

STROKE GROUP NEWS

July 2016, Issue 9

Welcome to the ninth issue of **Stroke Group News**.

In this issue, we profile one of our members, Mick Langley, to find out more about what life after stroke is like for a stroke survivor.

The dates of our stroke group meetings for your 2016 diaries can be found below. We will be at the David Rayner Centre every Thursday afternoon from 1 – 4pm except for those Thursdays when the DRC has already been pre-booked or when Stroke Group trips are planned (these dates are highlighted in red below).

STROKE GROUP – MEETING DATES

Thursday 21 July 2016	Stroke Group meeting at DRC (from 1-4pm)
Thursday 28 July 2016	Stroke Group meeting at DRC (from 1-4pm)
Thursday 4 August 2016	Stroke Group meeting at DRC (from 1-4pm)
Thursday 11 August 2016	Stroke Group meeting at DRC (from 1-4pm)
Thursday 18 August 2016	Stroke Group meeting at DRC (from 1-4pm)
Thursday 25 August 2016	Talk by Gerard Murray on 'The London Ambulance Control Centre' (starts 2.15pm) at DRC
Thursday 1 Sept. 2016	Stroke Group meeting at DRC (from 1-4pm)
Thursday 8 Sept. 2016	Stroke Group meeting at DRC (from 1-4pm)
Thursday 15 Sept. 2016	Talk by Sue Pethers on 'Communicating with people with aphasia' (starts 2.15pm) at DRC

VISITORS TO THE CENTRE

We are grateful to all the guest speakers who have visited and shared their knowledge with us.

In recent months, this has included **Lindsey Powell and Katie Ellis** (from Able Label Clothing), **Dr Cat Ford & Taneisha Scanlon** (on the Stroke Pathway Redesign), **Mike Levy** (Kindertransport Children), **Dr Gordon Campbell** (Geriatric Medicine) and **Peter Jackson** (from Scotsdales).



FUTURE SPEAKERS

Thursday 25 August 2016 Talk by Gerard Murray on 'The London Ambulance Control Centre' (starts 2.15pm) at DRC

Thursday 15 Sept. 2016 Talk by Sue Pethers on 'Communicating with people with aphasia' (starts 2.15pm) at DRC

GROUP TRIPS IN 2016

The National Stud - Members of the Stroke Group visited The National Stud in Newmarket on Thursday 12 May 2016.

On a hot sunny day, we all enjoyed the tour; taking in the Foaling Unit and nursery paddocks; the Stallion Unit and various yards and paddocks to watch the mares and foals, before enjoying lunch in the café at the Stud.



Cambridge University Botanic Gardens – members of the Group enjoyed the best of the Cambridge summer weather on Thursday 9 June 2016 when we visited the City's Botanic Gardens.



GROUP MEMBER PROFILE



Mick Langley talks about life after stroke

I had my stroke in the morning while driving on 7 May 2014.

I feel that I was very lucky to have survived this. I had a sudden pain in my left arm which left me unable to move it. This was followed with my left leg being affected in the same way. There was worse to come. I then had a terrific pain in my head which moved and was concentrated behind my left ear (I had never felt pain like this in my life and my thoughts were that this must be the end). Despite not been able to move my left arm or leg, I managed to negotiate a roundabout and turn into a Supermarket carpark. I spotted a woman and shouted help and said that I thought I had had a stroke and would she please call for an Ambulance which she thankfully did.

I was taken to Ipswich Hospital which was 14 miles away. My memory is vague of what happened there other than my family arrived and I was assessed. It was decided that I should be moved to Addenbrooke's Hospital in Cambridge.

For the next month I was on antibiotics because I had contracted a very severe case of pneumonia. I don't remember much during this time other than my family coming and going. I do remember being very frightened and trying in my mind to stay awake because of having terrible nightmares. When I did say anything, I believed that what I had dreamt was real.

I left hospital after four months. I could just about walk with the aid of a frame or a walking stick. We were not given any advice on what to expect or what help we could receive. Other problems I had were "double vision" (which I was still under the hospital for), "weak voice" (just a whisper), "unable to swallow" (so all liquids, medication and food had to go directly through a Peg Feed into my stomach).

During this time my family were (and still are) absolutely brilliant. I couldn't have asked for any more. I have also had a lot of friends around me, who have all been there for me. We were very socialable but I am afraid that has changed since having a stroke and is more limited because of my eating problems.

We first heard about the Cambridge Stroke Group from Alison Murray in September 2014. My wife, Mary, contacted her for advice when we needed support and didn't know where else to go to after searching on the internet. I was not feeling great at this time and I was not doing any of my speech therapy exercises that I should have been doing. The Occupational Therapist who came to help me walk, arranged a visit from a psychologist who suggested that I contacted my GP to seek medication. The Doctor came to see me and I agreed to go onto anti-depressants. Within a week, I was in a better place and was starting to cope, move and exercise again.

By February 2015, my wife (the big bully) talked me into going to our first Stroke Group meeting at the David Rayner Centre in Great Shelford. I must admit I was not expecting that it would be any good for me. I found it hard to be disabled having been a very able man. However, to my pleasant surprise, we felt comfortable straight away. We have been going at least twice a month ever since. It is a very friendly environment. We have found that it is good to talk to other people who are or have been in similar circumstances. It is a great place, not only for finding help, but also to help others.

It is one of the best choices I have made since having my stroke and I would suggest that everyone who has had a stroke should give the Stroke Group a try.

If there is one thing that I would like to see happen in the future, it would be to ensure that stroke survivors are far better prepared for going home and what help and support is available for them. In addition, there should be follow-up appointments regarding their stroke from their hospital. Besides from the appointment for my eyes and feeding, I have never had any contact from the Hospital regarding my stroke since I was discharged as a very disabled stroke recovering patient.

Two years on, and after having a private operation (due to being postponed continuously from the NHS), I am now able to talk with some volume. It's not my normal voice but at least I can be included in a conversation. I can eat and drink to some degree although this is difficult for me (I can cough a lot while eating and it makes me not want to eat out as much as I did before). I am not allowed to have my peg removed as they are not sure if my eating will be a permanent thing or if I will have to at some point be peg fed again. I can also drive now so that is a big help with my mobility.

So in conclusion, wherever you are in your Stroke journey, don't lose hope. Things will get better in time.

WHAT'S COMING UP?

Aerobility

We will be repeating last year's successful Aerobility day out by organising for members of the Stroke Group to fly for the day. Flying is very much a possibility for stroke survivors and can provide a level of challenge and exhilaration that is difficult to find anywhere else. Working in partnership with Aerobility, a registered charity set up in 1993 who offer disabled people, without exception, the opportunity to fly an aeroplane, there will be an opportunity for any member of our Stroke Group to take part.

We will visit the Blackbushe Airport in Camberley, Surrey. Aerobility operates a mixed fleet of light aircraft, balanced for capability. The main training aircraft used is the Piper Warrior 161, adapted so that it can be flown by people with disabilities, and even severely disabled people can be hoisted into the cockpit, using specially developed hoisting techniques, and electric robotic or manual hoists. Ideally we will have use of a flight simulator for training and an introductory learning session on the day before members take to the real aircraft and enjoy an individual 'experience of a lifetime' trial flying lesson.

NB. We will be going flying in September 2016 (not on Thursday 4 August as previously discussed). If you are interested in joining us, please express your interest to Hannah ASAP

Fundraising for the group

An enormous thank you from everyone at the Group to Laurie Coppersmith who donated £415 to Cambridge Stroke Group in May 2016 – having asked for donations in lieu of gifts as part of his 70th birthday celebrations. A fantastic gesture and one we are very grateful for. Thank you Laurie (aka Hannah's dad).

Shelford Feast

A big thank you to everyone from the Group who helped run our stall at the Shelford Feast on Sunday 17 July 2016 and to those who donated items for the tombola. An especially big thank you to Mick, Mary and all the Langley family, Hannah, Ali, Ray and Sheila for all their hard work on the day.

Cambridge Open Studios 2016

This year's Open Studio events offer an opportunity to view Michael Walton's extraordinary work and meet him. Michael is a stroke survivor - a former architect turned artist over the course of his recovery. His website houses some of his work and short film about his story: www.michaelwalton.org The event runs on Sat. 23 July & Sunday 24 July from 12 noon – 4pm at Oak Farm Barn, Woodditton Road, Kirtling, Newmarket, CB8 9PG.

Board games

The Stroke Group have games available for any members to play at any time during meetings. These include *playing cards, dominos, Uno, Dobble, Connect Four and Rummikup*. Please ask Hannah, Steph or Ali should you want to play with these.

Birthday thank you

"A big thank you from me! Thank you so much for my birthday good wishes & gifts. They were absolutely lovely." (Steph)

AND FINALLY

Mick Gruby

We are devastated to announce the sad passing of Mick Gruby who died on Tuesday 5 July 2016, at Addenbrooke's Hospital, with his wife Irene and his three sons by his side. Mick was a hugely popular member of our Stroke Group. He brought humour and warmth to all that he did, was a friend to everyone and he will be missed enormously by us all.

Mick's funeral service took place on Friday 15 July 2016 at Sawston Free Church followed by committal at Sawston Cemetery and refreshments at The Red Lion in Hinxton where family and friends (wearing bright colours to celebrate Mick's life) shared memories of Mick.

The family asked that those attending the funeral who wanted to make a donation should make it to the Cambridge Stroke Group. On behalf of everyone from the Stroke Group, we would like to thank the Gruby family for their very generous gesture at this terribly sad time. We are very much thinking of Irene and her family.



GETTING TO THE CENTRE

Volunteer Car Schemes

For members who are unable to get to the DRC every week, here are details of Volunteer Car Schemes to get in touch with:

- **Royston & District Community Transport: 01763 245228** E-mail: info@roytrans.co.uk - for medical and social purposes to villages in South Cambridgeshire around Royston. Also offers wheelchair accessible transport
- **Cottenham Care Car Scheme: 01954 251929** Provides short-distance journeys for residents of Cottenham for social and medical purposes. Will also cover Oakington, Rampton and Histon if necessary
- **Foxton Social Car Scheme: 01223 572147 / 574327** Mainly offers short-distance journeys to those in the Foxton area for social & medical purposes, can offer transport into Cambridge if unable to make journey by any other means
- **Harston Car Scheme: 01223 870647** Short-distance journeys for residents of Harston for social and medical purposes
- **Histon & Impington Car Scheme: 07982 108927** Short-distance journeys for residents of Histon & Impington and surrounding area, for social and medical purposes
- **OWLS Community Car Scheme: 07505 254363** For residents of Over, Willingham, Longstanton and Swavesey. Offers transport for social and medical purposes
- **Shelford Support Group: 01223 843856** For residents of Great & Little Shelford and Stapleford for social and medical purposes, including trips to Addenbrooke's Hospital
- **Trumpington FISH Scheme: 01223 515394** For Trumpington residents for short-distance journeys for social and medical purposes
- **Beaches Community Car Scheme: 07807 875878** For residents of Waterbeach, Landbeach, Horningsea, Milton and Chittering. or social and medical purposes or any essential journey that could not be made by any other means
- **For more transport schemes visit www.cambridgeshire.gov.uk/info/20123/community_transport**

OVER TO YOU – GET INVOLVED

If you have any ideas to help support the Group, are inspired to organise an event and/or your friends and family would like to be involved as a volunteer, we would love to hear from you. It is a great way to make new friends and be part of a rewarding and fun group of people with a common aim.

Please pop in and speak to the team, we are always happy to see you.

We can be found at The David Rayner Centre (Scotsdales Garden Centre, 120 Cambridge Road, Great Shelford, CB22 5JT) every Thursday afternoon from 1pm.

We are actively looking for volunteers to support the group on a weekly basis. Please let us know if you know anyone who might be interested & available

STROKE GROUP CONTACT DETAILS

Alison Murray (Coordinator, The Stroke Association)

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Stephanie Branston (Group Volunteer)

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Have you had a family member or friend admitted to hospital with a traumatic brain injury?

The National Institute for Health Research (NIHR) Brain Injury Healthcare Technology Co-operative (HTC) is delivered in partnership by Cambridge University Hospital NHS Foundation Trust and University Cambridge, and is based at Addenbrooke's hospital.

The NIHR Brain Injury HTC is committed to 'Patient and Carer Inspired Innovation' to ensure that all perspectives of the care pathway are heard. A recent initiative focused on hearing from the patients directly (find link below), which highlighted the need to hear from families and friends of those who have cared for someone admitted to hospital with a Traumatic Brain Injury (TBI).

First of all, if you are a family member or friend of someone who has been admitted to hospital with TBI, the HTC asks that you kindly complete a short survey about your experience. This will give you the opportunity to tell us about your experiences, both the ups and the downs, with the choice of anonymity. The survey findings will provide the HTC with enough details to inform the next phase.

The online survey can be found here:

<https://addenbrookes.onlinesurveys.ac.uk/htc-family-carer-tbi>

Secondly, again if you are a family member or friend of someone who has been admitted to hospital with TBI, the HTC would like to invite you to participate in the Family & Carer Workshop on Thursday 22nd September 2016 in Cambridge Central Library. The workshop will be from 10am to 1pm with lunch and refreshments provided, and travel expenses will be reimbursed.

The workshop will be an informal discussion with family members, friends and carers to explore the anonymous findings of the survey and share their experiences following the admission to hospital with a traumatic brain injury.

**If you would like to be sent a copy of the survey via email or post,
like to attend the workshop, or would like more information please contact
the NIHR Brain Injury HTC office (T: 01223 336940 or E: involve@brainhtc.org).**

To find out more about the NIHR Brain Injury HTC, please visit: www.brainhtc.org

To find out more about how to Get Involved, please visit: <https://brainhtc.org/get-involved/>

To read the summary from the "Patient Inspired Innovation Acute Care: Brain Injury and Intensive Care" initiative held in November 2015, please visit: <https://brainhtc.org/wp-content/uploads/2016/04/Intensive-Care-and-Brain-Injury-PPIE-Findings-Report-Final-Draft-Brain-Injury-HTC.pdf>