



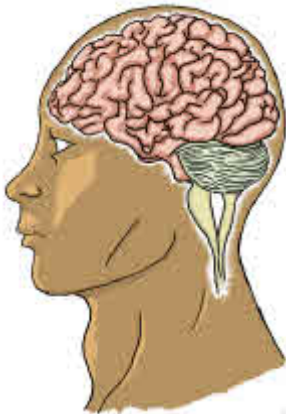
LTNC Newsletter 3

Research into Long Term Neurological Conditions

Autumn 2008

EasyRead Version

What LTNC is about



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



The Department of Health set up this project to find out how people with these conditions get the help they need from health and social services.



What we find out may be used to write policies and plans.



The research started in 2006 and will finish in 2010. When it is finished, we will tell the government what we have found out and give them advice.



We want to tell as many people as possible about our research. Our website is

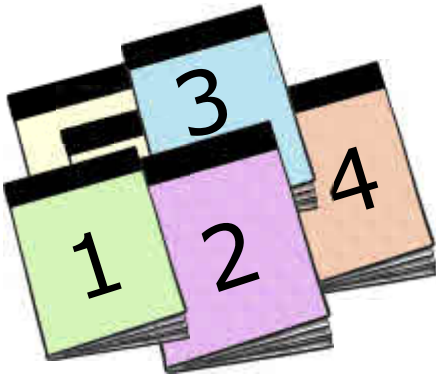
www.ltnc.org.uk



A few words by Maggie Winchcombe, Science Adviser



We are now half way through our research into long term brain, nerve and muscle conditions.



We are working on 7 different projects and I am happy to tell you that we have 4 new projects starting soon. This newsletter will tell you the latest news about the 7 projects and more about the 4 extra ones.



We can let have you this newsletter in different forms, like tape or cd. Just ask.



I hope you find our newsletter interesting. Please tell me what you think!



Email me at maggie@ltnc.org.uk

4 new projects starting in September



Project 1: Finding out more about unusual long term brain, nerve and muscle conditions



UNIVERSITY OF
BIRMINGHAM

Professor Cath Sackley at the University of Birmingham will lead this project.

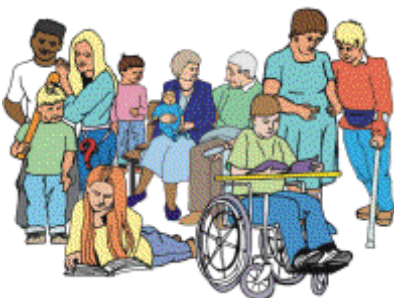


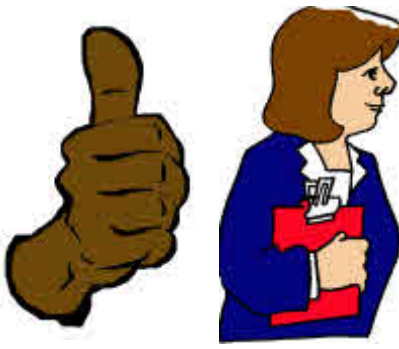
She tells us that her research will support those with more unusual long term brain, nerve and muscle conditions. They need special support which most services do not provide.



To do that, we need to find out more about:

- how these rare conditions can happen
- how often they happen
- how many people are affected
- and what exactly goes on when they happen.





What we find out will help make services better for people with long term brain, nerve and muscle conditions. It will make it easier to check how well they do what the National Service Framework says they should do.



Project 2: What do carers think about respite care?

Dr Diana Jackson at Kings College London will lead this project. She tells us that:



Carers need support too. Respite care is when a carer takes a break from caring for someone and someone else takes over for a while. It is sometimes called replacement care.



We want to make support for carers better. We will do this by finding ways to help service providers make better services.



We will also be looking more closely at carers from different races and cultures.



We will look at the cost of different kinds of care.



We will ask carers what kind of respite care they want.



We will look at what the best care is for different people and how much it costs. There is no information about this right now.

Project 3: Why it is important to get as many people involved as possible in services



This project will look at how people feel about being included in helping to plan services and how this has made their lives better.

Dr Tina Cook of Northumbria University tells us that:

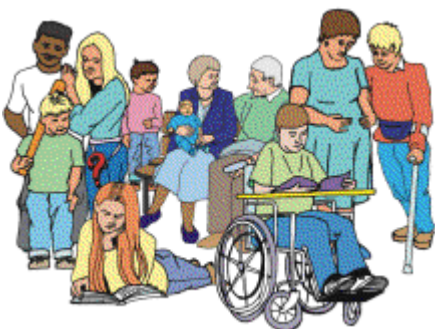


“This project will be led by people who use and work in services. We will use special ways of researching to find out what people think and feel.



What we find out will help us to:

- make services easier to use



- get services to more people



- and let people know that leaving people out or keeping them separate, stops them from doing things.”



Project 4: Services that help people to get work, or go back to work - making a tool to help us measure how these services are doing



When we wrote this newsletter, we didn't know a lot about this project. But we will in the next newsletter. If you would like to know before then, please go to

www.ltnc.org.uk/news

A special report about the Quality Neurology project



The MS Society, Parkinson's Disease Society (PDS), Motor Neurone Disease (MND) Association and Ataxia UK are working together on this project.



They are making a tool to check how well the National Service Framework is being used to improve services for people with long term brain, nerve and muscle conditions. The tool is a form which can be filled in like a checklist.

This tool will help service providers check their work in the same way.



Alun Davies of the MS Society tells us the latest news:

“We have started testing the tool. 8 service providers will be using it to see how well they are doing. We hope 2 more will join us.



The tool works by asking people who use services special questions about the service. We then check their answers against what the government says they should be.



We have set up different groups of people who use services.



People in these groups can talk freely about what they think. No-one will be able to tell who has said what, but their ideas can be used to help make improvements.



We have also set up a group of service providers who know a lot about services. They will test all our work and make it official.



There have been some small problems with the tool.



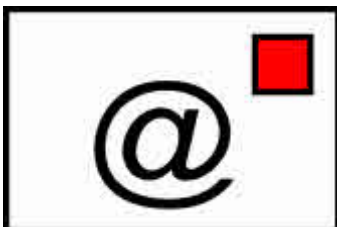
Some people used the tool wrongly. We think it's because of the way we have told people how to use it. We will fix that problem as we go along.



Every service provider is using the tool differently. We think this is ok but we will keep an eye on it to make sure it doesn't go wrong.

September 2009						
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We think we will finish in September next year.”



You can email Alun at:

adavies@mssociety.org.uk

Project Updates

The latest news about the projects we are working on now



1. **Asking people with brain, nerve or muscle conditions, their families and carers what services are like**



This research looks at people with these conditions:

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



Professor Ray Fitzpatrick from Oxford University gives us the latest news:



“We have now finished interviews with more than 400 people. Their answers are being looked at and a report will be sent to the people who helped us with the interviews.



People will also be able to read the report on our website.



We will talk about the report with the people who took part and the group set up to advise us. This group is called the Research Advisory Group.



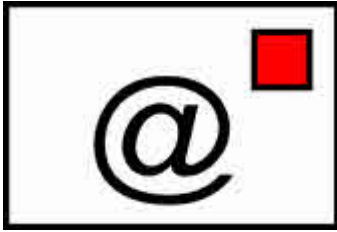
The next step is to send out a questionnaire to lots more people. It will tell us how things work in different parts of the country for people who have 1 of these conditions.



We have been talking to people who use services about what is the best way to get people involved.



We are talking about whether email or post is better.”



You can email Professor Ray Fitzpatrick at:
raymond.fitzpatrick@nuffield.ox.ac.uk



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



This project looks at what helps or gets in the way of making services more joined-up for people with conditions that affect their brain, nerves or muscles.



A service is joined-up when different organisations work together so that it is better for the people who use it.

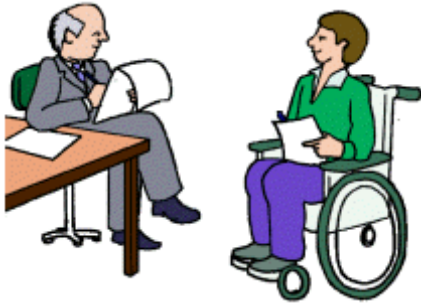


Dr Sylvia Bernard tells us the latest the news:

“We have now started looking at all the reports and papers that have been written about joined up services.



We are also halfway through talking to people with long term conditions, organisations that speak up for them, carers and health and social care workers.



Our talks with them will tell us what is good about their services. This will help us make the questionnaire for the next stage.

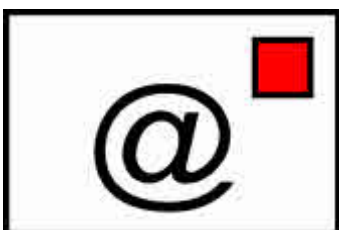


We are still working well with the Quality Neurology team. Quality Neurology is the new way of checking how well the National Service Framework is being used.



This summer, our Project Advisory Group advised us on how to go on to the next stage.

We will write about what we have learned so far in the autumn.”



You can email Sylvia at: smb509@york.ac.uk



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

This research wants to find out more about the support needed by people who care for a person with a long term brain condition.



We want to learn what kinds of support helped or what would have helped if it had been offered.

Dr Diana Jackson tells us the latest news:



“We are in the middle of interviewing a lot of different carers.

They have told us that they need help getting the right support.



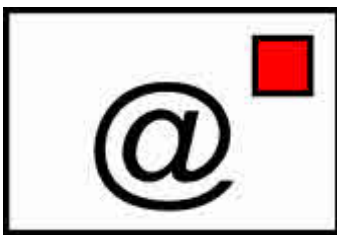
We now have a much better idea of what they need help with and they have given us ideas about how to make things better for them.



We are putting these together into a guide to help make services better in the future.



The new project about respite care that we talked about earlier in the newsletter, will help make our research better.”



You can email Diana at:

diana.m.jackson@kcl.ac.uk

4. Keeping fit



Fitness and physiotherapy treatment for people with long term brain, nerve and muscle conditions usually happens in hospitals and is led by doctors and nurses.



People need support to go to sports centres like everyone else to keep fit



This work will find out what kind of support they want.



It will also find out if keeping fit at local sports centres is a good way of helping people with long term brain, nerve and muscle conditions get and stay more active.



We are looking at whether the 'Physical Activity Support System' or PASS is working well with this.



Dr Helen Dawes tells us the latest news:

“The 2nd part of the project has now started. We are now looking closer at what have found out from the 1st part.



We worked with people with these conditions:

- Muscular Dystrophy (MD)
- Parkinson’s Disease (PD)
- Motor Neurone Disease (MND)
- and Multiple Sclerosis (MS).



Some of these people live in care homes.



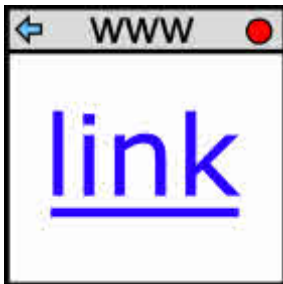
We haven’t been able to get many people with Cerebral Palsy involved. But we will keep trying.



People have told us that they are not getting more involved because it is hard to travel to the centres.



Another reason is that there are not enough Inclusive Fitness Initiative centres in Oxford and Birmingham. These are leisure centres that have been made to include as many people with disabilities as possible.

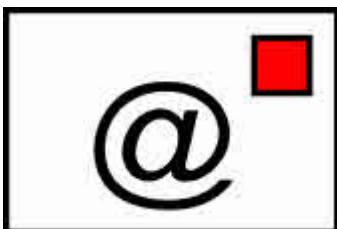


If you would like to know more about these centres, go to

<http://tinyurl.com/peopleactive>



We are now writing up what we have found out so far.”



You can email Helen at:

hdawes@brookes.ac.uk



5. Becoming an adult - how it is for young men with Duchenne Muscular Dystrophy and their families.



This project looks at how the lives of young men with this condition and their carers can be made better. We hope that what we find out will also help make support better for other young people with long term brain, nerve and muscle conditions.

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David Abbot tells us the latest news:

“We hope to finish the work in December.



We talked to young men who finished college and went home.



We found out that:

- Many of them just stayed at home not doing a lot. Some of them were unhappy about this.
- Many of them said they felt bored and lonely.



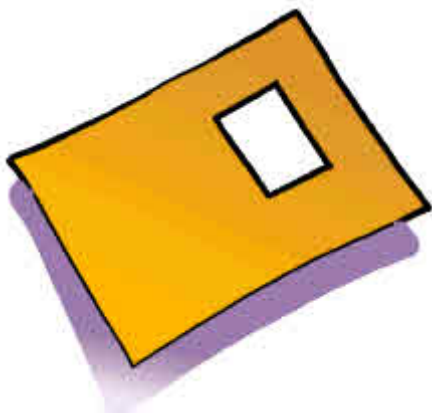
- None of them had jobs but some had tried to get a job.



- Some of them said they were too ill to get a job.

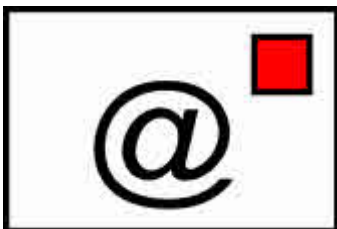


- Some said firms don't want to hire them.



When we have finished our work, we will write it up in a big report.

We will tell everyone who took part about what we found out. We will also write a shorter report that will be helpful to young people with long term brain, nerve and muscle conditions.”



You can email David at:

D.Abbott@bristol.ac.uk



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



This research looks at the support people need when they are near the end of their lives. There is no information about this at the moment.



We need to understand the experiences of people affected. This is so that we can find out how to give people the support they want and need at the end of their lives.



This work will help develop health and social care services in the future and information for voluntary groups, families and friends.



Tariq Saleem tells us the latest news:

“We are glad that people with these conditions have been keen to take part.



More than 40 people and their carers have finished our 1st interviews. We hope to get 60 more people involved by December. We hope to follow each of them for a year.



We have also finished:

- interviewing 15 people and their carers for the 2nd time
- interviewing 10 other people and their carers for the 3rd time.

January 2009						
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We will finish interviewing people in January next year.



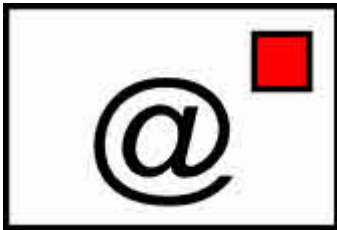
We have now started to put together what we have found out on a computer. In November, we will look at all the information together carefully.



We will talk about what we have found out with the advisory group. This is a group of people who know all about these conditions.



What they tell us and what we have found out ourselves will help us make a new questionnaire for the next part of the project.”



You can email Tariq Saleem at:

Tariq.Saleem@kcl.ac.uk

News about work that has been written about:



1. Report from the Foundation of Assistive Technology (FAST)

The latest news about the research into disability equipment is now ready for you to see. You can get it from:

<http://fastuk.org/home.php>



2. The lives of people with disabilities and what they want



This report is about a project that looked at all the issues that people with disabilities have and the government policies about them.



The policies they looked at included:

- jobs



- schools and colleges



- transport



- health



- discrimination.



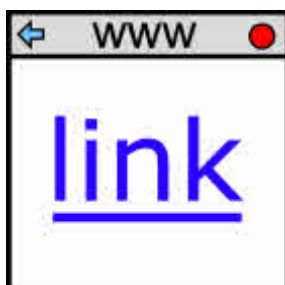
The Office for Disability Issues asked for this report and it was made by different organisations working together.



The report was a big change from other reports because the writers worked with people with disabilities all the way through the project.



Almost 2,000 people with disabilities were involved.



You can read all about it at

<http://tinyurl.com/odiresearch>

What the some of the letters mean

- AT** This is short for Assistive Technology. This is a name for things that help people to stay independent.
- IFI** This is short for Inclusive Fitness Initiative. It is a programme in England to make sports centres easier for disabled people to use.
- LTNC** This is short for Long Term Neurological Conditions. This is another way of saying “conditions that affect the way that the brain, nerves and muscles work”.
- 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, nerves and muscle conditions.
- PCT** This is short for Primary Care Trust. It is a local organisation that plans and runs the health services.
- QR** This is short for Quality Requirements. They are used in the National Service Framework to explain how services should be organised.



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