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Lifelong Learning Programme

Leonardo da Vinci

Educative Programmes for Patients and Care Givers

www.leonardo.org.pl

www.leonardo.org.uk

www.leonardodavinci.nl

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Community Rehabilitation in Neurology Training Programme



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Presented educational materials were developed in 2008-2010 with support from European Union funds as a part of the Leonardo da Vinci project titled: Community Rehabilitation in Neurology Training Programme



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Educative Programmes - Rationale

- Information is power!
 - Enlightening
 - E.g. latest treatments; how to access services
- Improve individual's ability to manage own symptoms/disease
 - Empowering
- Collaborative working: professionals, charities, service users, private and public sectors.
 - Encompassing
 - Connecting people with the services that might benefit them and other people who might share and understand their lived experience.



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Educative Programmes - Examples

- Generic
 - E.g. The expert patient programme
- Disease specific
 - E.g. Getting to Grips with Multiple Sclerosis
- Symptom specific
 - E.g. Fatigue management programme



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The Expert Patient Programme

- <http://www.expertpatients.co.uk/>
- Mostly led by trained tutors who live with a long term condition.
- Promote self-management, self-advocacy and partnership working.
- Information, skills and techniques to manage condition e.g. managing emotions, finding community resources
- Initial course for chronic disease self-management, now run a variety of more specific course too, e.g. for parents of children with a disability, recovery after mental health problems.



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Fatigue Management Programme

- Group or individual programme
- Factors which affect fatigue including:
 - Medication
 - Exercise
 - Sleep hygiene
- Advice on practical measures to help manage fatigue.



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Fatigue Management Principles

- Set the right balance between rest and activity
- Prioritise activities
- Plan ahead
- Work simplification
- Consider posture and positioning
- Consider lifestyle aspects
- Manage other symptoms of your condition that may be contributing to fatigue, e.g. bladder problems, pain
- Consider core body temperature

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Example of Good Practice- Disease Specific Programme

- **Getting to Grips with MS**
 - An MS Society of Great Britain and Northern Ireland endorsed programme: www.mssociety.org.uk
- **Newcastle/Gateshead Programme**
 - Has been running now for approx 10 years
 - One evening session a week over 4 weeks
 - Each week focussing on different aspects of living with MS, can be adapted to suit the needs of a particular group
 - Newly diagnosed people invited within 6 months to 1 year of diagnosis
 - Invited to attend with a companion for support and for their information too.



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Week One

- Presentations:
 - Living with MS
 - MS Nurse presentation on the symptoms of MS
 - Personal perspective presentation from a person living with MS
 - Exercise and Fitness
 - Physiotherapist presentation





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Week Two

Presentations:

- **Fatigue Quiz**
 - Occupational Therapist, group work on fatigue awareness and management
- **Rehabilitation in MS**
 - Consultant in Rehabilitation medicine



Walkergate Park

**Centre for Neuro-Rehabilitation
and Neuro-Psychiatry**



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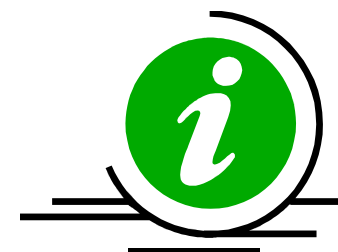
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Week Three

Information Market Place

- Employment
- Benefits
- Carers
- Complementary Therapies

And many more.....





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Week Four

Presentation:

- Overview of MS
- Drug Therapies
 - A two-part presentation by Consultant Neurologist





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What Previous Participants Have Said

- **Week One:**
 - Having someone with MS talk really helped!
- **Week Two:**
 - The quiz encouraged more participation and interaction
- **Week Three:**
 - I thought today was the best week so far, I enjoyed the informal setting and mixing with others with MS and finding out how they cope. Very useful evening
- **Week Four:**
 - Excellent information. Realised there was so much I actually didn't know. Feel very well informed.
- Just would say thank you for all the information given