



LTNC Newsletter 5 Research into Long Term Neurological Conditions

Winter 2009

EasyRead version



Welcome to the Winter edition of the **LTNC** newsletter.

LTNC stands for Long Term Neurological Conditions. Neurological is a word for conditions that affect the way that the brain, nerves and muscles work.



In the last newsletter we talked about different projects that are looking at different **LTNC** services to see how well they are doing.

We can now tell you how some of these are going.

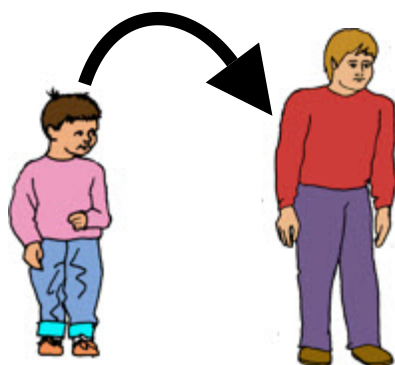
Growing up with Duchenne Muscular Dystrophy (DMD)



This project looked at the lives of young men with Duchenne Muscular Dystrophy (**DMD**) and their families.



DMD is a muscle condition that boys can be born with.



Our better health services are helping them to live longer and the project is looking at the support they need as they become adults.



In the last newsletter we spoke to David Abbot, one of the researchers who has written a paper about what was learnt from this project.



This is now on our website as a full report or shorter version:

www.ltnc.org.uk

Other studies are nearly finished and should be on our website soon.

These have been studies to find out more about:



What people with brain, nerve or muscle conditions, their families and carers think about the services they get and whether they are what they really need.



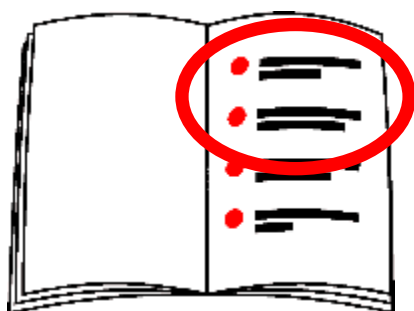
Keeping fit, by having the right support to use Leisure centres to get exercise.



The Quality Neurology project. In this project some charities that support people with LTNC got together to find a way to measure how well services were doing.



Joined-up services – finding out if the Government's National Service Framework is helping to make things better.



There is information about the first two of these in this newsletter.



Information about all the projects will be on our website later in the year. All the projects will finish in 2011.



We can email you to tell let you know when there is new information on our website.

Please contact sophie@ltnc.org.uk if you would like to be on the list to get an email with the latest information.



There is also a website where you can go to for more information or to get this newsletter in other formats:



www.ltnc.org.uk

Please let us know what you think.



Maggie Winchcombe
Advisor, RI LTNC

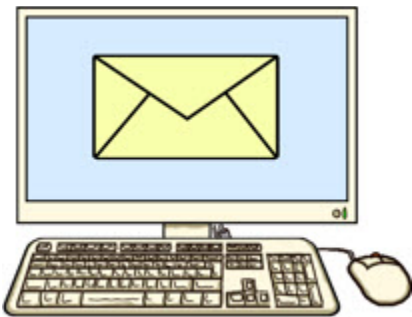


Email: Maggie@ltnc.org.uk

Information about the next two projects to finish



Asking people with brain, nerve or muscle conditions, their families and carers what the services they receive are like and if they are what they need.



The researcher is Ray Fitzpatrick

Email:

Raymond.Fitzpatrick@nuffield.ox.ac.uk



This is a study to find out how well services are working for people with:

- Parkinson's disease (**PD**)
- Multiple Sclerosis (**MS**)
- Motor Neurone Disease (**MND**)



This will help us to see if the National Service Framework is helping to make services better.



2,563 people with **LTNC** and 1,910 carers have filled in question sheets.



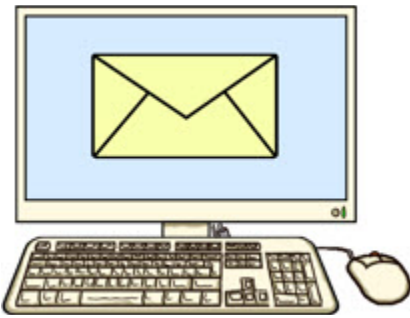
This has given us lots of new information about what people's lives are like and whether services are working in the ways the National Service Framework says they should.



The full report will be on the website as soon as the researchers have finished writing up what they found out.



Keeping fit, by having the right support to use Leisure centres to get exercise



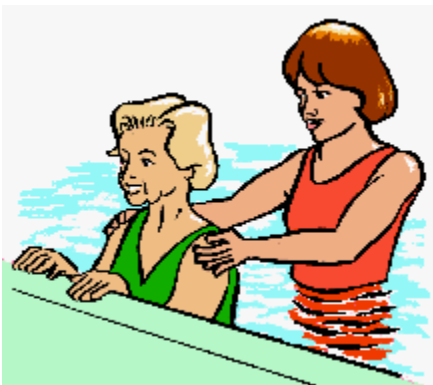
The researcher is Helen Dawes

email: **h.dawes@brookes.ac.uk**



It might be easier and cheaper for people with **LTNC** to do exercises to keep fit if they used leisure centres instead of having to go to see a physiotherapist in hospital.

A Physiotherapist is someone who is trained to help people with LTNC and knows how to use exercise to get better.



The study is finding out whether this works and what support people need to do it.



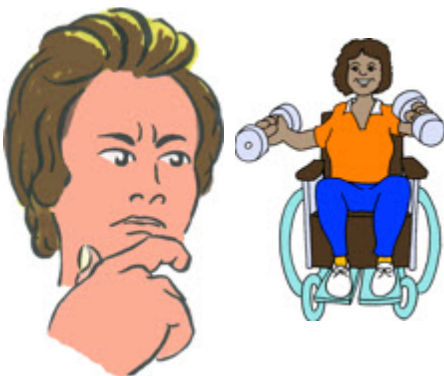
People who help people with LTNC to get fit in leisure centres and in the NHS have been involved in the study.



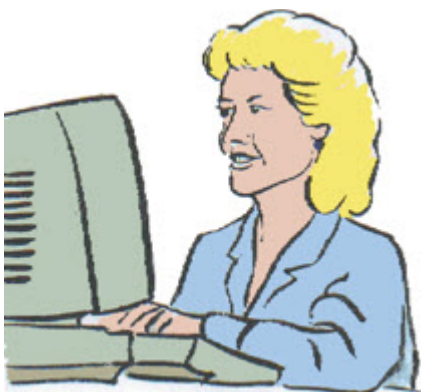
Because of the study we have more information on how much people with different types of **LTNC** keep active.



Researchers also now know more about supporting people with **LTNC** to keep fit and have written a handbook.



It looks like this may have only made a small difference to people's fitness but we need to find out more about how else it helps people with **LTNC**.



The full report will be on the website as soon as the researchers have finished writing up what they found out.

Other projects



1. Joined up services – finding out if the National Service Framework is making things better.



2. The Quality Neurology project.



3. Support for carers - paying more attention to people who care for more than one person.



4. Understanding the care needs of people who have had Parkinson's Disease, Multiple System Atrophy or Progressive Supranuclear Palsy for a long time.



5. Finding out more about unusual long-term brain, nerve and muscle conditions.



6. What carers think about respite care.



7. Why it is important to get as many people as possible involved in decisions about services.



8. Finding out how training and support for getting a job can help people with **LTNC** stay in work or get a new job.



There is information about all these projects on our website:

www.ltnc.org.uk

News about another new research study



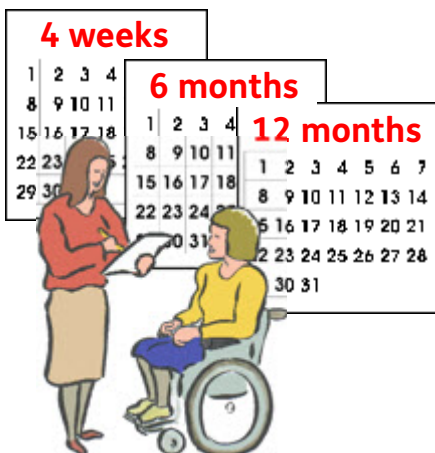
Finding the best way to help people with LTNC get used to life after they first leave hospital, and learn new skills in the community.



The study is finding out about what people with LTNC think are the best ways of adapting and learning new skills in daily living.



Researchers will use question sheets with people with **LTNC** who have been in 9 special hospital units in London.



They will ask them questions after 4 weeks, 6 months and 12 months after they leave.



We want to find out what stops people getting support to help them live with **LTNC** and why different people get different levels of support.



This will tell us about the support people with **LTNC** need to get back into their lives and their communities and show us if there is anything that could be done better.

What some of the letters mean:

DMD This is short for Duchenne Muscular Dystrophy. It is a muscle disease that some boys are born with.

LTNC This is short for Long Term Neurological Conditions. This is another way of saying health conditions that affect the way the brain, nerves and muscles work.

MS This is short for Multiple Sclerosis

MND This is short for Motor Neurone Disease

NSF This is short for National Service Framework. It is a government plan that says how services should be run for people with long term brain, nerve and muscle conditions.

PD Parkinson's Disease

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