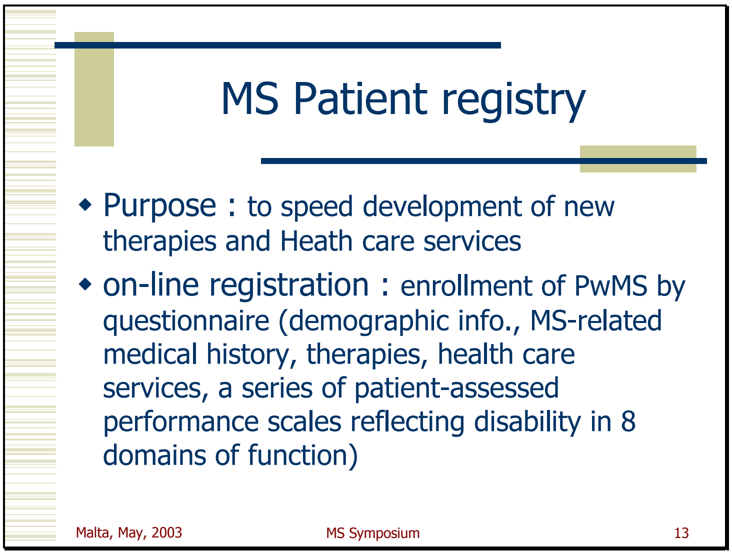
- Integration between communication technologies and state of the art man-machine interfaces in the field of neurological rehabilitation
- Provision of a new process of rehabilitation aimed at providing a continuous care to the patient reducing the associated social costs
- Provision of clinical data related to standard methodologies currently used in the rehabilitation of people with MS, stroke and TBI
- Provision of interactive clinical data through the internet

Slide 12

NARCOMS Registry

- North American Research Committee on MS (NARCOMS)
- Patient driven database
- Multiple Sclerosis Quarterly Report (MSQR)

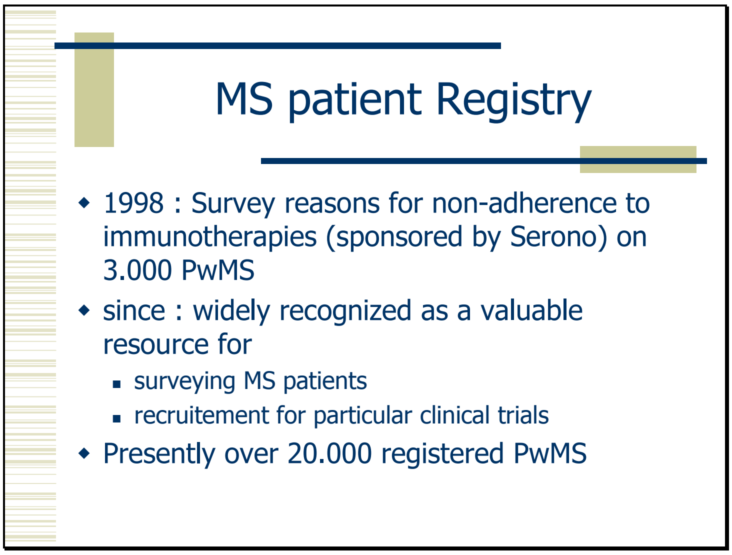
Slide 13



MS Patient registry

- Purpose : to speed development of new therapies and Heath care services
- on-line registration : enrollment of PwMS by questionnaire (demographic info., MS-related medical history, therapies, health care services, a series of patient-assessed performance scales reflecting disability in 8 domains of function)

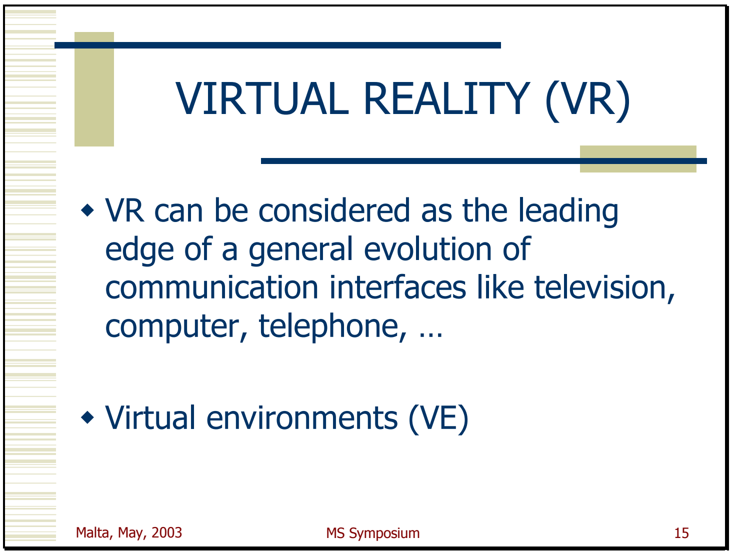
Slide 14



MS patient Registry

- 1998 : Survey reasons for non-adherence to immunotherapies (sponsored by Serono) on 3.000 PwMS
- since : widely recognized as a valuable resource for
  - surveying MS patients
  - recruitement for particular clinical trials
- Presently over 20.000 registered PwMS

Slide 15

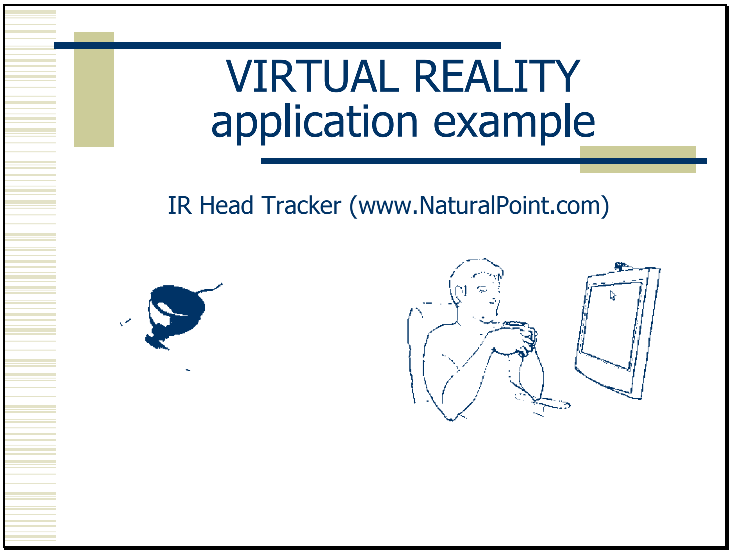


VIRTUAL REALITY (VR)

- VR can be considered as the leading edge of a general evolution of communication interfaces like television, computer, telephone, …
- Virtual environments (VE)

Malta, May, 2003 MS Symposium 15

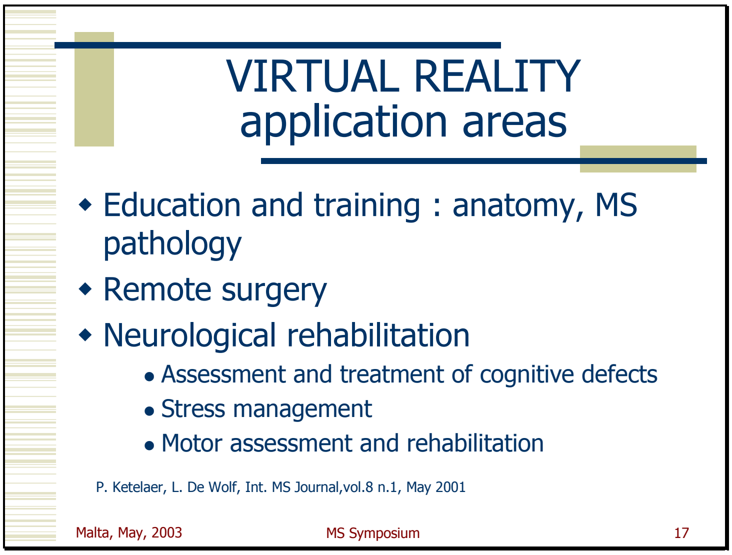
Slide 16



VIRTUAL REALITY application example

IR Head Tracker (www.NaturalPoint.com)

Slide 17

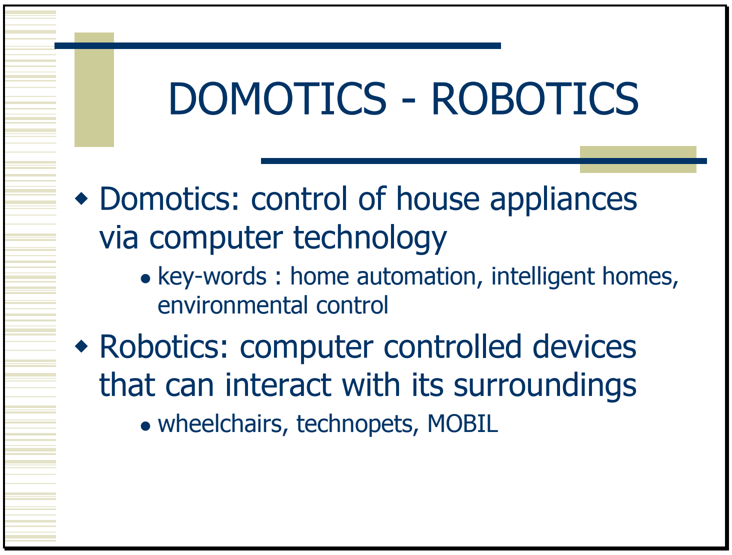


VIRTUAL REALITY application areas

- Education and training : anatomy, MS pathology
- Remote surgery
- Neurological rehabilitation
    - Assessment and treatment of cognitive defects
    - Stress management
    - Motor assessment and rehabilitation

P. Ketelaer, L. De Wolf, Int. MS Journal,vol.8 n.1, May 2001

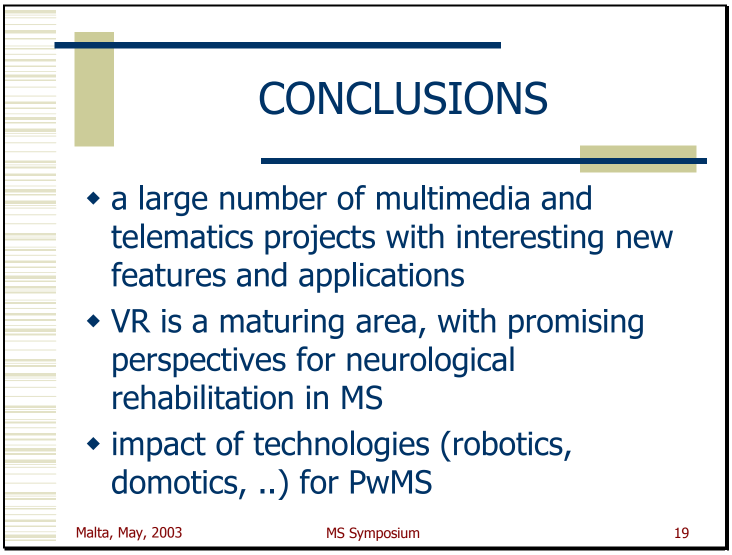
Slide 18



DOMOTICS - ROBOTICS

- Domotics: control of house appliances via computer technology
    - key-words : home automation, intelligent homes, environmental control
- Robotics: computer controlled devices that can interact with its surroundings
    - wheelchairs, technopets, MOBIL

Slide 19



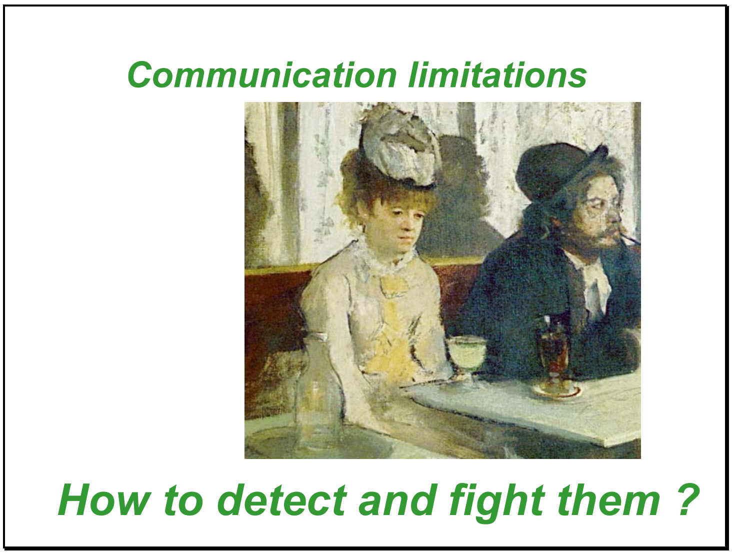
CONCLUSIONS

- a large number of multimedia and telematics projects with interesting new features and applications
- VR is a maturing area, with promising perspectives for neurological rehabilitation in MS
- impact of technologies (robotics, domotics, ..) for PwMS

WORKSHOP 4
COMMUNICATION LIMITATIONS: HOW TO DETECT AND FIGHT THEM

Guy Ganty

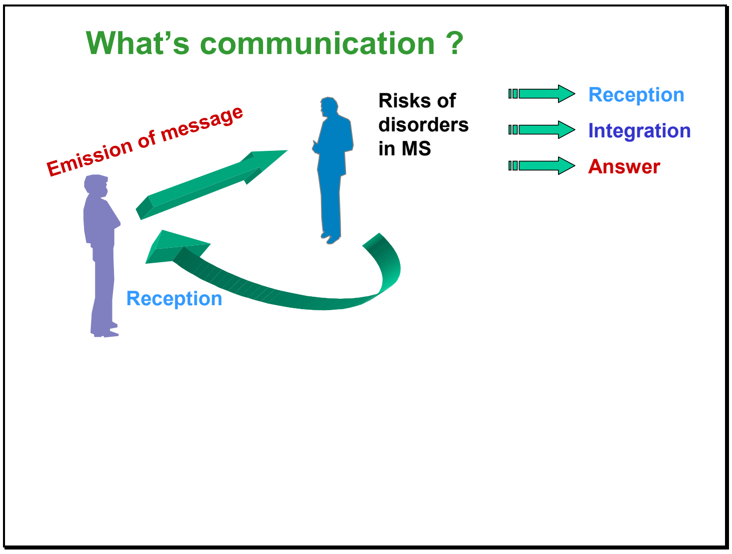
Slide 1



Communication limitations

How to detect and fight them ?

Slide 2



What's communication ?

Emission of message

Reception

Risks of
disorders
in MS

- Reception
- Integration
- Answer

Slide 3

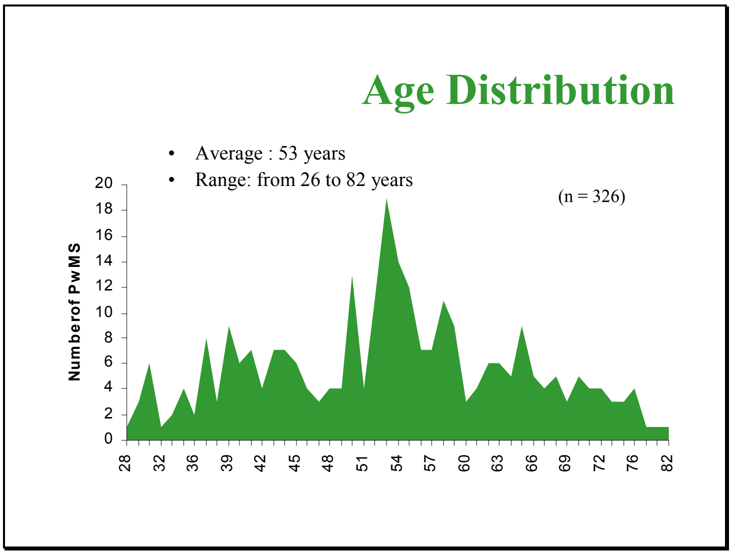
Questionnaire Communication

SLP Department – Melsbroek
APF – Mission MS
2002

10.000 PwMS through the magazine
« APF Mission SEP »

350 answers

Slide 4

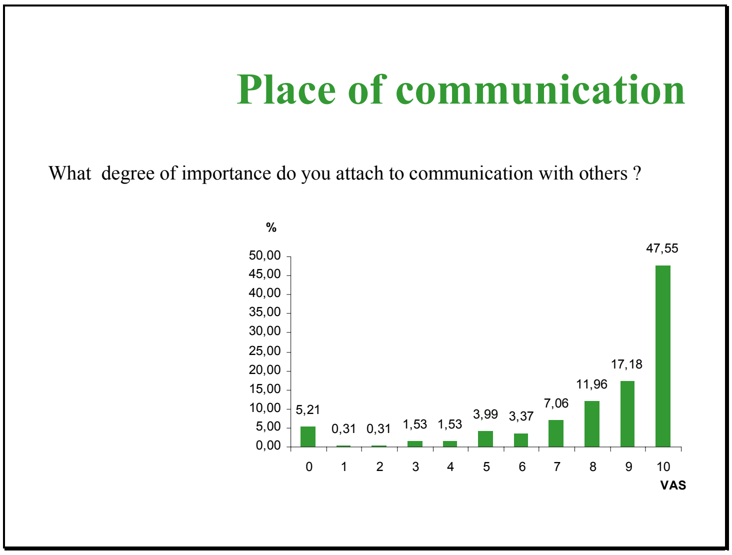


Age Distribution

- Average : 53 years
- Range: from 26 to 82 years

(n = 326)

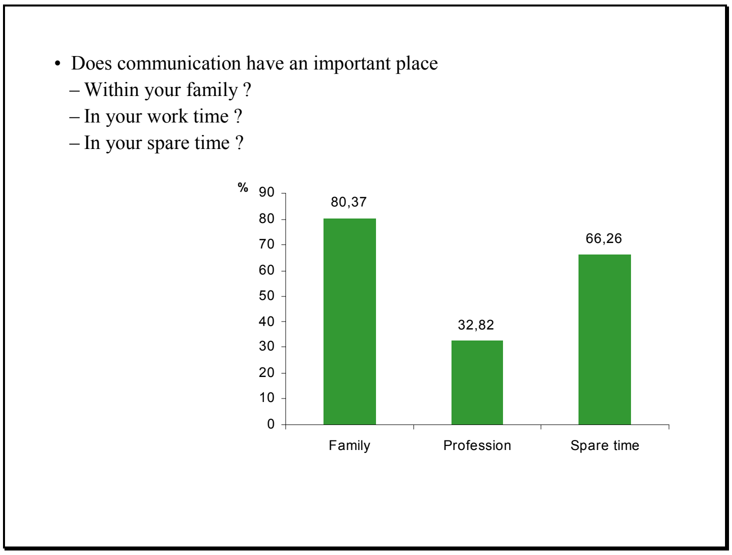
Slide 5



Place of communication

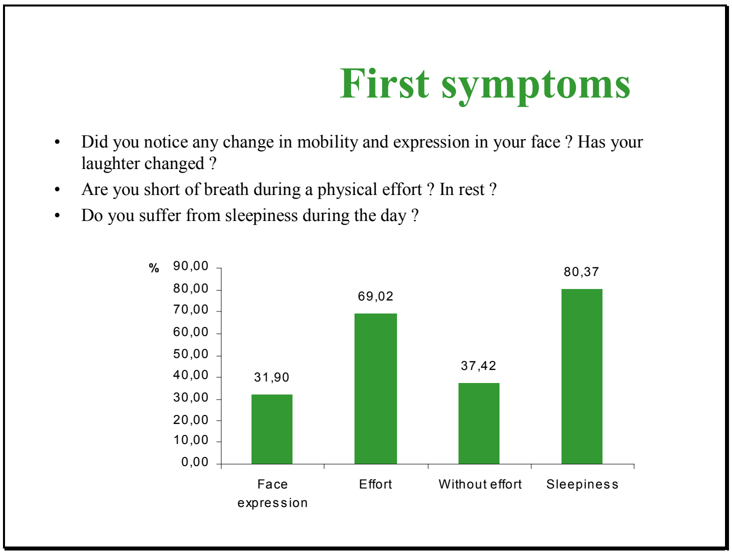
What degree of importance do you attach to communication with others ?

Slide 6



- Does communication have an important place
  - Within your family ?
  - In your work time ?
  - In your spare time ?

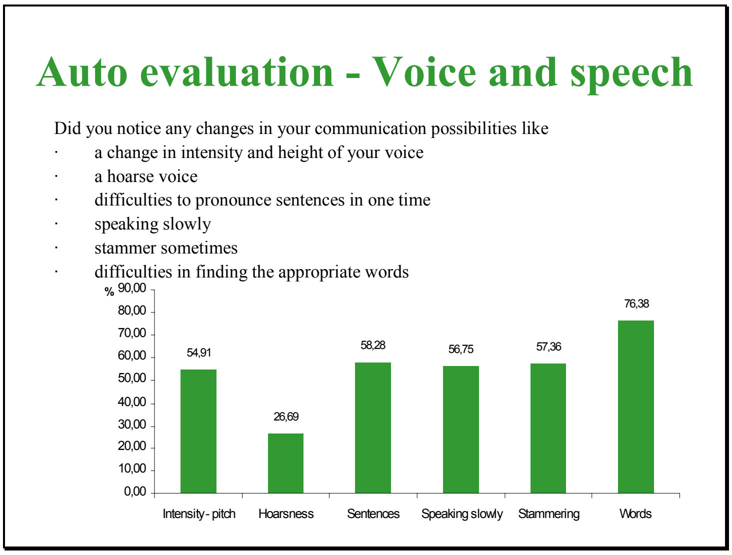
Slide 7



First symptoms

- Did you notice any change in mobility and expression in your face ? Has your laughter changed ?
- Are you short of breath during a physical effort ? In rest ?
- Do you suffer from sleepiness during the day ?

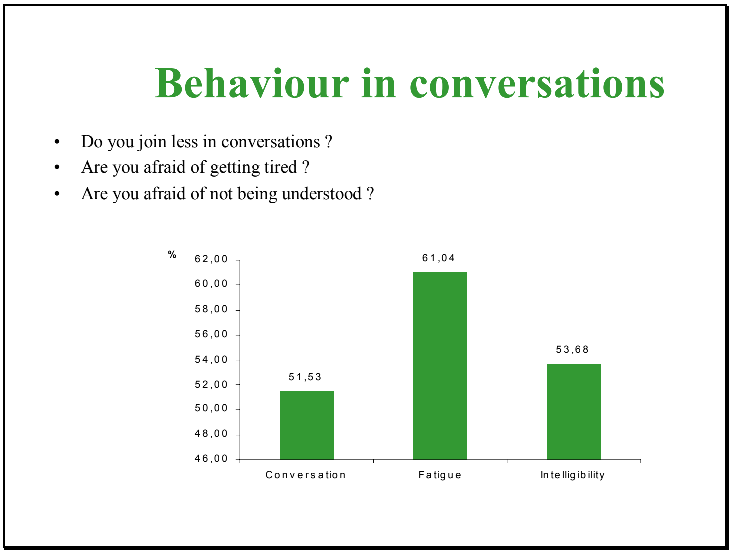
Slide 8



Auto evaluation - Voice and speech

Did you notice any changes in your communication possibilities like
- a change in intensity and height of your voice
- a hoarse voice
- difficulties to pronounce sentences in one time
- speaking slowly
- stammer sometimes
- difficulties in finding the appropriate words

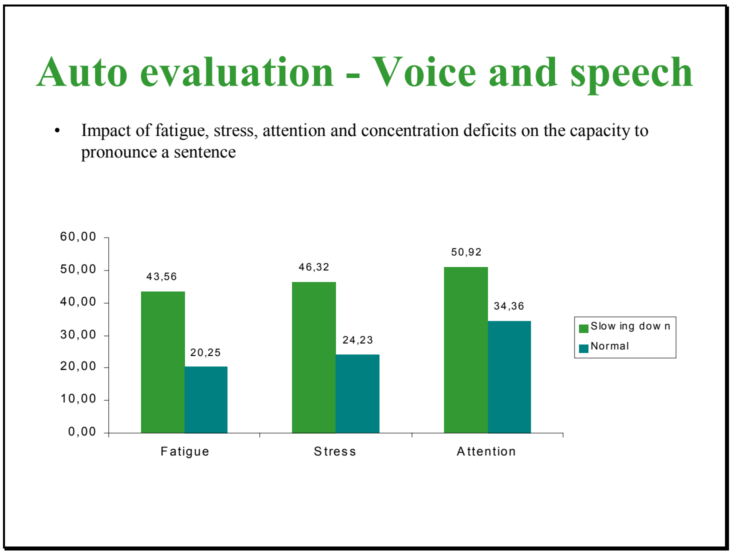
Slide 9



Behaviour in conversations

- Do you join less in conversations ?
- Are you afraid of getting tired ?
- Are you afraid of not being understood ?

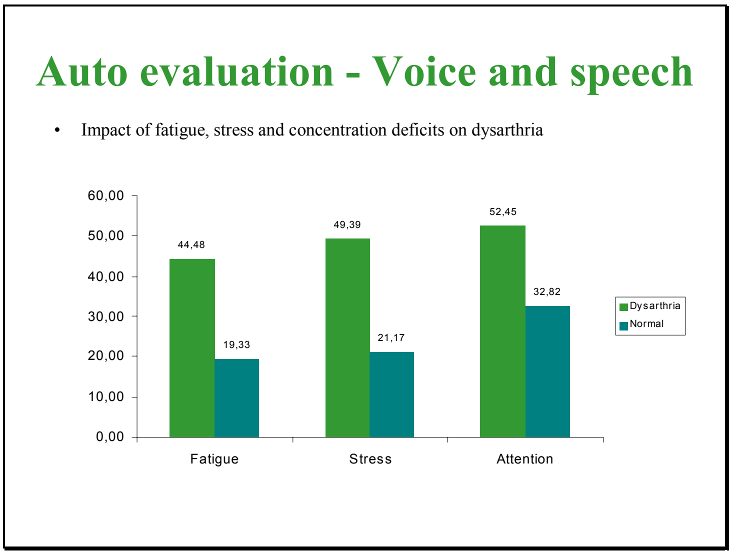
Slide 10



Auto evaluation - Voice and speech

- Impact of fatigue, stress, attention and concentration deficits on the capacity to pronounce a sentence

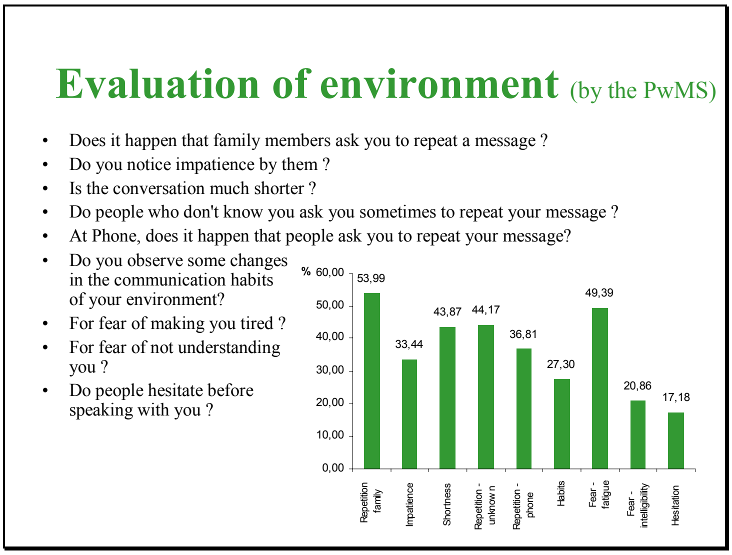
Slide 11



Auto evaluation - Voice and speech

- Impact of fatigue, stress and concentration deficits on dysarthria

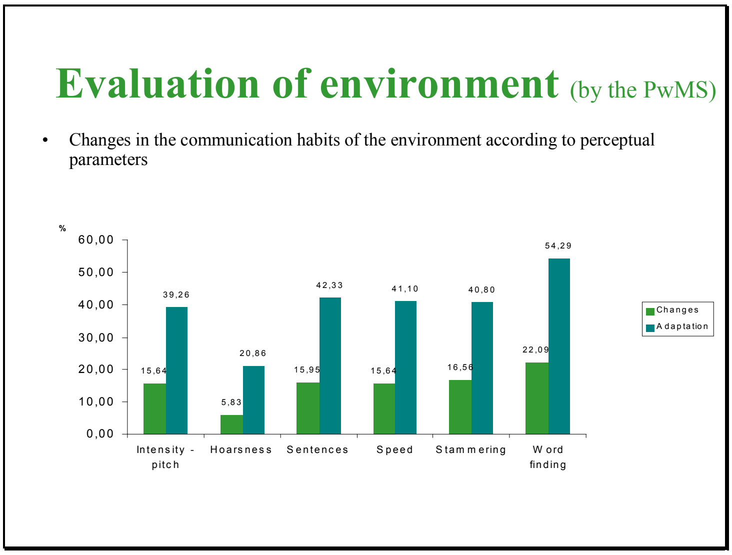
Slide 12



Evaluation of environment (by the PwMS)

- Does it happen that family members ask you to repeat a message ?
- Do you notice impatience by them ?
- Is the conversation much shorter ?
- Do people who don't know you ask you sometimes to repeat your message ?
- At Phone, does it happen that people ask you to repeat your message?
- Do you observe some changes in the communication habits of your environment?
- For fear of making you tired ?
- For fear of not understanding you ?
- Do people hesitate before speaking with you ?

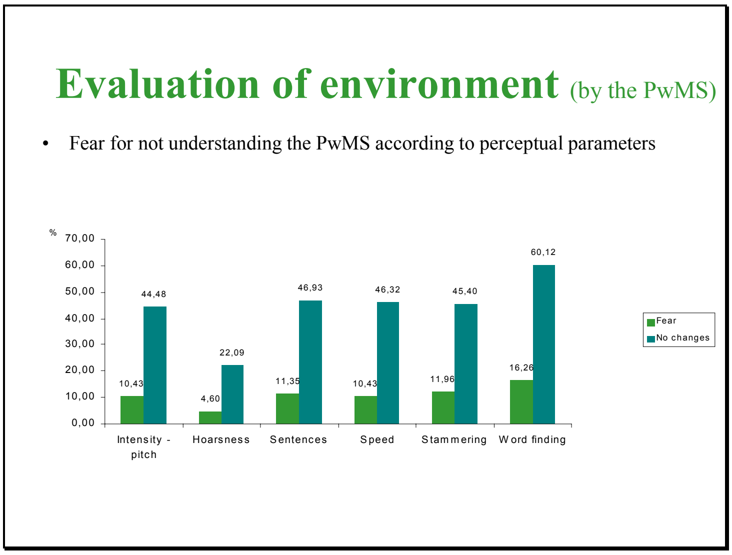
Slide 13



Evaluation of environment (by the PwMS)

- Changes in the communication habits of the environment according to perceptual parameters

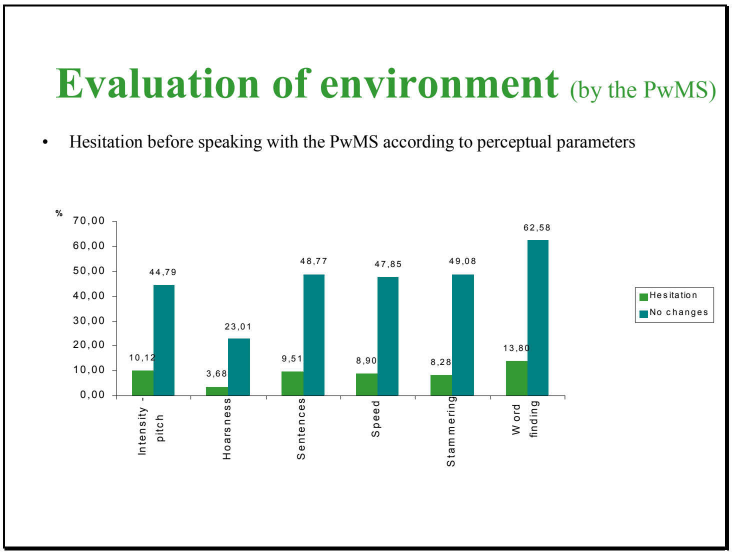
Slide 14



Evaluation of environment (by the PwMS)

- Fear for not understanding the PwMS according to perceptual parameters

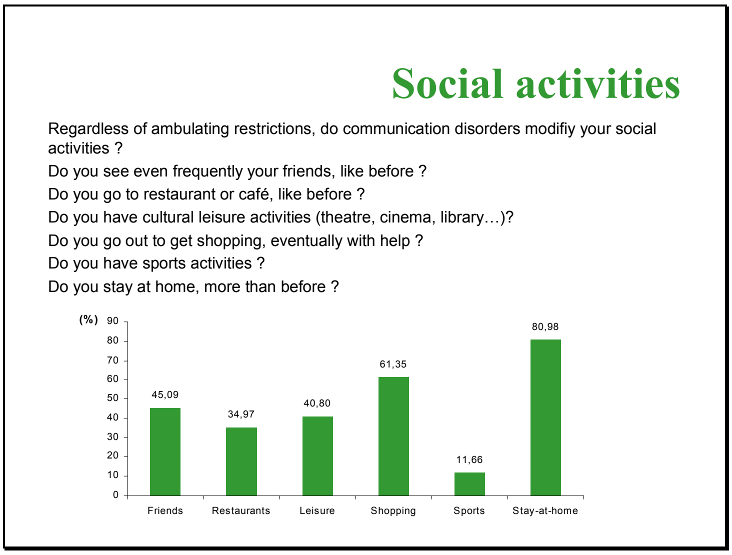
Slide 15



Evaluation of environment (by the PwMS)

- Hesitation before speaking with the PwMS according to perceptual parameters

Slide 16



Social activities

Regardless of ambulating restrictions, do communication disorders modifiy your social activities ?

Do you see even frequently your friends, like before ?

Do you go to restaurant or café, like before ?

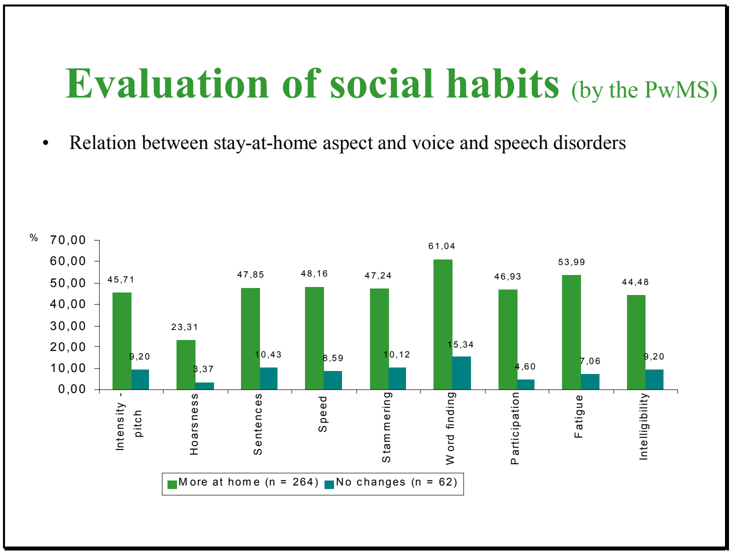
Do you have cultural leisure activities (theatre, cinema, library…)?

Do you go out to get shopping, eventually with help ?

Do you have sports activities ?

Do you stay at home, more than before ?

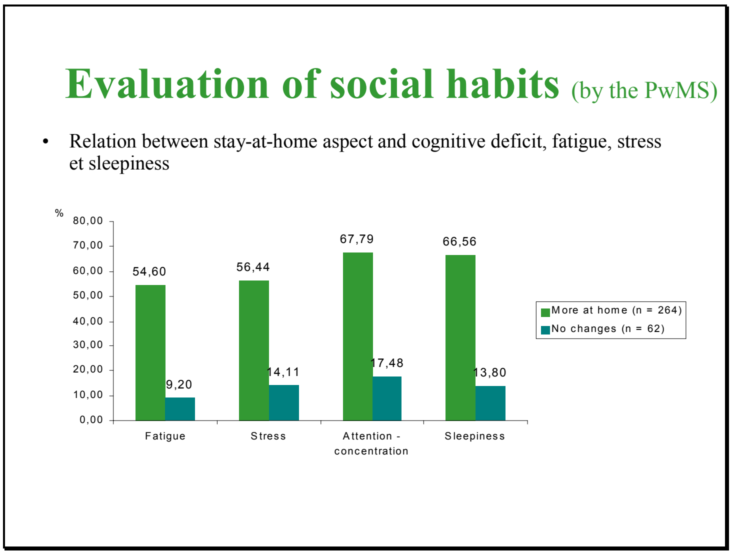
Slide 17



Evaluation of social habits (by the PwMS)

- Relation between stay-at-home aspect and voice and speech disorders

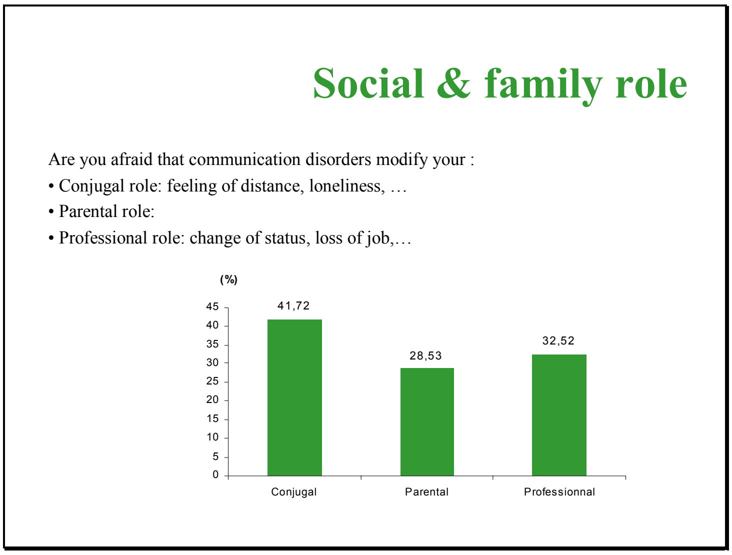
Slide 18



Evaluation of social habits (by the PwMS)

- Relation between stay-at-home aspect and cognitive deficit, fatigue, stress et sleepiness

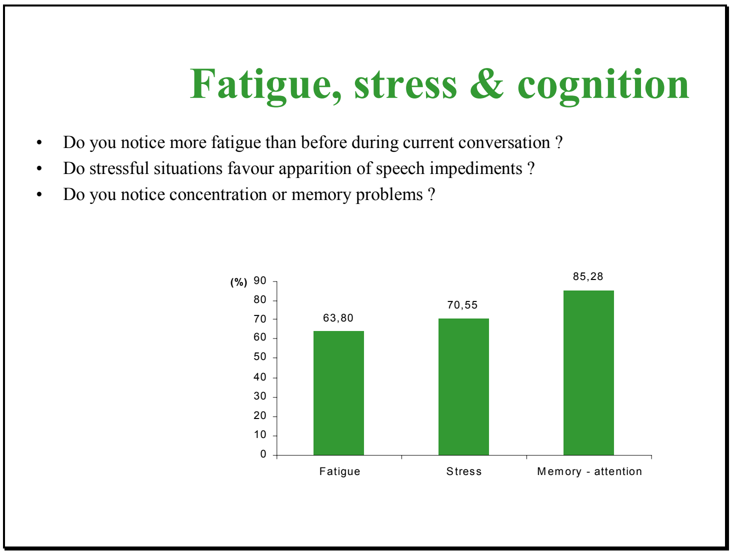
Slide 19



Social & family role

Are you afraid that communication disorders modify your :
- Conjugal role: feeling of distance, loneliness, …
- Parental role:
- Professional role: change of status, loss of job,…

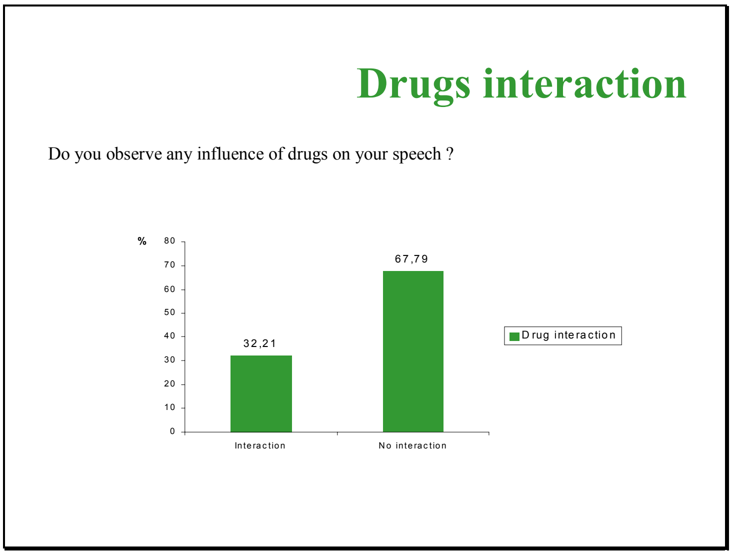
Slide 20



Fatigue, stress & cognition

- Do you notice more fatigue than before during current conversation ?
- Do stressful situations favour apparition of speech impediments ?
- Do you notice concentration or memory problems ?

Slide 21



Drugs interaction

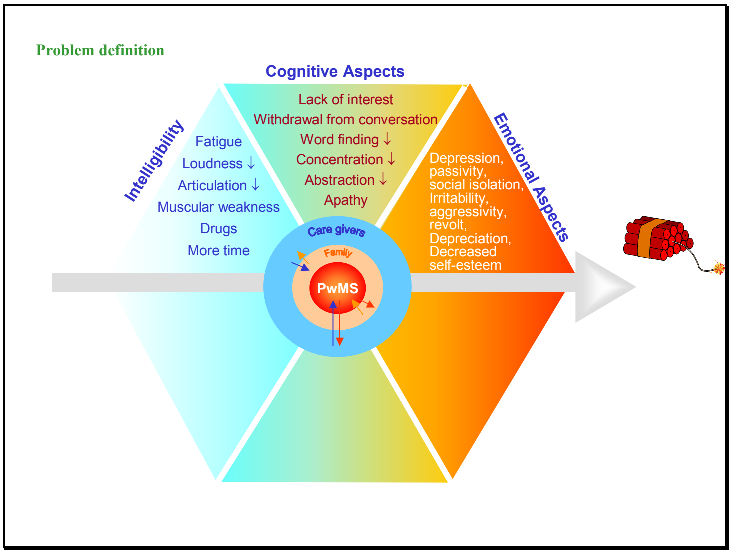
Do you observe any influence of drugs on your speech ?

Slide 22

Communication limitations
How to detect them ?

1. Voice & Speech Disorders - Intelligibility
2. High Level Language Problems – Cognition
3. Emotional aspects

Slide 23



Problem definition

Cognitive Aspects

Lack of interest
Withdrawal from conversation
Word finding ↓
Concentration ↓
Abstraction ↓
Apathy

Intelligibility

Fatigue
Loudness ↓
Articulation ↓
Muscular weakness
Drugs
More time

Emotional Aspects

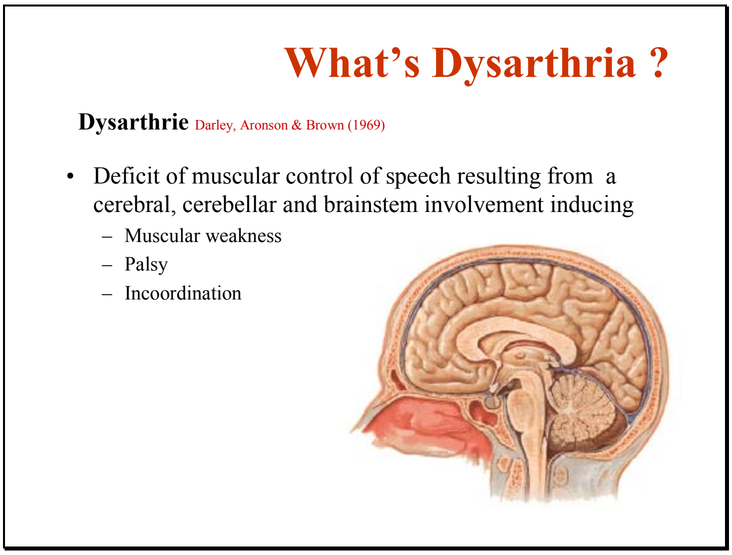
Depression,
passivity,
social isolation,
Irritability,
aggressivity,
revolt,
Depreciation,
Decreased
self-esteem

Care givers

Family

PwMS

Slide 24



What’s Dysarthria ?

Dysarthrie Darley, Aronson & Brown (1969)

- Deficit of muscular control of speech resulting from a cerebral, cerebellar and brainstem involvement inducing
  - Muscular weakness
  - Palsy
  - Incoordination

Slide 25

What’s Dysarthria ?

Dysarthrie Darley, Aronson & Brown (1969)

- Affects speed, force, variations, timing and precision of all movements inducing
  - Respiratory process
  - Phonatory process
  - Nasality
  - Articulation
  - Prosody (speed, stress, intonation)

Slide 26

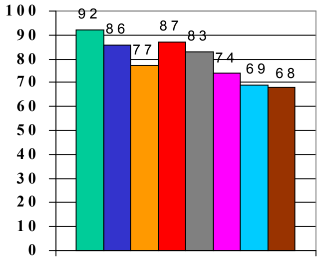
- Categorized according to different combinations of auditivo perceptual impressions corresponding probably to different underlying neuropathophysiologies:
  - flacid: inferiors motoneurons
  - spastic: superior motoneurons
  - ataxic: cerebellum
  - hypokinetic or hyperkinetic: extrapyramidal
  - mixed: combination

Slide 27

Dysarthria Assessment

- Perceptual assessment
  - 38 items of Darley, Aronson et Brown (1972)
  - Assessment of Intelligibility of Dysarthric Speech (Yorkston & Beukelman, 1981)
  - Frenchay Dysarthria Assessment (Enderby, 1983): 54 items: respiration, phonation, motor performance, articulation, prosody and intelligibility

Slide 28



Imprecise articulation
Hoarsness
Reduction respiratory support
Prolonged intervals
Modified accentuation
Reduction of speed
Reduction of pitch variations
8 Reduction of intensity variations

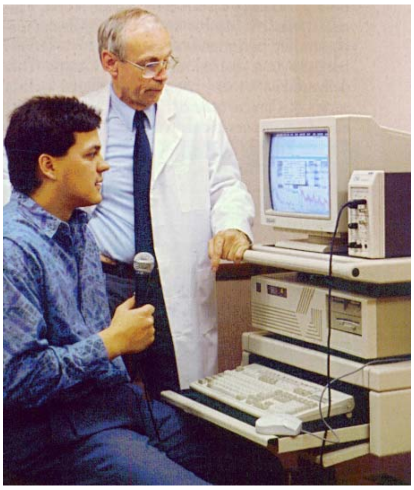
Slide 29

Methods for assessment

- Acoustic analysis : temporal and spectral exploration of the acoustic signal of the speaker
  - temporal characteristics = syllables duration, segments, subsegments (voyels, formantic transitions, occlusion …)
  - spectral characteristics = energy distribution according to frequency
  - phonatory characteristics = exploration of the glottic wave (fundamental frequency, pitch variations, duration and amplitudo by cycle, relations between periodic and aperiodic energy)

Perceptual reflect of voice

Slide 30



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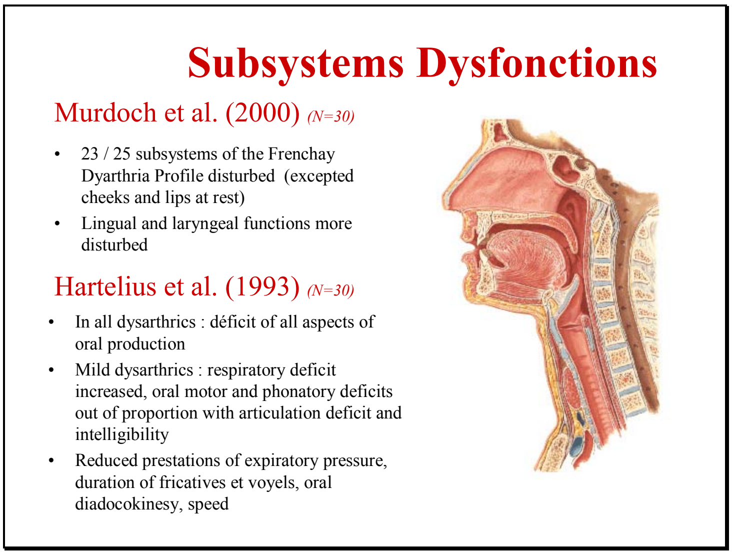


Subsystems Dysfonctions

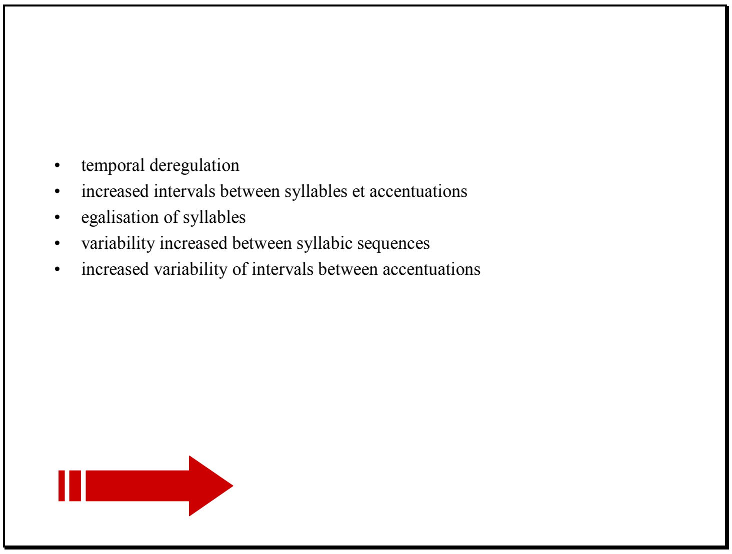
Murdoch et al. (2000) *(N=30)*

- 23 / 25 subsystems of the Frenchay Dyarthria Profile disturbed (excepted cheeks and lips at rest)
- Lingual and laryngeal functions more disturbed

Hartelius et al. (1993) *(N=30)*

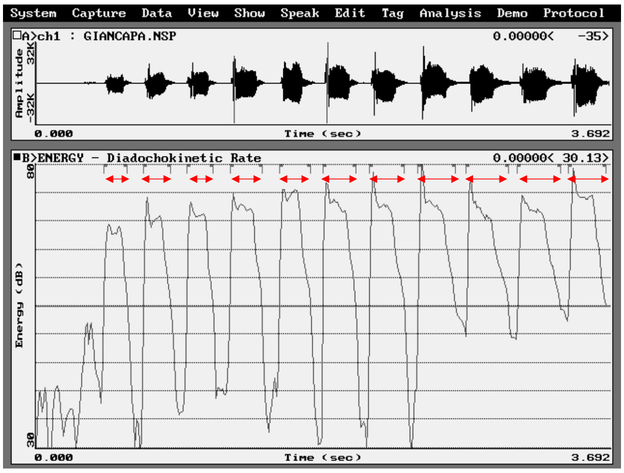
- In all dysarthrics : déficit of all aspects of oral production
- Mild dysarthrics : respiratory deficit increased, oral motor and phonatory deficits out of proportion with articulation deficit and intelligibility
- Reduced prestations of expiratory pressure, duration of fricatives et voyels, oral diadocokinesy, speed

Slide 32



- temporal deregulation
- increased intervals between syllables et accentuations
- egalisation of syllables
- variability increased between syllabic sequences
- increased variability of intervals between accentuations

Slide 33



Slide 34

Phonatory Characteristics

Darley et al. (1972) - FitzGerald et al. (1987)

- Control of intensity
- Pitch variations
- Hoarsness

} = most common perceptual symptoms

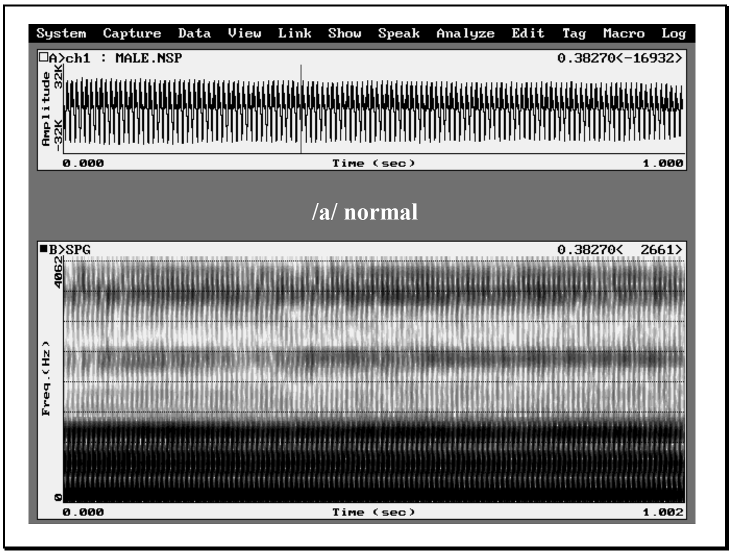
Hartelius, Buder & Strand (1997)

Long term Phonatory instability (tremor) measured by:

- Coefficient of variation of pitch and intensity
- Spectral Analysis

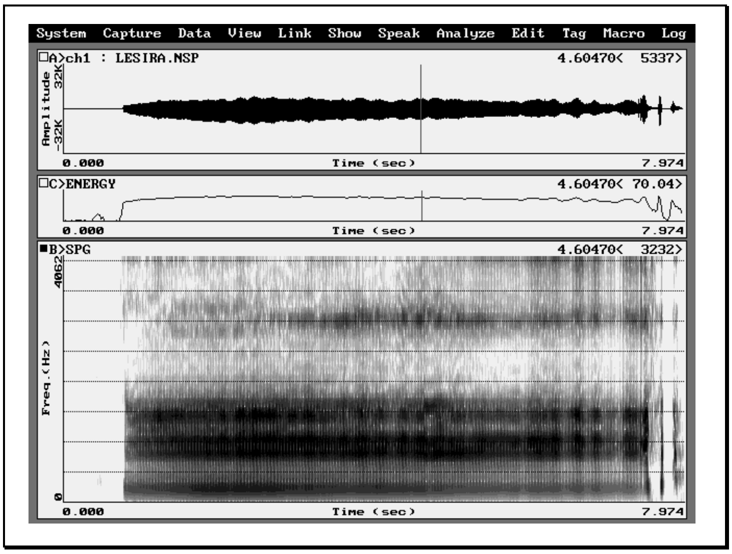
Infra clinic symptoms dysarthria in MS

Slide 35



/a/ normal

Slide 36



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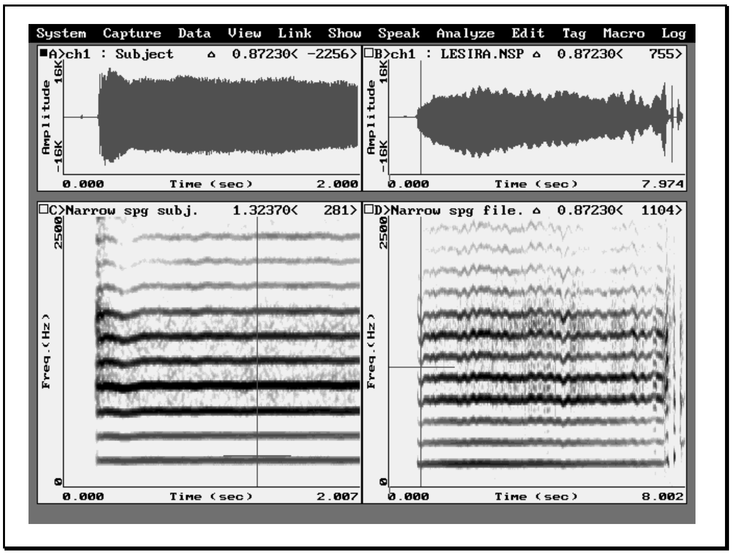

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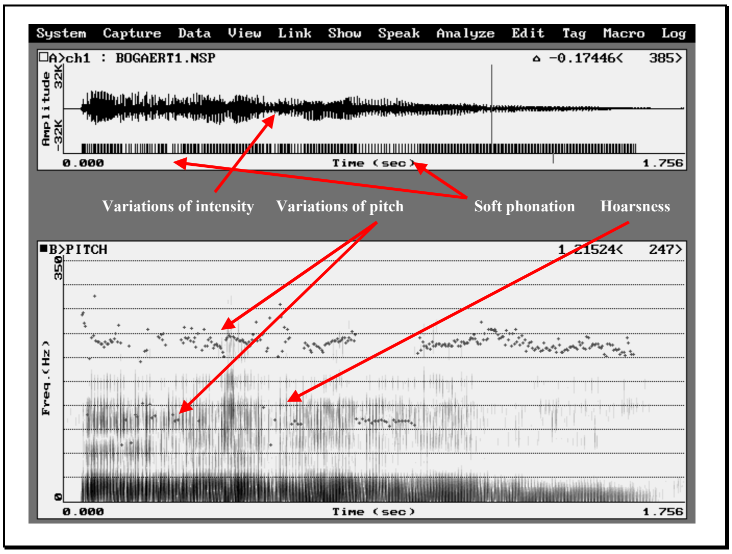


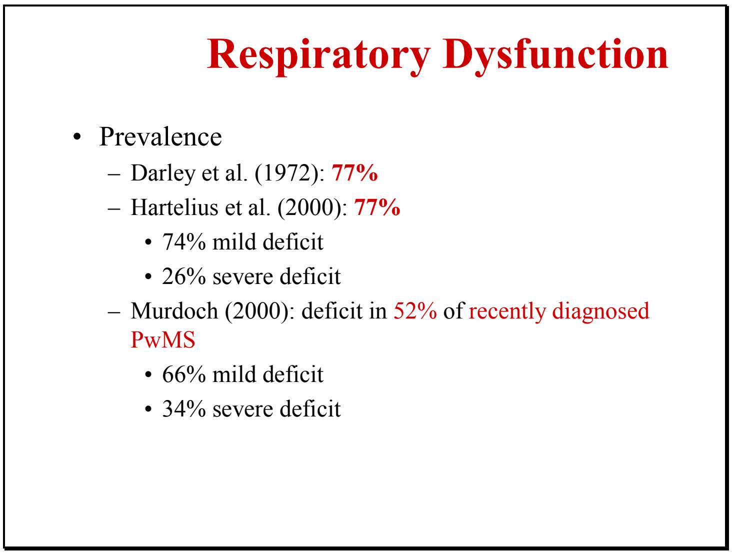
Variations of intensity

Variations of pitch

Soft phonation

Hoarsness

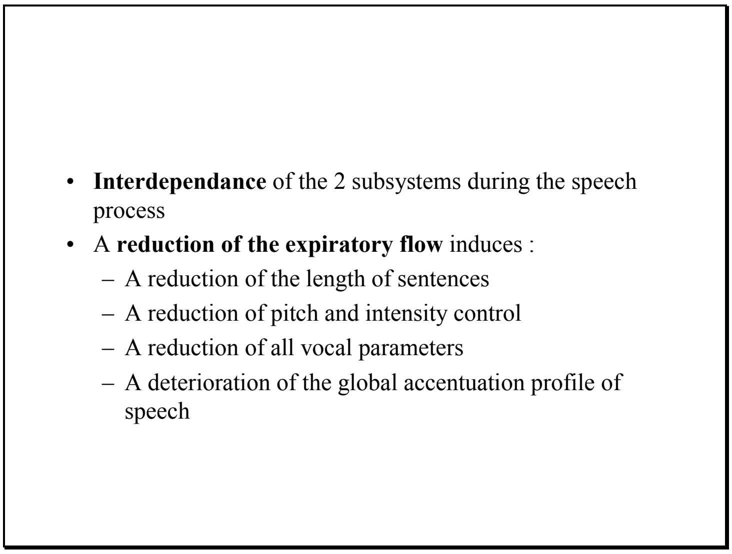
Slide 39



Respiratory Dysfunction

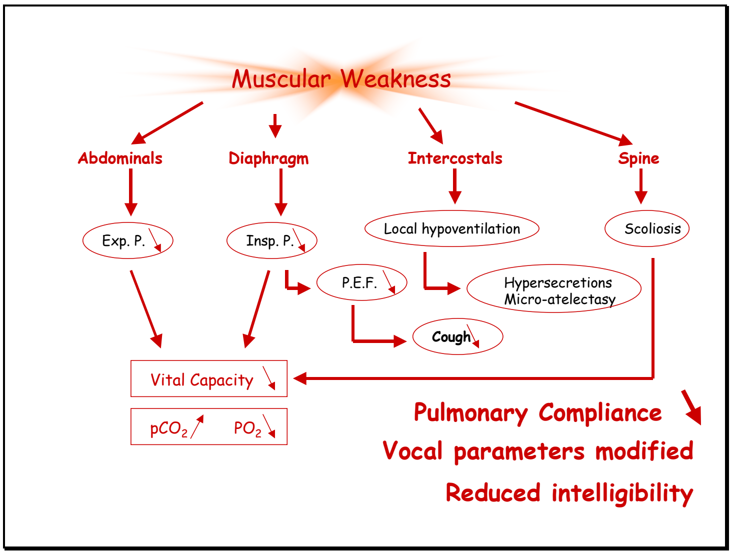
- Prevalence
  - Darley et al. (1972): **77%**
  - Hartelius et al. (2000): **77%**
    - 74% mild deficit
    - 26% severe deficit
  - Murdoch (2000): deficit in 52% of recently diagnosed PwMS
    - 66% mild deficit
    - 34% severe deficit

Slide 40



- **Interdependance** of the 2 subsystems during the speech process
- A **reduction of the expiratory flow** induces :
  - A reduction of the length of sentences
  - A reduction of pitch and intensity control
  - A reduction of all vocal parameters
  - A deterioration of the global accentuation profile of speech

Slide 41



Muscular Weakness

Abdominals

Diaphragm

Intercostals

Spine

Exp. P. ↘

Insp. P. ↘

Local hypoventilation

Scoliosis

P.E.F. ↘

Hypersecretions
Micro-atelectasy

Cough ↘

Vital Capacity ↘

pCO_2 ↗ PO_2 ↘

Pulmonary Compliance ↘

Vocal parameters modified

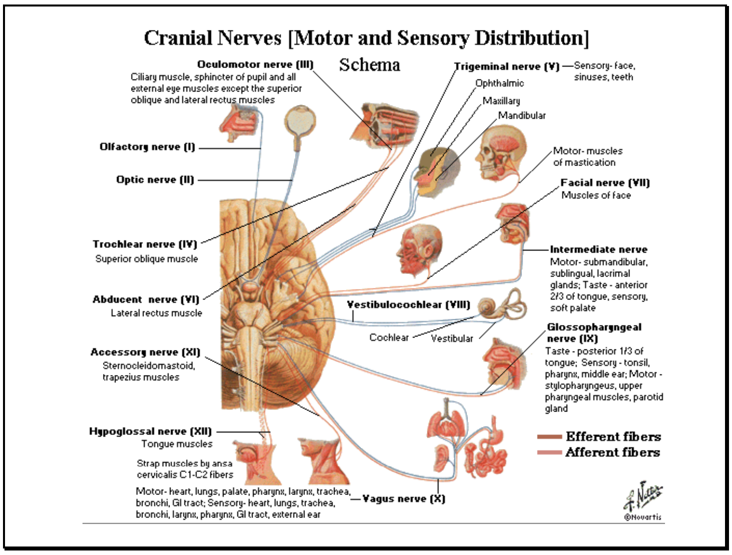
Reduced intelligibility

Slide 42

- Trigeminal nerve
- Facial nerve
- Glosso-pharyngeal et pneumogastric nerve
- Spinal nerve
- Hypoglossis

- Motor aspect
- Sensitive aspect
- Reflexes

Slide 43



Cranial Nerves [Motor and Sensory Distribution]

Slide 44

Communication limitations
How to fight them ?

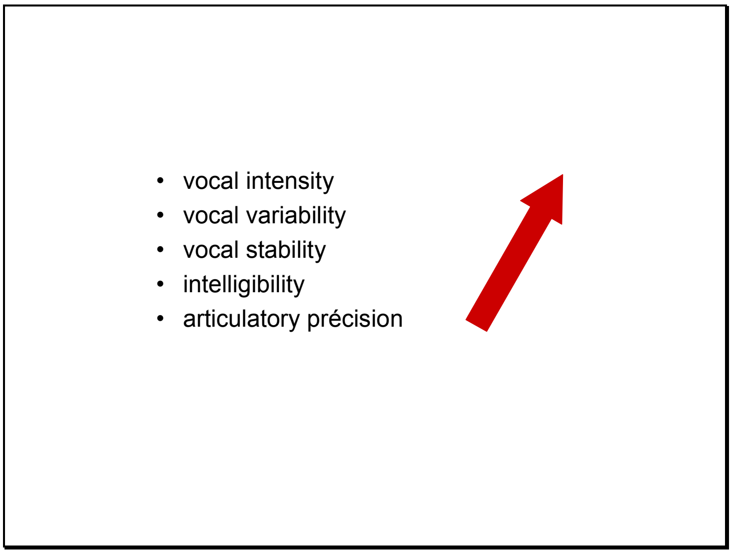
1. Dysarthria
   a. Respiratory function
   b. Oral motor function
   c. Voice
   d. Communication strategies
2. High Level Language Problems
3. Guidelines for better communication

Slide 45

Basic principles of dysarthria rehabilitation

- Precocity
- Improvement of respiratoiry support
- Improvement of vocal efficiency
- Stimulation of motricity, sensibility and reflexes
- Improvement of capacity to produce contrasted accentuations
- Feedback
- Current situation (group therapy)

Slide 46



- vocal intensity
- vocal variability
- vocal stability
- intelligibility
- articulatory précision

Slide 47

Daily training

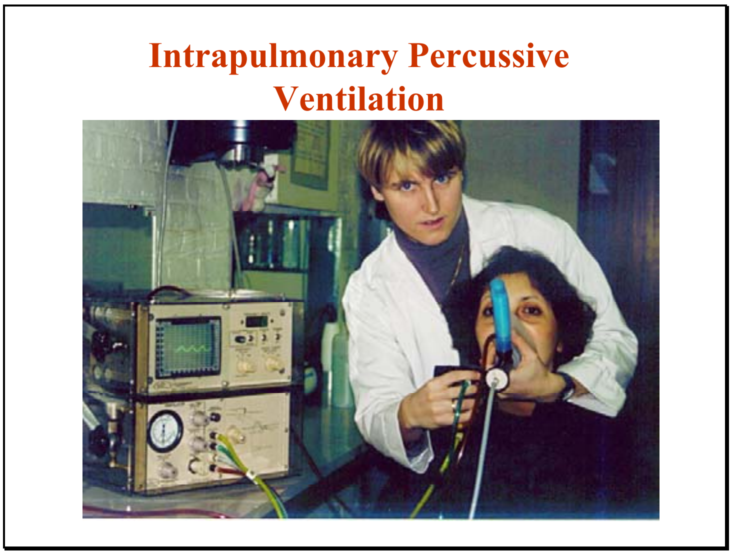
Mobilisation
- Head - trunk
- Shoulders
- Joints
    - costo-transverse
    - costo-vertebrals

Support instrumental
- Inspiratory phase
    - InspirX
    - Triflo
    - DHD Coach
    - Volurex
- Expiratory phase
    - Bottles
    - Resonance tube
    - Therapep

Comportemental
- Posture
- Abdominal support
- Inspiratory checking
- Respiratory patterns
- Accentuation

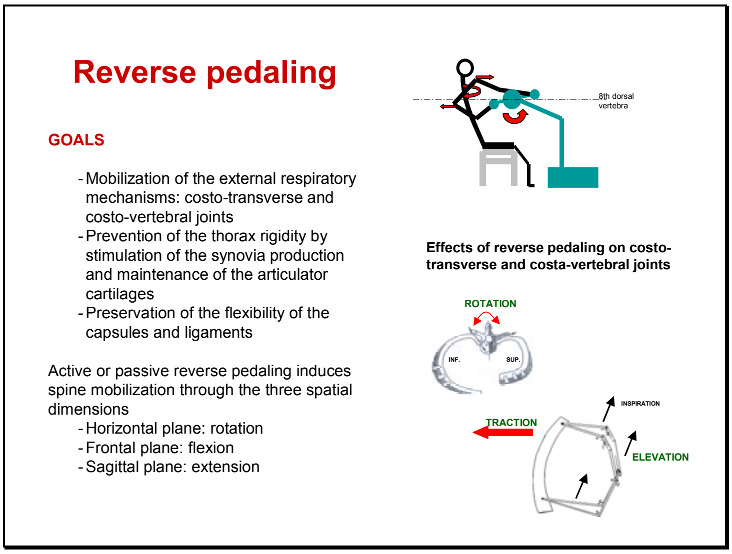
Slide 48

Slide 49



Intrapulmonary Percussive Ventilation

Slide 50



Reverse pedaling

GOALS

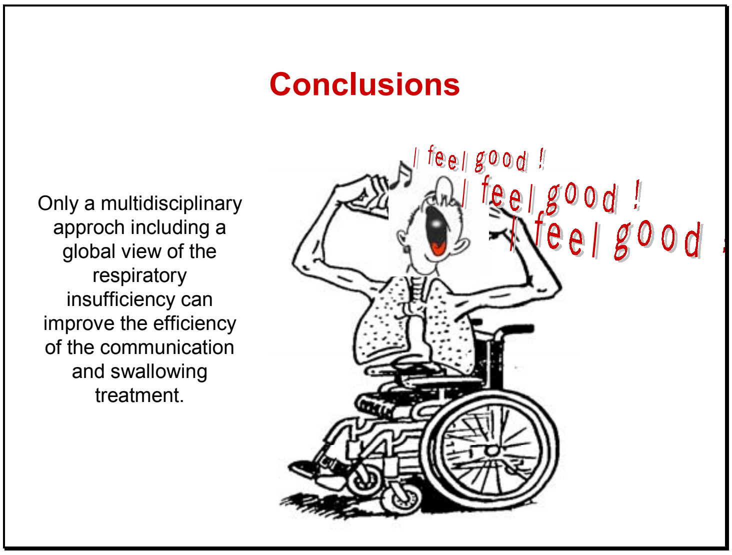
- Mobilization of the external respiratory mechanisms: costo-transverse and costo-vertebral joints
- Prevention of the thorax rigidity by stimulation of the synovia production and maintenance of the articulator cartilages
- Preservation of the flexibility of the capsules and ligaments

Active or passive reverse pedaling induces spine mobilization through the three spatial dimensions

- Horizontal plane: rotation
- Frontal plane: flexion
- Sagittal plane: extension

Effects of reverse pedaling on costo-transverse and costa-vertebral joints

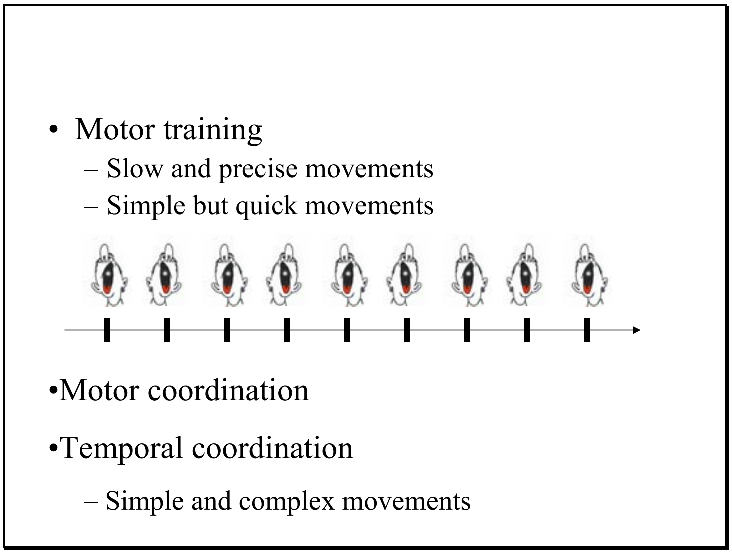
Slide 51



Conclusions

Only a multidisciplinary approch including a global view of the respiratory insufficiency can improve the efficiency of the communication and swallowing treatment.

Slide 52



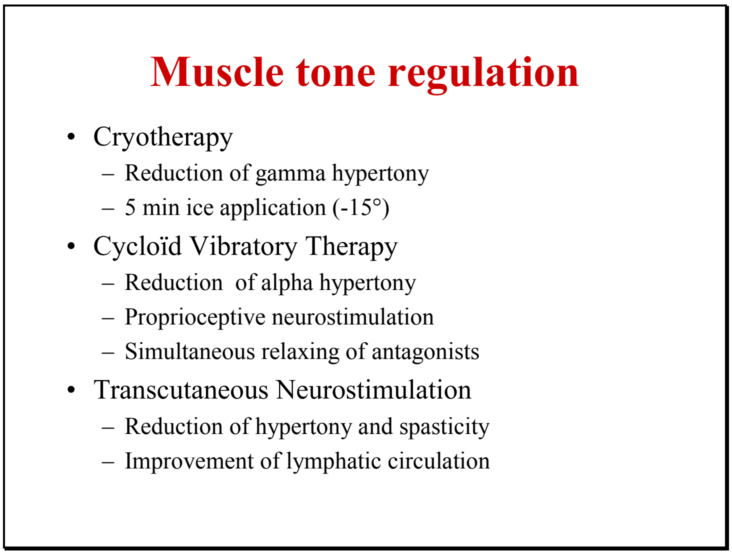
- Motor training
  - Slow and precise movements
  - Simple but quick movements

•Motor coordination

•Temporal coordination

  – Simple and complex movements

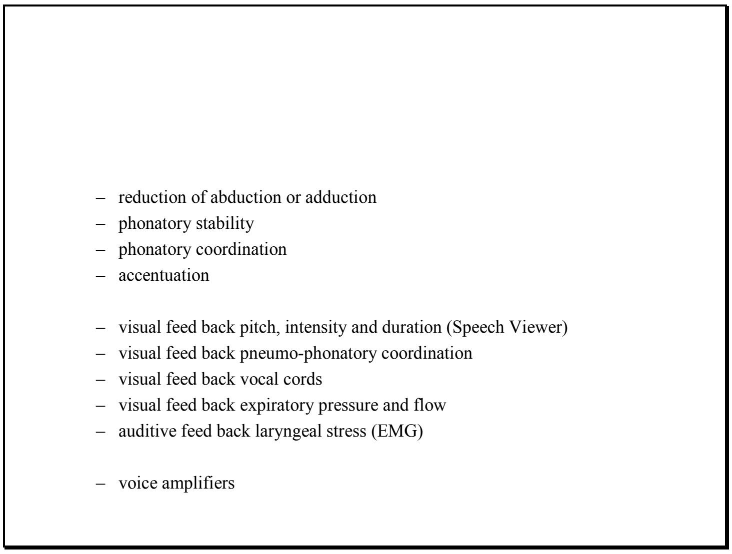
Slide 53



Muscle tone regulation

- Cryotherapy
  - Reduction of gamma hypertony
  - 5 min ice application (-15°)
- Cycloïd Vibratory Therapy
  - Reduction of alpha hypertony
  - Proprioceptive neurostimulation
  - Simultaneous relaxing of antagonists
- Transcutaneous Neurostimulation
  - Reduction of hypertony and spasticity
  - Improvement of lymphatic circulation

Slide 54



- reduction of abduction or adduction
- phonatory stability
- phonatory coordination
- accentuation

- visual feed back pitch, intensity and duration (Speech Viewer)
- visual feed back pneumo-phonatory coordination
- visual feed back vocal cords
- visual feed back expiratory pressure and flow
- auditive feed back laryngeal stress (EMG)

- voice amplifiers

Slide 55

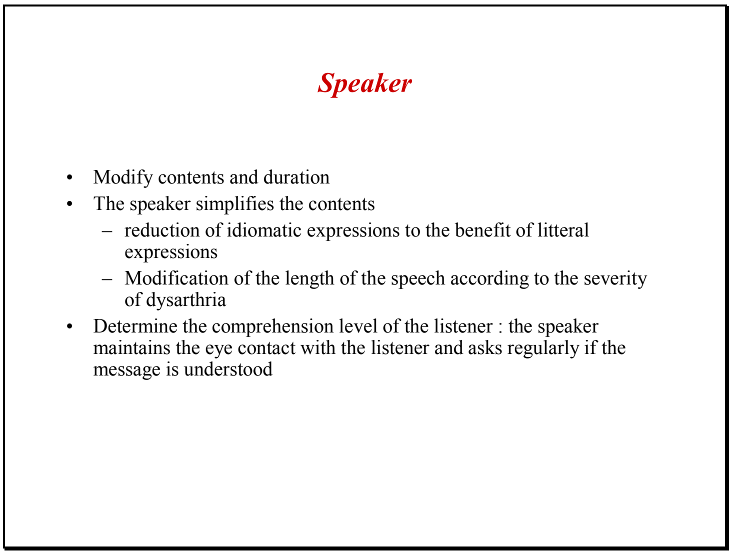
Adaptation at home

Interactive communication strategies

Slide 56

- When using an alphabet
  - The speaker points the first letter of the word
  - The listener asks a repetition of each word or sentence
  - The listener asks a clarification in case of a lack of understanding
- Identify context and topic of conversation
  - The speaker identifies contextual signes : name of the person, feading, animal, etc…
  - The speaker identifies explicitly the topic of the conversation, particularly when topics are changing

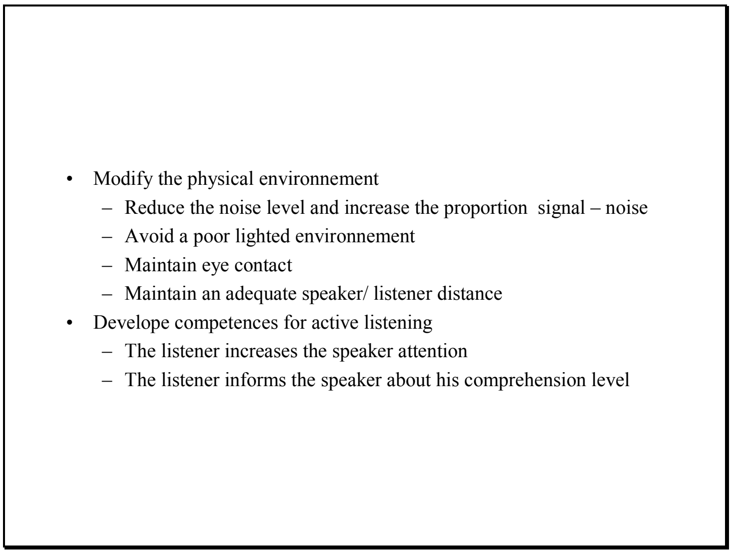
Slide 57



Speaker

- Modify contents and duration
- The speaker simplifies the contents
  - reduction of idiomatic expressions to the benefit of litteral expressions
  - Modification of the length of the speech according to the severity of dysarthria
- Determine the comprehension level of the listener : the speaker maintains the eye contact with the listener and asks regularly if the message is understood

Slide 58



- Modify the physical environnement
  - Reduce the noise level and increase the proportion signal – noise
  - Avoid a poor lighted environnement
  - Maintain eye contact
  - Maintain an adequate speaker/ listener distance
- Develope competences for active listening
  - The listener increases the speaker attention
  - The listener informs the speaker about his comprehension level

Slide 59

Interactive strategies

- Eye contact
- Determine feedback methods
  - immediate or delayed
  - specific or when incomprehensible
  - topic definition
  - resume contents and identify erroneous information
  - specific gesture indicating incomprehensibility
  - signs facilitating the intelligibility

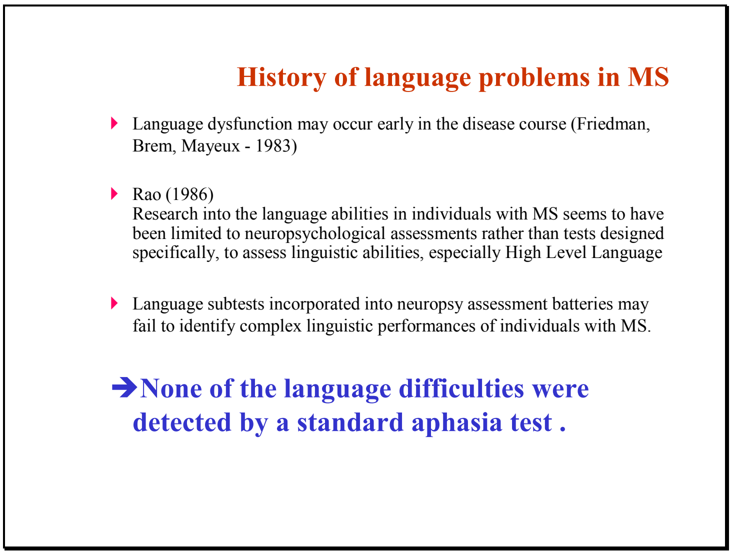
Slide 60

High Level Language Problems in MS ?

A new concept !

With the contribution of Antonella Nota – SLP – Melsbroek - Belgium

Slide 61



History of language problems in MS

- Language dysfunction may occur early in the disease course (Friedman, Brem, Mayeux - 1983)
- Rao (1986)
  Research into the language abilities in individuals with MS seems to have been limited to neuropsychological assessments rather than tests designed specifically, to assess linguistic abilities, especially High Level Language
- Language subtests incorporated into neuropsy assessment batteries may fail to identify complex linguistic performances of individuals with MS.

➔None of the language difficulties were detected by a standard aphasia test .

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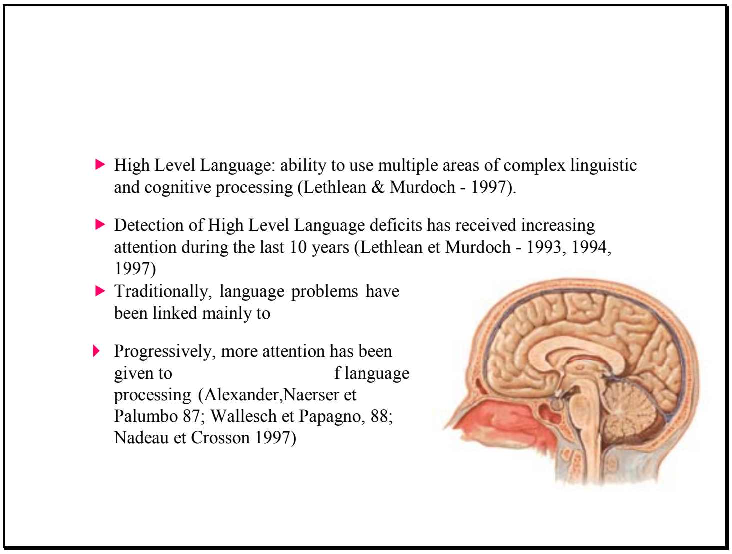


- High Level Language: ability to use multiple areas of complex linguistic and cognitive processing (Lethlean & Murdoch - 1997).
- Detection of High Level Language deficits has received increasing attention during the last 10 years (Lethlean et Murdoch - 1993, 1994, 1997)
- Traditionally, language problems have been linked mainly to
- Progressively, more attention has been given to f language processing (Alexander,Naerser et Palumbo 87; Wallesch et Papagno, 88; Nadeau et Crosson 1997)

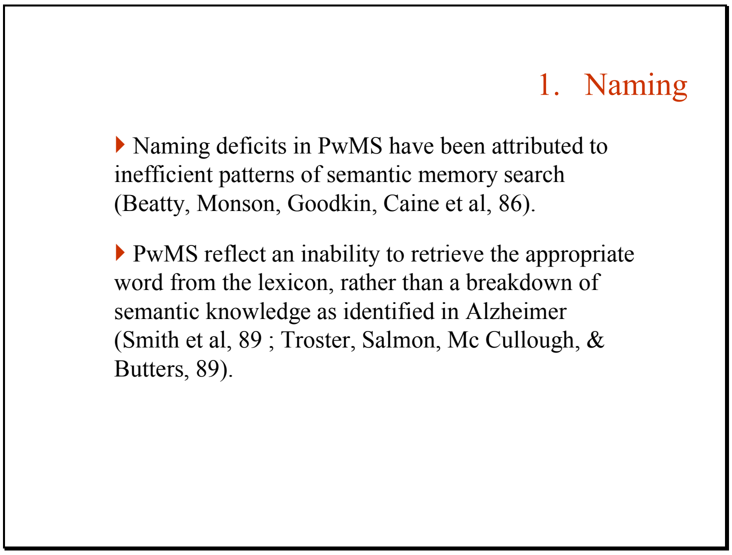
Slide 63

Language problems in MS

- Although language impairment does not necessarily result from impaired cognition, **every aspect of language requires cognitive processing** and an interdependent relationship exists between the two
  (Kennedy & De Ruyter - 1991)
- **Deficits of memory and attention** can be expected to affect basic language processes while impairments of problem solving may affect High Level Language processes (Uomoto 1991)

Slide 64

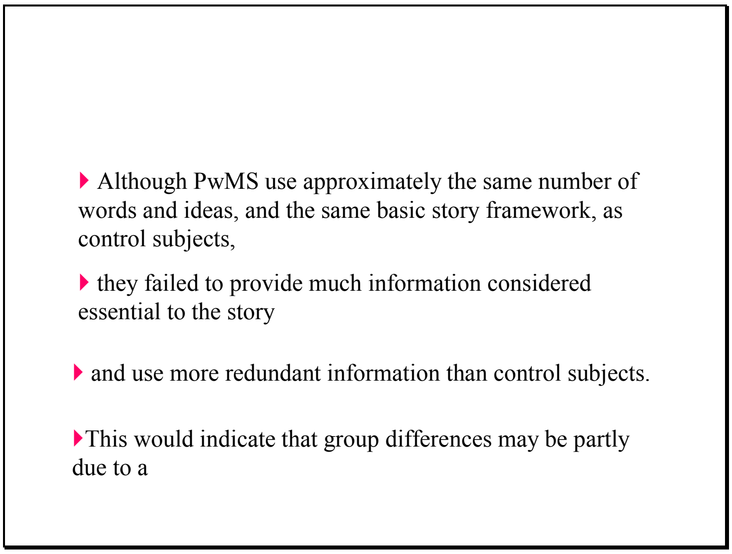
Slide 65



1. Naming

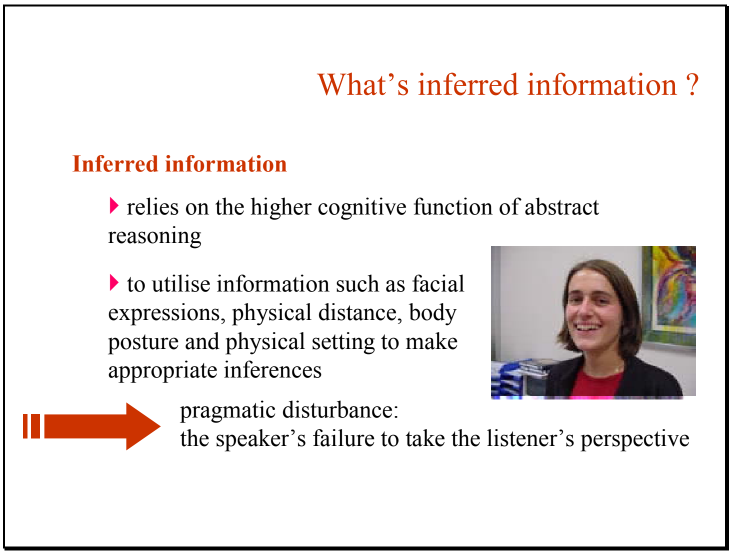
- Naming deficits in PwMS have been attributed to inefficient patterns of semantic memory search (Beatty, Monson, Goodkin, Caine et al, 86).
- PwMS reflect an inability to retrieve the appropriate word from the lexicon, rather than a breakdown of semantic knowledge as identified in Alzheimer (Smith et al, 89 ; Troster, Salmon, Mc Cullough, & Butters, 89).

Slide 66



- Although PwMS use approximately the same number of words and ideas, and the same basic story framework, as control subjects,
- they failed to provide much information considered essential to the story
- and use more redundant information than control subjects.
- This would indicate that group differences may be partly due to a

Slide 67



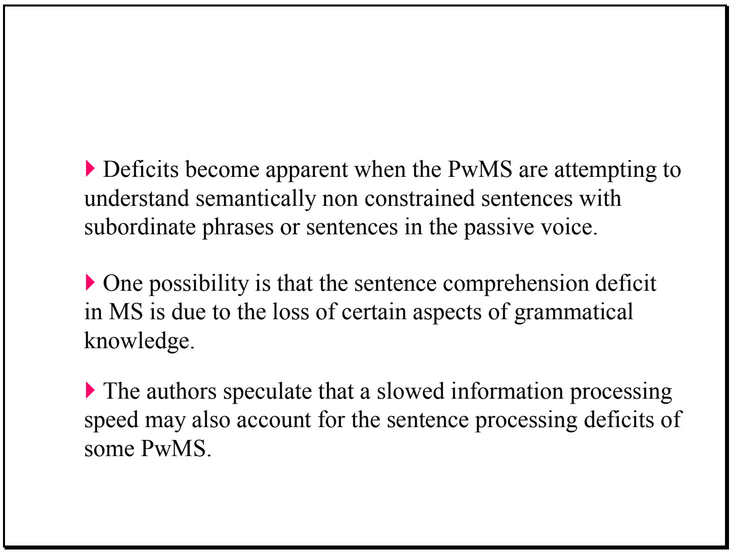
What’s inferred information ?

Inferred information

- relies on the higher cognitive function of abstract reasoning
- to utilise information such as facial expressions, physical distance, body posture and physical setting to make appropriate inferences

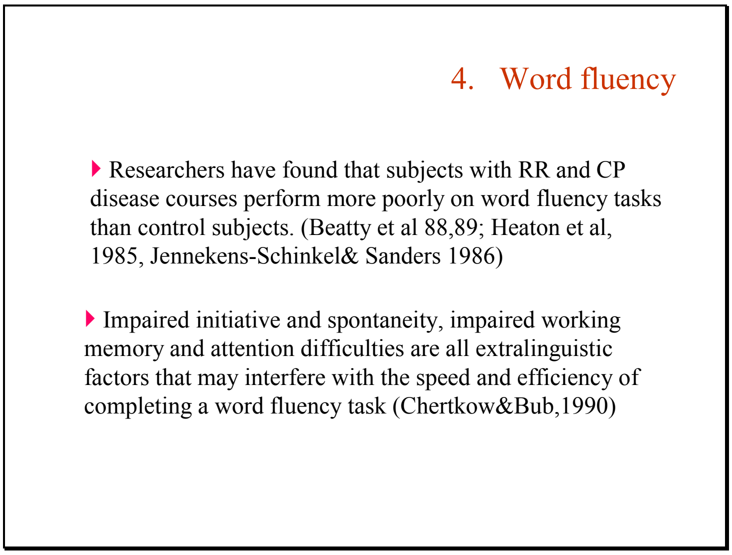
→ pragmatic disturbance:
the speaker’s failure to take the listener’s perspective

Slide 68



- Deficits become apparent when the PwMS are attempting to understand semantically non constrained sentences with subordinate phrases or sentences in the passive voice.
- One possibility is that the sentence comprehension deficit in MS is due to the loss of certain aspects of grammatical knowledge.
- The authors speculate that a slowed information processing speed may also account for the sentence processing deficits of some PwMS.

Slide 69

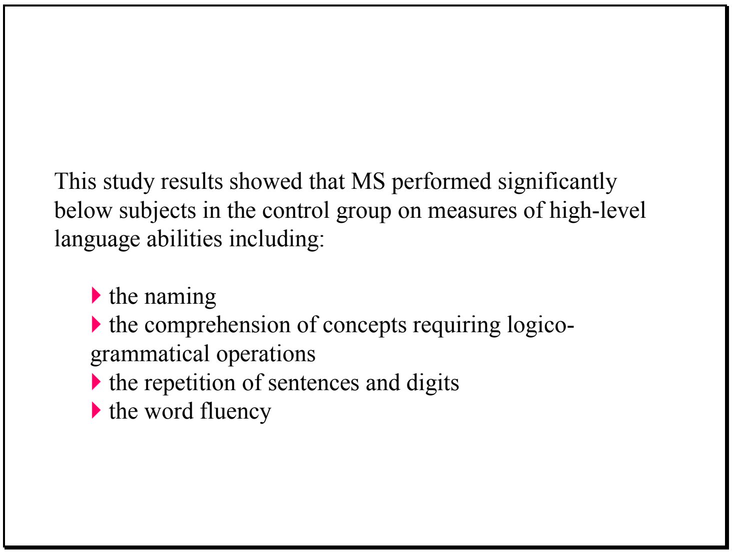


4. Word fluency

- Researchers have found that subjects with RR and CP disease courses perform more poorly on word fluency tasks than control subjects. (Beatty et al 88,89; Heaton et al, 1985, Jennekens-Schinkel& Sanders 1986)

- Impaired initiative and spontaneity, impaired working memory and attention difficulties are all extralinguistic factors that may interfere with the speed and efficiency of completing a word fluency task (Chertkow&Bub,1990)

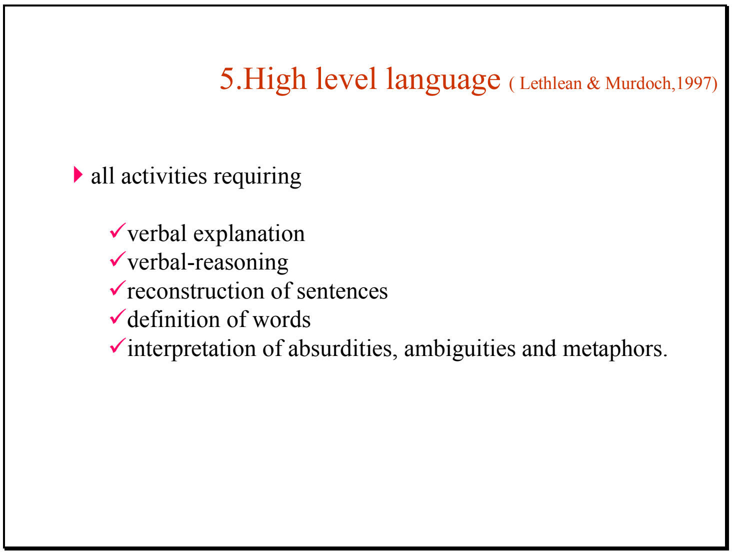
Slide 70



This study results showed that MS performed significantly below subjects in the control group on measures of high-level language abilities including:

- the naming
- the comprehension of concepts requiring logico-grammatical operations
- the repetition of sentences and digits
- the word fluency

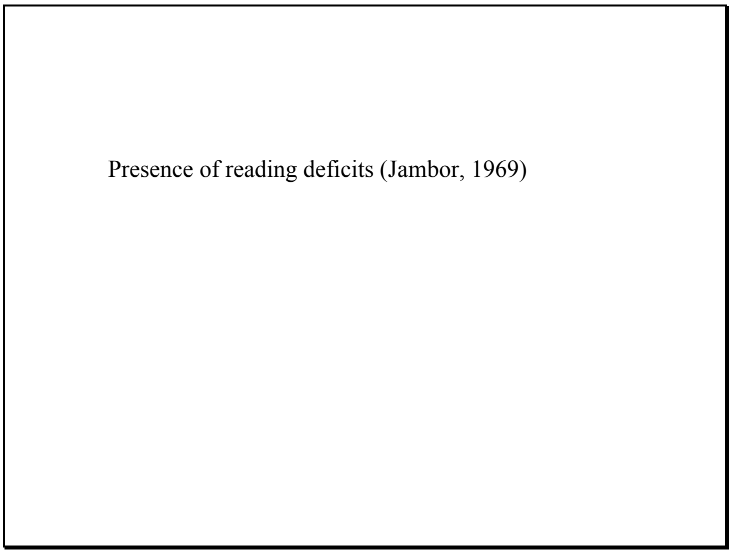
Slide 71



5.High level language (Lethlean & Murdoch,1997)

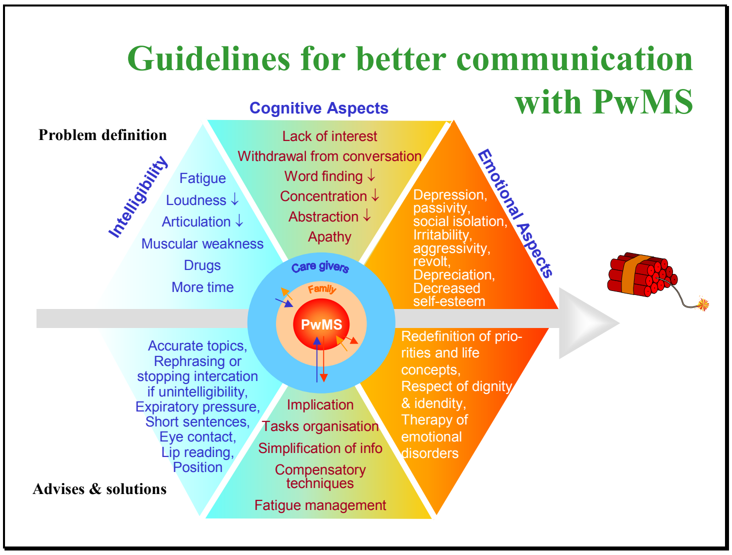
- all activities requiring
  - ✓verbal explanation
  - ✓verbal-reasoning
  - ✓reconstruction of sentences
  - ✓definition of words
  - ✓interpretation of absurdities, ambiguities and metaphors.

Slide 72



Presence of reading deficits (Jambor, 1969)

Slide 73



Guidelines for better communication with PwMS

Problem definition

Cognitive Aspects

Lack of interest
Withdrawal from conversation
Word finding ↓
Concentration ↓
Abstraction ↓
Apathy

Intelligibility

Fatigue
Loudness ↓
Articulation ↓
Muscular weakness
Drugs
More time

Emotional Aspects

Depression, passivity, social isolation, Irritability, aggressivity, revolt, Depreciation, Decreased self-esteem

Care givers
Family
PwMS

Accurate topics, Rephrasing or stopping intercation if unintelligibility, Expiratory pressure, Short sentences, Eye contact, Lip reading, Position

Implication
Tasks organisation
Simplification of info
Compensatory techniques
Fatigue management

Redefinition of priorities and life concepts, Respect of dignity & idendity, Therapy of emotional disorders

Advises & solutions

Slide 74

« The music of human language is the most beautiful art »
Leos Janacek (1854 – 1928)

Thank you for your attention.

WORKSHOP 6
INNOVATIVE MODELS FOR PHYSIOTHERAPY IN THE UK

Jill Anderson and Tracey Mifflin

Slide 1

Physiotherapy Service Development Programme

Multiple Sclerosis Society

Innovative models for physiotherapy in the UK

Jill Anderson and Tracey Mifflin

50 Years Striking Back

Slide 2

Physiotherapy Service Development Programme

Multiple Sclerosis Society

Workshop objectives

- To share the learning from the MS Society and MS Relief physiotherapy service development programme
- Specifically around user involvement in service development

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Physiotherapy Service Development Programme

MS
Multiple Sclerosis Society

Workshop objectives

- Highlight the range of different levels of physiotherapy services at different stages of MS; for people with minimal impairment to people with more severe impairment
- Agree the importance of providing targeted physiotherapy services

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Physiotherapy Service Development Programme

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The MS Society and MS Relief Physiotherapy service development programme

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A partnership programme

- MS Relief
- The Chartered Society of Physiotherapy
- The National Hospital for Neurology and Neurosurgery

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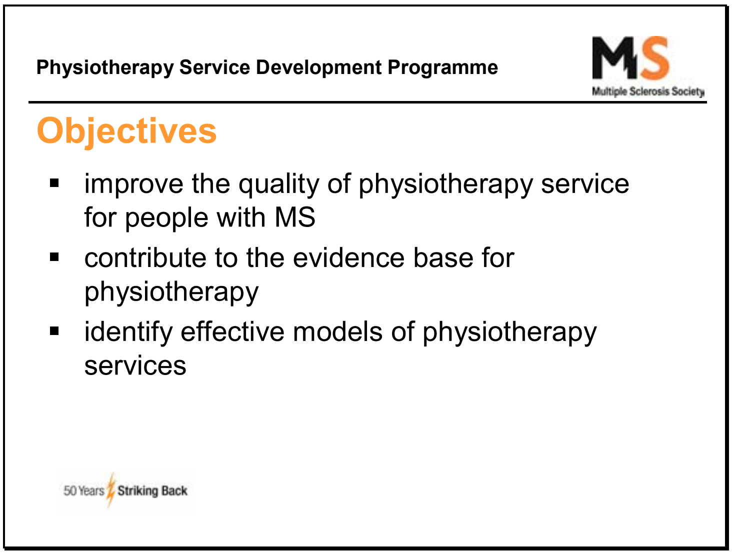

Physiotherapy Service Development Programme

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Objectives

- improve the quality of physiotherapy service for people with MS
- contribute to the evidence base for physiotherapy
- identify effective models of physiotherapy services

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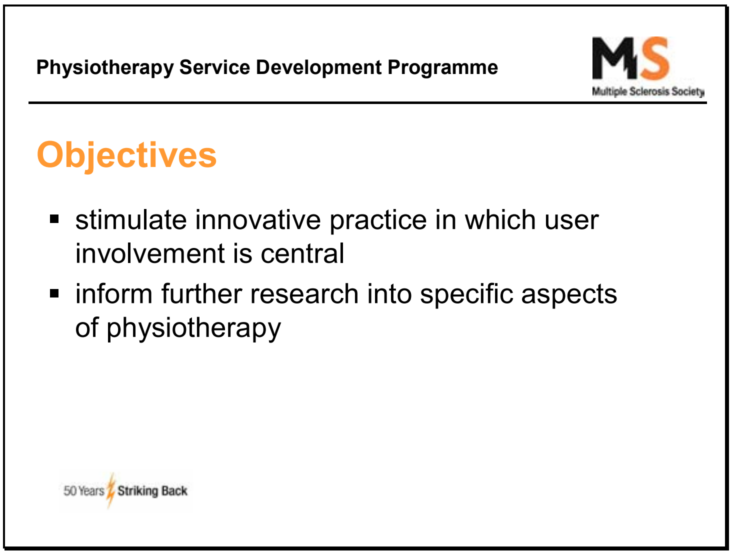

Physiotherapy Service Development Programme

MS Multiple Sclerosis Society

Objectives

- stimulate innovative practice in which user involvement is central
- inform further research into specific aspects of physiotherapy

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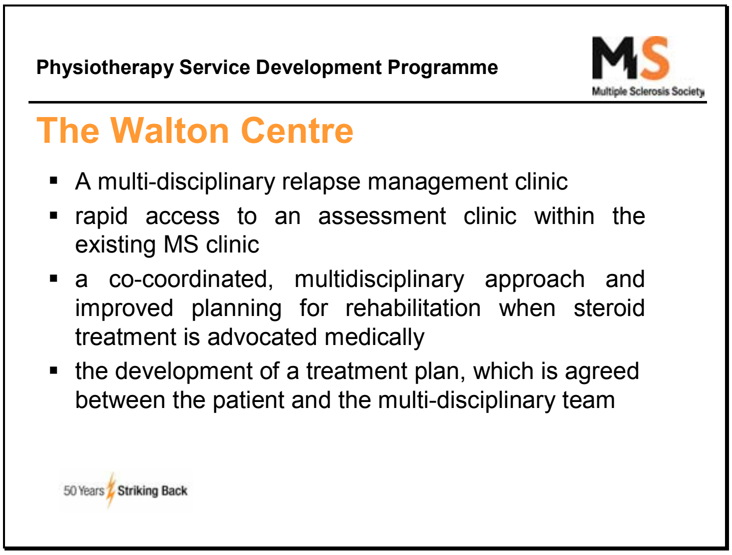

Physiotherapy Service Development Programme

MS Multiple Sclerosis Society

The Walton Centre

- A multi-disciplinary relapse management clinic
- rapid access to an assessment clinic within the existing MS clinic
- a co-coordinated, multidisciplinary approach and improved planning for rehabilitation when steroid treatment is advocated medically
- the development of a treatment plan, which is agreed between the patient and the multi-disciplinary team

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Physiotherapy Service Development Programme

MS Multiple Sclerosis Society

North Tees and Hartlepool NHS Trust

- self-management and education programme, through groups
- advice and information sessions
- individually tailored exercise programmes and
- an ongoing programme in a local leisure centre with the support of a health and fitness advisor

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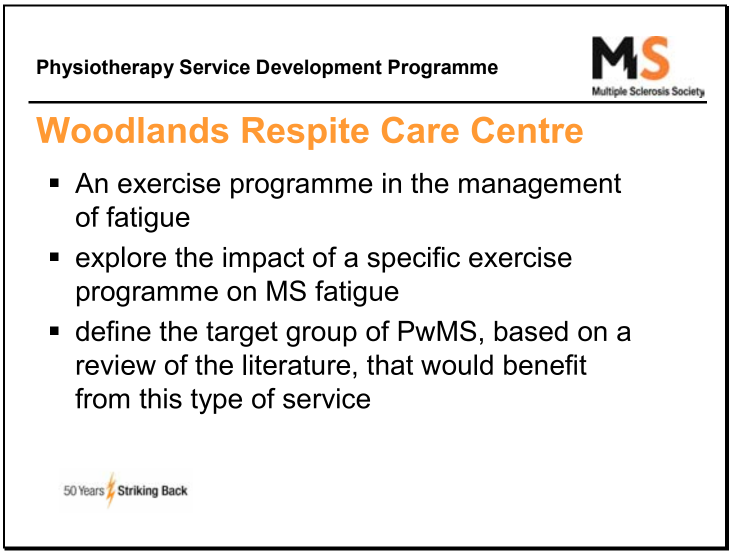

Physiotherapy Service Development Programme

MS Multiple Sclerosis Society

Woodlands Respite Care Centre

- An exercise programme in the management of fatigue
- explore the impact of a specific exercise programme on MS fatigue
- define the target group of PwMS, based on a review of the literature, that would benefit from this type of service

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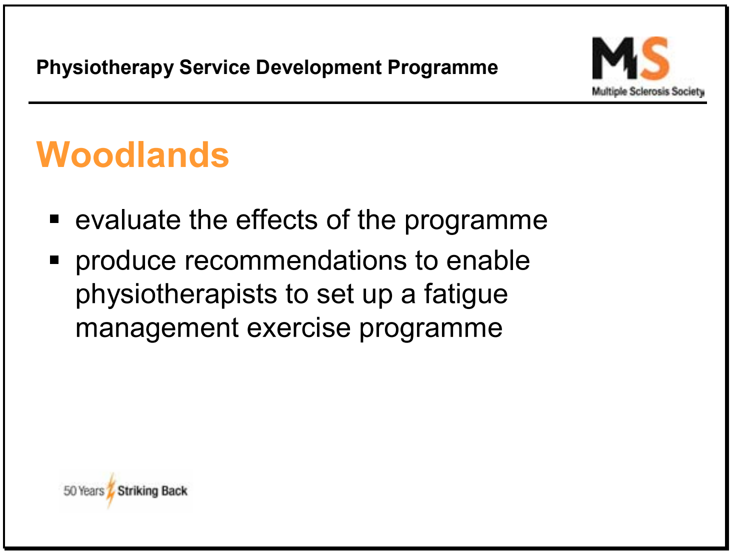

Physiotherapy Service Development Programme

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Woodlands

- evaluate the effects of the programme
- produce recommendations to enable physiotherapists to set up a fatigue management exercise programme

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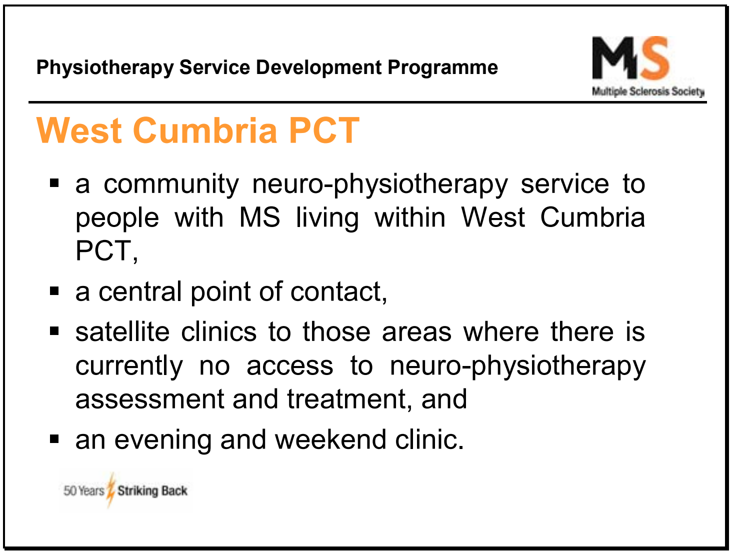

Physiotherapy Service Development Programme

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West Cumbria PCT

- a community neuro-physiotherapy service to people with MS living within West Cumbria PCT,
- a central point of contact,
- satellite clinics to those areas where there is currently no access to neuro-physiotherapy assessment and treatment, and
- an evening and weekend clinic.

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Physiotherapy Service Development Programme

MS
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The evaluation

Aims To asses each services ability to:

- Deliver effective interventions for people with MS
- Involve users in service development
- Offer timely and appropriate access to service provision

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Physiotherapy Service Development Programme

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The evaluation

- Provide information, education and advice
- Meet agreed standards

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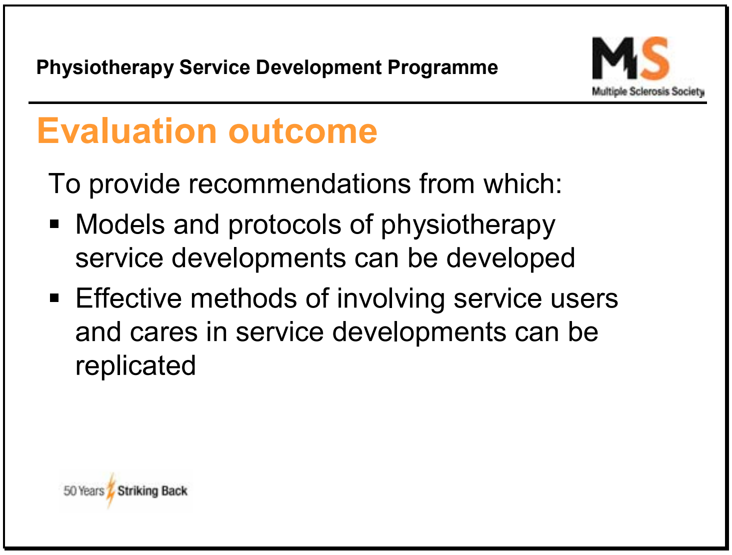

Physiotherapy Service Development Programme

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Evaluation outcome

To provide recommendations from which:

- Models and protocols of physiotherapy service developments can be developed
- Effective methods of involving service users and cares in service developments can be replicated

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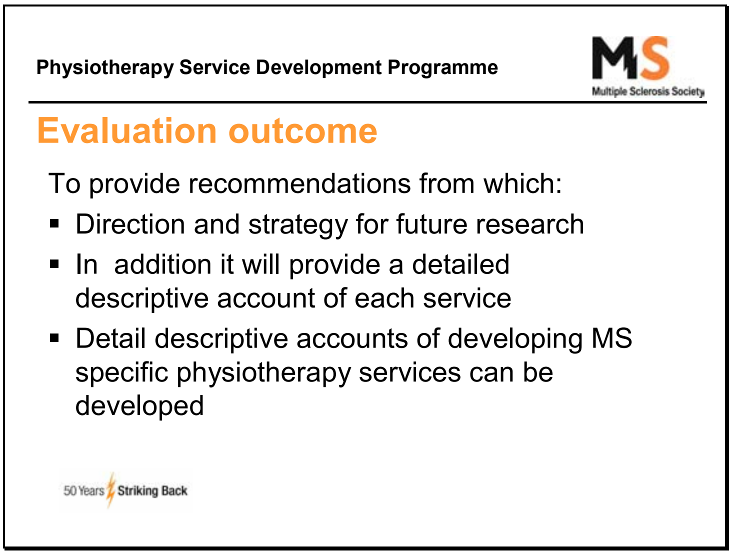

Physiotherapy Service Development Programme

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Evaluation outcome

To provide recommendations from which:

- Direction and strategy for future research
- In addition it will provide a detailed descriptive account of each service
- Detail descriptive accounts of developing MS specific physiotherapy services can be developed

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Physiotherapy Service Development Programme

MS Multiple Sclerosis Society

Questions

are there common issues on accessing physiotherapy for people with MS?

access; how/where/specialist care?

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Physiotherapy Service Development Programme

MS Multiple Sclerosis Society

More questions

is there a common level of demand/need for physiotherapy service across borders?

what are the different roles and responsibilities for a neurophysiotherapist in different countries?

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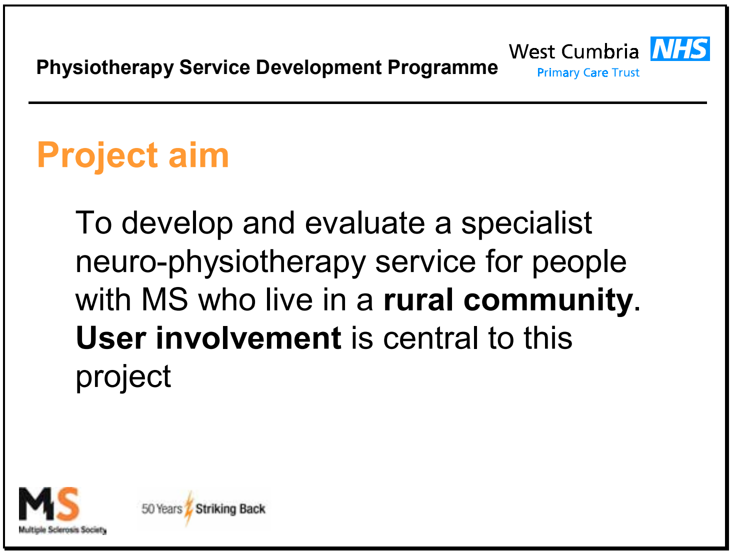
Physiotherapy Service Development Programme

West Cumbria Primary Care Trust

Physiotherapy service development project

Tracey Mifflin

Slide 2

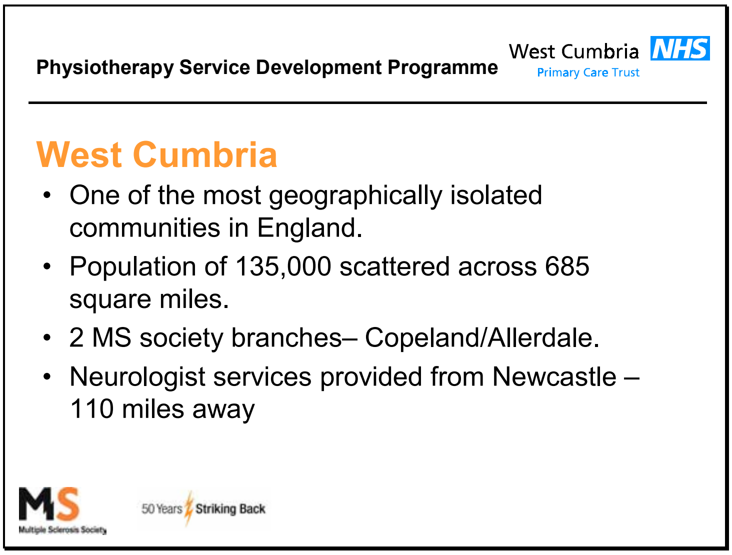


Physiotherapy Service Development Programme

Project aim

To develop and evaluate a specialist neuro-physiotherapy service for people with MS who live in a **rural community**. **User involvement** is central to this project

Slide 3



Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

West Cumbria

- One of the most geographically isolated communities in England.
- Population of 135,000 scattered across 685 square miles.
- 2 MS society branches– Copeland/Allerdale.
- Neurologist services provided from Newcastle – 110 miles away

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Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Physiotherapy services before the project

- Lottery – referral, neurophysiotherapy
- No community service
- Referrals from GP or other health care professional
- Long waiting list

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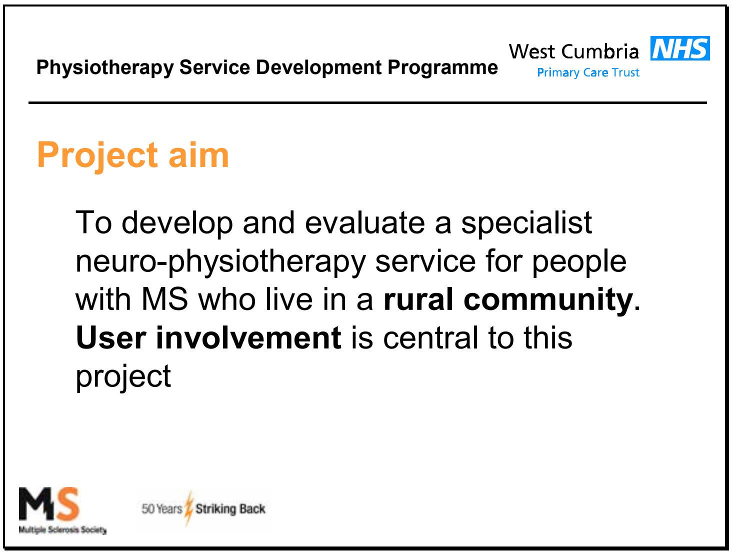

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Project aim

To develop and evaluate a specialist neuro-physiotherapy service for people with MS who live in a **rural community**. **User involvement** is central to this project

MS
Multiple Sclerosis Society

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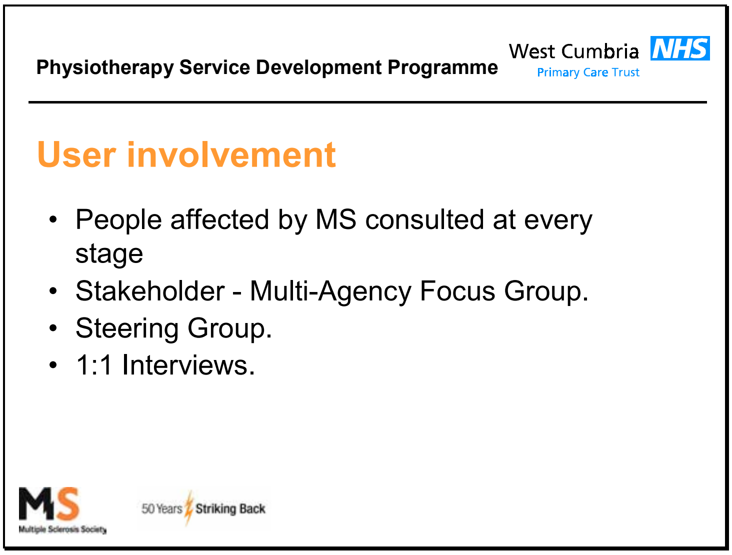

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

User involvement

- People affected by MS consulted at every stage
- Stakeholder - Multi-Agency Focus Group.
- Steering Group.
- 1:1 Interviews.

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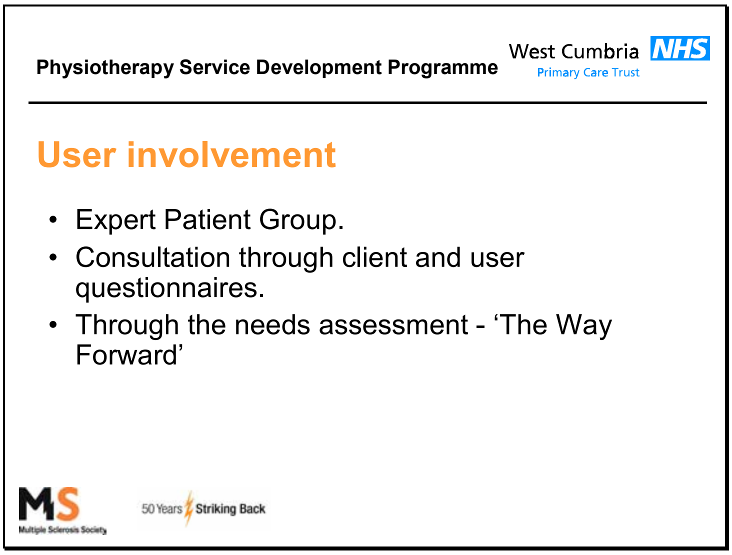

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

User involvement

- Expert Patient Group.
- Consultation through client and user questionnaires.
- Through the needs assessment - 'The Way Forward'

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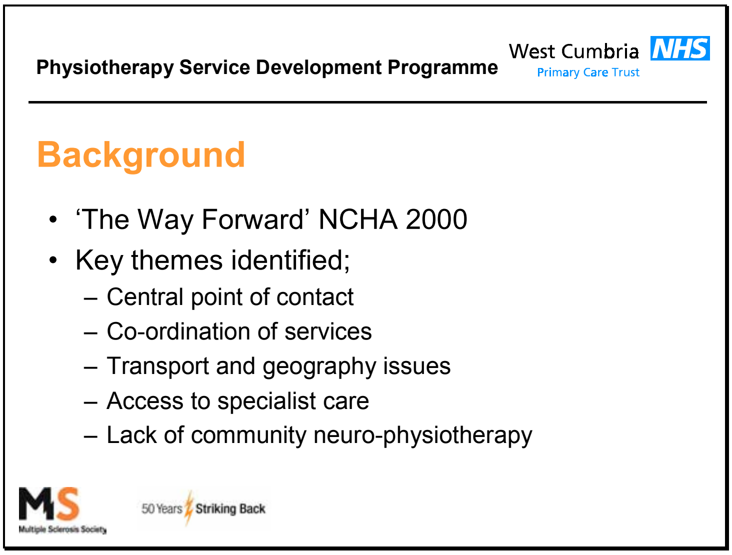

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Background

- 'The Way Forward' NCHA 2000
- Key themes identified;
  - Central point of contact
  - Co-ordination of services
  - Transport and geography issues
  - Access to specialist care
  - Lack of community neuro-physiotherapy

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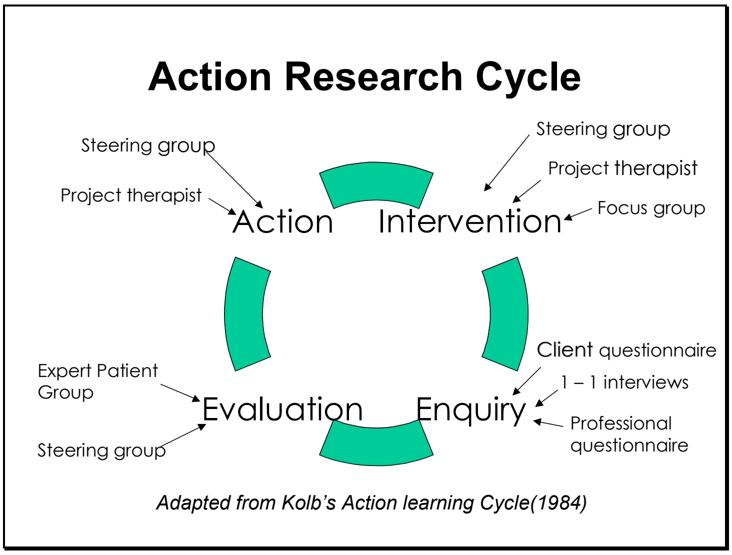

Action Research Cycle

Steering group
Project therapist
Action

Steering group
Project therapist
Focus group
Intervention

Client questionnaire
1 – 1 interviews
Professional questionnaire
Enquiry

Expert Patient Group
Steering group
Evaluation

Adapted from Kolb's Action learning Cycle(1984)

Slide 10

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Interventions

- A community neuro-physiotherapy service for people with MS living within rural West Cumbria PCT. (18hrs/week).
- A central point of contact.
- Satellite clinics to those areas where there is currently no access to neuro-physiotherapy assessment and treatment.

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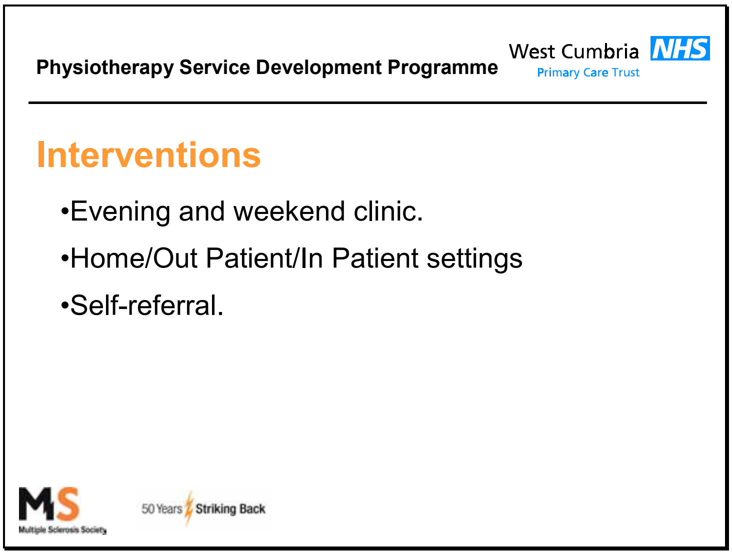

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Interventions

- Evening and weekend clinic.
- Home/Out Patient/In Patient settings
- Self-referral.

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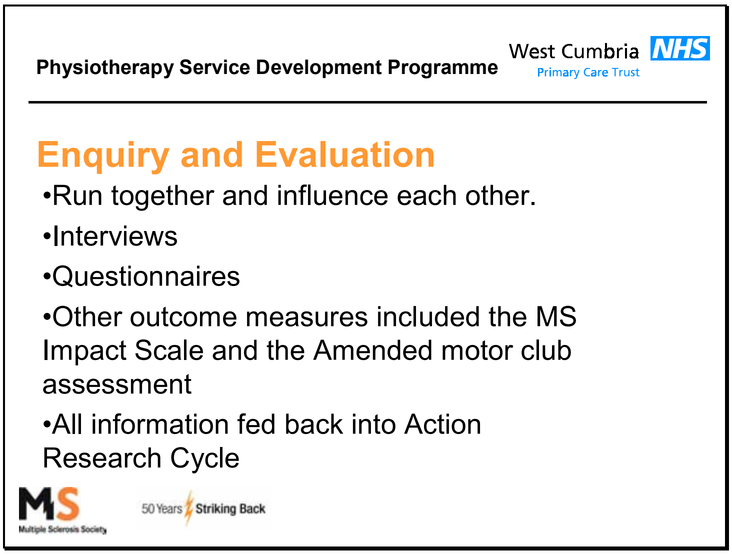

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Enquiry and Evaluation

- Run together and influence each other.
- Interviews
- Questionnaires
- Other outcome measures included the MS Impact Scale and the Amended motor club assessment
- All information fed back into Action Research Cycle

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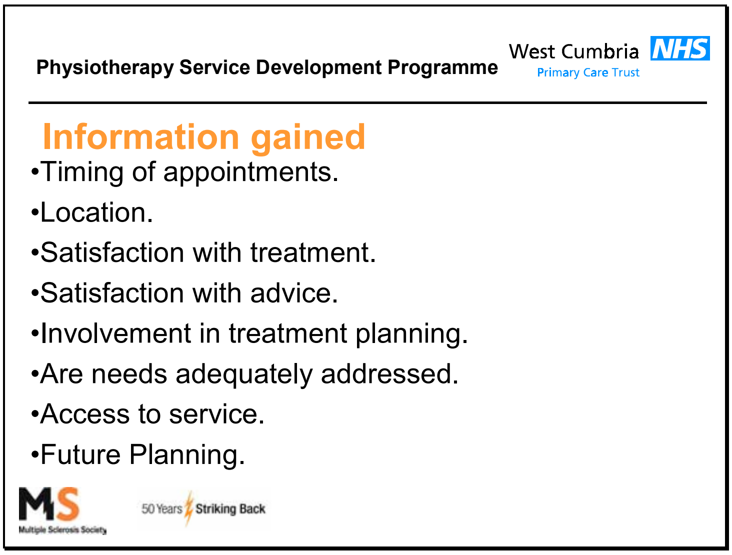

Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Information gained

- •Timing of appointments.
- •Location.
- •Satisfaction with treatment.
- •Satisfaction with advice.
- •Involvement in treatment planning.
- •Are needs adequately addressed.
- •Access to service.
- •Future Planning.

MS Multiple Sclerosis Society

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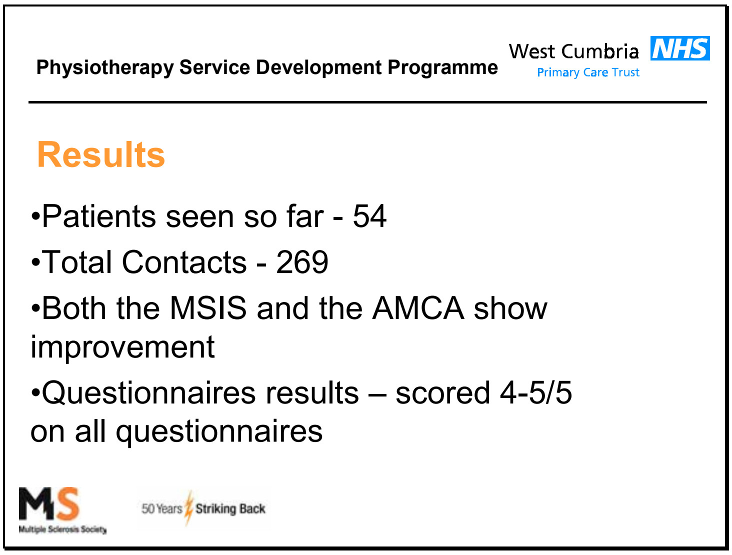


Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

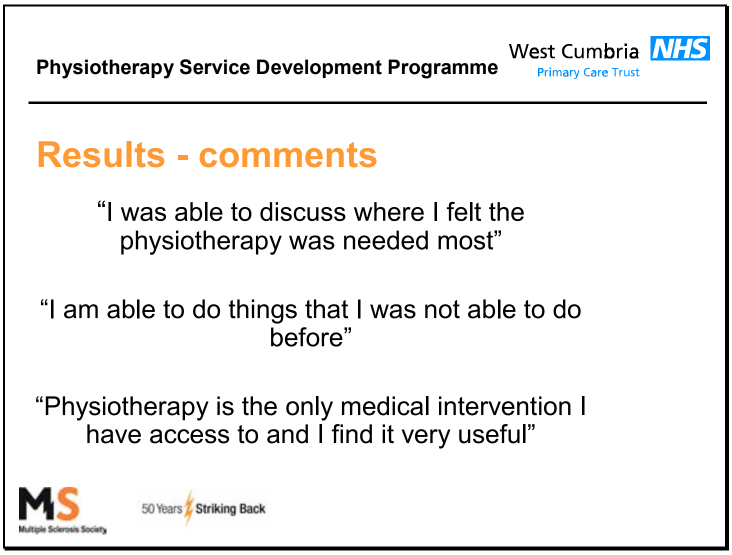
Results

- •Patients seen so far - 54
- •Total Contacts - 269
- •Both the MSIS and the AMCA show improvement
- •Questionnaires results – scored 4-5/5 on all questionnaires

MS Multiple Sclerosis Society

50 Years Striking Back

Slide 15



Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Results - comments

"I was able to discuss where I felt the physiotherapy was needed most"

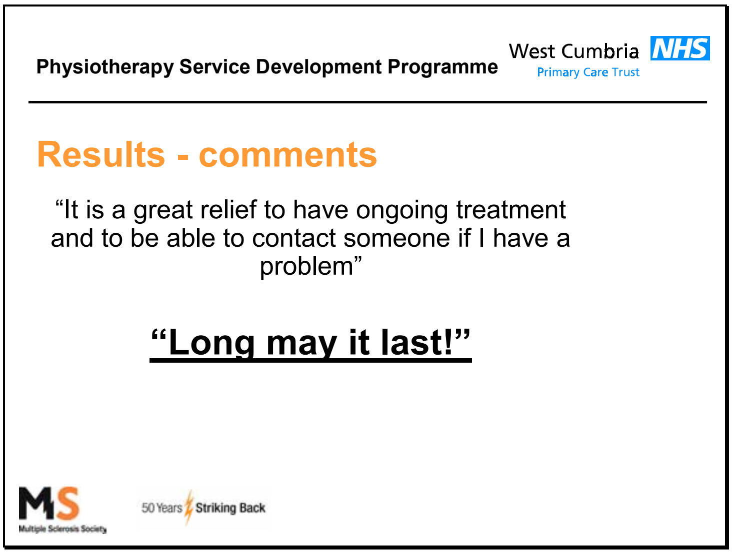
"I am able to do things that I was not able to do before"

"Physiotherapy is the only medical intervention I have access to and I find it very useful"

MS Multiple Sclerosis Society

50 Years Striking Back

Slide 16



Physiotherapy Service Development Programme

West Cumbria NHS
Primary Care Trust

Results - comments

"It is a great relief to have ongoing treatment and to be able to contact someone if I have a problem"

"Long may it last!"

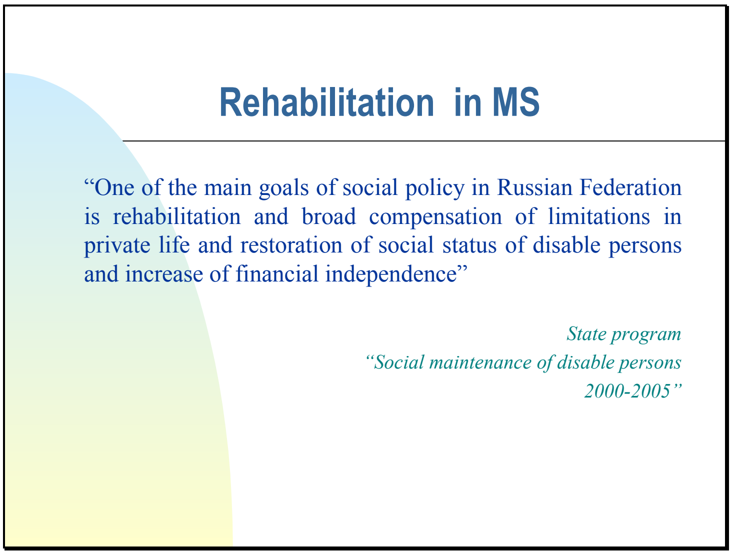
MS Multiple Sclerosis Society

50 Years Striking Back

DEVELOPMENT, STRUCTURE AND TASKS OF THE RUSSIAN MS ORGANISATION

Yan Vlasov

Slide 1

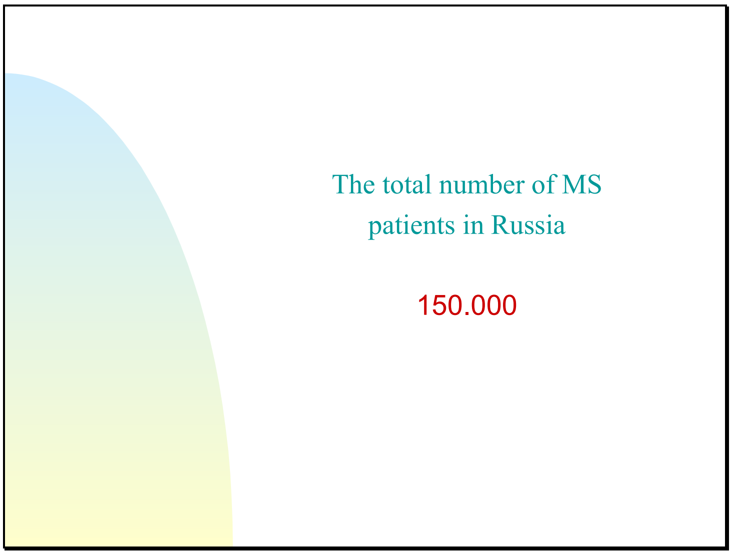


Rehabilitation in MS

"One of the main goals of social policy in Russian Federation is rehabilitation and broad compensation of limitations in private life and restoration of social status of disable persons and increase of financial independence"

State program
"Social maintenance of disable persons
2000-2005"

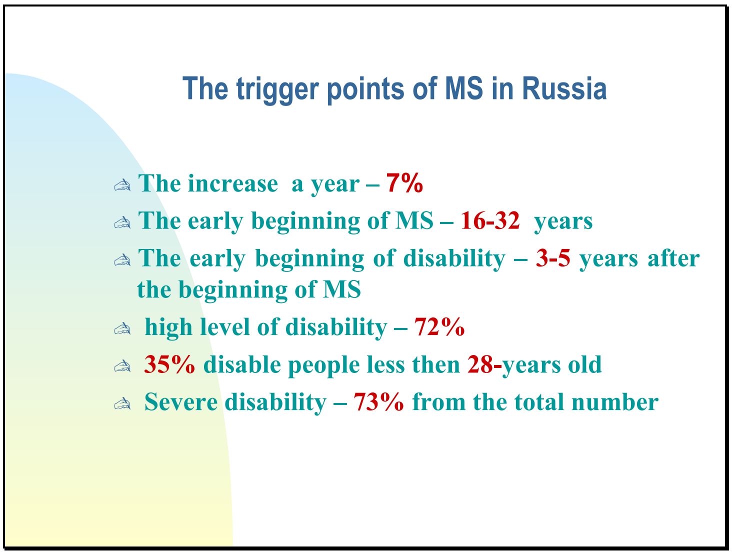
Slide 2



The total number of MS patients in Russia

150.000

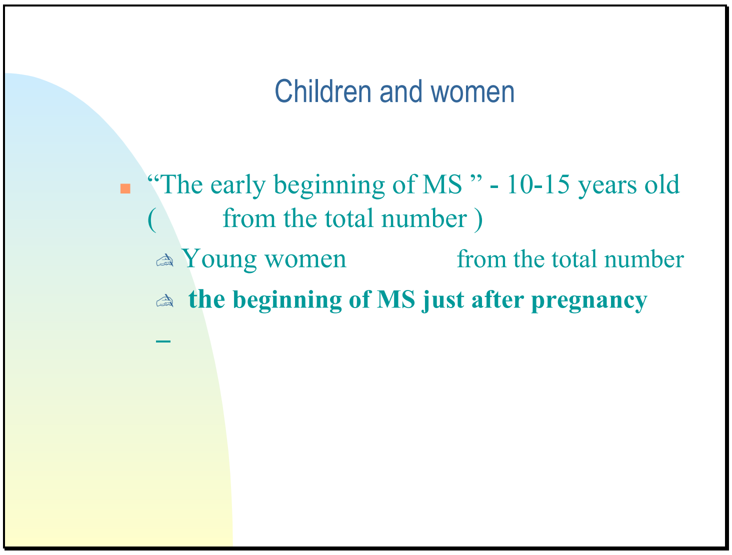
Slide 3



The trigger points of MS in Russia

- **The increase a year – 7%**
- **The early beginning of MS – 16-32 years**
- **The early beginning of disability – 3-5 years after the beginning of MS**
- **high level of disability – 72%**
- **35% disable people less then 28-years old**
- **Severe disability – 73% from the total number**

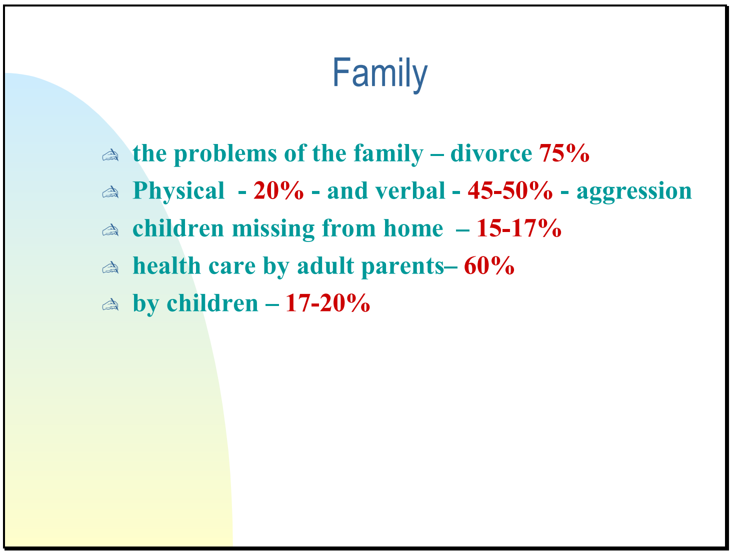
Slide 4



Children and women

- “The early beginning of MS ” - 10-15 years old (from the total number)
  - Young women from the total number
  - **the beginning of MS just after pregnancy**
  - –

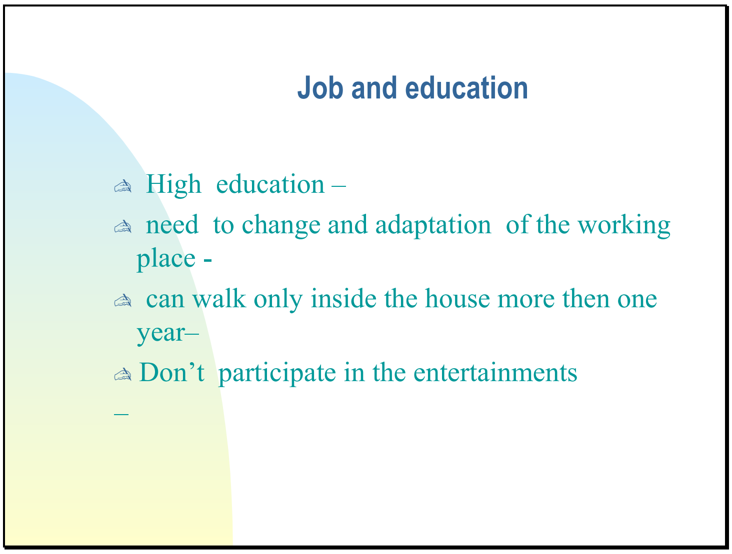
Slide 5



Family

- **the problems of the family – divorce 75%**
- **Physical - 20% - and verbal - 45-50% - aggression**
- **children missing from home – 15-17%**
- **health care by adult parents– 60%**
- **by children – 17-20%**

Slide 6



Job and education

- High education –
- need to change and adaptation of the working place -
- can walk only inside the house more then one year–
- Don’t participate in the entertainments

–

Slide 7

Treatment

- without special treatment - 90%
- the price for special treatment one patient a year – 15000 $ (reimbursement by insurance companies is not adequate)
- the level of income of families with MS patients is 30 - 65 $ for patients per month – more then 80%

Slide 8

Social service

The whole amount of social service
(medical, social, professional, psychological)
is availably for not more then
-

Slide 9

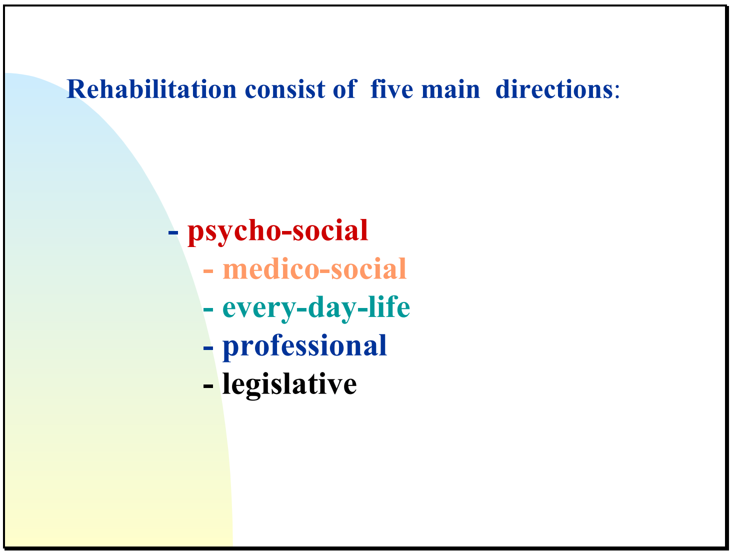
The whole amount of suicidal deaths
of young MS patients
is 600%
in comparison with the average level
in total population.

Slide 10

The strategy of rehabilitation.

- Foundation of special rehabilitation centers for MS patients
- Introduction of complex social, medical, scientific, psychological and legislative programs for multidisciplinary accesses to social adaptation

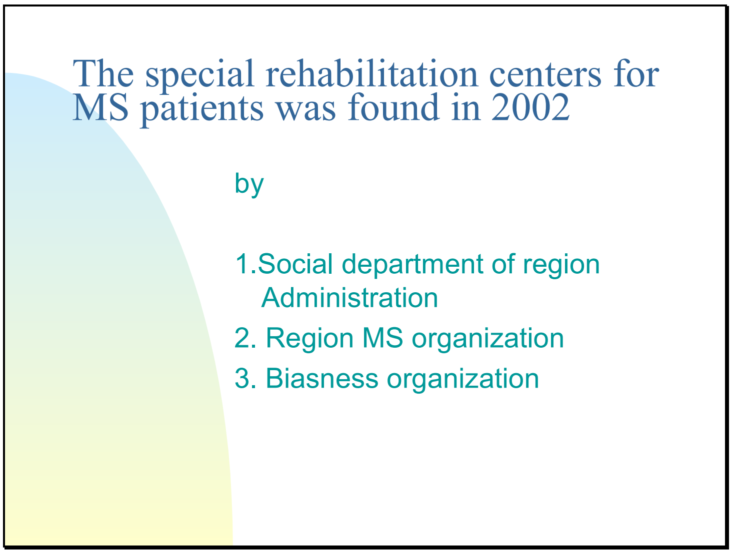
Slide 11



Rehabilitation consist of five main directions:

- **- psycho-social**
- **- medico-social**
- **- every-day-life**
- **- professional**
- **- legislative**

Slide 12



The special rehabilitation centers for MS patients was found in 2002

by

1.Social department of region Administration

2. Region MS organization

3. Biasness organization

Slide 13

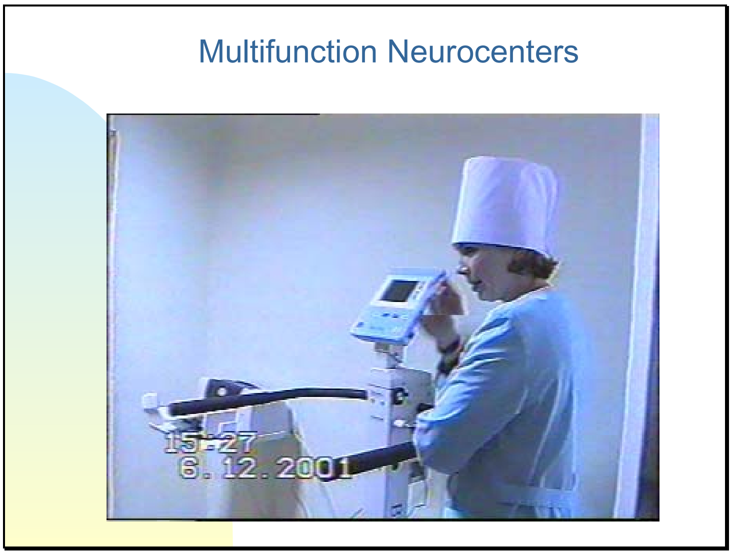
The rehabilitation serves consist of Multifunction Neurocenters

- Medico-social department
- Department of psycho-social rehabilitation
- The family serves
- Department of professional rehabilitation
- The cabinet of legislative consultation
- The every-day-life department

Slide 14

Multifunction Neurocenters

Slide 15



Multifunction Neurocenters

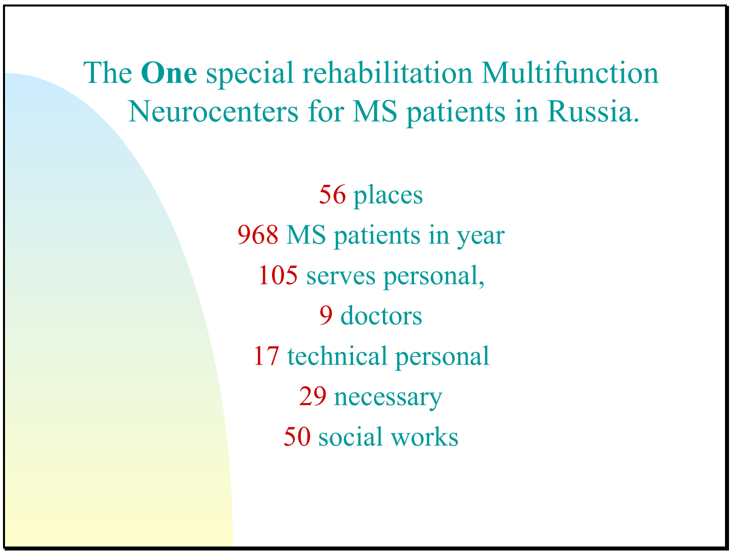
15:27
6.12.2001

Slide 16

Multifunction Neurocenters

15:30
6.12.2001

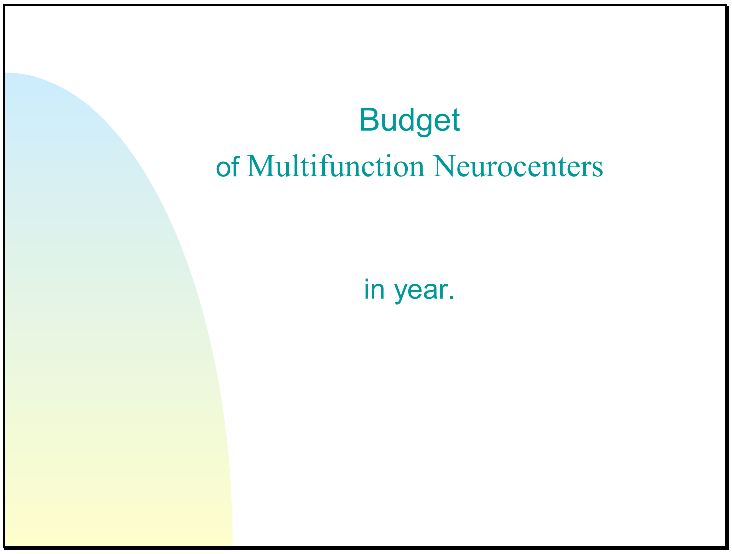
Slide 17



The **One** special rehabilitation Multifunction Neurocenters for MS patients in Russia.

56 places
968 MS patients in year
105 serves personal,
9 doctors
17 technical personal
29 necessary
50 social works

Slide 18



Budget of Multifunction Neurocenters

in year.

Slide 19

The Allrussia MS organization (ARMSO)

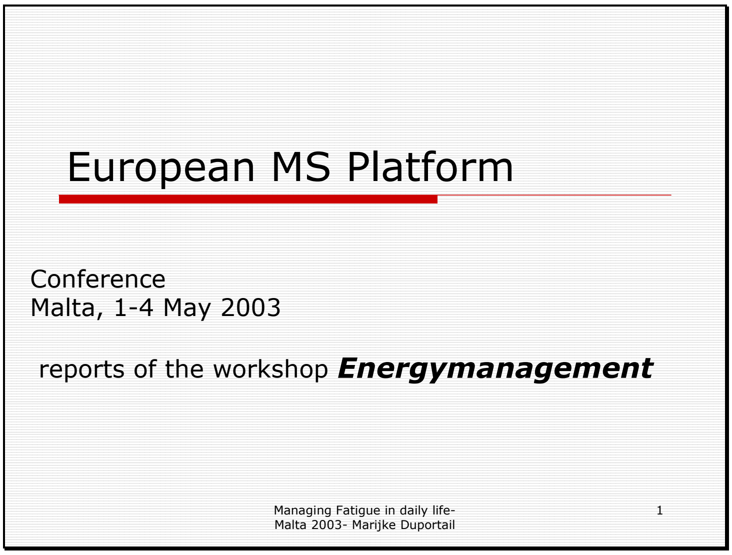
- Foundation in 2001 year in May.
- Consist from 47 regions organizations
- Associated near 50000 MS patients
- The center in Samara (+7-846-232-03-74, Yan)
- The direction in Moscow (+7-095-402-29-68, Andrei)
- Mail: sams99@inbox.ru

Slide 20

Необходимо научить человека умению жить
с этой болезнью,
борясь созидая,
побеждать без разрушительных последствий.

REPORT FROM WORKSHOP 1
MANAGING FATIGUE

Slide 1

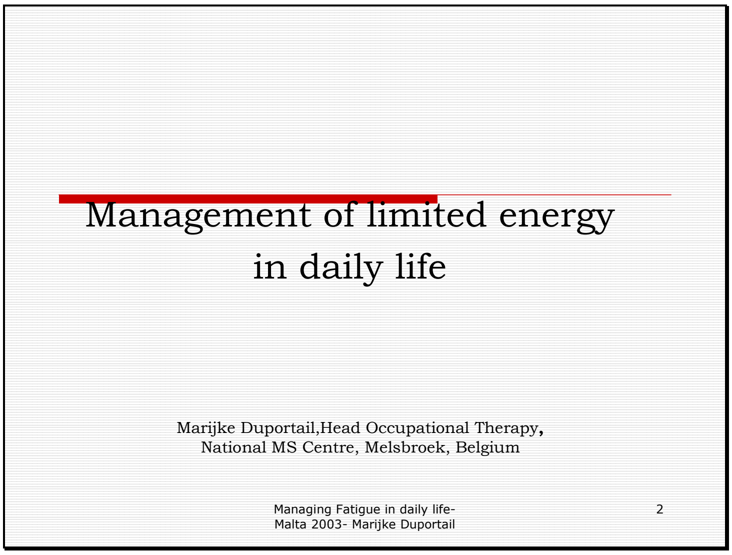


European MS Platform

Conference
Malta, 1-4 May 2003

reports of the workshop ***Energymanagement***

Slide 2



Management of limited energy
in daily life

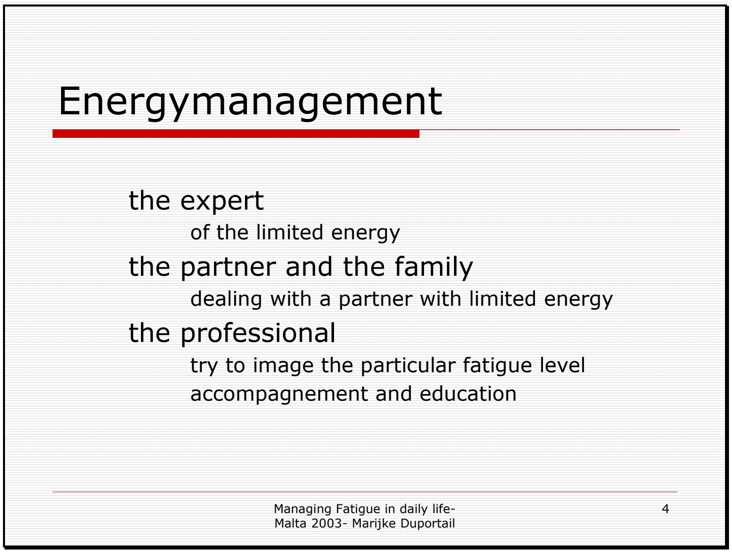
Marijke Duportail,Head Occupational Therapy,
National MS Centre, Melsbroek, Belgium

Slide 3

MS related fatigue

- ☐ Fatigue is most common among the most disabling symptoms of MS (75 - 95%)
- ☐ Fatiguemanagement -dealing with fatigue- versus management of limited energy- Energymanagement?
- ☐ But what means fatigue in daily life to you, what are the strategies you apply, what do you integrate already, what’s missing for you?

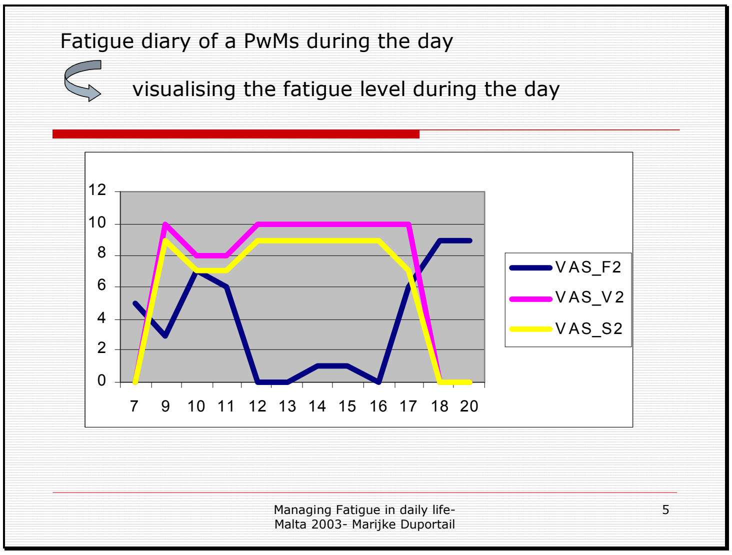
Slide 4



Energymanagement

the expert
    of the limited energy
the partner and the family
    dealing with a partner with limited energy
the professional
    try to image the particular fatigue level
    accompagnement and education

Slide 5



Fatigue diary of a PwMs during the day

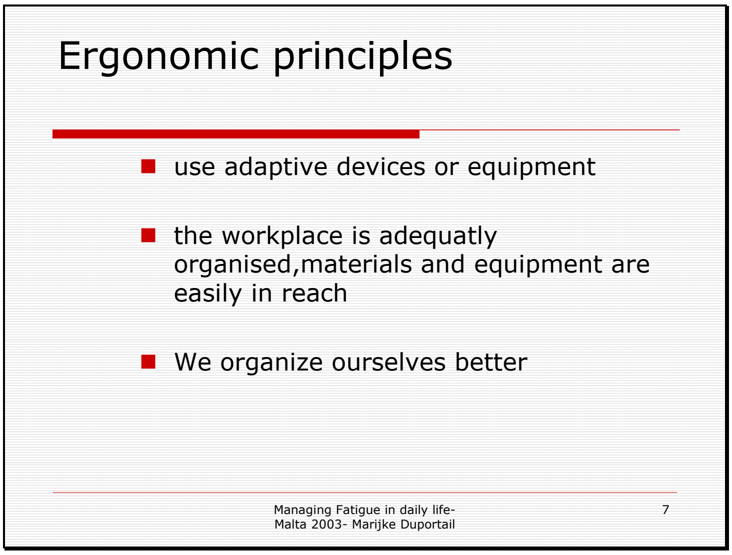
visualising the fatigue level during the day

Slide 6

Principles of energymanagement

- Encourage a healthy lifestyle
    - ☐ Try to keep as fit as possible with sensible rest, sufficient exercises
    - ☐ Training relaxation techniques Physical exercise is important
- Diet, find a good balance
- Implement ergonomic principles

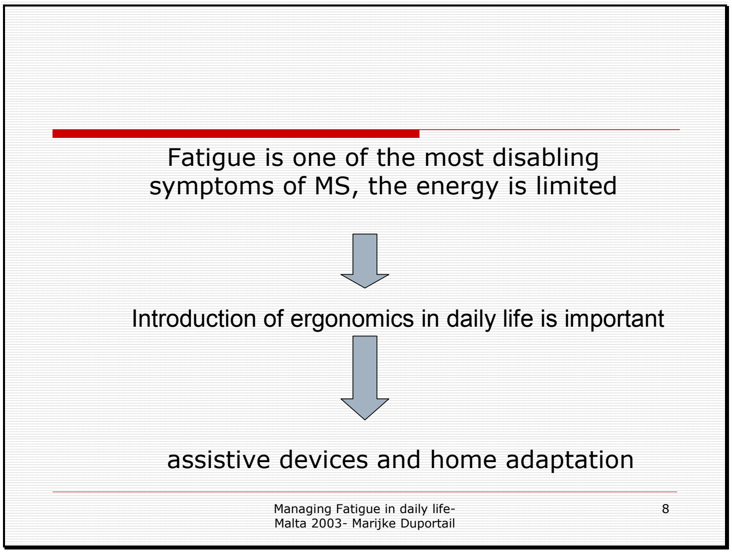
Slide 7



Ergonomic principles

- use adaptive devices or equipment
- the workplace is adequatly organised,materials and equipment are easily in reach
- We organize ourselves better

Slide 8

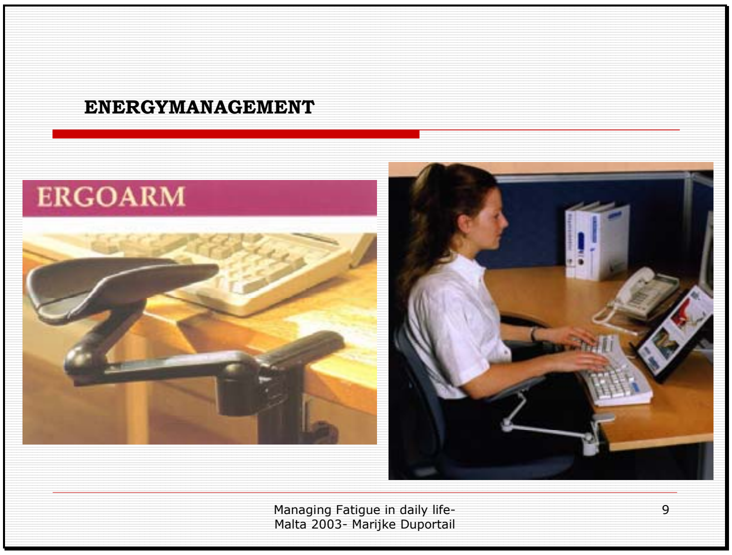


Fatigue is one of the most disabling symptoms of MS, the energy is limited

Introduction of ergonomics in daily life is important

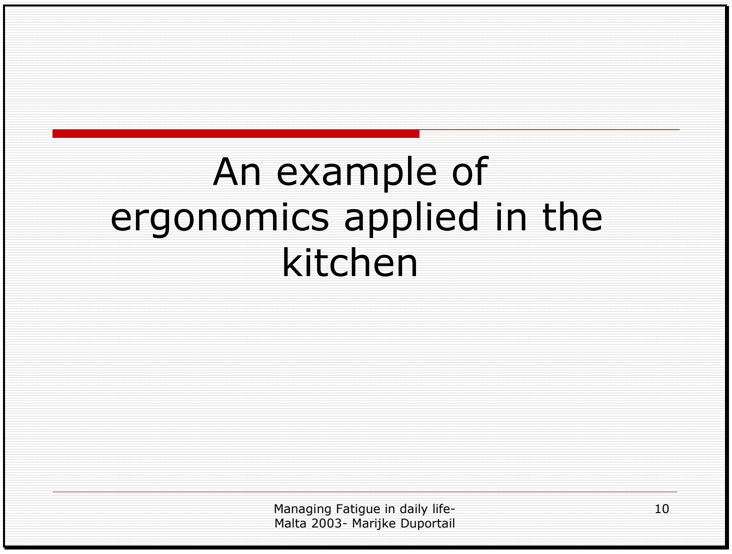
assistive devices and home adaptation

Slide 9



ENERGYMANAGEMENT

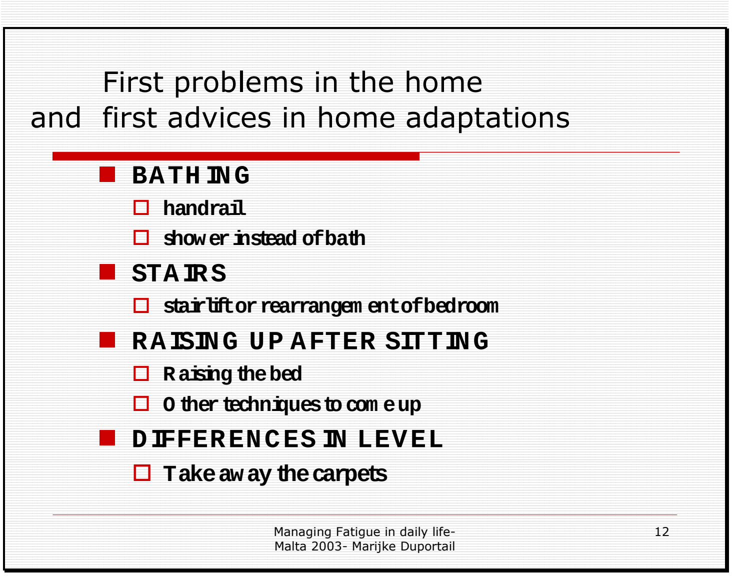
Slide 10



An example of
ergonomics applied in the
kitchen

Slide 11

Slide 12



First problems in the home and first advices in home adaptations

- BATHING
  - ☐ handrail
  - ☐ shower instead of bath
- STAIRS
  - ☐ stairlift or rearrangement of bedroom
- RAISING UP AFTER SITTING
  - ☐ Raising the bed
  - ☐ Other techniques to come up
- DIFFERENCES IN LEVEL
  - ☐ Take away the carpets

Slide 13

Change the bath into a shower

Slide 14

Principles of energymanagement

There is no physical disability!

There is only a disabled attitude of seeing things!

Good morning everybody,

As Alan already told you I am going to report from our yesterday's workshop with the topic of "Managing Fatigue"

Could anybody tell me what is the definition of fatigue?

- Too tired to do something?

It could be many things. When it comes to explain to other people how it feels, we have difficulties. They can not really understand us and often they think that we are lazy or selfish etc. which is not the case.
Yet fatigue is the most common symptom of MS (75%-95% are suffering from that) and is affecting our daily life.

As a term "Managing Fatigue" includes something negative, we have decided to give a more optimistic and hopeful perspective by changing it into : "Management of limited Energy in daily life" / "Energy management" It's like the way of seeing a glass of water half filled or half empty. *Half filled* is optimistic, *half empty* is pessimistic.

☐ Fatigue is most common among the most disabling symptoms of MS (75 - 95%)
☐ Fatigue management_-dealing with fatigue- versus management of limited energy-Energy management?

☐ But what means fatigue in daily life to you, what are the strategies you apply, what do you integrate already, what's missing for you?

The involved parts are:

- the expert of the limited energy
  The person with MS is the expert. He knows better than anybody. I strongly believe that we are the best doctors of ourselves
- the partner and the family
  - dealing with a partner with limited energy
- the professional
  - try to image the particular fatigue level
  - accompagnement and education

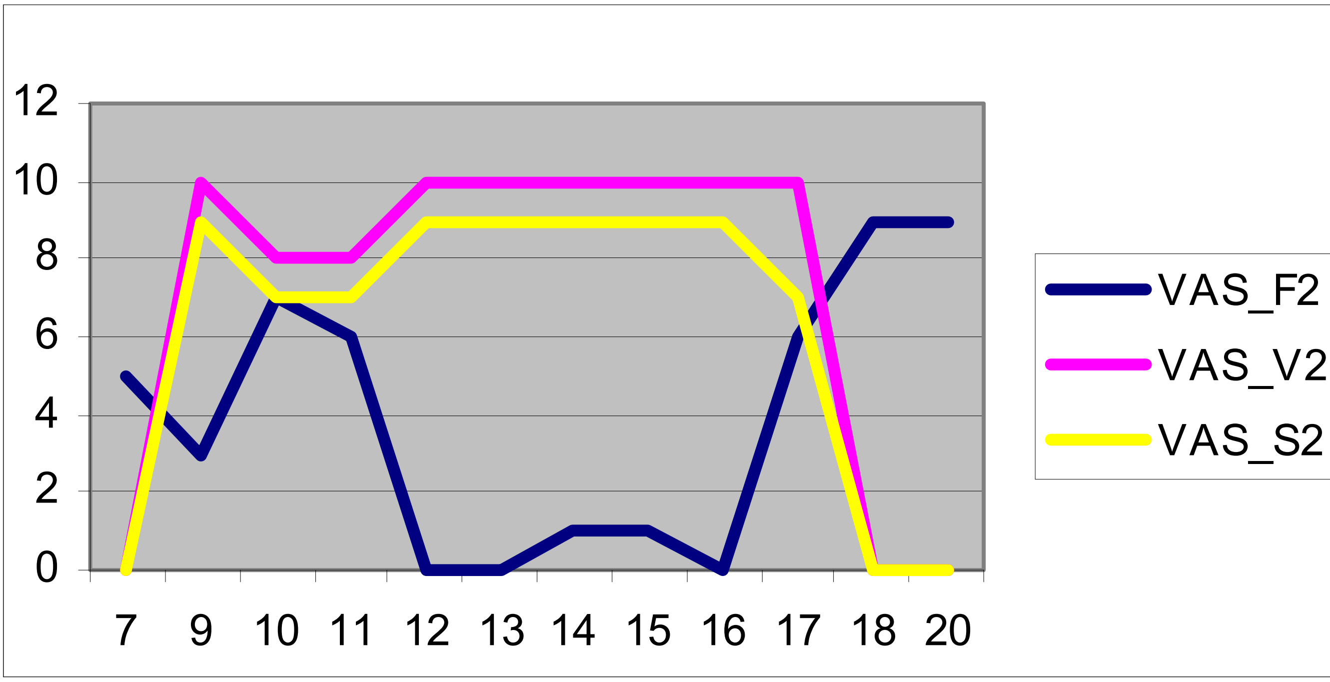
Before attending this congress, some of us received a "homework". We got a questionnaire that should be filled in and sent back to the leader of

the workshop for valuation. Yesterday we discussed about the results of this “questionnaire”.
According to that in general terms, although we are quite aware of what is good and what is bad for us but we do not apply it in our daily life.
Among other things we had to fill in a diary, where we were marking our activities every hour, deciding if the activity was important or not, how we were feeling after that (if we got satisfaction and if we experienced fatigue and at which level)

I will show you a graphic

- The blue line is the fatigue level
- The yellow line is the value
- The pink line is the satisfaction

Fatigue diary of a PwMs during the day / Visualising the fatigue level during the day



We can see that the most important thing is the satisfaction. When satisfaction is in high level and the activity is important even if fatigue level is high as well, IT IS NOT THAT IMPORTANT!

Another thing we discussed was techniques about ENERGY MANAGEMENT.
They can be divided in two parts

a. Physical techniques

b. Ergonomical principles

PHYSICAL TECHNIQUES

- Encourage a healthy lifestyle
    - Try to keep as fit as possible with sensible rest, sufficient exercises
    - Training relaxation techniques. We should avoid stress and tension when this is possible. My little experience says that we suffer a lot because we are very sensitive persons. We take over the problems of the others which makes us stressed and we feel sad. We should make the distinction of what concerns us and what concerns the others. If it is ours we should try to work on it. If it is others let them deal with, and don't bother about it. You WILL AVOID A LOT OF TROUBLE!
    - Physical exercise is important.
- Diet, find a good balance
  There are several diets available. A PwMS can choose a suitable one with the help of a professional

  Ancient Greeks had an old saying : «παν μέτρον άριστον», which means:
  Do everything but in good measure.
  Don't prevent yourselves from doing things, but on the other hand do not overdo! Find a balance. That will give you quality in your daily life.

ERGONOMIC PRINCIPLES

- use adaptive devices or equipment

- the workplace is adequately organised, materials and equipment are easily in reach

- We organize ourselves better

- Fatigue is one of the most disabling symptoms of MS, the energy is limited

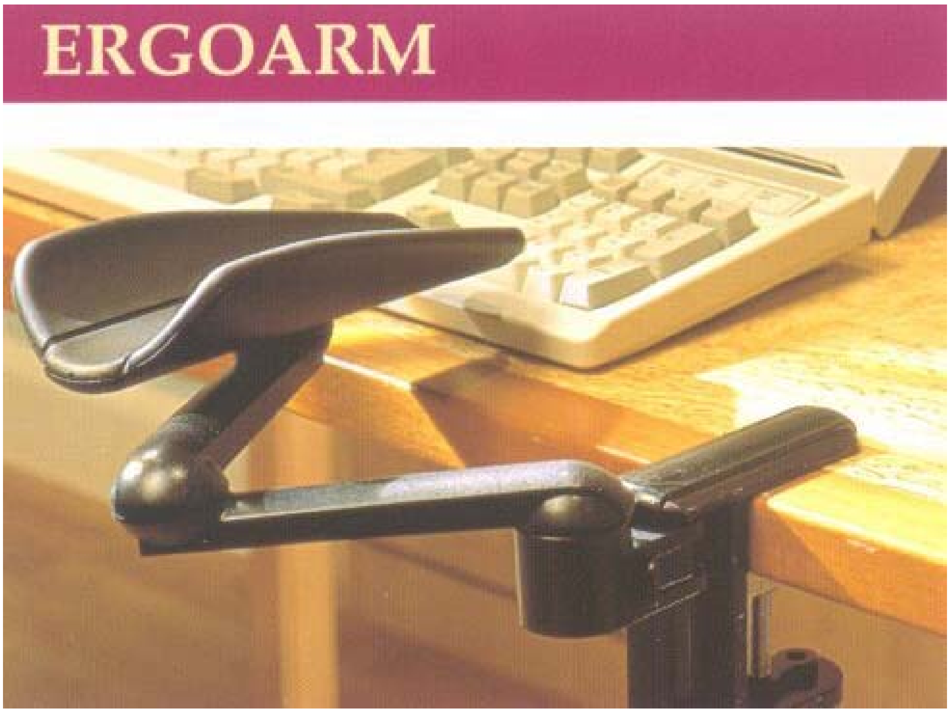
⬇

Introduction of ergonomics in daily life is important

↓

assistive devices and home adaptation

ENERGYMANAGEMENT



An example of
ergonomics applied in the kitchen

First problems in the home
and first advices in home adaptations

- BATHING

  - ☐ handrail
  - ☐ shower instead of bath
- ■ STAIRS
  - ☐ stairlift or rearrangement of bedroom
- ■ RAISING UP AFTER SITTING
  - ☐ Raising the bed
  - ☐ Other techniques to come up
- ■ DIFFERENCES IN LEVEL
  - ☐ Take away the carpets

Change the bath into a shower

Concluding I would like to say that WE CAN STILL DO THINGS. The only thing we have to do is realize that we must do them in a different way then the one we used before.
As a good friend of mine says:
There is no physical disability. There is a disabled attitude of seeing things!

So think positive, do not give up! Don’t get disappointed!

As a French composer and singer Georges Moustaki says:
Nous avons toute la vie pour nous amuser, nous avons toute la mort pour nous reposer.
(We have the whole life to enjoy ourselves and the whole death to rest)

REPORT FROM WORKSHOP 2

The report from Workshop 2 is incorporated into the summary of the workshop.

REPORT FROM WORKSHOP 3
TELECOMMUNICATION AS A MEANS FOR SELF-HELP IN MS

This workshop focused on how new technologies can help persons with MS to improve their quality of life.

<u>TELEMATICS:</u>

Mobile phones
PDA – personal digital assistant
Internet – email, ecommerce, elearning

Internet enables empowerment of persons with MS and the role of the MS societies should be to help educate people and increase confidence.

The Internet can also be used for telemedicine and telerehabilitation which is already happening in the U.S. This involves consultation, support, renewing prescriptions and giving advice over the internet.

The NARCOMS registry in the U.S. is a patient driven database for persons with MS. The process is that persons with MS fill in a questionnaire which asks questions about demographics, health care resources, medical history, care providers, disability, systematic therapies and alternative therapies. The results have been used to show the relationship between fatigue and mobility.

It was proposed that something similar be set up in Europe.

VIRTUAL REALITY:

Education and training	
Neuro rehabilitation	cognitive effects
	Stress management
Eg. Cognitive defects	memory testing, virtual tours
	Attention deficits
	Interactive driving simulation

DOMOTICS:

Control of house appliances via computer

ROBOTICS:

Computer central devices that can interact with surroundings eg. Wheelchairs with laptops, sensors etc.

TAKE HOME MESSAGES:

- Individuals do not have equal access especially Eastern European countries
- Could the EMSP help to resolve this inequity
- The Challenge – To ensure equal access to these innovative applications to ALL people with MS regardless of the country they live in.

REPORT FROM WORKSHOP 4 COMMUNICATION LIMITATIONS: HOW TO DETECT AND FIGHT THEM

This was a small workshop consisting of only 3 delegates.

Problems with reception, integration, answers and speech problems were discussed.

In a questionnaire survey carried out 55% of participants had intensity or pitch problems. People were afraid of getting tired and therefore joined in less with conversations.

Experience of impatience was reported and the need to repeat was a big problem. Therefore people tended to stay at home more, limited shopping and other activities.

Fatigue, stress, cognitive problems, memory and attention problems all affected the strength of voice.

Intelligibility:	Fatigue, loudness, articulation, drugs, muscle weakness
Solutions:	Rephrasing, accurate topics, short sentences, good positioning, lip reading, eye contact
Cognitive Aspects:	Lack of interest, withdrawal, lack of concentration, apathy
Solutions:	Task reorganisation, fatigue management, compensatory techniques
Emotional Aspects :	Depression, passivity, irritability, low self esteem
Solutions:	Emotional support

REPORT FROM WORKSHOP 5 “URO-REHABILITATION” – AN IMPORTANT TOOL TO TREAT URINARY DYSFUNCTION

More than 80% of persons with MS suffer from this problem.

BLADDER MANAGEMENT:

- Assessment
- Pharmacological treatments
- Rehabilitation strategies

WORKSHOP GROUP PROPOSALS/CONCLUSIONS:

- Screening: questionnaire, nutrition diary
- Assessment before treatment
- Regular reviews
- Awareness of side effects of medication
- Urodynamic evaluation – included as part of the rehabilitation programme
- More qualified doctors to assess – with experience
- Ask lots of questions
- Needs to be discussed at early stages of the disease
- More studies on this subject specifically relating to MS

Methods and costs were discussed in the workshop – again an inequity of access in different countries.

TIPS/TAKE HOME MESSAGES:

- Early intervention
- Full explanation to the person with MS and the team about bladder management and rehabilitation techniques.

REPORT FROM WORKSHOP 6 INNOVATIVE MODELS FOR PHYSIOTHERAPY IN THE U.K.

Slide 1

Innovative models of physiotherapy in the UK

Jill Anderson
(MS Society)
Tracey Mifflin *(West Cumbria Primary Care Trust)*

Slide 2

Service Development Programme

Example of partnership working between

- MS Society (UK)
- MS Relief (another UK MS charity)
- Chartered Society of Physiotherapy

Slide 3

Objectives of the Programme

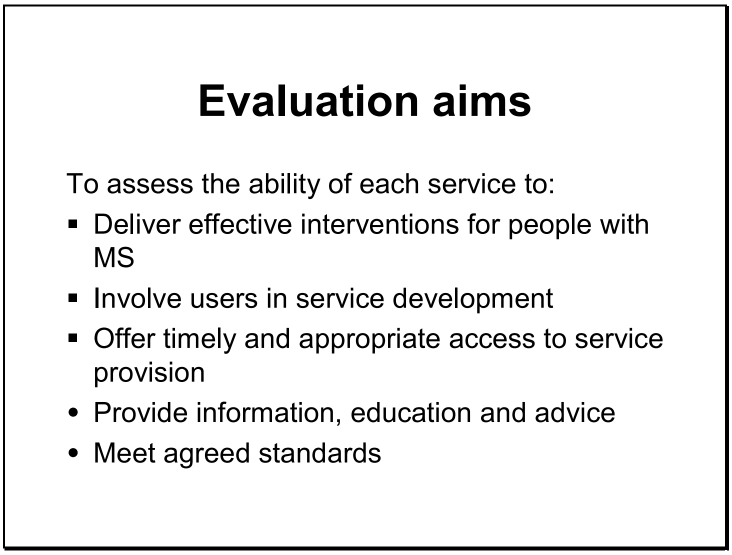
To reflect the range of different physiotherapy interventions and find out as much as possible about physiotherapy for people for people with MS to contribute to evidence base, identify models, stimulate innovative practice (esp. user involvement) & inform further research

Slide 4

The 4 different services

- Self-management programme (Stockton-on-Tees)
- Relapse management clinic (Walton Centre,Liverpool)
- Fatigue management programme (Yorkshire)
- Model for delivery of equitable neuro - physiotherapy service to people with MS in a rural district (Cumbria)

Slide 5

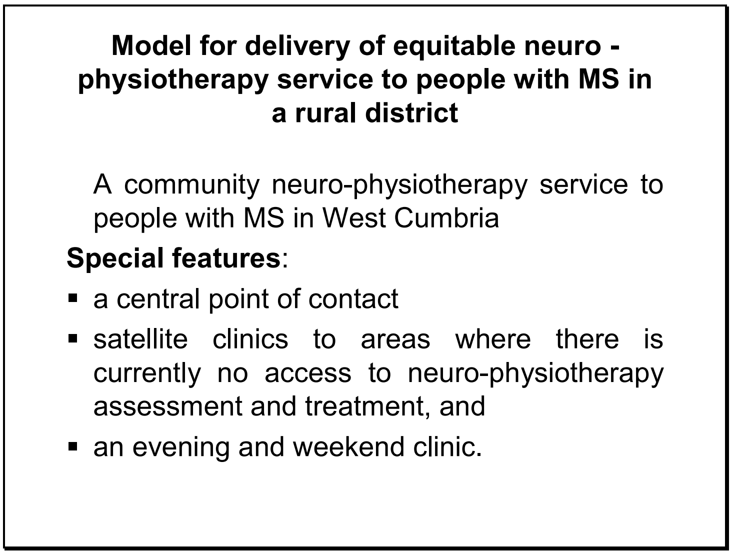


Evaluation aims

To assess the ability of each service to:

- Deliver effective interventions for people with MS
- Involve users in service development
- Offer timely and appropriate access to service provision
- Provide information, education and advice
- Meet agreed standards

Slide 6



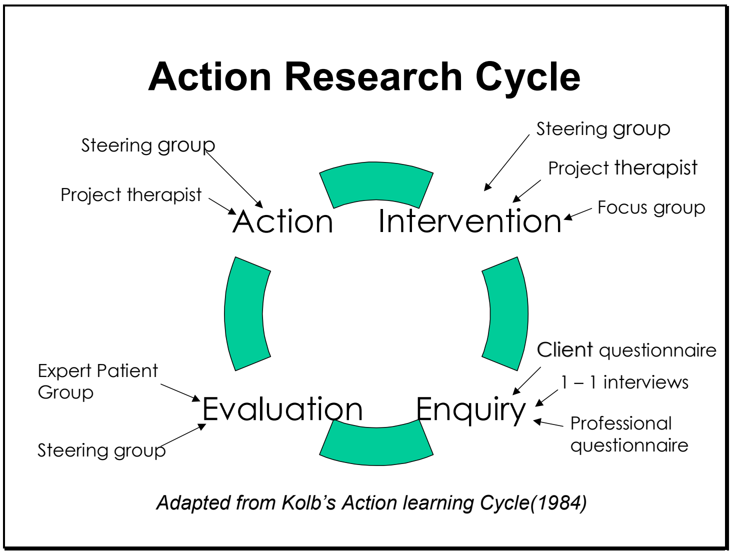
Model for delivery of equitable neuro - physiotherapy service to people with MS in a rural district

A community neuro-physiotherapy service to people with MS in West Cumbria

Special features:

- a central point of contact
- satellite clinics to areas where there is currently no access to neuro-physiotherapy assessment and treatment, and
- an evening and weekend clinic.

Slide 7



Action Research Cycle

Steering group

Project therapist

Action

Steering group

Project therapist

Focus group

Intervention

Client questionnaire

1 – 1 interviews

Professional questionnaire

Enquiry

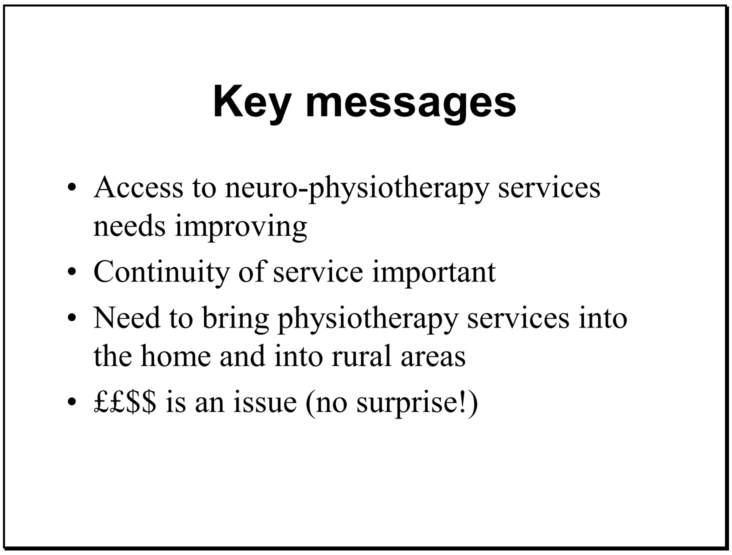
Expert Patient Group

Steering group

Evaluation

Adapted from Kolb's Action learning Cycle(1984)

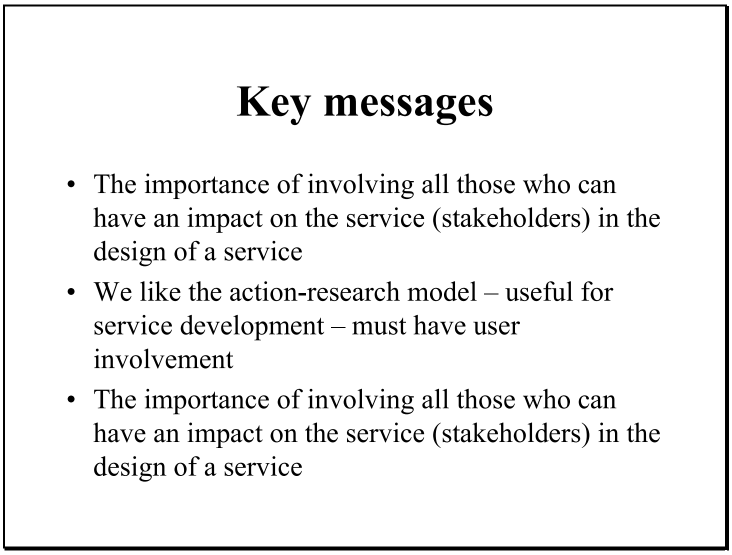
Slide 8



Key messages

- Access to neuro-physiotherapy services needs improving
- Continuity of service important
- Need to bring physiotherapy services into the home and into rural areas
- ££$$ is an issue (no surprise!)

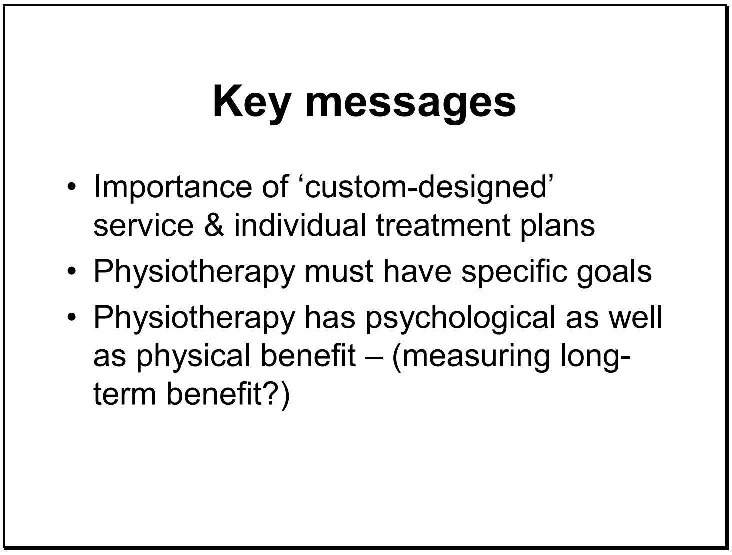
Slide 9



Key messages

- The importance of involving all those who can have an impact on the service (stakeholders) in the design of a service
- We like the action-research model – useful for service development – must have user involvement
- The importance of involving all those who can have an impact on the service (stakeholders) in the design of a service

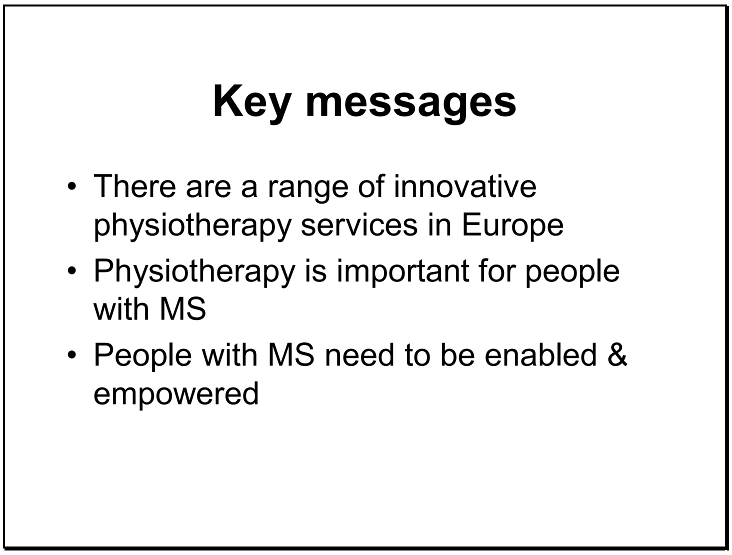
Slide 10



Key messages

- Importance of ‘custom-designed’ service & individual treatment plans
- Physiotherapy must have specific goals
- Physiotherapy has psychological as well as physical benefit – (measuring long-term benefit?)

Slide 11



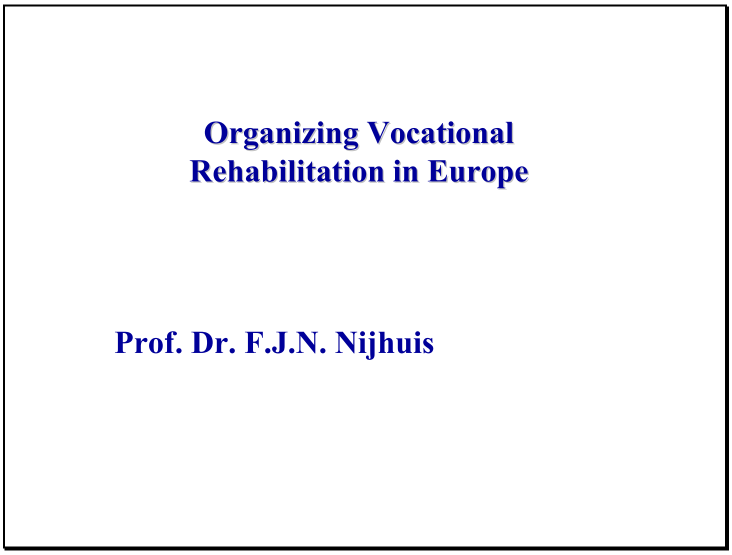
Key messages

- There are a range of innovative physiotherapy services in Europe
- Physiotherapy is important for people with MS
- People with MS need to be enabled & empowered

FURTHER DEVELOPMENTS IN THE FIELD OF REHABILITATION IN EUROPE – WHAT PERSONS WITH MS CAN EXPECT FROM RIMS AND EMSP ON A POLITICAL LEVEL

Frans Nijhuis

Slide 1



Organizing Vocational Rehabilitation in Europe

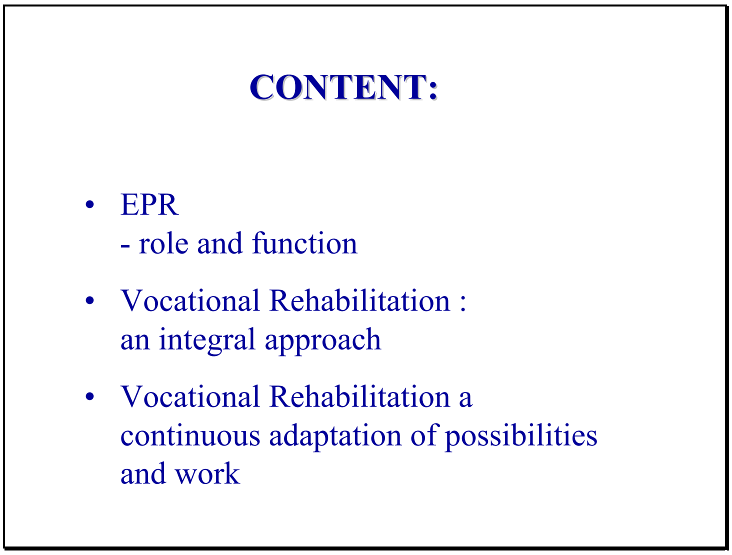
Prof. Dr. F.J.N. Nijhuis

Slide 2

THE EUROPEAN PLATFORM FOR REHABILITATION

A transnational network in vocational rehabilitation

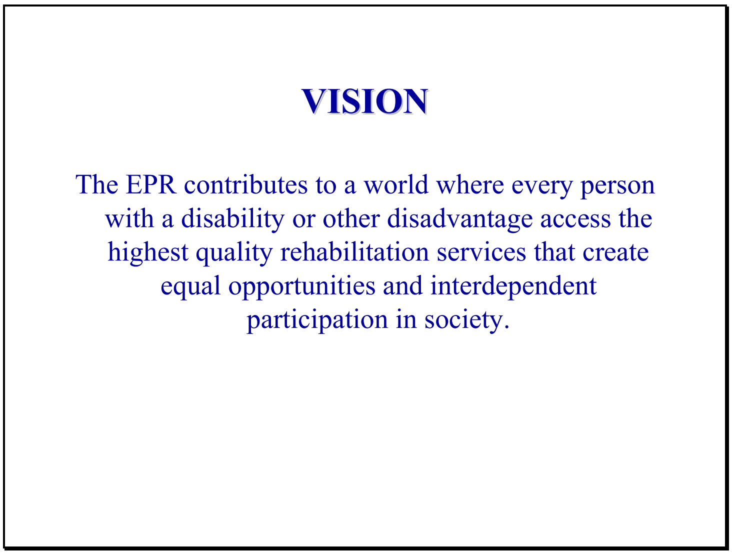
Slide 3



CONTENT:

- EPR
  - role and function
- Vocational Rehabilitation : an integral approach
- Vocational Rehabilitation a continuous adaptation of possibilities and work

Slide 4



VISION

The EPR contributes to a world where every person with a disability or other disadvantage access the highest quality rehabilitation services that create equal opportunities and interdependent participation in society.

Slide 5

MISSION

Drawing strength from global diversity, the EPR is an innovative force and generator of expertise increasing the quality of rehabilitation services. Recognised as the outstanding and influential forum of service providers in Europe and in cooperation with service-users, the EPR realizes continuous improvement and lasting change through:

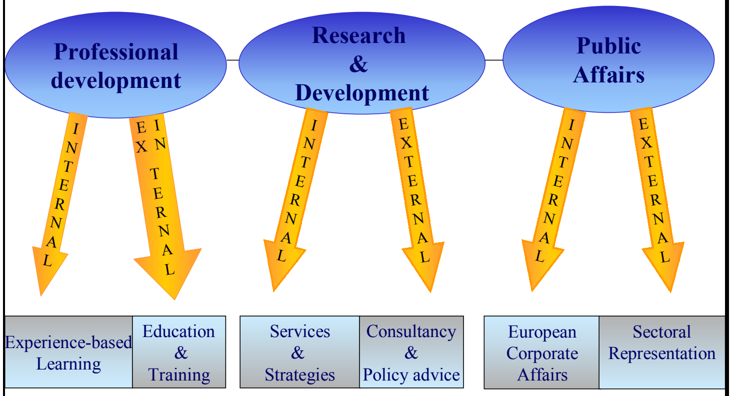
Providing professional development platforms that enhance the capacity of individual professionals, service providers and the entire rehabilitation sector.

Researching and developing methods, models and modes of delivery that directly innovate and improve rehabilitation service systems.

Influencing policy development, promoting the rehabilitation sector, and providing information and assistance to service providers on European and International affairs.

Slide 6

EPR ACTIVITIES

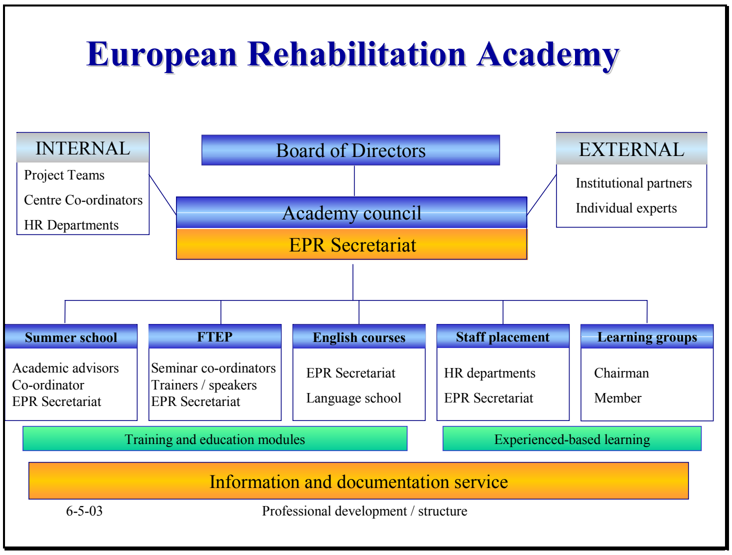


Professional development
INTERNAL
EX INTERNAL
Experience-based Learning
Education & Training

Research & Development
INTERNAL
EXTERNAL
Services & Strategies
Consultancy & Policy advice

Public Affairs
INTERNAL
EXTERNAL
European Corporate Affairs
Sectoral Representation

Slide 7



European Rehabilitation Academy

INTERNAL
Project Teams
Centre Co-ordinators
HR Departments

Board of Directors

Academy council

EPR Secretariat

EXTERNAL
Institutional partners
Individual experts

Summer school
Academic advisors
Co-ordinator
EPR Secretariat

FTEP
Seminar co-ordinators
Trainers / speakers
EPR Secretariat

English courses
EPR Secretariat
Language school

Staff placement
HR departments
EPR Secretariat

Learning groups
Chairman
Member

Training and education modules

Experienced-based learning

Information and documentation service

6-5-03 Professional development / structure

Slide 8

European Rehabilitation Academy

GOAL

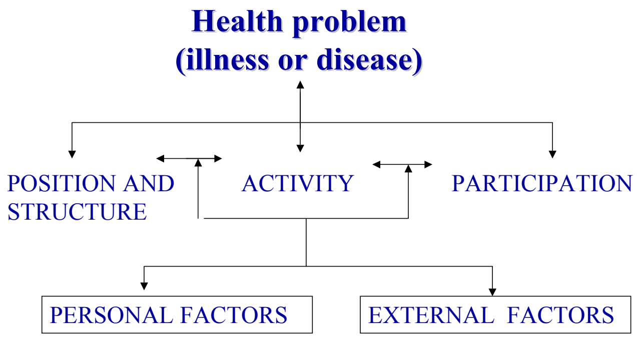
To equip practitioners within the field of (vocational) rehabilitation for the challenges to be faced in a rapidly changing environment

Slide 9

How to reach this goal?

- Continuous professional improvement
- Optimising the knowledge management needs of professionals within the sector
- Tailor-made staff development activities

Slide 10



Health problem
(illness or disease)

POSITION AND STRUCTURE

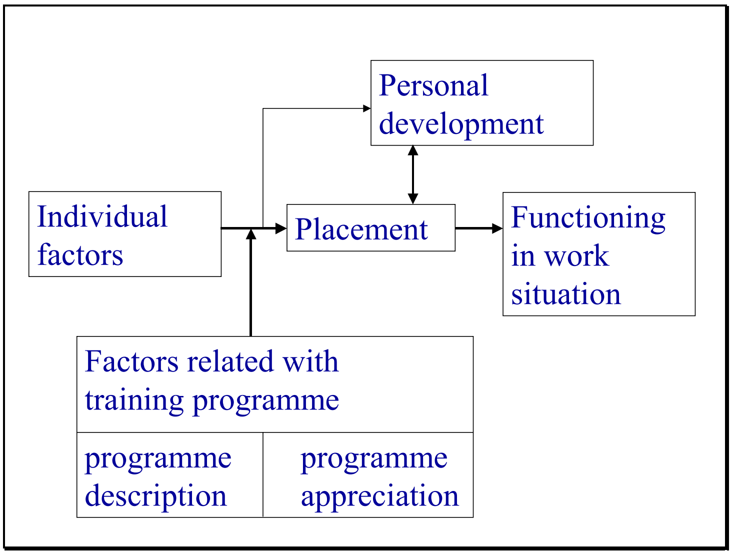
ACTIVITY

PARTICIPATION

PERSONAL FACTORS

EXTERNAL FACTORS

Slide 11



Slide 12

Questions

Personal development

Short-term and long-term placement

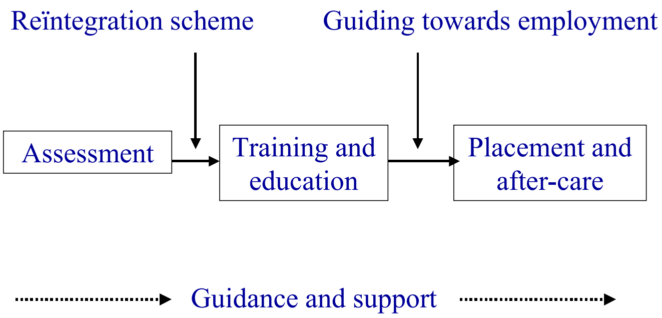
Functioning in work situation

Costs versus benefits

Predictors of succesful placement

Slide 13

Process model of labour integration



Reïntegration scheme

Guiding towards employment

Assessment

Training and education

Placement and after-care

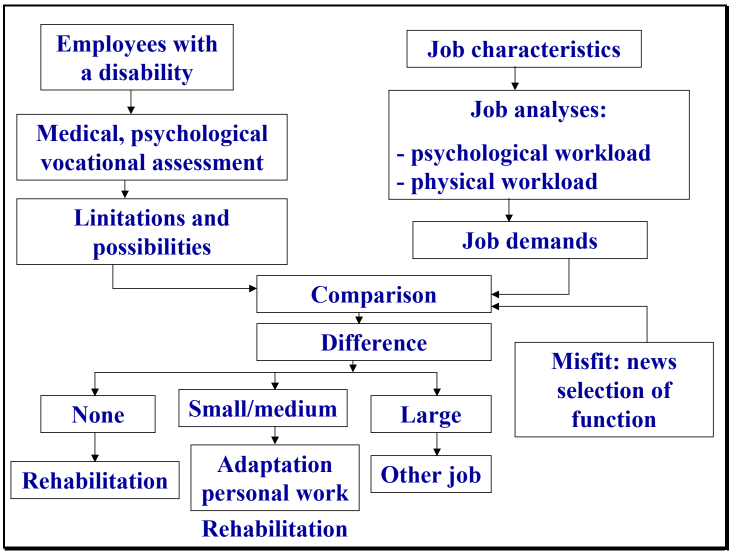
Guidance and support

Slide 14

Vocational Rehabilitation:

an integral approach

Slide 15



Employees with a disability

Medical, psychological vocational assessment

Linitations and possibilities

Job characteristics

Job analyses:

- psychological workload
- physical workload

Job demands

Comparison

Misfit: news selection of function

Difference

None

Small/medium

Large

Rehabilitation

Adaptation personal work

Rehabilitation

Other job

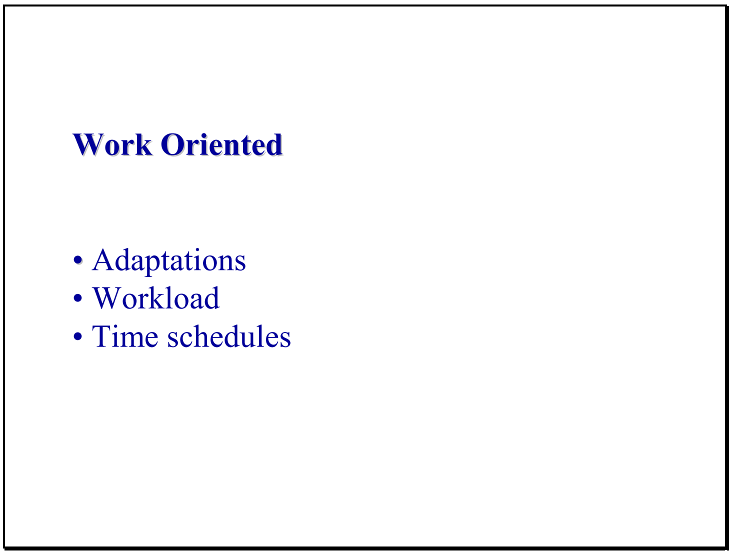
Slide 16

Chronic disease

Interactive strategy of possibilities and job demands

- work
- person
- employment in process

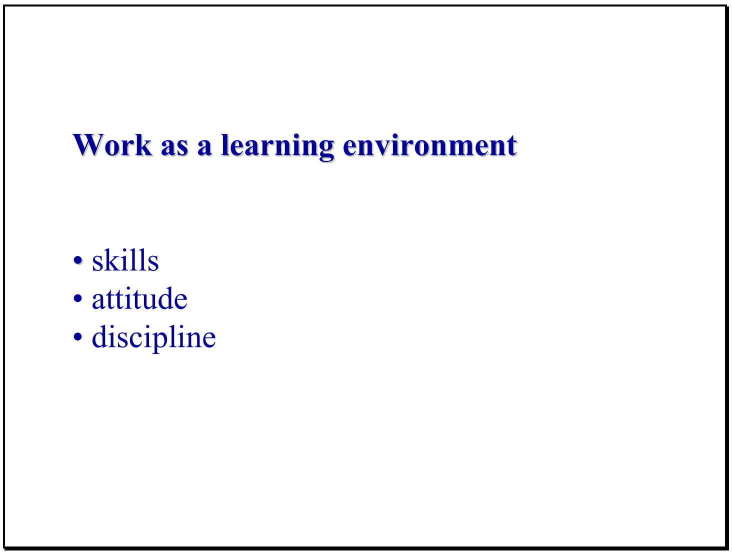
Slide 17



Work Oriented

- Adaptations
- Workload
- Time schedules

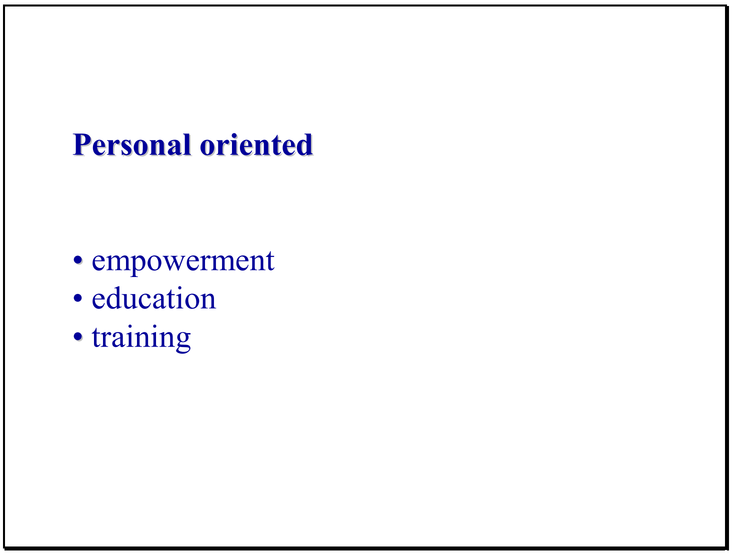
Slide 18



Work as a learning environment

- skills
- attitude
- discipline

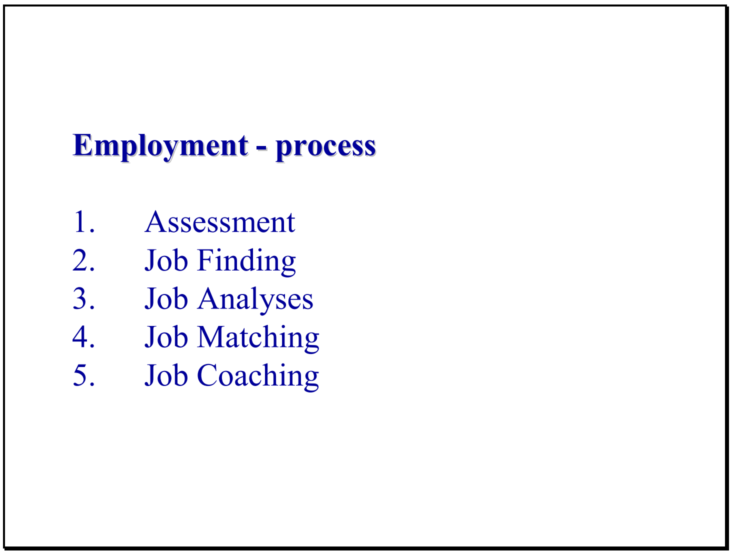
Slide 19



Personal oriented

- empowerment
- education
- training

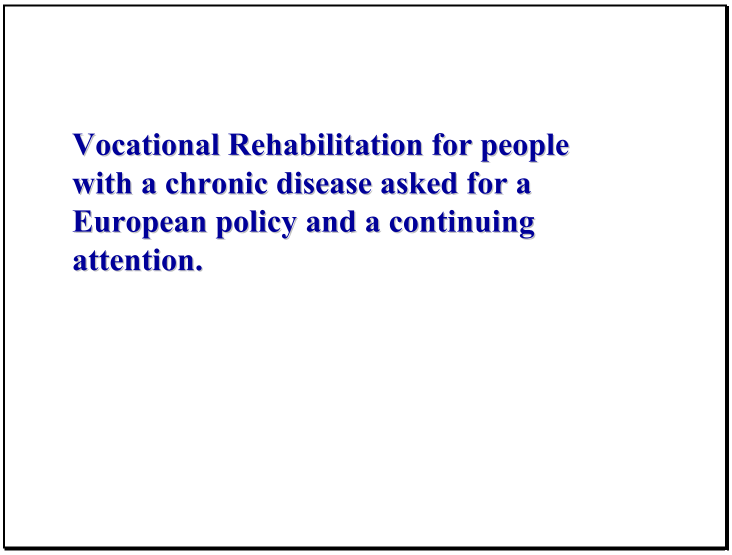
Slide 20



Employment - process

1. Assessment
2. Job Finding
3. Job Analyses
4. Job Matching
5. Job Coaching

Slide 21



Vocational Rehabilitation for people with a chronic disease asked for a European policy and a continuing attention.

DECLARATION

by the participants of Meeting of the European Multiple Sclerosis Platform, Malta, May 2003

Acknowledging the dramatic differences across Europe faced by citizens affected by Multiple Sclerosis, we, representatives of EMSP, call for treatments and services that

- recognise personal dignity
- seek to maximise personal potential
- enable people affected by MS to be fully involved in and influence decisions about service provision
- take account of the full range of physical, cognitive, emotional and social implications of being affected by MS
- meet agreed European quality standards
- are subject to continual evaluation and improvement
- are accessible and timely
- are delivered by appropriately skilled and experienced professionals
- are provided equitably and efficiently, irrespective of geography or organisational professional boundaries

To achieve these goals, we affirm our commitment to:

- Working collaboratively with the European Institutions' programmes and policies on health, social inclusion and non discrimination to promote the principle, and practice of equal treatment and services for people affected by MS across Europe

- Supporting concerted action and co-operation with relevant European medical NGOs and governmental agencies for the implementation of “**European Wide Guidelines on Therapies for People affected by MS** ”

- Holding high level discussions with the EU Institutions to explore, in the framework of the Convention on the future of Europe, new EU competencies that can advance our endeavours for
    - more **MS related research** on national, European and world-wide level
    - better awareness on the **importance of continued employment** for persons with MS
    - achieving **high quality equitable treatment and services** for all Europeans affected by MS
    - **universal access** to public buildings and services throughout Europe
- Engaging in a major awareness campaign across Europe to ensure stakeholders at all levels support our drive towards a better quality of life and brighter future for every European affected by MS.

This declaration was adopted on May 3rd , 2003 in Malta. It constitutes the central message from 29 national MS Societies represented by the European MS Platform to fellow Europeans in this, the

European Year of People with Disabilities.

WHAT WERE YOUR FEELINGS ABOUT THE CONGRESS?

“Thank you for your help. The meeting was wery usefull for russians. Sure we will arrange feature collaboration with EMSP.”

“I'm back in Slovakia and from Saturday, back to my home town. I would like to thank you for organising such a great conference that for me was so fantastic.”

“This is our first experience at a conference of this sort. We are pleased that we were made so welcome and have felt comfortable enough to take part fully in the proceedings.”

“We have been encouraged by the positive attitudes and outlooks displayed by the conference as a whole.”

“We found some of the facts and figures presented frightening, but are optimistic that the situation is rapidly improving in those areas. With these presentations has come the realisation that we as a country are behind in many ways and ahead in many others, therefore we should appreciate what we have and strive to improve what we don’t and encourage all to the same high goals.”

“It was appreciated that the conference was held in English and appreciate the efforts made by others who had to listen in one language, think in another and then speak in the first language again.”

“On a personal level we have exceeded Peter’s (Kauffeldt) target of 10 new friends. We expect to maintain close contact with several of the people that we have met this week and look forward to perhaps renewing acquaintances with many others at future events”

“After the conversations with these people I got deeper understanding where we are as an organization and what are our strong and weak points. Observations of how other MS Societies work help me to orientated what is the situation in Europe as a whole and how to set our priorities.”

Do you have any comments – good or bad – about this year’s congress. If so, please contact Rebecca Jestico on rjestico@aol.com

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