

European Guideline for physiotherapy in Parkinson's disease

Newsletter 3, November 2011



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What has been done, since July 2011

- Barriers in current care identified through the survey and meetings with nursing home professionals
- Survey rounded off: 19 countries, 11 languages, over 4,000 physiotherapists participated!
- Data (nearly) cleaned to be shared with participating physiotherapy associations
- Barriers in current care transformed into key questions for the future guideline
- Literature update started
- A guideline's specific section created at APPDE website

Upcoming dates	January 2012	Representatives contacted for collection of <i>other considerations</i>
	February 2012	2 nd meeting Writing Group
	March 2012	Newsletter 4 (e.g. introduction Steering Group members)

APPDE website

Looking for information on the guideline project? Please go to www.appde.eu/EN/european-guideline.asp. Here, on the website of the Association of Physiotherapists in Parkinson's Disease Europe, a special section has been created for our collaborative project. It provides our newsletters, but also the current guideline (KNGF 2004), and dates of interesting events. Patients and health professional who do not yet receive the newsletters personally, but would like to, or even become involved in the development process, can subscribe here.

Introduction of Reading Group members

Where in Newsletter 2 we have introduced the Writing Group members, we now would like to introduce the Reading Group members to you. At every step the Writing Group members take (e.g. transformation of barriers into key questions), the Reading Group members provide feedback and keep them on the right track.



Erick Kerckhofs, Representative of AXON, Belgium

Eric has a PhD-degree in rehabilitation sciences and physiotherapy and a Master's degree in clinical psychology. He is affiliated as a fulltime professor in neurological rehabilitation and rehabilitation psychology at the Vrije Universiteit Brussel (Brussels, Belgium). His main research topics are situated in the overlapping domain of neurorehabilitation and psychology of patients with central nervous systems diseases like parkinson's disease, stroke, multiple sclerosis covering e.g. cognitive dysfunctions in Parkinson's, fall problems in Parkinson's, quality of life, pusher behavior in stroke, robot-assisted gait training. He is member of the medical advisory board of the Flemish Parkinson League information.



Katja Krebber, Representative of the Zentralverband der Krankengymnasten (ZVK), Germany

Katja received diplomas in physiotherapy (1988), manual therapy (1997), PNF (1998) and in physiotherapy on weight training machines (2005). Since 2007 she has been working for the Quality Circle Parkinson's Disease of Physiotherapy ZVK Berlin. For over 18 years she has been running her own community practice, specialising in Parkinson's disease. As member of the Quality Circle Parkinson's Disease of Physiotherapy ZVK Berlin, she has organised patients information events and held presentations on the issue 'Falls prevention in the home'. Since 2010 she has been working as a course instructor for 'physiotherapy in evidence-based therapy for Parkinson's'.



Roisin Moloney, Representative of the Irish Society of Chartered Physiotherapists (ISCP)

After having gained her BSc in physiotherapy (2003), Roisin worked in the field of neurology in hospitals in Dublin (Ireland), followed by the Mater Hospital Brisbane, while travelling in Australia in 2005. She has been working as Senior Physiotherapist in neurology in Beaumont Hospital, Dublin since 2006. She has developed a specialised interest in movement disorders and provides physiotherapy input at weekly multidisciplinary team Parkinson’s Disease/Movement Disorder clinic. She is currently working towards a Masters in Neurology and Gerontology in Royal College of Surgeons Ireland and is in the process of writing a thesis investigating outcome measures in Parkinson’s disease.



Maria Nilsson, Representative of Sjukgymnastförbundet (LSR), Sweden

Since Maria became a physiotherapist (1993), she evaluated and treated at least 4 Parkinson patients each week, until 2007. Both her Bachelor, Master and PhD thesis (2009) concerned Parkinson’s. She has participated in a “roadshow” in Hungary, organised by the EPDA, the national patient organisation and the Swedish Parkinson Disease Association. The latter awarded her with a ‘medal of honor’ in 2010. The same year she attained an award for best Parkinson’s PhD thesis (Sweden). She is a board member of the Swedish Movement Disorders organisation for health sciences (VfMD). She currently has a post-doctoral position (Lund University). Both her prior and present research target Parkinson’s.



Silvia Nowotny, Representative of Physio Austria

Silvia graduated as physiotherapist in 2000 and received her Masters degree in neurorehabilitation in 2006. She worked in Bad Pirawarth, one of Austria’s biggest neurorehabilitation facilities. After that, she spent some years being a community physiotherapist, offering home visits. In addition, she developed a therapeutic horseriding programme for people with Parkinson’s. Currently she is a member of the academic staff at the University of Applied Sciences for Health Professionals in Upper Austria. Here she teaches evidence based practise, clinical reasoning and physiotherapy in neurology.



Inge Riesum Nielsen, Representative of Danske Fysioterapeuter, Denmark

Since her physiotherapy graduation (1995), Inge has worked in both hospital and the municipal system. Since 2000, she is working in Skive municipality, where she focuses on orthopedic rehabilitation, and (since 2005) on Parkinson’s, both in patient’s homes and in the health center. She teaches healthcare professionals in Parkinson’s rehabilitation, and trains patients and their relatives (Parkinsons school). Since 2008, she has been using the KNGF Guideline for Parkinson. In collaboration with the Danish physiotherapists association she is supporting the KNGF guideline’s implementation in Denmark. Since November 2011 she is responsible for Parkinson in the Section for Neurological Physiotherapy.



Vladan Toufar, Representative of the Unie Fyzioterapeutu České Republiky

After gaining his diploma in physiotherapy (1994), Vladan specialised in manual medicine (1997) and applied physiotherapy. In 2008, he obtained his MSc degree in physiotherapy. Currently he is head of the physiotherapy department of the Břeclav Hospital. Here he works both with in and outpatients, dealing with Parkinson’s every day. He is a member of the executive committee of the Union of Physiotherpists of Czech republic, where he works with special interest groups. Since 2004 he coordinates groups for the development of national standards. In addition, in 2011 he became a member of the editorial board of the journal Nursing Diagnosis.



Annette Vistven, Representative of the Norsk Fysioterapeutforbund (NFF), Norway

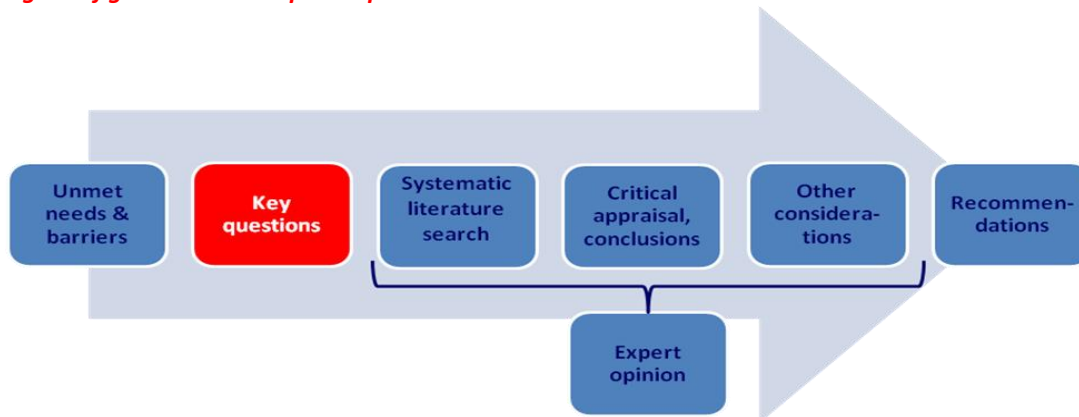
Annette holds a Bachelors degree in Physiotherapy (Denmark, including studies at Marymount University, U.S.A.). She has 11 years professional experience, of which 5 years in London (UK), working with children with neurological disorders and special needs. The past 6 years, Annette has worked at Fram Helsehelse (Norway), specializing on people with Parkinson’s. She has worked on several projects, including ‘rehabilitation post DBS surgery’ and, as project manager, for LSVT BIG training for people with Parkinson’s (Norwegian Directorate of Health sponsored). Moreover, she has worked closely with the Norwegian Parkinson’s Association to create a network for people involved in this type of therapy.

From barriers in current care to the future guideline

As a first step in the guideline development, we have gained insight in barriers in current care, and wishes for improvement by patients and therapists. For this, we have used results of patient and therapist focus groups, of our web-based survey (see Newsletters 1 and 2), and of personal contact with Parkinson’s experts physiotherapists (of Parki sonNet). The survey has been carried out between February and October 2011, in 19 countries. Over 4,000 physiotherapists have provided us answers about their expertise, the care they provide for persons with Parkinson’s and barriers they perceive in providing optimal Parkinson’s care. This information collected is very important for both the development and implementation of the guideline. Barriers can be transformed into questions for which recommendations can be developed, or general information provided. For example, therapists report being unsure how cognitive impairments may influence their treatment options, and patients express the wish to play a more active role in their treatment. For this, information will be

provided in the future guideline. Also, when for example developing recommendations for the use of measurement tools, we will take in account the current frequency of use of specific tools, as well as problems perceived in using these tools. Thus we aim to increase the feasibility of the future guideline implementation.

Figure of guideline development process:



Formulating key questions

The thorough search for barriers in current care, including points for improvement of the current guideline, has provided us 39 unique barriers. Over the summer, the 10 Writing Group members have transformed these, together with the 43 recommendations of the current guideline, into key questions for the future guideline. For each key question, the importance for the quality of care and the need for a systematic literature search was scored by both the Writing and Reading Group members. Based on the results, we have now started with the systematic literature search for a selection of key questions. After critical appraisal, this will lead to conclusions to the questions (see Figure above). We then will collect the so-called *other considerations*, e.g. on the feasibility in daily care. For other key questions, we have started describing expert opinion.

Translating evidence into recommendations: GRADE

One of the essential steps in guideline development is grading the evidence found through systematic literature search. Many grading systems, with different recommendation languages are being used, e.g. ‘level II’, ‘level B’ and ‘strong evidence’. After consultation of the Steering Group, we have decided to use the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system. GRADE is more complex than other grading systems available. However, with this system, recommendations are not simply based on significant effects found in scientific research, but also on e.g. the magnitude of the effect, the importance of specific outcomes to patients and therapists, and the burden the specific treatment. Moreover, many important organisations endorse GRADE, e.g. the WHO, Cochrane Collaboration, NICE and BMJ. A detailed overview of benefits of GRADE compared to other grading systems can be found on www.gradeworkinggroup.org/FAQ/gradecomp.htm



Main activities until March 2012:

- December → Systematic literature search
- January → 1st Consultation public (patients & therapists)
- February → Critical appraisal evidence to draw conclusions
- February → Collect ‘other considerations’
- March → Writing Group meets to discuss (development) recommendations
- March → Submission of manuscript about European survey

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