



Summer
NEWSLETTER

JULY 2018

A Message from the Trustees

Update from Jayne Stevens, Participation Co-Ordinator | **Face 2 Face**

Looking back... | **Parent Reps** | Exclusion Survey Results

Aiming High Board for SEND | ME Awareness | **Exotic Zoo Feedback**

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Picnic in the Park | Dates for your Diary



Win a £100 shopping voucher!!

Please complete our enclosed Annual Survey and return to us by the end of August to be entered into our raffle for a chance to win!

Welcome from the Team

We hope you are enjoying this wonderful weather and are busy planning your summer holidays. We would like to take this opportunity to say a huge thank you to all the Staff and Volunteers.

We personally have learnt a lot about the amazing work that everyone does and how dedicated all the staff and volunteers are in their quest to spread the word, provide opportunities for Parent/Carers voices to be heard which help to influence services whether this be via our family groups, social media, conversations and direct contact.

Jayne and Shana are working tirelessly to bring more events and opportunities for Parent/Carer involvement via the forum and Face 2 Face scheme.

It's exciting that PODS is celebrating its 10th anniversary and seeing how much it has grown over the years, we have began celebrating this with a Question Time Panel involving 12 professionals from LA/Health as part of our Annual General Meeting.

Elaine Pearce is now well and truly in her new post and is doing a great job, thank you Elaine.

Please see our Annual Report which we've shared on our website. Further events and celebrations are planned, please see page 26 for our Parent/Carer Party Night.

Thank you to everyone who attended our Question Time/AGM in July - report will be available via our website over the summer.



PODS PARENT CARER FORUM AT A GLANCE

"TOGETHER WE CAN MAKE A DIFFERENCE"



MEMBERSHIP

790 across the whole county
Members given Consent to be contacted by PODS since new GDPR Rules: 225



FACEBOOK

Followers in T&W: 1332



TWITTER

Followers: 628



MEETINGS ATTENDED

Between March'18-June'18: 36



FAMILY GROUP

How many attended March'18-June'18: 132

Make a difference...

**PARENTS
OPENING
DOORS** 
PARENT CARER FORUM

BECOME A TRUSTEE

Our committed and enthusiastic team are keen to recruit to our Committee Board of Trustees:

We welcome interest from potential trustees who are willing to engage with our Charity and who can offer any of these:

- **Share your personal experience**
(NB: you do not have to have a child/young person with a disability/additional need)
- **Demonstrate your commitment to our work**
- **Donate your professional expertise**
- **Get to know and understand our community of families**
- **Help us to make a difference.**

Trustee meetings take place once a month and additional information is available on our website (eligibility and Role Description). You do not need previous Trustee experience. We welcome applications from our Parent Rep network, and also wider membership and community.

Interested? Please get in touch:

**01952 271532 or email: info@podstelford.org
www.podstelford.org**



Company/Charity number: 1150871

Feedback from our current Trustees

How would you describe PODS?

- Assisting families with children and young adults with issues.
- An invaluable resource for local families.
- A very valuable resource for parents and families.

What does your role entail?

- Supporting the staff, attending Trustee Meetings. Supporting development of services.
- Support the staff, attend Trustee Meetings. Make decisions together. Help to ensure funding is distributed appropriately to achieve the best outcomes.

What inspired you to become a Trustee?

- Asked at another meeting.
- My own Son has ASD and ADHD. Like many people, I needed support at many parts over the years.
- To gain more knowledge of what PODS was about, and what they offered.

What does PODS mean to you?

- It's been a great support to me and I value the friendship and companionship of other parents.
- Support for families and improving lives. Making a difference.

How do you see the future of PODS shaping up?

- Hopefully with funding it continues.
- We need to think about the future, how we can fund PODS in the future and how services can be developed.
- Growing, going forward with support, reaching more families. Sharing resources, building groups and support.

What would you say to those considering becoming a Trustee?

- Come along and see what we do.
- Very worthwhile, important, not as scary as it might seem.
- Please join us. PODS do a valuable job, and we need more Trustees to help us continue to support staff. It's interesting.

How do you feel PODS supports its families?

- From feedback, Excellent, this will become more important with Government cuts.
- Fantastic. There can never be too much support for PODS families.
- It's a valuable resource, it provides support, training, groups, meetings, information, guidance and sign posting.

What else could PODS do to help support our families?

- Be there when needed.
- I would like to see PODS beginning to offer some advice and guidance to families.
- I am relatively new to the Trustee's, and feel they do an amazing job.



A New Changing Place

Opened at The Place,
Oakengates

A new Changing Place has opened at The Place in Oakengates, the library staff will have the key to The Changing Facility should you wish to use it. There are also Changing Facilities at Southwater, at Morrisons in Lawley and Attingham Park.



UPDATE FROM JAYNE STEVENS, PARTICIPATION CO-ORDINATOR



This year is very exciting for us as a forum as we celebrate 10 years in existence. I would like to personally thank those parent carers who were in it from the beginning or very near to it – Nina MacLeod, Debbie Holding, Debbie and Dave Hart, Julie Stafford who all played a very important role – some of whom are still involved to some extent.

I was really pleased to be able to invite past and current members of our team (alongside Shana's Face 2 Face Team) to an Afternoon Tea Party that was held in Admaston (not too far away from one of our first family groups at HLC) to celebrate 'Volunteers Week'. Thank you everyone who joined us and if you weren't able to attend don't worry, there are plenty of opportunities for a get together later in the year – take a look at our events page for more information.



A special thanks should be given to T&W CVS, in particular the Parent Partnership Service (now IASS) who hosted the forum in the very early days before giving us the confidence to fly and be truly independent. Thank you to Debbie Gibbon, and particularly to Julie Collins who I shadowed in my role for a year before true independence and also to Lesley Perks and Alex Hiam.

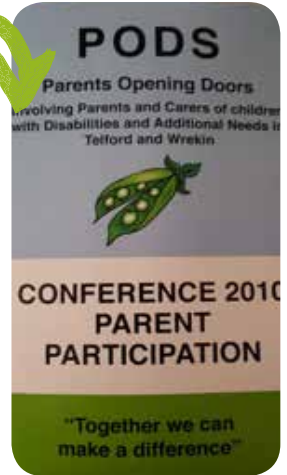
Best wishes,

Jayne Stevens

PARTICIPATION CO-ORDINATOR

Looking back through our archives I found some memories: One of our first conferences was held in 2010 – who remembers the peas logo?!

A photo from our 'Communication' conference in 2011 with Maggie Johnson.



CHARITY STATUS

We are currently in the process of applying for charity status to enable our forum to become more sustainable in the future.

We are committed to ensuring that our work continues for the benefit of the 300+ families we hold on our mailing list and we look forward to sharing news with you on our future project plans for the next 12 months

HOSPITAL FOCUS GROUP

We've been given the opportunity to participate in discussions around the new Women & Children's Hospital Focus Group - particularly design plans. We are pleased to be able to tell you that following PODS input the following considerations have been included in the designs: a quiet area, room for wheelchairs to manouvre in waiting areas, adequate changing facilities, seperate feeding areas, oncology ward will be suitably designed to prevent cross infection.

We would love to have your memories to share and putting a special celebration together for later this year. Please send anything in - photos or comments are welcome - contact details on the back of newsletter.

Parent Reps

Our Parent Reps continue to meet once a month for our 'Strategic Participation' Meeting – we discuss the meetings we have been too, key areas of discussion taking place out in the community and via our social media Facebook page and group.

We have just completed a 'Confidence for Reps' course ran by Julia Butler, a fellow Parent Rep who is also a trained and experienced coach and mentor. She has given skills to our parent reps to help us all think about what confidence is and why do we need it, ideas and approaching to thinking how we can develop confidence and a practical tool and action plan to build confidence. One of exercises we completed was around 'zones' – discussing our comfort zones, our stretch zones and then panic zones. It's my role as Participation Lead to understand where my reps sit in these zones and offer support by building confidence in those stretch zones to enable them to become comfort zones. This is an ongoing process and through workshops offered to our parent reps and training opportunities alongside mentoring and coaching opportunities we continue to build a strong team that can take PODS Forum forward into the future.

At our meeting in June we completed an exercise with our Parent Reps.

How would you describe PODS?

- A voice and support for families, passionate, motivated and determined to do the best for our children and the services they require.
- PODS is becoming more and more a valuable service and is becoming a more prominent voice within Telford regarding all issues re disabled children/transitioning.
- Fantastic, helpful, giving parent/carers a voice.

What inspired you to become a Parent Rep?

- I was helped a lot, through the family meetings and trips that are put on. I want to help the next lot of parents struggling with "experts" CAMHS etc.
- Wanting to increase my own understanding and also to help make sure our children's voices are heard and needs met.
- My Daughter, and to get involved in meetings that can help other parent/carers.

How helpful did you find the training?

- Extremely useful with good information and also helped to form the feeling of a team. A good understanding of what our role is and how to carry it out effectively.
- Very useful, continuous training makes me feel that we are doing a good job and we are prepared for all issues.
- Excellent, the training was really good, useful, gave me a better understanding of PODS.

Within your role do you feel supported and part of a team?

- Yes, very much so. The Steering Group meetings also help with this.
- Yes definitely.
- Yes, I do definitely feel supported and part of the team. It's a wonderful team of very enthusiastic Parent/Carers.

How does the work Parent Reps do help our families?

- Helps shape the services and decisions at a local level.
- Families need support of information about SEND.
- It helps to voice their concerns and difficulties to the appropriate authorities/services.
- Our family's voices get to be heard within services.

What else could PODS do to help support our families?

- Get more Families involved.
- As they are, as a voice for Parents within meetings/ letting families know what is happening. I don't think there is much more they could do.
- Already doing a fantastic job.

What does the role of a Parent Rep involve?

- Talking in meetings and informing other people about people.
- Representing the PODS and making sure the facilities and services provided are suitable for access to our children and their families.
- Being a voice for parents/ children. Getting our issues heard by the relevant services.

What have you personally gained from your role as Parent Rep?

- Support, understanding of processes, a feeling of giving back.
- A bit more confidence, more understanding about SEND. Also, some control of the future.
- A better understanding of PODS and how it helps families, more confidence.



Family Groups



Our Family Groups continue to be popular some of the matters we have discussed and reported back on have included: Silverlight IAPT, Prescription Ordering Direct, Schools reading reports prior to meetings. Babysitting service needed; PODS Pamper info, Future in Mind, Crisis support for CAMHS/A&E at PRH, North Staffs Adventure Playground, School trips and exclusions, IASS, PDA.



One of the best **"Oh Wow"** conversations goes to a family who regularly attend our Hollinswood Family Group who told us how they set up their Amazon Echo to help with bedtime routines and reminders. Not been too tech savvy myself I was impressed by how simple it was to set up via the Amazon app (other devices are available that do the same sort of thing I believe).

Exclusions survey results

You might have seen the National press work on School Exclusions Review by now. We took the decision to focus on the local picture and these are the results from our respondents:



Exclusions review

Call for evidence

Launch date 16 March 2018

Respond by 6 May 2018

- 11% of respondents were encouraged to be home schooled;
- 76% respondents were isolated in school (taught separately because of their SEND);
- 77% asked to be taken home early or come in late;
- 84% not allowed to participate in certain activities such as school trips;
- 62% have been unofficially excluded (asked to be kept at home for more than a day);
- 21% have attended 2 schools or settings due to lack of suitable provision;
- 84% of exclusions from mainstream, with 23% from academies. Although small minority from specialist provision attached to mainstream or special schools this is still concerning;
- 53% of children were excluded in secondary, closely followed by primary at 47%. One preschool and some post 16 also reported;
- 99% of children have a diagnosis (or awaiting diagnosis) of ASD, ADHD, Autism, Aspergers, Anxiety, Sensory Processing Disorder, PDA, with some Hypermobility, violent behaviour, attachment, specific learning difficulties.

This information has already been highlighted as part of a subgroup of the Aiming High Board, via the Communication and Consultation group that we are member of.

Work is taking place internally within the council to identify key schools where exclusions are high and it is also a key focus of Her Majesty's Inspectorate OFSTED Regional Team so we welcome that the matter will be continually reviewed.

Aiming High Board for SEND

This is the key strategic board that I attend alongside one of my Parent Reps (Julia, previously Keiron) and where everything to do with SEND comes together for discussion and action, under the Chair Heather Loveridge who is the Assistant Director for Education and Corporate Parenting.

“The purpose of the Aiming High Board is to oversee, support and challenge the implementation of the SEND Reforms and to ensure appropriate, timely assessment, planning and support for all young people with SEND in Telford and Wrekin”

The work of the board includes

- Providing a strategic direction and oversight for children and young people with disabilities and special educational needs, as detailed in the SEND Strategy
- Ensure the delivery of the agreed action plan.
- Monitor and hold to account all partners in the Local Area (led by the Local Authority) to meet the statutory requirements set out in the SEN legislation including:
 - Developing the Local Offer,
 - Developing systems and processes for assessment,
 - Education, Health and Care Plans,
 - Develop personal budgets,
 - Plan provision of information, advice and support with service users,
 - Develop Joint Commissioning Approaches,
 - Engage local partners, including further education and training providers
- Ensure that an active Parent Carer Forum is in operation
- Ensure robust project planning processes are in place.
- Report on the developments of the Task & Finish sub groups

The task and finish groups also have a parent rep to represent parent carers voice and in some cases there are two reps where our key work is highlighted as a priority (currently Transition). As part of the ongoing review of the SEND Action Plan that you can find on the Local Offer the Task and Finish Groups will be headed up by key SEND Leads and they include the following:

**Parent Carer and
Young Person
Communication
and Local Offer
Group**

**High Needs
Review and
Implementation**

**EHC
Pathway**

**Joint
Commissioning**

**16-25 Preparing
for Adulthood**

**SEND Workforce
Development**

Cerebra Accessing Public Toolkit Workshop



We hosted a Cerebra 'Accessing Public Toolkit Workshop' in May which was attended by ___ families. The focus of the workshop was to give an insight into understanding what types of disputes are faced by families and how by using the 'toolkit' these can be navigated.

Types of disputes covered include Inter-agency disputes, No such word as 'can't, The budget is spent, The panel/manager says 'no', Too difficult to think about, Delay, 'I don't have the authority to...', Personalities, Highly contested fact disputes.

The families who attended all found the information shared very beneficial. For anyone who did not attend all the information is available on Cerebra website along with model letters to use when writing about a dispute.

Mystery Shopper for the Local Offer

We are continuing to ensure that the Local Offer is updated to meet the needs of our families and highlighted areas we have raised for review include the following. Hopefully by the time of reading some of these will have been actioned. Will ask Natalie for update

- Short Breaks Information
- Transport Policy
- EHCP Reviews and Annual Reviews
- Carers Assessments
- Bus Passes
- Complaints & Compliments Link
- Search Bar for searching information within 'Local Offer'



Transport



Summary Information shared from [Telford.gov.uk](http://www.telford.gov.uk) website. More information is available via this link: http://www.telford.gov.uk/info/20025/school_information/10/home_to_school_transport

Did you know

if you call (and leave a message) before any taxi is despatched from depot, then the council will not be charged for it (we've been told that the savings amount to £1,000's).

Telephone: **01952 384620**

Email: **transport.contracts@telford.gov.uk**

opening times are 8am-5.15pm.

For families used Fleet/Integrated Transport their contact number is **01952 384831** and they are open from 6.30am-6pm.

"If you are unable to transport your child to school and believe you are eligible for support from the Council under our statutory duty, please do ensure that the Transport team receive your online transport application no later than 1 August 2018. Phone number for Transport team is

In line with online school admission process, paper applications are no longer accepted and all applications must be made through the online portal.

If we do not receive your application by 31 July 2018 we cannot guarantee your application will be considered before the start of the new September 2018.

It's worth noting that due to the various eligibility checks that must be undertaken by different Council departments when considering an application, it can take 20 working days to process. As you can imagine, our summer months are extremely busy and therefore applications can take longer which is why the earlier you can apply, the more likely you are to hear an outcome before the new term starts in September.

If you are already in receipt of transport assistance and have moved house since you initially applied or your child is moving school you must reapply as your eligibility could have changed. Again, please apply online".

NB: Parents and carers for children over the age of 16 MUST re-apply for assisted transport every academic year.

Face 2 Face

Parents supporting Parents
of disabled children

Befriender Training

We now have 8 new Befriender's that have completed the 9 week course. Congratulations to Denise Meir, Tracy Cashmore, Tracey Gordon, Sarah Richards, Amy Byrne, Uma Bhatia, Sarah Peach and Matt Meir. They are currently going through the DBS process, and are eager to start offering support asap. I'd also like to thank Jayne Stevens, a trained Face 2 Face Befriender herself who supported me with delivering the Face 2 Face training.



Picture Exchange Communication System (PECS) Level 1

Lian Smith is one of Befriender team that have trained at level 1 in PECS. Which covers Phases 1-6 How to communicate, Distance and Persistence, Picture Discrimination, Sentence Structure, Attributes, Responding to 'what do I want' and Commenting. We will be enrolling on level 2 training with PECS which will be completed in December. We feel this is a great addition to the practical support we are currently able to offer parent carers. Through personal experience we understand how important PECS can be for families with children who are non verbal or have complex communication difficulties. If you would like more information on PECS please get in touch with the Face 2 Face Scheme.

Lego Based Therapy

Uma Bhatia is one of the Befriender team trained in Lego Based Therapy. Lego based therapy is a play based social skills intervention designed to improve social and communication skills in children with autism and related conditions. We will be running a taster mini workshop at AGM and then running some workshops for families following this.



Sleep Practitioner Training

We have been lucky enough to have been accepted for one of the Children's Sleep Charity's fully funded places on their Sleep Practitioner Training. This was offered to us after we submitted an application for one of their limited funded places. The course is run in Doncaster and it will comprise of lectures being given by 7 professionals covering areas around medication, sleep disorders and children with additional needs. Also an insight into links with bedwetting and sleep, lectures in attachment, anxiety and sleep, and the bedroom environment. Following the training we will be looking for a family to support and write a case study on to complete the accredited training (if this is something you would be interested in gaining support around please get in touch via - 07557 130 091) We are also looking at securing some sleep workshops for parent carers as well as our Befriender's to attend more locally.



Hub Sessions

We hold our Face 2 Face drop in session at the Information Hub, Stepping Stones (Malinslee) on Thursday's between 12-2.30pm. During these sessions we have been helping parent carers make visual aids and resources and sharing the growing library of reference books we have for our parent carers. It's been a great base also being able to talk to parents who's children are just starting the multi disciplinary assessment (MDA) journey, ensuring they know what our befriending scheme offers, that in our experience the importance of peer to peer support is invaluable and also how they can get in contact with us. Pop in and say hello

Family Groups - We co-host the 5 monthly Family Groups alongside PODS across Telford and Wrekin. Everyone is always offered a warm and friendly welcome, a great opportunity to get to know others locally, where we share support, experiences, ideas as well as a good old catch up.

Wendy Usher Workshops - We are finalizing details of securing Wendy Usher creator of 'Play Doctors' to come and deliver 2 days of workshops for our parent carers. Some of you may remember Wendy as she did deliver some workshops for us last year. We have a number of options for workshops a few being

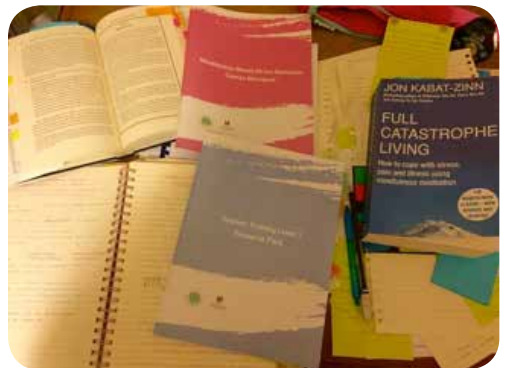
- Supporting children and young people with ADHD

- Dyspraxia is not just about being clumsy
- Supporting children and young people's mental health
- Creating sensory calming activities, Learning how to make and use resources for visual learners

We are hosting workshops on the 10th and 11th September, an Eventbrite link will be set up for parents and carers to book places once we have decided which workshops to run.

Inclusive Family Trips - We are very excited to be able to support the inclusive family trips again this summer after so much positive feedback and lots of happy families last summer. Details and booking info will be confirmed shortly.

Mindfulness Training - Teacher training has now been completed, this is going to be fed out to the wider Befriender team and then introduction taster sessions directly to parent carers. Details will be circulated once dates and venues confirmed.



Thank you for your continued support and engagement. If you are interested to learn more about our Befriending scheme, how we can support you please don't hesitate to get in touch.

Shashama Weare
Face 2 Face Co-Ordinator

For Face 2 Face contact details, please see the back page.

**From 17 July the telephone number
for urgent out-of-hours medical help
or advice will be 111.**



**It's free to call,
24 hours a day, 365 days a year.**

Designated Clinical Officer for SEND

My name is Catherine Smith and I am the Designated Clinical Officer for SEND. The role is part of the SEND reforms and is a key role within health. It has a broad remit so is developing differently around the country.

Since starting in the post last September the initial focus has been on developing an oversight of the different health teams and their contributions to the EHC process, in particular the health advice in EHC plans and supporting the LA teams including schools to understand medical conditions. A key element to the role is attending EHC panel and assuring health contributions in the plans. It also includes participating in the quality assurance process.

I am also the Children's Continuing Care assessor and have links with the Designated Nurse for Looked After Children and we are working to ensure processes are in place and we start to coordinate / align those health assessment processes. I am starting to work on any improvements we can make to the Local Offer and how services are reflected in the offer.

The role sits alongside the Children's Commissioners in health (i.e. CCG) so that they are aware of how services can better support children's outcomes. The role is very much concerned with quality improvement and assurance all of which must be done with children, young people and family participation and engagement to inform strategic development.

Direct support to schools is to answer any queries and support them to work alongside health professionals to ensure the correct support is in place to manage health needs in schools. This may include ensuring the right questions are asked to ensure the correct individual health care plans are in place. If indicated via health professionals I will undertake a continuing care assessment where the needs are very significant.

Catherine Smith

Senior Practitioner Children and Young Peoples Continuing Care and
Designated Clinical Officer for SEND, Telford and Wrekin Clinical Commissioning Group

SEND Team Structure

Following the release of the new structure chart for the SEND team last month, there have been a few queries about who is leading the team. To confirm the SEND team lead position is currently being shared between Mark Wadhams and Natalie Bevan. Below provides further information about their role and responsibilities and how to contact them.

Mark Wadhams

Interim SEND Team Lead
&
Lakeside Locality SEND Officer



I have oversight of the Hadley, Wrekin and Lakeside locality teams. I am also the SEND Officer for Lakeside.

Please contact the SEND Officer allocated to your school for any queries. If you need to raise issues further then please call me on **01952 384458** or email **Mark.Wadhams2@telford.gov.uk**

Natalie Bevan

Interim SEND Team Lead
&
SEND Project Lead



I have oversight of the Early Years and Preparing for adulthood (PfA) locality teams. I am also the SEND Project lead.

Please contact the SEND Officer allocated to your setting for any queries. If you need to raise issues further then please call me on **01952 567364** or email **Natalie.Bevan@telford.gov.uk**

These arrangements are in place until 31st August 2018 by when recruitment into a permanent leadership role will be shared.

Help with 'Moving and Handling' for your child or young person.

A new service has been commissioned and you can self-refer directly to them by phoning: 01952 607783.

Could your handling tasks be made easier when you are caring for child or young adult at home? Ask yourself the following

- Do you get problems with back or shoulder strain?
- Are you struggling with a particular transfer - for example helping someone stand up or rolling someone in bed?
- Do you have an existing injury which is getting in the way of caring?
- Do you have moving and handling equipment in your home that you are struggling to use?
- Has the person you are caring for deteriorated and has it become more difficult to move them?

We offer free one to one home based assessments by a moving and handling advisor which can include:

- Advice and practical input given.
- Individual assessments in the home
- Practical ways to help prevent injury
- Information and advice about back care
- Suggested and possible provision of equipment

This will help your confidence in handling tasks and improve your own physical wellbeing.

Jill Tiernan who has commissioned this services tells us "We see this role as an important part of improving the well being of parent carers and carer in general and Jo Britton Asst Director is keen to see this role develop which is great news".

ME AWARENESS, A Mother's Story...



doing things like days out, holidays, get together, with family & friends, meals out etc etc. A normal family living a normal, happy family life.

And then ME hit and everything changed.

Our gorgeous brave boy now suffers 24 hours a day with horrendous symptoms including unrelenting and debilitating physical and mental fatigue, heightened sensitivities, pain, severe cognitive impairment, weakness, dizziness, insomnia and many, many, many more. He never has respite from his symptoms not even for a minute.

He is bedbound 75% of the time and sofa/housebound the rest. He doesn't have the energy to dress or shower very often. It's been 3 and a half years since he went to school and he has lost all but one of his friends - a lovely girl who keeps in touch by text. The only other contact he has with his peers is if they happen to be on the computer when he has the energy to go online. He only leaves the house very rarely and when he does he has to use a reclining power chair as he's too weak to sit in a normal wheelchair. He regularly cannot cope with conversation or even having someone sitting quietly in the same room as him. If he does 'too much' - which for him might be having a conversation/coming downstairs (on his stairlift)/going on his computer/having a shower/sitting quietly in the garden etc - he will suffer dreadful 'post exertion malaise' (payback) which will take hours/days/weeks to recover from. Even the most basic of tasks such as coming downstairs or showering or even sitting semi upright have to be supported by mobility equipment to ensure he is safe and the exacerbation of his symptoms are as minimal as possible.

ME has also caused the secondary

My name is Kathryn Woodvine, and this is my Son's story on his battle with severe ME.

I don't tend to focus on things too deeply because, to be honest, it breaks my heart, but this is our story, a story of how Myalgic Encephalomyelitis (ME) has destroyed my Son's life and in turn has devastated my entire family.....

Our 11 year old Son was a happy, active, sociable young lad who had just started secondary school which he was loving. He was an enthusiastic and committed member of the local Scouts and Archery clubs and enjoyed all the activities they involved. He had weekly ice skating & guitar lessons and he was part of a large group of longstanding friends. Like most young lads he enjoyed playing on his computer & Xbox, but he also loved being outside - hill walking, camping, hiking or simply walking our dog in the countryside. He was just a normal 11 year who was enjoying life to the full. And we were just a normal little family of 4 who loved spending time together

conditions of PoTS (Postural Tachycardia Syndrome) and, unsurprisingly given his situation, depression and anxiety. These cause him even more awful and debilitating symptoms in addition to his ME. He takes 27 tablets a day, but these are only to help minimise his symptoms, they are not actually treating the ME itself. This is because there is no treatment for this unbelievably cruel disease which affects every single system in the body.

He is lucky to have a good medical team around him but they can't fix him or make him better, all they offer are strategies on how to live with ME such as pacing advice (living within your very tiny energy limits) The only 'treatment' the NHS offers is CBT (even though ME is a physical illness and not a psychological condition) and GET (Graded Exercise Therapy) which has harmed many sufferers and the UK trials supposedly showing they work have now been proven to be incorrect and misleading. However, very scarily this is still the basis of NHS treatment, hopefully the U.K. will soon catch up with many other countries and remove GET (Graded Exercise Therapy) and CBT from their guidelines once NICE have completed their review in 2020.

As our son is severely affected (and as such is too ill for things like physio to help with his severe muscle wastage) he does not receive any medical help or support except medication to help reduce some of the individual symptoms (but many cannot be alleviated by medication). This is because there is literally nothing anyone can offer. I cannot think of another illness where a severely ill sufferer would be left with no medical support at all for years and years and years.

This is our life, our heart breaking daily life watching our son/brother/grandson/nephew suffer all day every day with no end in sight and being unable to make it better. We would give anything in the world to be the normal family that we were 4 years ago. But our heartbreak pales into insignificance compared to what our brave

15 year old boy has to cope with physically and mentally day in day out, 24 hours a day with absolutely no respite.

But we are not alone, through online support groups I have got to know lots of ME families whose lives very sadly echo ours.

ME can affect anyone of any age at any time irrespective of class, lifestyle, religion or background and when it strikes, it strikes with no warning and completely obliterates your entire life. Take a moment to imagine if this was your story, your family, your child.

At present there is no treatment, no cure and no prognosis for this debilitating life changing condition. There has been so little research worldwide that the doctors don't even know what causes ME or why the sufferers bodies react the way they do even though this illness has been known about for generations and generations. Until they know the cause there is little chance of finding treatments that work. The only biomedical research happening in the U.K. is being funded by charities in particular, Invest in ME who are working in collaboration with doctors from Scandinavia and around the world but this in the very early stages.

Although we hold onto the hope that things will improve and life won't always be this horrendous, no one knows what the future holds for our boy and that is a very scary place to be.....



Exotic Zoo Feedback

As a result of us working with the Carers Commissioner, we highlighted the needs of our families to access activities together. We were delighted to receive vouchers for Exotic Zoo and Lamb Feeding over the Easter Holidays. Families tell us they appreciate the opportunity to spend time together as a family unit – some incorporating grandparents and siblings too. Exotic Zoo are all really welcoming and supportive of our families. A true gem and worth winner of their Telford50 award.

Did the voucher make you feel supported?

- Exotic Zoo go out of their way to support children with special needs and their families as they gave her some food to feed the animals as we had missed the lamb feeding. On a previous visit we had the Meerkats experience and the staff were very patient with my daughter – answering her endless questions!
- It did, it's nice to be considered as a family and great for siblings.
- Yes, it did make us feel supported and enabled us to engage with the wider community. My Mum actually looked after my daughter (who has autism and global development delay) and younger son quite a bit over Easter while I worked so it was great to give her this code to use.

Did it help your family engage with the wider community?

- It was so lovely to go somewhere where you can have no worries about getting around and be with other children and families.
- It was nice as we felt as they were prepared to offer the tickets the zoo would be accepting of a family with additional needs.
- Everyone made us extremely welcome especially the staff at the zoo, they fitted us in to feed the baby lambs even though they were extremely busy.

Did your family enjoy your visit to the Exotic Zoo?

- We all enjoyed our visit to the zoo, my oldest especially likes being hands on with the animals as it calms/relaxes him.
- We had a fab time there, the way it's laid out made it easy with the wheelchair. Very interactive with being able to touch or hold the animals. Would certainly visit again.
- Yes, staff were brilliant and very understanding of special needs and did everything they could to accommodate us.
- The children thoroughly enjoyed it and Mum was impressed by how easy the whole process was...no queries, she had a code and my daughters name was clearly on the list. Thank you so much.
- Yes, we enjoyed it. My son, A, enjoyed stroking a snake too. Thank you for your help and the opportunity to go to that Zoo.



PARENT CARER NIGHT!

COME AND JOIN US AS WE CELEBRATE OUR
10TH ANNIVERSARY!

FRIDAY 14TH SEPTEMBER 2018

7pm - 11:30pm at St. George's Cricket Club
Church Street , St George's TF2 9LU

The celebration is being held at St George's Cricket Club, there will be a live band and a DJ! The tickets are £5 and will include a drink and food.

We look forward to seeing you there

**This is an Adults only event.*



IRONBRIDGE GORGE MUSEUM TRUST FREE PASS OFFER!!!

As a member of PODs and a Carer of a child/young person with a disability or additional need, you can take advantage of this amazing offer made by the Ironbridge Gorge Museum, the Carers Centre and Telford and Wrekin Council.

The offer entitles you the carer and up to 4 other people of your choice free access to Ironbridge Gorge Museums. Not only that you can also claim 10% off your purchases in the Museum shops when you spend over £5

Each pass will be valid for 1 week and you can visit any number of the participating museums any number of times.

If you would like a pass please contact a member of staff or pop along to a Family Group or the Hub. All passes must be collected in person and there will be a £20 deposit that will be refunded when the pass is returned. Passes can only be used with a valid form of photo ID and the carer it has been issued to is present.

This offer is made in recognition of the important and valued role you have as a Carer.

THE PASS ALLOWS YOU TO VISIT:

- Blist Hill Victorian Museum
- Enginuity
- Coalbrookdale Museum of iron
- Darby Houses
- Jackfield Tile Museum
- Coalport China
- Museum of the Gorge/
Tollhouse
- Tar Tunnel
- Broseley Pipeworks

Face 2 Face
Parents supporting Parents
of disabled children

PARENTS
OPENING
DOORS
PARENT CARER FORUM



LOTTERY FUNDED

PODS Picnic IN THE Park

No need to
book - Just
turn up!

MONDAY 6TH AUGUST 2018

10AM-4PM AT ADMASTON HOUSE, ADMASTON, TF5 0BN

All families who have a child or young person with a
disability/additional need aged 0-25 are welcome

**Quad Bikes, a Bouncy Castle, Gaming Van,
Little Rascals, a Princess Van
and lots more!**

CELEBRATING
10
YEARS



Sponsored by
Rotary



Please park in the car park opposite Admaston House
Small charge for Hot Dogs and Burgers

Company/Charity number: 1150871

DATES for your DIARY

**COME AND JOIN US AT ONE OF OUR FAMILY
GROUPS OVER THE SUMMER HOLIDAY**

FRIDAY 27TH JULY

Dawley Town Hall
(opposite Langley School/CAMHS)
New Street, Dawley, Telford, TF4 3JR

MONDAY 6TH AUGUST

Picnic in the Park (See poster for details)

THURSDAY 9TH AUGUST

Elephant and Castle Pub, Dawley, Telford,
TF4 2ET

WEDNESDAY 15TH AUGUST

Hollinswood Community Centre, 7
Downmead, Telford, TF3 2EW

FRIDAY 31ST AUGUST

Dawley Town Hall (opposite Langley
School/CAMHS) New Street, Dawley,
Telford, TF4 3JR

MONDAY 3RD SEPTEMBER

Admaston House, Admaston, Telford,
TF5 0BN

**Further Family Groups are held on the First Monday, Second Thursday,
Third Wednesday, Last Monday and the Last Friday of the month for
details and updates on all our Family Groups please visit our website**

www.podstelford.org/family-groups/



Jayne Stevens

☎ **01952 271532**

☎ **07775 342092**

✉ **info@podstelford.org**

🖱 **www.podstelford.org**

📘 PODSForumTelford
🐦 PODSTelford

🏠 **PODS (Parents Opening Doors)**
P O Box 772, Telford,
Shropshire TF7 9FD

Face 2 Face
Parents supporting Parents
of disabled children

Shashama Weare

☎ **07557 130 091**

✉ **Face2Facepods@hotmail.com**

📘 Face2FaceTelfordandWrekin
🐦 Face2Face T&W
📷 face2facetelfordwrekin

🏠 **C/O Parents Opening Doors,**
P O Box 772, Telford, Shropshire
Tf7 9FD