

# Information, Support and Social Events 2015/16



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## The year ahead

Thanks to the hard work of the team at SMA Support UK and our volunteer advisers we are able to bring you early news of events for next year. I know that these events are not for everyone. For some of you who are bereaved they may bring great sadness. For others the travel and logistics is too daunting. But we also know that many of you do want the chance to meet up with others affected by SMA, to share experiences and get to know each other.

As SMA varies greatly in its effects, in 2016 we are moving away from the 'one conference fits all' model towards hosting separate information and support days for individuals and families affected by the different types of SMA. However, as we are all part of an inclusive SMA community we still want to provide an opportunity for everyone to meet up, which is why we are also offering our Saturday evening entertainments and National Fun Day in April.

I hope you are able to join us and look forward to meeting you at some time in 2016.

Best Wishes

Doug Henderson, Managing Director

## Social Events Open to All

### 2015 Regional Christmas Parties



We would be delighted if you would join us at any of the following:

- Northern Ireland, Belfast – Saturday 28th November 2015
- Midlands, Stratford upon Avon – Sunday 29th November 2015
- Eastern, Harlow – Sunday 29th November 2015
- Southern, Bournemouth – Saturday 5th December 2015
- Scottish, Glasgow – Saturday 5th December 2015
- Northern, Darlington – Sunday 6th December 2015

For more information or to book your place, please visit <http://www.smasupportuk.org.uk/christmas-parties-2015>

### 2016 Saturday Night Social

**Saturday 2nd April 2016 7.00pm – 11.00pm**  
**Ettington Chase Hotel, Stratford upon Avon CV37 7NZ**

Three options catering for all age ranges:

- Mobile Cinema and Pyjama Party for children and families
- Chill out space for young people aged 12+
- For adults – a night out on the town in Stratford upon Avon.

Please see the back page (4) for further details.

### 2016 National Fun Day

**Sunday 3rd April 2016**  
**Ettington Chase Hotel,**  
**Stratford upon Avon**  
**CV37 7NZ**

Everybody Welcome!

Please see the back page (4) for further details.



## Information and Support Events

### For Families affected by SMA Type 1

Some families may find that the programme on offer in April (see below) will work for them but we are aware that for many others it will not. Later this month we will begin consulting with families affected by SMA Type 1 to ask if another information and support event is wanted and, if so, what it would include.

### 'Talking Together' – For Children, Young People, Adults and Families affected by SMA Types 2 or 3'

**Saturday 2nd April 2016**  
**Ettington Chase Hotel,**  
**Stratford upon Avon CV37 7NZ**

This may also be of interest to those affected by other forms of SMA – please have a look at the programme and, if you are unsure, call Support Services to find out more. Professionals also welcome.

**"It was our first event and our children had an epic time.**

**It has been inspiring seeing teenagers with SMA Type 2. Given us hope for the future. We learn a lot from others parents."**

Parent of 2 year old with SMA Type 2.

### 'Talking Together' – for Adults affected by Adult Onset SMA

**Saturday 11th June 2016**

A chance to meet up, talk with a leading expert and help SMA Support UK develop the Adult Onset Route Map. Programme details coming later, or contact Support Services.

### For those affected by rarer forms of SMA

Depending on your individual circumstances, different days will be relevant to you. Please give Support Services a ring if you are unsure which day would be the one for you. Call **01789 267520**.





# Talking Together

Information and Support Day for Children, Young People, Adults & Families affected by SMA Types 2 or 3. Professionals also very welcome.

## PROGRAMME

9.00 – 10.00

Registration

10.00 – 11.00

Workshop Session A

11.00 – 11.30

Refreshment break

11.30 – 12.30

Workshop Session B

12.30 – 14.00

Lunch break

14.00 – 15.00

Workshop Session C

15.00 – 15.30

Refreshment break

15.30 – 16.30

Clinical Care Research Round Up, Going Forward, Young People's Presentation

16.30

Close

Information stands, including latest research findings, may be visited during the breaks. A number of equipment providers will also be present.



Participants choose one of the 6 workshops below and stay with that group for sessions A, B and C.

### Workshop 1 for Parents and Carers of children aged up to 11 years

Facilitated to create an environment where anyone can ask questions and add their ideas and experiences. Parents/carers who have experience of the topics being discussed will lead sessions A and C.

**Session A** Day and night at home and on holiday – practical issues and tips

**Session B** Looking after all the family – what it's like and how to manage. Taking care of everyone's emotional health

**Session C** School, making friends, clubs and activities

### Workshop 2 for Parents and Carers of children aged 12 – 18 years

Facilitated to create an environment where anyone can ask questions and add their ideas and experiences. Young people with SMA who have experience of the topics being discussed will participate in sessions A and C.

**Session A** Moving On – College, university, work, learning to drive

**Session B** Looking after all the family – as young adults move towards independence, what it's like to 'let go'. Taking care of everyone's emotional health

**Session C** Managing Increasing Independence – field trips, social life and work experience

### Workshop 3 for Young People aged 12 – 15 years: 'Through our eyes'

Be film-makers for the day! Get behind the lens if you're a budding director or in front of the lens if you're an actor in the making. Arts charity, Create, and their professional artists will guide your group to create and produce your very own short film by the end of the day.

<http://www.createarts.org.uk>

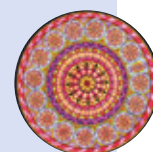
**CREATE**  
ARTS CHARITY



### Workshop 4 for Young People aged 15 – 17 years

Chill, chat and share!

Come along and take part in a guided meditation practice. Learn how to become more mindful, to calm thoughts, respond less stressfully to tricky situations, and boost creativity. Later, we will be free to chat and share experiences while doing some Mandala art. Keep it simple with colouring pencils or go wild and wacky with all sorts of bits and bobs!



## Saturday 2nd April

### Ettington Chase, Stratford upon Avon CV37 7NZ

This may also be of interest to those affected by other forms of SMA. Please have a look at the workshops and, if you are unsure, call Support Services to find out more.

### Workshop 5 for Adults

Facilitated by members of the SMA Support UK & SMA Trust 'Adult Insight Group', this session will tackle the relevant topics of adulthood and SMA. Come along, chat with others who share similar experiences, and participate in all sessions. Anyone can ask questions and add their own ideas and experiences. Partners and PAs welcome.

**Session A** Latest research, plus Q&As with Professor Kevin Talbot

**Session B** Talking to each other

**Session C** Problem solving. What are the issues and what can we do about them?

### Workshop 6 for Professionals

**Session A** Listen in to either: Workshop 1, 2 or 5

**Session B** Talking with other professionals, a chance to meet up and share issues and ideas

**Session C** Listen in to either: Workshop 1, 2 or 5

### Personal Assistance, Accessible Facilities and Accommodation Options

We regret we are unable to provide any personal assistance. It is also a hotel requirement that parents/carers of children and young people aged 16 and under are responsible for them at all times and remain on the hotel premises. This includes during workshop or childcare sessions.

Ettington Chase Hotel provides accessible toilets. There will also be a fully accessible toilet and changing room with portable hoist and bed and an outside mobile toilet/ changing facility parked close by.

The hotel has some accommodation available over the weekend so if you wish to stay you will need to book this directly with the hotel and pay for your own accommodation. Check in is from 2pm. The hotel has offered rooms, including breakfast, for people attending at the following rates:

Single occupancy	£79
Double occupancy	£89
Family Room	£119

If you are bringing your own portable hoist and need a raised bed, make sure to let the hotel know.

**For more information and to book your accommodation, call the hotel direct on 01789 740 000 and quote SMA Support UK.**

**Please note to guarantee you receive this discount, please ensure you have made your booking by 5pm on Thursday 3rd March 2016.**



### Childcare aged up to 12 years

Children will have the opportunity to meet and get to know each other in a relaxed, safe and play oriented environment. This will again be provided by Nipperbout who were such successful providers at our 2014 Conference. All costs covered by SMA Support UK. Places are limited so please book early – see booking form.

Parents must be on site at all times to help with their children's toileting needs and lunch.

**'Safe, relaxed environment for all the children, keep them interested and stimulated with a wide variety of activities and capable staff. Particularly inclusive and a wider variety of activities than other groups he's experienced as a child.'**  
Parent at Conference 2014



**For more information about Nipperbout go to [www.nipperbout.com](http://www.nipperbout.com)**

### Costs and how to book

The day is **free** for individuals and families affected by SMA, their PAs and carers. It includes lunch and refreshments.

Booking form enclosed or download from: <http://smasupportuk.org.uk/booking-form-april-2016>

Donations towards the cost of the day are welcome: <http://smasupportuk.org.uk/donate>

### Professionals

Fee for the day is **£30**. Please download the booking form from <http://smasupportuk.org.uk/booking-form-april-2016> or contact [supportservices@smasupportuk.org.uk](mailto:supportservices@smasupportuk.org.uk)



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## Saturday Night Social

Saturday 2nd April 2016 7.00pm – 11.00pm  
Ettington Chase Hotel,  
Stratford upon Avon CV37 7NZ

- Mobile cinema and pyjama party with one of the latest films suitable for families with children. Beanbags, ice cream and other refreshments provided.



- Chill out space for young people aged 12+ – bring your own music for the sound system. Games consoles, beanbags and snacks will be provided, and more.



- Adults (18 and over) – a night out on the town – transport to and from Stratford upon Avon, suggested places to go to enjoy the nightlife.

## National Fun Day – Easter ‘Eggstravaganza’

Sunday 3rd April 2016  
10.00am – 2.00pm

Ettington Chase Hotel,  
Stratford upon Avon CV37 7NZ

Join us and meet other families and individuals living with SMA. For some of you this may be your first opportunity, for others it’s a time to catch up with old friends. Here is what two parents said about events they attended last year with their children with SMA Type 2:

“Thanks for an amazing day at the weekend. She loved it and said to me, ‘Mum it was like going on holiday!’ Thank you everyone!”

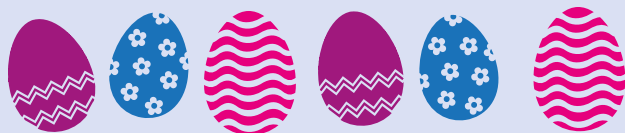


“Thank you so much. We had a great time, and so did our son. He met a best friend for life and they enjoyed whizzing around the park in their power chairs. We enjoyed chatting with the other families affected by SMA and hearing how they are getting on with their lives”



**Our ‘Eggstravaganza’ will cater for all ages and will include:**

- Mobile Farm (including a pony, sheep, goats and ducks)
- Fairground Stalls
- Chocolate Decorating and Truffle Making
- Magician and Balloon Modeller
- Face Painting
- Beautician
- Easter Egg Hunt
- Raffle
- Name the Bunny
- Candy Floss
- BBQ Lunch
- Our very own SMA Support UK Coffee and Cakes



**To book your place for any of these Social Events, please complete the relevant sections on the enclosed booking form.**

**Please note we will not be providing child care for these social events.**