

Cambs Tinnitus Support Group

No. 161

NEWSLETTER

April 2022

MEETING

Saturday 23 April

at

10.00 for 10.30 am

"Evidence-based research behind a tinnitus app"

Speaker: Dr James Jackson
Reader in Psychology
Department. of Psychology and Therapeutic Studies
Leeds Trinity University

James is a Chartered Psychologist and holds a BSc (Hons) degree in Psychology from the University of Sheffield as well as MSc and PhD degrees in Psychology from the University of Hull. His doctorate considered the effects of tinnitus on concentration and task performance. Research interests include how tinnitus affects individuals, how personality affects tinnitus distress, and whether objective measurement of tinnitus is possible. He is also interested in the concept of 'resilience' and how personality and environment moderate pain tolerance.

Meadows Community Centre

1 St Catherine's Road, Cambridge, CB4 3XJ, off
the junction between King's Hedges and Arbury Rds
(Link to directions to temporary C/P will be provided)

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EDITOR'S CHAT

Our February meeting was a great success, with some 23 attendees, including several newcomers who signed up as members after the meeting. It really felt like old times, at least pre-Covid, with the chairs in rows, a projector, a speaker and our members making the new attendees feel at home. Rachel unfortunately was not able to attend due to illness, but I'm pleased to say she is back up and running now. However, her colleague Mark Smith stepped into the breach and gave us a thoroughly interesting talk on somatosensory tinnitus. This was certainly an area that I knew little about, except TMJ = Jaw, from reading about it in one of BTA's excellent information leaflets. We are hoping to back this up with a visit from a osteopathist practicing cranial osteopathy in September-watch this space!

The restriction on numbers at the Meadows has now been relaxed so 'booking' your places isn't no longer strictly necessary, although if you want to flag up you are attending in April, then that's fine. We had a great turn-out for Dr James Jackson last visit, so it would be excellent if we could equal or even better that attendance in April meeting, particularly as we had to rearrange the date because of the Easter weekend.

Knowing that some of our members belong to the BTA, I try not to use too much material from them, although their excellent website does make it difficult sometimes! However the piece describing their winning the best research poster award at the recent BAA conference really deserved a wider audience, together with the Swedish research work that might eventually lead to a way to objectively measuring tinnitus.

I'm always trying to encourage our members to put pen to paper for the newsletter, so it was nice to receive a piece from Martin (see page 6). It would nice if some members could respond; it certainly got me thinking!

Unfortunately it's that time of the year again, and after having a year off, I must remind the majority of our members that April is subscription month! I hope the Newsletter and Zoom meetings have kept you informed, interested and also amused enough for you to continue to support us now that 'normal' service has finally been resumed. As is custom, all new members who have joined since November 2021 will not need to pay until April 2023.

Each year at the AGM Janette, our treasurer, briefs us about the accounts for the previous year. Unfortunately because of the pandemic, the last time this happened was in 2018-19. Accordingly she has had to produce the sum of 3 years accounts, and the task has been made more involved because this year John Dring, our president Avril's husband, has sadly had to decline to verify our accounts, a exercise he has carried out for the CTSG over many years, and for which we are very grateful. We are not a charity, and our accounts do not need to be professionally audited, however they do need checking and verifying by a competent third party. Fortunately we have found someone who has stepped into the breach at short notice this time, but we really need someone to perform this task next year, ideally from within our membership (or a relative). If you think you are such a person, or know someone who might be, then please let me know. Happy Easter

Somatosensory Tinnitus

Report on February meeting by Alan Yeo

Our speaker, Mark Smith, has worked at Addenbrookes for 15 years; his roles include working with people who may have tinnitus, hyperacusis and single sided deafness, conducting research and supervising the training of junior staff.

There are two main types of tinnitus: one is objective, where someone else can also hear it, usually with the help of an aid like a stethoscope. It's actually very common up to the age of about 18, and occasionally it is loud enough to be measured. The reasons for this particular type can be problems with the middle ear, jaw and palate, or hormonal changes or neurological problems.

OBJECTIVE	SUBJECTIVE
Can be heard by others, recorded or observed	Heard only by the patient (with possible exception of low freq. noise complaint)
Usually clicking sounds or pure tones	Usually otic in nature
Most often related to middle ear, or jaw problems, occasionally palate	Various subtypes depending on underlying pathology
Various causes: medication, trauma, hormone changes, neurological...	Various causes: hearing loss, medication, infection, vascular, immune, trauma, mental health...

The second, and much more common type, is subjective; meaning you can hear it yourself but nobody else can, and normally arises from irritation or damage to the ear itself. Causes include hearing loss, infection, damage to the blood supply to the ear, certain medications and immune system problems. It can be divided into three subtypes:

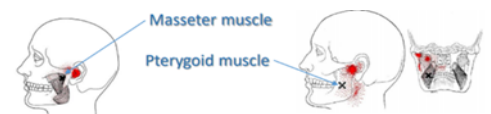
Otological - damage or irritation to the ear or hearing system.
Somatosensory tinnitus (SST) - sensory neurons and pathways that respond to changes (i.e. pain, touch, temperature) at the surface or inside the body (in the head, jaw or neck), and this is our topic today.

Somatosensory simply means of/from the body; and is not tinnitus arising from problems with the ear.

'Mixed' category (Oto+SST): is the most common, arising from damage/irritation to the ear plus some damage/irritation to another structure, usually in the head or neck. This involves the sensory system, including the skin, pressure, touch and temperature etc.

SST has three main triggers: 1. Muscular problems in the head and neck, 2. Cervical [neck/top of spine],

3. Problems with the jaw [the temporo mandibular joint or TMJ].



Muscular

The **Masseter** muscle at the side of the jaw is used for chewing, and for its size, is the most powerful muscle in the body. Inside the jaw are two more muscles called the **Pterygoid** and any irritation/inflammation/damage to these can lead to 'referred' pain in the ear. Damage to



the second group of muscles called the **Sub-occipital** around the base of the skull can lead

to referred pain from the back of the ear to across the jawbone. The **Sternocleidomastoid** is the last big muscle group that runs from the base of the skull to the collar bone, and damage can cause stiffness along the

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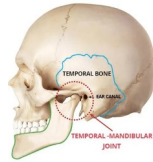
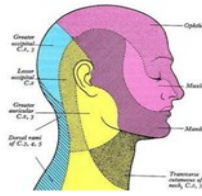
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cheek (NB. The red markings + splodges on the slides represent the areas of potential pain).

Cervical
Nerves emerging from C2, C3 vertebrae can get pinched or irritated and can cause pain in the areas shaded yellow and blue.

Jaw or TMJ
Any damage in this can cause similar problems to the neck; damage or wear to the bones can cause pressure in that area.



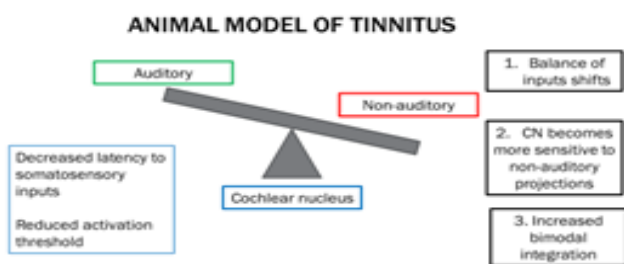
Research

A USA review found most people with tinnitus had no single (clearly definable) trigger i.e. a number of factors were acting synergistically, and most had some degree of hearing loss (~70%). Also, 30% of people with tinnitus who didn't have hearing problem, are much more likely to have SST (i.e. neck and head problems).

Researchers know a patient has SST because they can modulate their tinnitus by moving the head, clenching the jaw or teeth and pressing their face etc. M. Ralli et al. concluded that 68% of tinnitus patients exhibit some somatosensory modulation, however only 2 out of our audience of 23 agreed!

Researchers exploring possible treatments need to know the mechanisms which drive the condition.

Tinnitus is induced in animals (usually guinea pigs) either by exposure to loud noise or an injection of an ototoxic drug into the ear. The resultant interruption or destruction of nerve cells connecting to the brain leads to a reorganisation of the hearing system which then links to the tinnitus. The Cochlear nucleus is where all ascending information from the cochlea forms connections with the auditory brain. And this information can have an auditory or non-auditory (NA) source from such as the jaw, head and spine.



If NA information comes into the hearing part of the brain, this can upset the balance and can alter the connections to the auditory brain.

Clinical features of SST

These include fluctuations overnight: relaxed/restful – better, uncomfortable/undue pressure – worse. Other factors include hormones, noise and stress levels. Clenching of the jaw inevitably makes it worse, although treatment of TMJ (such as stretching or mouth guards) can help up to 40% of patients.

After removal of a vestibular schwannoma (a benign tumour that develops on the balance or hearing

nerves) 75% of patients develop the ability to modulate their tinnitus. Recorded examples include moving the eyes, or the hands when washing, or just when touching the fingertips.

Robert Levine, a long-time researcher in the USA, investigated why a lot of people who, when they have their ears syringed to remove wax, end up with tinnitus. He suggested that the application of water stimulates certain nerve endings, and thinks that of all non-auditory sensory systems, only the somatosensory system seems to be related to tinnitus.

What to do about it – the 3 Rs

Recognize – is it truly related to a damaged structure?

Record – What is the effect of the damage?

Respond – Explain to the patient so they understand, and make appropriate referrals.

Mark says his questions would encourage the patient to tell him of any known head, neck or jaw problems, (including oral pain or trauma), current or past, and any history of treatment.

On a typical morning is your tinnitus noticeably better, or worse; and if yes, for how long, and describe in detail any changes (pitch or loudness) in your tinnitus related to certain head, jaw or eye movements.

An increased likelihood of SST is likely if:

- Trauma/irritation to head/neck/jaw preceded the onset of tinnitus, or both seemed to start at the same time.
- Both tinnitus and muscle or joint pain/stiffness get worse together.
- The tinnitus increases with poor postures, like computer work, or reading.

Screening Results

Mark emphasised that clinicians have to be careful of contraindications such as known (or suspected) head, neck, jaw or joint problems possibly related to Ehler-Danlos syndromes; osteo or rheumatoid arthritis; recent (last 6 months), head, neck or jaw surgery; Spondylitis or vascular issues. Also recent dental work.

A physiotherapist in Chester has produced a basic screening video talking about SST, and demonstrates some of the related triggering movements. The video is available via this link (<https://tinyurl.com/2b6z5kbb>).

Improving the symptoms

A few easy ways of improving your symptoms could be a good pillow, massage or physio and good posture at all times. Clinicians may suggest a referral from your GP to a physiotherapist or a self-referral to a dentist. Further treatments may involve ENT/Neurosurgery, Dental (mouth guards etc.) and specific physiotherapy.

Bimodal stimulation

Various devices in development using combined auditory and somatosensory stimulation. The device apparently nearest to commercialization is the Michigan Tinnitus Device [see pp5/6 February N/L-Ed), however it was quoted that an undesirable side effect of these somatosensory inputs, which are excitatory, is the development of tinnitus!

The session concluded with a lively Q & A session, and enthusiastic applause for our speaker.



Mark at work!

Constant tinnitus and altered brain activity

(from BTA website)

A new paper published in The Journal of Clinical Investigation shows that people with constant tinnitus have different auditory brainstem response test results compared to people with either no tinnitus, or only occasional tinnitus.

Why?

Currently, the presence of tinnitus is confirmed by a report from the person experiencing it, and its impact and improvement is measured by questionnaires, and these have limitations. If tinnitus can be detected by changes in brain activity, this could lead to the development of a reliable objective measure of tinnitus. Such a measure would allow future treatments to be accurately assessed, leading to more effective management of tinnitus. This ultimately would also be able to confirm that someone's tinnitus is 'cured'.

Who?

Researchers from Karolinska Institute in Sweden were able to access data collected by two large biobanks, the Swedish Longitudinal Occupational Survey of Health (SLOSH) and the Swedish Tinnitus Outreach Project (STOP) [See graphics at bottom of article]. Data from almost 21,000 people was used in the study.

How?

Survey data from SLOSH had been collected every two years which enabled the researchers to see changes in people's tinnitus over time. Similar data had been collected from the STOP participants, but these people have also had auditory brainstem responses (ABR) measurements taken. ABR measures brain activity in response to a specific sequence of sound stimuli.

Results

The researchers found that people with constant tinnitus showed clear differences in their ABR measures compared to people with no tinnitus, or only occasional tinnitus. There were no differences between results of people with no tinnitus and occasional tinnitus.

The researchers have suggested that constant tinnitus can be classed as a distinct subtype (grouping

within those experiencing tinnitus). The SLOSH data revealed that people with occasional tinnitus are at increased risk of developing constant tinnitus, especially if it recurs often. The study also found that for those who already experience constant tinnitus, the chances are that the problem will persist.

What does this mean for people with tinnitus?

ABR measurements may be able to be used to diagnose tinnitus, and to determine its subtype. This could lead to more tailored treatments.

If the ABR measurement is characteristic of occasional tinnitus, this may provide reassurance and again, more tailored treatments.

People with occasional tinnitus should be aware of the risks that the condition could become more constant and use appropriate precautions.

What happens next?

As always with new research, more research will need to be undertaken to see if these results can be replicated. More research is also needed to find out if ABR measurements can assess the effectiveness of tinnitus treatments.

The BTA said: "We're excited by a paper from Karolinska Institute. It shows results that could be real progress in developing a reliable objective measure of tinnitus. This could allow treatments to be assessed, leading to better management of tinnitus."

"We have awarded one of our Large Research Grants to a team from Macquarie University who are also examining recordings of brain waves using artificial intelligence to see if this may provide an objective measure. We are eagerly awaiting the first results of this study."

I. Epidemiology

Swedish Longitudinal Occupational Survey of Health ($n = 20,349$)



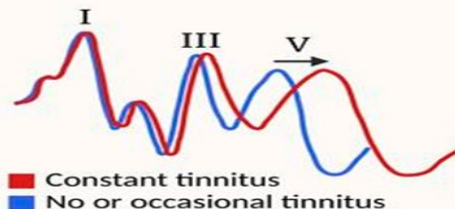
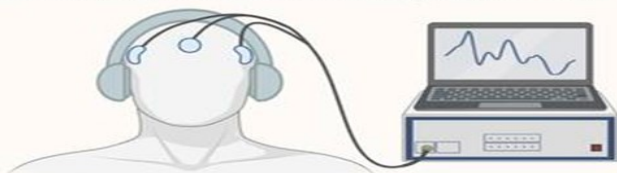
Longitudinal records of tinnitus status: none, sometimes, often, always



- 1) More frequent occasional tinnitus increase the odds of transitioning to constant tinnitus.
- 2) Constant tinnitus increase the odds that tinnitus will persist.

II. Electrophysiology

Swedish Tinnitus Outreach Project ($n = 405$)



- 3) Abnormalities in auditory brainstem response (ABR) wave V latency distinguish constant tinnitus from occasional tinnitus and controls.

IMAGINARY WORDS

Talcoholic ~ Someone who uses too much baby powder **Hipso facto** ~ Inherently cool **Perkpetual** ~ Forever cheerful

Canscious ~ Keenly aware of recycling **Whistrionics** ~ A theatrical fit of pique during a card game **Nillicit** ~ Anything goes

Deafinite ~ Stubborn refusal to listen to any expression of uncertainty **Tacitorn** ~ Unconvinced that silence is golden

Sawrong ~ A loose Malaysian skirt wrapped around the body incorrectly **Toenality** ~ The colour scheme used by a pedicurist

Prize-winning BTA poster

(Edited from Quiet article)

The 2021 BAA Conference attracted over 500 delegates, and offered the opportunity for organisations to submit a poster to display the latest findings in the field. With nearly 100 posters on display the BTA were delighted that their poster - 'A patient perspective on definitions for tinnitus and tinnitus disorder' research poster, produced by Dr Georgina Burns-O'Connell with contributions from Lucy Potter, Nik Wray and our Consultation Group, won best research poster. This was a fantastic achievement for the authors and the BTA.

Tinnitus and tinnitus disorder

Clinicians and researchers [De Ridder et. al. 2021] recently proposed a new definition for 'tinnitus' and also 'tinnitus disorder':

Tinnitus = perception of sounds with 'no identifiable corresponding external acoustic source'

Tinnitus disorder = tinnitus with associated suffering. (Suffering is defined as emotional distress, cognitive dysfunction, and/or autonomic arousal, leading to behavioural changes and functional disability).

Gathering perspectives

To the best of our knowledge, individuals with lived experience of tinnitus were excluded from developing the proposed definitions, so the BTA team aimed to gather views on these definitions from those with lived experience of tinnitus. Their survey provided the definitions of tinnitus, tinnitus disorder and other statements about tinnitus and asked the participants whether they agreed or disagreed; they were also able to elaborate on their choice via free text responses. Those taking part were members of the BTA Consultation Group, and thirty two responded to the survey.

Strong views

The majority of participants [94%] agreed with the proposed definition of tinnitus saying it felt factual, clear and broad. However only 66% of participants agreed with the definition of tinnitus disorder.

Over three-quarters [78%] of participants felt the proposed definitions would not impact on the way they live with tinnitus:

'whatever label is applied to experiencing tinnitus is irrelevant'

The definition of tinnitus disorder was disputed by some participants, and some found it inaccessible and difficult to understand. Areas of disagreement included:

- Whether they had experienced any changes in behaviour
- Whether they had experienced functional disability
- Classing tinnitus as a psychological problem.

Some strengths of the definition of tinnitus disorder were recognised; participants acknowledged that it:

- May increase awareness of the condition
- Could lead to standardised approaches to medical care acknowledges that tinnitus can have a wider impact
- Recognises it is a serious condition that can affect everyday life.

Participants felt by excluding their perspective from the initial proposal of the definition, the paper was not written with them in mind:

"Whilst this paper draws upon many aspects of medical knowledge, it demonstrates seemingly little understanding from the perspective of those with lived experience of tinnitus, or that of their family, friends and colleagues".

In summary

The debate around the best way(s) to define tinnitus is an important one, with the outcomes likely to have significant impacts on how people with tinnitus access healthcare and the availability of treatments.

It is essential that those with lived experience of tinnitus are included in developing research proposals as well as future discussions and research about defining tinnitus and tinnitus disorder.



MEDICAL CHUCKLES

- A woman goes to the doctor to get some medication for her elderly husband. She is given some pills and is told that he should take two every Sunday, Tuesday and Wednesday and skip the remaining days in the week. A month later the woman returns to tell the doctor that her husband has died of a heart attack. 'I don't understand it,' says the doctor. 'His heart hasn't bothered him before; I hope it wasn't a side effect of the medication.' 'Oh no,' replies the wife. The pills did him good, it was the skipping that killed him.'
- A man with terrible back problems is forced to go to a chiropractor even though he doesn't believe in the treatment they offer. Reluctantly he gets on the examination table and let the chiropractor get to work. 30 minutes later he gets up with his problem completely cured. 'So' says the chiropractor. 'How do you feel about Chiropractors now?' The man replies, 'I stand corrected.'
- A doctor is walking down a hospital ward when he hears a shriek and sees a nun running out of another doctor's office. Curious, he steps in to find out what's going on. 'Oh, I just told that nun she's pregnant, says the second doctor. 'Heavens, is she?' asks the first doctor. 'Of course not,' says the second doctor. 'But it cured her hiccups.'
- A hospital patient is chatting to his wife. 'I've got the doctors baffled,' he says. 'Why do you think that?' asks the wife. The husband replies, 'They've put a suggestion box at the bottom of my bed.'
- I'm not an organ donor, but I did once give an old piano to the Salvation Army.
- A man goes to his doctor with a sprig of green sticking out of his bottom. 'Doctor, I think I have a lettuce growing out of my backside,' he says. The doctor examines the greenery and says, 'I'm afraid I have bad news - it's only the tip of the iceberg.'

WHAT IS THE RIGHT QUESTION?

After nearly two years of living with the threat of Covid - 19, yesterday I tested positive for the first time. Fully vaccinated and boosted, it just feels like a bad cold. Upside is I can smell the coffee and taste the cake (s). However, as the management has restricted my external ramblings, I'm giving your editor some internal ramblings which may help fill out this newsletter.

I was thinking about some of the questions towards the end of our last session and it occurred to me that it might be interesting to express them in a more binary manner. We all know what a wrong question looks like, "is there a cure for my tinnitus?", with the correct but unhelpful answer "no". And adding "but it does get better or less worse" isn't necessarily well received either. So, what is a right question? Possibly one asked by the right people that attracts funding for research towards finding a cure. The right people know what a wrong question looks like. It's one that doesn't attract funding. In the binary scenario, if I as a 'wrong' person (i.e. not involved in research) were to formulate the right question, would it attract funding? Probably not, as only the 'right' people can make a proposal to answer the right questions. I've just re-read that and I don't think it's appropriate to call myself and fellow tinnitus 'experiencers' (if there is such an expression 'wrong' people). If researchers and medical professionals are the 'right' people, then with a little bit of gymnastic English, we could refer to ourselves as the 'wronged' people. That's why the 'right' people need questionnaires and support groups to elicit the right questions from us 'wronged' people.

In a similar binary fashion we could consider cause and effect. What causes tinnitus? Loud noise? Wrapping our heads in cotton wool after the event is unlikely to give much relief. If it's not just the noise that's the trigger, is it damage to the ear? And then we learn that a trigger may be somewhere other than the ear. As for effects/symptoms, there are some common experiences, but I'm coming to the conclusion that each person's

Interesting thoughts from member Martin Middleton

experience of tinnitus is unique [*I agree* - Ed], which makes finding the right questions very difficult for the researchers.

Bear with me as I digress here for a while. If I have a jigsaw 10 pieces x 10 and then use the same picture in a puzzle 100 pieces x 100, I've made it more complicated to solve. If I take the 10 x 10 puzzle and remove the picture, making sure that it's cut so it's impossible to tell which is the top or bottom side, I've made the puzzle more complex. And removing the edge pieces so that it's only 8 x 8 makes it almost impossible to solve. The researchers are trying to solve a similarly complex problem.

When I started writing this piece, I mentioned living with Covid-19 for the last two years. During this time I decided to finish reading some of the many books on my to-read list. One of them was Bill Bryson's 'The Body'. I'm a big fan of Bill and his clarity with explaining things in an entertaining way. I was convinced he'd said something about tinnitus but checking the index, I didn't see any reference to it. Maybe the answer is in the title, 'The Body'. If tinnitus is all in the mind, perhaps we can coax him out of retirement to collaborate with Ruby Wax who's written several books (e.g. "How to be Human") that have helped me calm my tinnitus.

Getting back to Bill, in the concluding chapter he gives an insight to funding and the law of diminished returns. "If we eliminated all cancers it would extend life by 3.2 years. Eliminating every heart disease would add 5.5 years. Eliminating Alzheimer's (one of about 100 types of dementia) would add 19 days. Since 1990, for every year of added life, only 10 months is healthy. We are good at extending life but not necessarily the quality of life". Since tinnitus per se is not life limiting it doesn't get similar funding attention. And here I see how us 'wronged uns' should frame the right questions. How do we improve the quality of our lives for the 83% (10/12ths) of any extended life and 100% of our lives up to that point?

THE BEST OF BRITISH WIT

- My children are not royal; they just happen to have the Queen as their aunt ~ Princess Margaret
- Money is the most envied but least enjoyed. Health is the most enjoyed but the least envied ~ Charles Caleb Colton
- It took me 20 years of studied self-restraint, aided by the natural decay of my faculties, to make myself dull enough to be accepted as a serious person by the British public ~ George Bernard Shaw
- Silence is foolish if we are wise; but wise if we are foolish ~ Charles Caleb Colton
- I think the British have the distinction above all other nations of being able to put new wine into old bottles ~ Clement Atlee
- True friendship is like sound health; the value of which is seldom known until it is lost ~ Charles Caleb Colton

Please remember

This is your newsletter and all comments, letters, contributions or editorial copy relevant to tinnitus or CTSG, or anything you think maybe of interest to our members would be very welcome. Please send to:- Alan Yeo, c/o Newsletter Editor, 4 Claygate Road, Cherry Hinton, Cambridge CB1 9JZ (Tel. 01223 243570 alan.yeo622@outlook.com)

CONNECTIONS

CTSG website: www.cambstsg.com Facebook: [Cambs Tinnitus Support Group](#)

CTSG is an independent voluntary organisation with a good supporting relationship with the Audiology Department at Addenbrookes Hospital. It is also a BTA-registered tinnitus support group. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting room, printing and postage of Newsletters, replacement equipment and associated activities. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Our next meeting is on Saturday 18 June at the Meadows Centre, when we welcome back Fara Afifi, Tai Chi expert. If the weather is good, hopefully we will be able to exercise outdoors, as before.