

# UK Stroke Assembly

Hosted by  
**Stroke**  
association

Tuesday 30 – Wednesday 31 May 2017  
Crewe Hall, Cheshire

*Giving a voice to those affected by stroke and aphasia...*



# Welcome to the UK Stroke Assembly North 2017

The UK Stroke Assembly is the largest gathering of people affected by stroke and aphasia in the UK. It was launched in 2011 recognising the importance of sharing and listening to the views of those living with stroke and aphasia. So far 740 people affected by stroke and aphasia have attended a UK Stroke Assembly event and shared their hopes and concerns.

Now in our seventh year our aim is to connect with a wider audience who had never attended a UK Stroke Assembly event before. This year we are delighted to be holding events in Cheshire and Essex for the first time. We also have exciting plans to expand our reach with those living in the devolved countries.

You are the experts on life after stroke and your voice needs to be heard by the charities and those who are researching new treatments, improving services, and making decisions about health and social care.

Throughout the event please take every opportunity to have your say, learn from each other and reflect on how far you've come on your own personal stroke journey.

We are keen that the wonderful connections and conversations from the event continue in the future. Let us know what you have gained from the event. Stay in touch by signing up for our newsletter by contacting us: [info@strokeassembly.org.uk](mailto:info@strokeassembly.org.uk) or **01527 903 917**.



*I look forward to meeting  
you all and remember,  
**together we can conquer stroke.***

**Nicola Stanford  
Chair, UK Stroke Assembly  
Reference Group**



# What to expect:

We know that attending a conference might not be something you are used to. The venue and programme is chosen with the needs of stroke survivors in mind. Please take the event at your own pace and rest whenever you need to.

**Purpose:** The aim of the UK Stroke Assembly is to give a voice to people affected by stroke and aphasia, providing an opportunity to meet with and influence decision makers. Stroke survivors and their families can express their hopes and concerns in a UK-wide forum, engage with like-minded people and collectively influence action on stroke and aphasia.

**What we want to achieve:** Through networking, the UK Stroke Assembly encourages stroke survivors and their families to share experiences and inspire others similarly affected. The event highlights latest developments in stroke care and research, and ways in which individually and collectively you can take action. It also showcases products and services to support the stroke recovery journey and actively promotes life after stroke.

**What we will use your input for:** The UK Stroke Assembly enables timely discussion of issues to inform the policy and action of stroke patient charities. These key messages will be shared with government and health and social care decision makers, with particular focus on outcomes for those living with stroke and aphasia. Results of feedback will be considered in the organisation of future events and campaigns.

'It was so helpful to be together, hear positive experiences and to be encouraged by others who understand and who experienced a 'life changing' stroke.'

'I met so many interesting people all with a resilient attitude to life.'

'The knowledge about stroke and overall friendliness was the best we have seen in an event for stroke survivors.'





# The UK Stroke Assembly Reference Group

The UK Stroke Assembly is hosted and supported by the Stroke Association. It is organised and planned by leading stroke organisations and individual stroke survivors who sit on the Reference Group. The Reference Group is made up of the following organisations:



## Stroke Association

Website: [stroke.org.uk](http://stroke.org.uk)  
Telephone: **020 7566 0300**  
Helpline – **0303 3033 100**  
**@TheStrokeAssoc**



## InterAct Stroke Support

Website: [Interactstrokesupport.org](http://Interactstrokesupport.org)  
Telephone: **020 7931 6458**  
**@InterActStroke**



## Different Strokes

Website: [differentstrokes.co.uk](http://differentstrokes.co.uk)  
Telephone: **0345 130 7172** or  
**01908 317 618**  
**@diffstrokes**



## Clinical Research Network: Stroke

Website: [nih.ac.uk](http://nih.ac.uk)  
Telephone: **023 8059 5628**  
**@NIHRCRN**

# Stroke survivor representatives

Stroke survivor representatives contribute as members of the Reference Group and represent the views of stroke communities in England, Scotland and Wales.



## **Julie Monk - England**

Stroke Ambassador  
Stroke Association volunteer  
Chairperson for 4Ward Strokes Leicester

### **My tips for life after stroke:**

- Wake each day with a smile. As a stroke survivor we can feel lonely and isolated, but having a positive attitude makes me feel so much happier, just try, it really works!
- Together we can conquer stroke!
- Support the Stroke Association by attending events they organise. Attending events is a way of being able to say 'Thank You' for all the hard work the charities provide to us all.



## **Andrew Davies - Wales**

Creator and Founder of i-ADA  
Ex Professional Press/PR Photographer  
Stroke Ambassador  
Welsh Assembly Government Role Model  
Community Engagement Consultant at Swansea University SoM

### **My tips for life after stroke:**

- Spirit: keep a positive mind-set.
- Determination: if you never give up, you cannot fail.
- Achieve: adapt to overcome obstacles.



### **Paul Hodson – Scotland**

Stroke Association and Speakability volunteer  
Committee member of Speakability Edinburgh

#### **My tips for life after stroke:**

- Celebrate the small things. Following my stroke I have problems with speech and numbers, but eight years later my vocabulary is still improving.
- Life can take an interesting tangent. I didn't know about aphasia before my stroke, but now I do, and want to explain this to people. I now give talks about aphasia for the Stroke Association, Chest, Heart and Stroke Scotland, and anyone who will listen.
- Laugh lots. When faced with difficulties, try to stay positive.

### **Are you interested in representing the views of stroke survivors and carers in Southern England or Northern Ireland?**

We're looking for a stroke survivor or carer from Northern Ireland and Southern England to get involved in the planning of future UK Stroke Assembly events. If yes then we would love to hear from you contact us on **01527 903 917** or email **info@strokeassembly.org.uk** for more information.



Stroke  
association

UK

Stroke

Assembly



# Housekeeping and useful information

We hope that you enjoy your UK Stroke Assembly experience. Here is some useful information to get the most out of the event.



## Parking

- All parking at the venue is **free**.

## Rooms

- **Bedroom** check in is between **4.00-5.00pm** at the **UK Stroke Assembly desk**.
- If you need your room before 4.00pm please ask.
- You will be given a letter with your key with more information.
- **Breakfast** is from **6.30-9.30am** in the Brasserie.
- To charge any expenses to your room set up an account with the hotel.
- If you have any questions about your room please speak to the hotel staff or the UK Stroke Assembly staff.

## Checkout

- Settle any expenses and check out of your room before **11.00am** at the **UK Stroke Assembly desk**.
- **Leave your luggage** at **reception** or leave in your car out of sight.

## Fire evacuation

- Make sure you know where the nearest fire exit is at all times.
- If you **hear the fire alarm**, use your **nearest exit** and make your way to the **assembly point** at the front of the Old Hall.
- If you need **help** in an emergency please arrange a **personal emergency evacuation plan** with the hotel staff and UK Stroke Assembly team.



### Communication support

- **Tell us** at the UK Stroke Assembly desk if you **need communication support**.
- Support in the main talks will be available at the **tables with orange cloths**.
- Dedicated communication support **staff** will be wearing an **orange name badge** and lanyard.

### Need help or support

- Ask the **UK Stroke Assembly** staff, wearing **blue name badges and lanyards**.
- **Call reception, dial 0** from the phone in your room.

### Wi- Fi

- There is free wi-fi access.
- Follow the instructions available from the UK Stroke Assembly desk or reception to log on.

### Refreshments and breaks

- Times for refreshment breaks are shown in the programme.
- **Refreshments** will be available all day in the exhibition area.
- Feel free to take as many breaks as you like and whenever you like.
- Water will be on the tables during the talks and workshops.
- You do not have to attend all workshops.

### Special diets

- If you have a **special diet** and requested a **specific meal** please speak to the catering team or a member of the UK Stroke Assembly team who will be able to assist you.

### First aid

- Come to the UK Stroke Assembly desk or reception if you are unwell or need first aid.
- **Call 0** from the **phone in your room** for help.

### Photography and filming

There will be a photographer and a film crew at the Assembly.

- Pictures and film may be used for social media or promotional purposes.
- Please let us know if you have any concerns about this.

### Feedback

Please tell us what you think by:

- Completing the **evaluation form**.
- Talking to a member of event **staff** wearing a blue badge.
- **Writing** your **questions** and comments on the slips on the tables.
- Contact us afterwards.

**The more we hear from you the more we can support you in the future.**

# Exhibition

In the exhibition area there are products and services to help you take action and support in life after stroke. Below are details of organisations that will be present on Wednesday 31 May 9.00am – 3.00pm. Refreshments will be available in the exhibition areas. There are two sittings for lunch to ensure you all get chance to meet all the exhibitors.

The UK Stroke Assembly North 2017 is sponsored by: Irwin Mitchell Solicitors and Dorset Orthopaedic

## Irwin Mitchell Solicitors



Irwin Mitchell Solicitors is one of the UK's most respected and successful full service law firms. Whether you need help writing a Will, you are moving home or you've suffered an injury or illness that wasn't your fault, we can offer clear guidance to help you and your family.

[www.irwinmitchell.com](http://www.irwinmitchell.com)  
[@irwinmitchell](https://twitter.com/irwinmitchell)

## Dorset Orthopaedic



'Strive for Better'. It's not just our slogan; it's our way of seeing the world. It's the driving force behind our history, philosophy and innovation and is why we have achieved worldwide reputation for excellence.

As an independent provider of prosthetic, orthotic, silicone and rehabilitation services, we pride ourselves in providing total rehabilitation for patients. It's this bespoke service and attention to detail that has gained us our reputation for quality and personalised service for almost 30 years.

[www.dorset-ortho.com](http://www.dorset-ortho.com)  
[@DorsetOrtho](https://twitter.com/DorsetOrtho)

# Being able to look to the future



Irwin Mitchell Solicitors is one of the UK's most respected and successful full service law firms. Whether you need help writing a Will, you are moving home or you've suffered an injury or illness that wasn't your fault, we can offer clear guidance to help you and your family.



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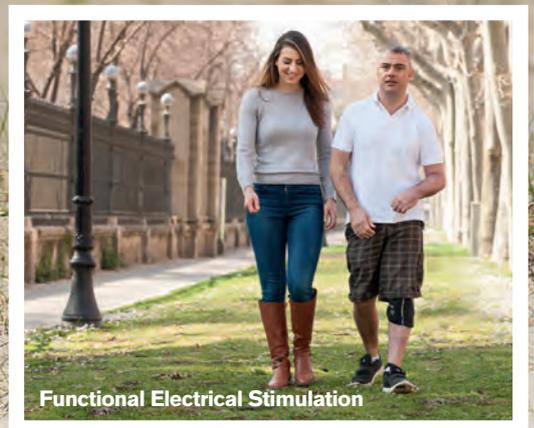
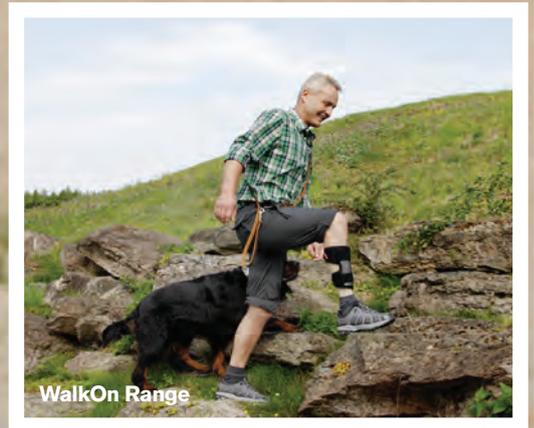
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Our nationwide clinics have a variety of solutions for people living with drop foot. Call today to make an appointment. Tel: 0800 433 2239 E: enquiry@dorset-ortho.com.

## Royal College of Physicians



The Sentinel Stroke National Audit Programme (SSNAP) is a project run by the Royal College of Physicians. SSNAP is a clinical audit project that aims to improve the quality of patient care by reviewing care against standards in hospitals and community services.

Services are encouraged to use their results to make improvements to the quality and delivery of care for stroke patients. SSNAP is guided by the Stroke Working Party which is made up of healthcare professionals other organisations such as the Stroke Association, and stroke survivors.

[www.strokeaudit.org](http://www.strokeaudit.org)  
[@SSNAPaudit](https://twitter.com/SSNAPaudit)

## University of Central Lancashire – Allied Health Research Unit



**Cycling after stroke:** As part of a European Regional Development Fund project the Allied Health Research unit at UCLan is looking for your opinion about cycling after stroke. Visit our stand to find out more about this project and the benefits of using an electric bike and possible adaptations to make them accessible.

[www.uclan.ac.uk/research/explore/groups/physiotherapy\\_sports\\_therapy.php](http://www.uclan.ac.uk/research/explore/groups/physiotherapy_sports_therapy.php)  
[@UCLanPaST](https://twitter.com/UCLanPaST)

## Say Aphasia



Say Aphasia is a Sussex based charity that supports people with aphasia and their families and carers. We run a weekly drop-in in Hove where people with aphasia can get together, chat, make friends and have fun.

Our aim is to help people get better. Our group is friendly and supportive and we make everyone welcome.

[www.sayaphasia.org](http://www.sayaphasia.org)  
[@SayAphasia](https://twitter.com/SayAphasia)

## I Cycle Ltd



We are a company that specialises in the supply, service and adaption of electric bikes and their accessories. We are not tied to any particular company so are able to give impartial advice depending on individual circumstances.

[www.icelectric.co.uk](http://www.icelectric.co.uk)

## MYoroface



IQoro® helps stroke survivors with problems with swallowing, facial paralysis, speech, snoring or sleep apnoea problems, and more. It is a new and unique neuromuscular treatment method that requires less than two minutes' exercise per day. It works by training and strengthening the muscles, and by stimulating the brain to regenerate the pathways that control them.

[www.iqoro.com](http://www.iqoro.com)  
[@IQ\\_oro](https://twitter.com/IQ_oro)

## Batherton Express Ltd



Batherton Express is the sole UK distributor of Gloop and works with the Stroke Association on their professional training courses with this product. Gloop is a natural swallowing gel developed to help people swallow solid medication with ease and is available both online and national retail stockists.

[www.batherton-express.co.uk](http://www.batherton-express.co.uk)  
[@BathertonEX](https://twitter.com/BathertonEX)

## See Beyond Stroke



Award-winning film director Karen Guthrie will share her 'Story of Stroke' to talk about the powerful film she made when her mother Ann suffered a devastating stroke.

Karen will also introduce a sister project **See Beyond Stroke** - an innovative training and outreach project offering free training resource aimed at carers.

[www.thecloserweget.com/sbs](http://www.thecloserweget.com/sbs)  
[@TheCloserWeGet](https://twitter.com/TheCloserWeGet)

## RNIB



We're the Royal National Institute of Blind People (RNIB) and we're here for everyone affected by sight loss. Whether you're losing your sight or you're blind or partially sighted, our practical and emotional support can help you face the future with confidence.

[www.rnib.org.uk](http://www.rnib.org.uk)  
[@RNIB](https://twitter.com/RNIB)

## The Stroke Association



We are the UK's leading charity dedicated to conquering stroke.

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research to develop new treatments and ways of preventing stroke.

We're here for you.  
Together we can conquer stroke.

Visit the exhibition stand to find out how we can support you and learn about Aphasia Voices and aphasia awareness month.

[www.stroke.org.uk](http://www.stroke.org.uk)  
[@TheStrokeAssoc](#)

## Synexus



Synexus is a company dedicated to conducting clinical studies. Your nearest research centre is not that far away. As a dedicated Research Organisation committed to helping find relief for people suffering from all kinds of condition. Synexus are currently helping to assess treatments that may help lower elevated levels of cholesterol and avoid side effects associated with exiting cholesterol lowering therapies.

[www.synexusclinic.co.uk](http://www.synexusclinic.co.uk)  
[@SynexusClinics](#)

## UK Stroke Forum Service User Reps



The UKSF service user reps are the voices of stroke survivors and carers to feedback to professionals at the UK Stroke Forum. Come and talk to them about the importance of patients, carers and the public getting involved in stroke research

The UK Stroke Forum is a coalition of over 30 organisations all committed to improving stroke care in the UK, hosted by the Stroke Association. If you would like to get involved and help develop the UK Stroke Forum and represent the voices of those affected by stroke come and talk to the service user reps to find out more about the vacancies they have to join the UKSF committee.

[www.stroke.org.uk/professionals](http://www.stroke.org.uk/professionals)  
[@ukstrokeforum](#)

# Meet our speakers

A copy of the programme is on the last page of this booklet. Here is a brief introduction to our chair and speakers of the main talks. If you wish to find out more about any of our speakers please ask at the UK Stroke Assembly desk or write your question on the comment slips placed around the venue, with your contact details.



## **Chairing event**

### **Nicola Stanford**

Chair, UK Stroke Assembly Reference Group.

Head of Volunteering and Community Partnerships, Stroke Association



## **Opening and closing address**

### **Juliet Bouverie**

Chief Executive, Stroke Association

## Plenary 1 – Our story: inspirational talks from stroke survivors and carers



**Nick Cann**  
Stroke Association  
Volunteer  
Aphasia – Project  
Phoenix  
Treasurer 'Strike a  
Chord' choir, Wales



**Karen Guthrie**  
Film Director,  
See Beyond Stroke



**Leila Neve**  
mother and carer  
**Charlotte Neve**  
stroke survivor

## Plenary 2 – Stroke and aphasia research: What's hot in 2017



**Dr Fergus Doubal**  
Consultant Physician  
and Senior Lecturer,  
University of  
Edinburgh



**Prof Jane Marshall**  
Professor at City,  
University of London

## Plenary 3 - What the National Clinical Guideline for stroke means for you



Royal College  
of Physicians

**Alex Hoffman**  
Stroke  
Programme  
Manager  
Royal College of  
Physicians London

**Robert Norbury**  
Stroke Survivor

## Plenary 4 – There is life after stroke, and we'll prove it!



**Margaret Biddle**  
Teacher  
Natural Voice Network



"I couldn't speak or write after my stroke, but I was desperate to get my voice back."

John, aged 60

# Change the Story

Every year thousands of stroke survivors like John are left struggling to communicate.

Without stroke research, John may never have relearned the speech he needs to enjoy life, from ordering a family meal out, to volunteering with other stroke survivors.

Donate now to fund stroke research and change the story for stroke survivors: [stroke.org.uk/change](https://stroke.org.uk/change) or text **CHANGE** to **70300** to donate **£3**.

You will be charged £3 plus one message at your standard network rate. Stroke Association will receive 100% of your donation.

Together we can conquer stroke

**Stroke**  
association

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Also registered in Northern Ireland (XT33805) Isle of Man (No 945) and Jersey (NPO369).

# Workshops

**Here is a reminder about what the workshops are and details of the speakers. Your workshop choices are printed on your badge. If you would like to know more about any of the workshop speakers please ask at the UK Stroke Assembly desk.**

## Optional workshops

Tuesday 30 May 3.00-4.00pm

### a) Help shape the Stroke Association's policy positions

Mark MacDonald - Senior Policy and Influencing Officer, Stroke Association

We are developing policies on the big issues which affect stroke survivors, their families and friends. Find out how we do this and share your thoughts on the latest policy position.

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### b) Raising the profile of stroke and the Stroke Association

Jane Cryer - Head of Brand, Stroke Association

As the leading UK stroke charity, the Stroke Association should be better known than it is. Take part in a consultation on how we can become better known and reach more people affected by stroke.

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### c) What support is available in your area?

John Wilde – Stroke Information Service Assistant Manager and

Doug Youngson – Helpline Information Officer, Stroke Association

Come and take part in this interactive session exploring what stroke support and care is available in your area.

**Please note:** This session is aimed at those who are not already receiving a Stroke Association service or member of a stroke club or group.

## Workshops 1

Wednesday 31 May 11.00am – 12.00noon

### a) Mental health, anxiety and depression

Kate Charles – Deputy Head of Operations (North West) and Susan Fitton – Emotional Support Coordinator

Explore the relationship between these hidden effects of stroke, with updates on what research is being done to support better care in this field.

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### b) Fatigue after stroke: what research tells us

Prof Avril Drummond – Professor of Healthcare Research, University of Nottingham and UK Stroke Forum

This is a repeat of the popular and informative session ran at the UKSA events in 2016.

Learn about the latest research into fatigue after stroke including what we still don't know.

**Please note:** This session is looking at the latest research and won't necessarily look at methods of coping with fatigue.

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### c) Managing finances after stroke

Stroke has a huge impact on your personal finances. Come and hear from others on how they have adapted to the financial shock of stroke and share your top tips.

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**a) Speaking out for stroke locally**

Esme Russell – Head of Policy and Influencing, Stroke Association

Find out how you can be a representative for stroke locally and get involved in taking action on stroke in your own area.

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**b) Campaigning for a national stroke strategy – one year on**

David Bridson – Campaigns Officer, Stroke Association

Last year the Stroke Association launched a new campaign 'A New Era for Stroke' calling for a new national stroke strategy. Come along to find out the progress we've made. You will also hear from a stroke survivor who has been involved in the campaign and find out how you too can get involved and take action.

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**c) Improving support for carers**

Elaine Roberts – Director Life After Stroke Services, North of England, Stroke Association, Katy Rothwell, and Dr Emma Patchick NIHR CLAHRC Greater Manchester

Hear about projects underway to improve the support currently available to those caring for someone affected by stroke.

**Please note:** This session is for carers only. Support will be available for stroke survivors wishing to attend other sessions at this time.

**Take some time out of the busy programme, or try something new:**

- Do not feel you have to attend every workshop
- Take time to rest
- Visit the wellbeing area
- Find your creative side and 'Have a go' at an activity
- Or visit the exhibition area

Available from 9.00am -3.00pm on Wednesday 31 May.

# Programme at a glance

## Day 1- Tuesday 30 May 2017

Time	Programme	Location
1.30-2.30pm	<b>Aphasia Voices – Invite only</b>	Red room (first floor)
2.00-4.00pm	<b>Registration and refreshments</b>	Events Centre Reception
3.00-4.00pm	<b>Optional fringe workshops</b>	Continental Suite:
	a) <b>Help shape the Stroke Association's policy positions</b> Mark MacDonald	 Blue Room
	b) <b>Raising the profile of stroke and the Stroke Association</b> Jane Cryer	 Purple Room
	c) <b>What support is available in your area?</b> John Wilde and Doug Youngson	 Yellow Room
4.00pm	<b>Bedroom check in</b>	Events Centre Reception
5.30pm	<b>Drinks reception</b>	Continental Suite Foyer
6.00pm	<b>Conference opens – Welcome</b> Nicola Stanford	Continental Suite
6.15pm	<b>Opening address</b> <b>A year on: what's happened since the UK Stroke Assembly 2016</b> Juliet Bouverie	 Continental Suite
6.30pm	<b>Plenary 1</b> <b>Our story: inspirational talks by stroke survivors and carers</b> Nick Cann, Karen Guthrie, Charlotte and Leila Neve	 Continental Suite
7.15pm	<b>Conference dinner</b>	Continental Suite

### Key

-  Plenary talks
-  Workshops



Life after stroke and aphasia



Take action



Developments in stroke care and research



Share and inspire

## Day 2 – Wednesday 31 May 2017

Time	Programme		Location
6.30am	Breakfast		Brasserie
9.00am	Exhibition and refreshments		Continental Suite Foyer
9.15am	Conference opens – Welcome Nicola Stanford		Continental Suite
9.25am	Plenary 2 Chair - Prof Avril Drummond Stroke and aphasia research: What's hot in 2017 Dr Fergus Doubal Prof Jane Marshall		Continental Suite
10.05am	Plenary 3 What the National Clinical Guideline for Stroke means for you Alex Hoffman and Robert Norbury		Continental Suite
10.30am	Exhibition and refreshments		Continental Suite Foyer
11.00am	Workshops 1 a) Mental health, anxiety and depression Kate Charles and Susan Fitton b) Fatigue after stroke: what research tells us Prof Avril Drummond c) Managing finances after stroke	  	Blue Room Purple Room Red Room (first floor)
12 noon - 12.45pm	Exhibition and lunch (Lunch will be served in two sittings)		Brasserie
1.20pm	Workshops 2 a) Speaking out for stroke locally Esmee Russell b) Campaigning for a national stroke strategy – one year on David Bridson c) Improving support for carers Elaine Roberts, Katy Rothwell, Dr Emma Patchick	  	Blue Room Purple Room Red Room (first floor)
2.20pm	Exhibition and refreshments		Continental Suite Foyer
2.50pm	Plenary 4 The year ahead Juliet Bouverie There is life after stroke, and we'll prove it! Margaret Biddle	 	Continental Suite
3.30pm	Depart		

# Conference Centre Map



Key	
	Plenary talks
	Red Room
	Exhibition area
	Lift
	Toilets



If you would like to know more about the history of Crewe Hall and view parts of the Old Hall join the tour on Tuesday evening. Meet in the Events centre reception at 4.40pm. The tour will be approx 30-40 minutes.

**Please note that as this is a listed building access around the Old Hall maybe limited for those with restricted mobility.**

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The Reference Group would like to thank the UK Stroke Assembly Delivery and Advisory Groups, and the Stroke Association's regional teams for their valuable contribution to shaping and organising this event.

In addition to all our wonderful speakers, sponsors and exhibitors we would also like to acknowledge Document Capture Co Ltd for their support in collating all the event feedback, as a gift in kind.

**[www.strokeassembly.org.uk](http://www.strokeassembly.org.uk)**

The UK Stroke Assembly is hosted by the Stroke Association. Registered Charity in England and Wales (No 211015) and in Scotland (No SC037789). Also registered in Northern Ireland (XT33805) Isle of Man (No 945) and Jersey (NPO 369).

# Time to reflect...

**'For me the UKSA means community! A community of survivors and carers brought together by the Stroke Association to support and help each other whilst working towards a common goal.'**

**Andrew, Reference Group representative**



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We would love to hear what you have gained from your UK Stroke Assembly experience. Stay in touch and email us [info@strokeassembly.org.uk](mailto:info@strokeassembly.org.uk) or call 01527 903917