

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 MND questionnaire study! We appreciate that the questionnaire was long but this has helped us understand how to better maintain quality of life for people with MND. 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 MND. 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 update.

More from us in 2017!



TONiC recruitment so far :

MND patients recruited to phase 2 and 3 = 1870

MND carers recruited to phase 3 = 652

MND patients recruited to phase 4 = 153

MND carers recruited to phase 4 = 108

Would you help further with this important research?

If you have already completed a phase 3 questionnaire pack, you are welcome to join **phase 4 of TONiC**. Phase 4 aims to chart your progress over a longer period of time. We are asking as many volunteers as possible, if they can complete at least two more questionnaires at home, separated several months apart. Your feedback on how your condition changes will really help us understand this illness, such as what may lead to a better outlook.

If you have taken part in phase 3 at your local hospital, you can contact them to take part in phase 4. If you have contacted the TONiC team directly and self-referred, then please contact us again. If you are willing to help with phase 4 and are not sure how to proceed, just get in touch with us!

TONiC findings presented at the International MNDA Symposium 2016



Dublin 2016

Thanks to all our MND participants and their carers who very kindly took the time to complete the TONiC questionnaire. We presented some of our findings at the International Symposium on ALS/MND on 7th-9th December. We presented nine posters on MND and TONiC.

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://tonic.study.org>

Stigma in people with Motor Neurone Disease/ALS *Young CA, Mc-Sloy Poli C, Tennant A on behalf of the Trajectories of Outcome in Neurological Conditions Study Group*

Stigma refers to people feeling they have a problem which causes them to be treated differently from other people. Our early work with people with MND showed that this is an understudied problem in MND. This analysis showed that stigma was particularly likely with certain MND symptoms, like drooling, choking episodes, or having bad neck weakness. Demonstrating that these symptoms are so embarrassing to people that they feel stigmatised is important evidence that more needs to be done to treat these problems, such as improving collar design or finding new safe treatments for excess saliva.

Future work will examine whether treating these problems improves quality of life, but for that we must await phase 4 follow up results (see opposite).

Depression and anxiety in People with Motor Neurone Disease/ALS

James E, Mills RJ, Young CA on behalf of the Trajectories of Outcome in Neurological Conditions Study Group

Depression and anxiety are important problems to study in MND. They distress patients and families and they have been shown to influence quality of life and survival. Results contributed by the TONiC volunteers provide the largest dataset on depression and anxiety to be studied so far. Depression was associated with breathing problems, and fatigue. Anxiety was more common in females, and the people who began their MND with speech or swallowing change. Anxiety was associated with fatigue.

Future work will examine how different treatments affect depression and anxiety, but for that we must await phase 4 follow up results (see opposite).

[Where can I get more information about TONiC ?](http://tonicstudy.org)

<http://tonicstudy.org>

tonic@thewaltoncentre.nhs.uk

Phone: 0151 529 5668/2980



MND centers participating in TONiC nationwide

TONiC sites for MND



If you did not get around to completing and returning your phase 3 pack, its not too late!
Please let your MND team know you still want to take part, or contact the TONiC team. It would help
if you know your TONiC or NHS number.