
Review of TM Society Family Weekend

The TM Society's second Family Weekend took place 14-17 July 2017 at the Calvert Trust in the Lake District. The following is a report on how the event went including learning.

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About the Family Weekend

The TM Society Family Weekend brings children and young people living with TM, ADEM, NMO, ON and AFM and their families to share, support one another, learn, and develop friendships.

The event is held at the [Calvert Trust](#), a residential outdoor centre which has over 35 years' experience delivering challenging outdoor adventure holidays for people with disabilities. It is located on the shores of Bassenthwaite Lake, in the Lake District National Park. The centre offers a warm welcome, an accessible venue, accommodation, meals and a programme of activities. This makes it feasible for an organisation the size and resource level of the TM Society to organise such an event.

The mission of the Calvert Trust is:

"...to enable people with disabilities to achieve their potential through the challenge of adventurous activities in the countryside in order for them to develop, change perceptions and make positive and lasting changes to their lives."

The Calvert Trust endeavours to offer life changing experiences which provide positive results that last long after the stay at the centre. Their experienced staff will work with you to ensure that everyone reaches their potential no matter what their level of ability, building confidence and developing a range of skills, which enables visitors to daily take up new challenges back at home.

This is what the TM Society wants for its children and young people who live with TM, ADEM, NMO, ON, or AFM, their siblings and parents.



Help to organise the weekend

The two parents who helped organise the 2016 Family Weekend helped again in 2017. A former participant, who is now above the age limit to attend, also joined the organisation team and is an excellent role model for our families.

Having participants involved in the organisation of the weekend helps to ensure its sustainability on an ongoing basis. It also continues to nurture the ethos and practice of the weekend being by families for families, thus ensuring their needs and wants are heard and taken into account.

The registration process

Advertising the Family Weekend started in December 2016 and included:

- Emailing paediatric neurology contacts at hospitals in the UK
- Emailing families who have a child with TM, ADEM, NMO, ON or AFM aged 4-17
- A post on the website homepage and dedicated web page
- Posts in the Facebook groups
- Email to Support Group Leaders

We increased the places available this year by using all of the spare beds and reserving the two cottages which the Calvert Trust has available. In the end, we did not use the cottages.

This year we had families returning for a third time and we wanted to achieve a balance of making spaces available for new and returning families. We therefore said that new families from the UK have priority, then Europe, and then returning families. Places were awarded on a first come first serve basis after phase 1 of registration had finished.

It was important to repeat that the Family Weekend is only for immediate family rather than have families bring cousins, grandparents, etc. This maximises the number of families who can attend and receive the important support the Family Weekend provides.

We continued with the two phase registration process as it works well. Phase 1 consisted of completing the initial registration form. Phase 2 consisted of families completing the medical and activity forms and paying the deposit. Once a family completed phase 2, their place at the weekend was secured.

We continued charging the £25 per person deposit, and this year were diligent in ensuring families paid it. If families attended the weekend, the deposit was returned.

We had 2 families cancel around May and we were filled their places from the waiting list. A family had to cancel a week before the weekend.

15 families attended totalling 60 people. There were 8 new families.

Of the children and young people:

- 10 had TM (including Owen)
- 4 had ADEM
- 1 had NMO

Activities

The following outlines the activities during the weekend. The outdoor activities included orienteering, bushcraft, canoeing, zip wire, rock and rope (swinging, climbing, abseiling), riding horses, trap driving, archery, and cycling.

	8 July - FRI	9 July - SAT	10 July - SUN	11 July - MON
8:00 – 9:30		Breakfast	Breakfast	Breakfast
9:30 – 12:30		Morning outdoor activity for families	Morning outdoor activity for families	Checkout by 10:30am Group photo Departure
12:30 – 13:30		Lunch	Lunch	
13:30 – 16:30	Families arrived between 15:00-17:00	Afternoon outdoor activity for children Educational Q&A for parents with medical professionals	Afternoon outdoor activity for children Educational Q&A for parents with medical professionals	
16:30 – 18:00	Neuro-physio sessions	Bladder & Bowel Q&A for children or Swimming, games room, aqua therapy sessions or rest	Swimming, games room, aqua therapy sessions or rest	
18:00 – 19:00	Dinner	Dinner	Dinner	
19:00 – 19:45	Ice-breaker activity	Educational Q&A for children with medical professionals	Swimming, games rooms	
19:45 – 21:00	Swimming, evening walk, games room, or aqua therapy sessions	Swimming, games room, or neuro-physiotherapy sessions	Swimming, games room or neuro-physiotherapy sessions 20:30 Disco	

Welcome packs

The parents received a welcome pack containing joining instructions, a TMS notepad, and pen. Given that many families received the wrist band, trolley coin key ring, and pin in previous years, these were left on the side for people to take if they wanted them.

The children received a goody bag containing bubbles, chalk, stretchy people, and a fidget toy. The purpose was to provide items which would encourage the children and young people to interact and have fun.

Every person attending receives a t-shirt and this year's design was:



Family Activity Groups

The way the activity groups were split in 2017 worked well for the most part. The following has to be taken into account when creating the groups: genders and ages of the children, disabilities (you can't have more than 2 wheelchairs in a group because of the room it takes up in the bus), the balance of returning and new families, and the activities the family wishes to do.

We used the same child minder as we did in 2015 and 2016 on the Saturday and Sunday afternoons so both parents could attend the Q&A with the medical professionals whilst their children attended the afternoon activity.

Exhibitors

We didn't have any exhibitors in 2017. We asked the company which was formerly known as Molton Rock, who demonstrated an outdoor wheelchair in 2016 at the weekend, but as it had just been sold off to another organisation, they weren't able to come.

Educational Q&A sessions

The educational Q&A sessions with medical and healthcare professionals experienced in treating TM, ADEM, NMO, ON and AFM were offered to both the parents and children/young people as we did in 2016.

For the parents the aim is to give them the opportunity to learn more about the condition their child has and what else they can be doing for their child.

For the medical professionals, it gives them an opportunity to hear and respond to the concerns and questions of families outside of a clinical setting. As a result, they often learn things they wouldn't during appointments which can impact their clinical practice and any research they do.

The medical professionals

5 medical and healthcare professionals attended. We get professionals from a variety of hospitals and organisations to help build the TM Society's network of medical and healthcare professionals and raise awareness of the TM Society. In some cases, it helps to have the same medical/healthcare professional attend due to research they are involved with.

Name	Profession	Hospital	Time with us
Dr. Ming Lim	Consultant Paediatric Neurologist	Evelina Children's Hospital, St. Thomas', London	15-16 July
Kiranjit Atwal	Dietician	Great Ormond Street Hospital - London	14-16 July
Joanne Teager	Under 18's services team	Backup Trust	14-16 July
Liz Cowan	Chartered Physiotherapist & Children's Specialist	SP Therapy Services	14-16 July
Karen Vercoe	Occupational Therapist & Children's Specialist	SP Therapy Services	14-16 July

Two healthcare professionals unfortunately had to cancel at the last minute due to their own or a family member's serious health issues – the child/adolescent psychotherapist and a urology nurse

from the NMO team at the Walton Centre. A neurologist cancelled in May due to a health issue as well. The organisation team tried to find replacements but were not successful.

All of the medical and healthcare professionals took part in the activities while they were with us and this gave parents additional opportunities to ask them questions.

Q&A for parents

It was highlighted to parents that the educational sessions were meant to impart information and signpost where and how to access services rather than clinical advice for individual cases.

The Q&A continued as in 2016, where we obtained questions from parents in advance to start the conversation and conducted it in an informal way. There were no presentations but the professionals were encouraged to bring handouts.

Of the 11 families who responded to the feedback form, 6 said the Q&A was 'excellent' and 3 said it was 'very good'. The other 2 families opted to attend the activities instead.

The only issue we experienced is that many of the returning families, and some of the new ones, chose not to attend the Q&A or attend one day of it only. This meant we had many more child minders than needed and the TM Society had paid for those child minders.

Q&A for children

We had one Q&A for the children and young people and it worked out well. For the children, the purpose is to give them their own opportunity to speak directly with the professionals. This is optional for them to attend.

We did not split them by ages or whether or not they are a sibling or have the condition as there isn't much room in the schedule to allow for separate sessions.

Based on feedback from last year, we made this year's Q&A a parent free zone. It worked very well. We also collected questions in advance. But it's almost not necessary as the children and young people asked a lot of questions.

We provided some guidelines for the kids such as raise your hand to ask a question and don't speak if someone else is speaking, and they followed that very well!

Of the 11 families who responded to the feedback form, 2 said the children's Q&A was 'excellent', 5 said it was 'very good' and 1 said it was 'good'. The other 3 did not attend the children's Q&A.

Neuro-physiotherapy and Aqua Therapy Sessions

This year we continued offering 30 minute neuro-physiotherapy sessions and were also able to offer aqua therapy sessions.

A learning from last year was to ask the parents to book this in advance. We did this and it worked well. However, it would be easier to integrate this into the registration process.

This year we offered aqua therapy sessions. The only issue is it was difficult to conduct the sessions in a pool where there are other families swimming and being noisy. If we continue to offer aqua therapy sessions, it is best to do that during the afternoon swimming slot and we would need to restrict the number of families in the pool.

The feedback on these sessions was favourable both anecdotally during the weekend and in the feedback form.

Of the 11 families who responded to the feedback form:

- 5 had a neuro-physio session and out of that, 3 said it was 'very beneficial', one said it was 'beneficial', and 1 family said it 'wasn't as beneficial as they had hoped it would be'.
- 5 had an aqua-therapy session and of that, 1 said it was 'extremely beneficial', 3 said it was 'very beneficial', and 1 family said it 'wasn't as beneficial as they had hoped it would be'.

Camp Counsellors

2 young people were asked to be camp counsellors, 1 who has TM and 1 sibling. They helped with:

- Welcoming families and registration
- Answering children's questions and being there for them
- Moving people along from one activity to another and answering their questions
- Encouraging children and parents to put questions in the Q&A box
- Ensuring children had a name badge and were introduced to the child minders during the afternoon sessions.

This role gives responsibility to some of the older kids, and their help can make a valuable contribution to the weekend. It also grows the ethos of the weekend being by families for families.

One young person proactively approached the organisers and said she would like to be a camp counsellor next year.

Budget

The original budget for the 2016 weekend was £30,833 as we increased the number of spaces available from 60 to approximately 72.

	2015	2016	2017
Budget	£25,713	£25,813	£30,833
Actual	£21,700	£24,400	£25,700
# participants	39	59	60
Cost per participant	£556.40	£413.54	£427.76
# Cancellations	17 people	1 person	5 people (a family)

The following helped to keep costs down in 2017:

- The cottages were not used in the end and the Calvert Trust did not charge us for them even though the second cottage we cancelled the week before the event.
- Two medical professionals did not claim their travel costs.

This year it is not known yet how much money was raised specifically for the TM Society Family Weekend so we are unable to say as of September 2017 how much of the charity's reserves were used to run the weekend.

Travel bursaries were mentioned during registration, however there was no take-up by families this year.

Feedback from families

A feedback questionnaire was circulated among the 15 families and 11 responded.

There were 18 questions, most of them multiple choice on a 5 point descriptive scale. Full responses can be found in the appendix. A summary is provided here.

Of the 11 families who responded:

- **Overall**, 10 families said the weekend was an 'excellent' experience and 1 said it was a 'good' experience.
- 10 families said the **outdoor activities** were 'excellent' and 1 said very good.
- 4 families said the **evening activities** were 'excellent', 6 said they 'enjoyed them very much', and 1 family said they didn't enjoy them as much as they had hoped to. The evening activities included an ice-breaker, evening walk, swimming, games room, socialising, and disco.
- 10 families said the **organisation by the TM Society** was 'excellent' and 1 said 'very good'.
- 8 families found the **Calvert Trust** (accommodation, food and organisation) 'excellent', 2 said 'very good' and 1 said 'good'.

When asked what was the one thing the parents got from the weekend, they responded:

- Talking with other parents going through the same or similar situation. This was also described as *very beneficial* and an *amazing opportunity*.
- *We came away from the weekend very positive and concentrated on our daughter's abilities rather than disabilities!*
- *Very informative, I enjoyed talking to other people going through similar experiences. Brilliant to talk to the experts. Everything was excellent. Very well planned and I felt relaxed and comfortable throughout the weekend. It was an excellent experience, I felt such relief that it helped my child come to terms with her illness she is not alone!!*

When asked what was the one thing their child with TM/ADEM/NMO got from the weekend, the responses included:

- *Helped to overcome fears about her condition.*
- *It made him more confident and independent and the aqua therapy session really benefitted him so he asked for it at the hospital and is doing weekly sessions now for 5 weeks which is great.*
- *He loved the weekend. Being able to do the activities and be with children like him made him less anxious and more confident.*
- *My child was delighted to meet others with the same or similar needs. The children benefit greatly from mixing with others 'the same'.*

We also asked how the weekend benefited the siblings.

- *My son loved it. He enjoyed being around all of the other children and taking part in the activities. It helped him to understand about disability. He realised that all children were included and can do the same with the right support. He loved the disco and Michael playing the guitar the best :-)*
- *They realised how lucky they were by interacting with children & especially teenagers with disabilities. They talked to us the whole way home about how amazing the kids they met were!*
- *He understood that it is not just his brother but there are more people that have differences and to live better with them.*

What, if anything, has changed for your family as a result of the Family Weekend?

- *We are more informed and aware. I think it helped us to bond as a family. We were there for our daughter but our son was included too. The activities made us work and support each other, including the wonderful people we met. Everyone was very kind/friendly and I hope to keep in touch with all of them in the future. We couldn't put a price on this valuable experience. Just perfect!*
- *We don't feel alone and have a network of people who can help and support when necessary.*
- Increased confidence was mentioned by several families.
- Increased knowledge about NHS services, such as a spinal rehabilitation unit and aqua therapy, and subsequently obtaining referrals.

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- *We got a lot of good ideas for physio, nutrition etc that we've implemented since we came home.*

The families' specific feedback for the Calvert Trust included:

- The instructors were very good and friendly; staff very helpful.
- Very good at catering for dietary needs.
- Activities were great.
- Food was delicious.
- Accommodation on the whole was very good.

The families' specific recommendations for any future Family Weekend were:

- 3 families said don't change a thing.
- A 10 minute break for the parents in the middle of the Q&A's.
- If the Calvert Trust cannot provide halal food, they could provide fish instead. This feedback was given to the Calvert Trust.
- More neuro support/doctors please.

Learning for the future

The following are key learning points which will be implemented for 2018.

- Continue to highlight that the event is only for immediate family.
- Continue to email contacts at hospitals with paediatric neurology departments to let them know we are holding this weekend.
- It works well having all the families onsite so we do not plan to use the cottages as they are 4 miles away.
- To maintain a balance between returning and new families, we have told returning families that if they've attended 3 years in a row, they will be last in the queue for getting a place in 2018 and so may not be able to attend.
- Have families sign up for neuro-physiotherapy and aqua therapy sessions as part of the registration process to reduce the amount of extra emails and phone calls to the families.
- If aqua therapy sessions are offered again, offer them in the afternoon and restrict the number of families who can use the pool at that time.
- Have families sign up for their time in the swimming pool during the registration process as this can take up too much time during the ice-breaker activity.
- Can consider having other equipment providers present but it may need to be kept to a minimum, possibly up to three, as the weekend is full of activities.
- When doing the t-shirts, it won't cost anything more to have t-shirts done up especially for the camp counsellors.
- Make sure to have 15 minute break during the Q&As for parents.
- From this year's experience, we know that the Calvert Trust can accommodate 66 people. If the cottages are used, that can increase to 77. However, the Calvert Trust would not want

more than 72 people total as it would mean the sizes of the activity groups would become too large and there wouldn't be space in the cafeteria for everyone. Also, it is not recommended to use the cottages as they are 4 miles away from the main site and we wouldn't want families to feel separated.

- Have camp counsellors help to ensure every child has someone to play with.

2018

The TM Society management committee has indicated there are enough funds to run the Family Weekend in 2018.

Dates have been reserved with the Calvert Trust and it will take place **6-9 July 2018**.

The organisation team is already speaking to parents who wish to help organise the weekend and determining which medical and healthcare professionals to invite.

by Barbara Babcock
18 September 2017