



Christmas wishes from the TONiC Team



It's Christmas and we just wanted to say a big "thank you" to all our participants and carers who completed the TONiC MS questionnaire study! We appreciate that the questionnaire was long but this has helped us identify factors which affect quality of life in people with MS. We wish you all a very happy Christmas and a Happy New Year!



Update from Professor Carolyn Young

On behalf of all the TONiC investigators from around the UK, I would like to thank you for the time and effort you have put into completing and returning questionnaires. You have provided a wealth of detailed information which we are analysing to help us understand more about your life with MS. You have done your part, so enjoy the holiday season and we will let you know more about the follow up questionnaires in the next newsletter. More from us in 2017!

TONiC recruitment so far :

MS patients recruited to phase 2 and 3 = 11,638

MS carers recruited to phase 3 = 2010

MS patients recruited to phase 4 = 683

MS carers recruited to phase 4 = 310

Would you like to contribute further to TONiC ?

If you have already completed a phase 3 questionnaire pack, you are eligible for phase 4 of TONiC. Phase 4 aims to chart the progress of your condition over a longer period of time. We are asking patients if they can complete at least a further two questionnaires as part of this phase. Your opinions on how your condition changes will have a significant impact on how patients with MS will be treated in the future. If you have taken part in phase 3 at your local hospital you can contact them to take part in phase 4 (please refer to the TONiC website to find your local hospital). If you have contacted the TONiC team directly and self-referred, then please contact us again.

[Where can I get more information about TONiC ?](http://tonicstudy.org)
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TONiC findings presented at ECTRIMS 2016



32ND CONGRESS OF THE EUROPEAN COMMITTEE FOR
TREATMENT AND RESEARCH IN MULTIPLE SCLEROSIS
21ST ANNUAL CONFERENCE OF REHABILITATION IN MS
14–17 SEPTEMBER 2016, LONDON, UNITED KINGDOM

Thanks to all our MS participants and their carers who very kindly took the time to complete the TONiC questionnaires. We presented our initial findings at the ECTRIMS conference (European Committee for Treatment and Research in MS). We presented **six** posters on MS and aspects of quality of life.

Please see below a brief summary of two of these posters. For further details of all of the posters presented please check out our website <http://tonicstudy.org>

Neuropathic pain in Multiple Sclerosis

Young CA, Mills RJ, Tennant A, on behalf of the Trajectories of Outcomes in Neurological Conditions Study Group.

Neuropathic pain is a type of pain caused by a problem with one or more nerves. The function of the nerve is affected in a way that it sends pain messages to the brain. Neuropathic pain is experienced by over 28% of MS patients. We examined the relationship of neuropathic pain with EDSS* score, gender, subtype, age and duration of pain. Our findings found that those with pain over 17 years or longer experienced a greater level of pain. Results also showed that at least two thirds of our patients experience Neuropathic pain. We also concluded that patients who had secondary progressive MS had higher levels of pain over other subtypes of MS this may be due to these patients having had the condition for a longer period of time.

* The Expanded Disability Status Scale (EDSS) is a method of quantifying disability in multiple sclerosis and monitoring changes in the level of disability over time. It is widely used in clinical trials and in the assessment of people with MS. The EDSS scale ranges from 0 to 10 in 0.5 unit increments that represent higher levels of disability.

Psychological Distress in Multiple Sclerosis and its Correlation with coping strategies

James E, Mills RJ, Tennant A, Young CA on behalf of the Trajectories of Outcomes in Neurological Conditions Study Group.

Psychological distress such as anxiety and depression are common in people with MS both have previously shown to have an impact on quality of life. Coping strategies may help in adjusting to the stressors of living with a long term illness. We identified a significant relationship between psychological distress and coping strategies in people with MS. People with MS aged 50 and over were found to be more anxious. Patients with EDSS* score higher than 4.0 were more likely to have both anxiety and depression. There was no difference between male or female patients experiencing anxiety or depression. We found that low levels of psychological distress are associated with problem focused approaches to coping. This method of coping includes looking at ways how to tackle the problem such as obtaining more social support or learning new skills to better manage a situation. In our previous research our findings showed that using a problem focused approach to coping is associated with a better outcome to psychological distress.



MS centers participating in TONiC nationwide

TONiC sites for MS

