

# hello

angelman   
support education research

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COVID-19 information  
for people with rare  
genetic conditions

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International Angelman  
Day (IAD) 2020

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Making PODD books

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The Power of Positive  
Language

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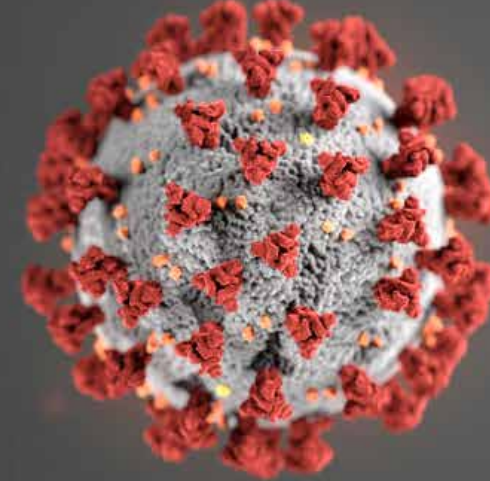
Community Ambassador  
program

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Conference 2020 update

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**#66**  
spring 2020



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## trustee news

Tracey Campbell and Louise Shaw have both stepped down as trustees. We are sure that many of you have appreciated the help and support you have received from Tracey and Louise over recent years and we wish them well in their future endeavours. **AngelmanUK**

Welcome to our first newsletter of 2020. We hope you find it an enjoyable and enlightening edition.

As you are aware, Coronavirus has dominated conversations and news reports over recent weeks. At the time of writing we are not aware of any of our families being affected but obviously things can change very quickly.

We appreciate that in these circumstances anxiety is high and concern for our loved ones is heightened. It is reassuring to know that the vast majority of people with Angelman Syndrome do not have compromised or suppressed immune systems and are therefore at no more risk of catching anything than anyone else, however we do have to be aware that catching any virus, novel or not can have implications for the people we care for. Fever and illness can lead to increased seizure activity, lack of sleep for all, chest infections etc as well as the general difficulty of caring for someone who may be unable to cough, keep their hands off their face or anyone else's face for that matter or tell you how they feel. Those who care for people who are more fragile will need to take as much care and as many precautions as possible – as I am sure you already are doing.

It is vitally important in these situations to follow government guidelines regarding hand washing, general hygiene and self-isolation if necessary. It also doesn't hurt to go with your gut or follow your own instinct – it's rarely wrong! One benefit of people with Angelman Syndrome liking water is that washing hands regularly shouldn't be a problem for most! General advice is to wash for a minimum of 20 seconds, or for the length of 'happy birthday' twice. There are probably many other songs which your family may enjoy – make a game of hand washing!

We hope that all our families remain safe and healthy in the coming weeks and months – if you do have to self-isolate please try keep in touch with friends in the AS community through our social media channels. AngelmanUK will do all we can to help and support you if you do find yourself or your family affected.

We are still planning to hold our family conference – see the announcement on in the panel alongside. Please note that plans may have to change at short notice if the Coronavirus situation escalates. AngelmanUK will follow all government guidelines but we will also err on the side of caution. You will be informed should the conference have to be rearranged. August is a long way off though so please keep your fingers crossed....

Rachel Martin, AngelmanUK

*At the moment the conference is NOT cancelled. Advice is to follow the government guidelines regarding isolation and social distancing. The government and its advisors are expecting the #Coronavirus crisis to peak in May or June. Because the conference is at the end of August we cannot cancel our booking with the hotel unless the government advise that we should.*

*We will be assessing the situation on a day-to-day basis. We will still offer the opportunity to split the cost of the conference should it go ahead however we do not know at this stage when we can start to take bookings. We will re-assess the situation in June/July unless things change sooner. Please be assured that we will act in the best interests of our families at all times and we will keep you fully informed of any changes. We are keeping everything crossed that this situation eases as soon as possible and we can look forward to seeing you all happy and healthy at our family conference.*

AngelmanUK are thrilled to announce that Dr. Karen Erickson from the Center for Literacy and Disability Studies will be joining us for our conference weekend and will be presenting a Communication, Literacy & AAC study day on Friday 28th August 2020 at The Doubletree Hilton hotel, Coventry. Karen will be supported by Erin Sheldon M.Ed and Penny Hatch SLP from the ASF communication committee.

This full day workshop is open to parents, carers and professionals who support people with Complex Communication Needs.

**Professionals £100**

**Parent/Carer £50**

Booking details to follow....subject to constant monitoring of the Covid-19 situation.  
[www.med.unc.edu/ahs/clds/directory/karen-erickson](http://www.med.unc.edu/ahs/clds/directory/karen-erickson)

N.B The workshop is in addition to our family conference programme.

## General advice regarding Coronavirus (COVID-19) for patients with rare genetic disorders

- Includes patients with developmental disorders and undiagnosed developmental delay, rare single- gene disorders and chromosomal disorders.
- Excludes patients with severe congenital heart disease, immunodeficiency disorders or lung disease e.g. cystic fibrosis, who should follow the advice of their existing specialist advisors e.g. cardiologist, immunologist or respiratory paediatrician. If your child has a pre-existing lung or breathing problem, please seek the advice of their specialist doctor.

We understand the Coronavirus (COVID-19) pandemic is very concerning for everyone but this may be especially so for families caring for individuals with developmental disorders, undiagnosed developmental delay, rare single-gene disorders and chromosomal disorders. Coronavirus can cause severe lower respiratory tract infection in some individuals especially the elderly and those with pre- existing disorders. In general, children appear to be more mildly affected than adults but anyone with a genetic disorder that compromises their swallowing or breathing or who suffers from frequent respiratory infections or has previously been hospitalised for respiratory problems may be at higher risk. There are as yet very few data about infection rate in children. Overall the death rate is much lower than in older people.

This is a rapidly changing situation with new guidance issued regularly as things evolve. Please check NHS guidelines available here:  
<https://www.nhs.uk/conditions/coronavirus-covid-19/>

If you are outside the UK, please check your country's guidelines, e.g. for the US:  
<https://www.cdc.gov/coronavirus/2019-ncov/>

Please see the WellChild website for a clear 10 point plan and information specifically for parents and carers of medically complex children:  
<https://www.wellchild.org.uk/2020/03/18/ten-ways-to-keep-my-child-with-complex-health-needs-safe/>

This includes a helpful link to a poster to put on your front door to advise visitors to your home of the precautions they need to take.

If, at any point, you think you or your child has developed symptoms of coronavirus, such as a new, continuous cough and/or high temperature (above 37.8 °C), seek clinical advice using the NHS 111 online coronavirus service  
<https://111.nhs.uk/covid-19/>

If you do not have access to the internet, call NHS 111. Do this as soon as you get symptoms.

The situation is rapidly evolving but the evidence to date suggests that it would be sensible for all vulnerable individuals, especially those with pre-existing respiratory problems or any immune- compromise, to take additional precautions to limit their exposure (e.g. minimising contact with people outside their immediate family group).

Please see this link for advice on social distancing and additional measures for those who may be at increased risk of severe illness from coronavirus (COVID-19):

<https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

*Helen Firth*

Dr Helen Firth,  
Chair, Joint Committee on Genomics in Medicine



*Frances Elmslie*

Dr Frances Elmslie,  
Chair, Clinical Genetics Society



*Eamonn Sheridan*

Prof Eamonn Sheridan,  
Chair, British Society of Genetic Medicine





# Fun play ideas for the home and adjusting to a new normal

Photos by Jenn Smith, Lottie Fox-Jones and Christyan Fox



In the coming weeks we all will be adjusting to a new normal - staying in with reduced access to grandparents, carers or respite services and many, if not all will be worried about the health of loved ones, our own health, financial responsibilities and job security. Please know that AngelmanUK is here for you. AngelmanUK is a 'home-based' charity and although we will have less time due to our own family responsibilities and children being off school we will try to continue as normal.

Our telephone helpline 0300 999 0102. Or email us [support@angelmanuk.org](mailto:support@angelmanuk.org)

You can contact any of the trustees via social media and we will listen and signpost if we can.

Try not to worry. Use the time to reassess, relax, start a new hobby or family activity, read together. Maybe now is the time to lower your standards and accept that children don't need 6 hrs of education or a perfectly tidy house to be happy. They need happy and healthy parents. Look after your own mental health (put your own

oxygen mask on first!) and remember that screen time isn't always a bad thing and neither is wine! There are plenty of easy home play ideas available of sites such as Pinterest and Instagram by searching tags such as: #homesensoryideas or #sensoryplayathome ... for example.

Here are some of our favourites:

## Sensory Fun

- Cornflour and water
- Hand/finger painting
- Water spray bottles
- Ice play – freeze safe or edible objects in water, explore them, melt them or break the ice to get the objects.
- Mud kitchens
- Sensory bath – toys, music, bath bombs, waterproof lights, shaving foam

## Fine Motor Fun

- Posting activities – cut a hole in a box and post items in
- Stick straws into playdough
- Playing with clothes pegs
- Threading

## Active Games

- Obstacle course – stepping stones, walking a line, crawling under something.
- Ten Pin Bowling with household objects
- Roll on a large ball
- Crashing into pillows
- Swinging
- Dancing to your favourite tunes

## Using Twinkl during the Coronavirus Shutdown

Twinkl provides instant access to a complete range of teacher created, engaging and inspiring teaching, planning and assessment materials. At the moment they are offering both teachers and parents a free month. This offers free resource downloads from health and hygiene, home routines, self-care for parents and key stage learning and visuals.

Schools across the UK are responding to the outbreak of the Coronavirus. In most cases schools have closed or have minimal staff and children present.

Twinkl have put together a simple, step-by-step guide about this offer of help, for you to use. The guide is not designed to

override or replace any official guidance, but is intended to advise on using the Twinkl website during this period. To sign up go to [twinkl.co.uk](https://www.twinkl.co.uk)

## Things to do while at home

If you're on Facebook: there are many new groups starting up to help families share ideas of things to do during the 'lockdown' – simply type 'lockdown tips' into your Facebook search bar to find them and join as you wish. Here's one to get you started: 'Family Lockdown Tips and Ideas'.

## Zoo and wildlife cams

You may not be able to visit zoos and wildlife parks at the moment, but many around the world have set up cams so that you can watch your favourite animals from the comfort of your own home. If you are not viewing this newsletter in a digital format simply type the following into google and follow the links.

- Cumbria Wildlife Trust
- Dublin Zoo
- Edinburgh Zoo
- Houston Zoo
- Kansas City Zoo

- Paignton Zoo
- San Diego Zoo
- Smithsonian Washington
- Explore (various animal webcams worldwide)

## Free virtual tours of world museums, educational sites and galleries for children

- Family Days Tried and Tested

## Educational and wellbeing resources

You may find the following useful for your children's learning and development, or simply to help keep them occupied: Some of these links may be more suitable for siblings to use.

- Activity Village
- Carol Vorderman's The Maths Factor
- CBBC
- CITV
- Cosmic Kids! Yoga and mindfulness (YouTube channel)
- Crayola (free colouring pages)
- David Walliams' free audio book a day
- Joe Wicks' YouTube Channel (keep fit)

- Mumsnet (list of best online learning resources for all ages)
- SEN Teacher
- Supercoloring.com (downloadable colouring pages)
- Twinkl

## Official updates and information on coronavirus

- Government website
- NHS website

## Mental health advice during the coronavirus outbreak

- Mind
- Mental Health Foundation

## Information for families with disabled children

- Contact

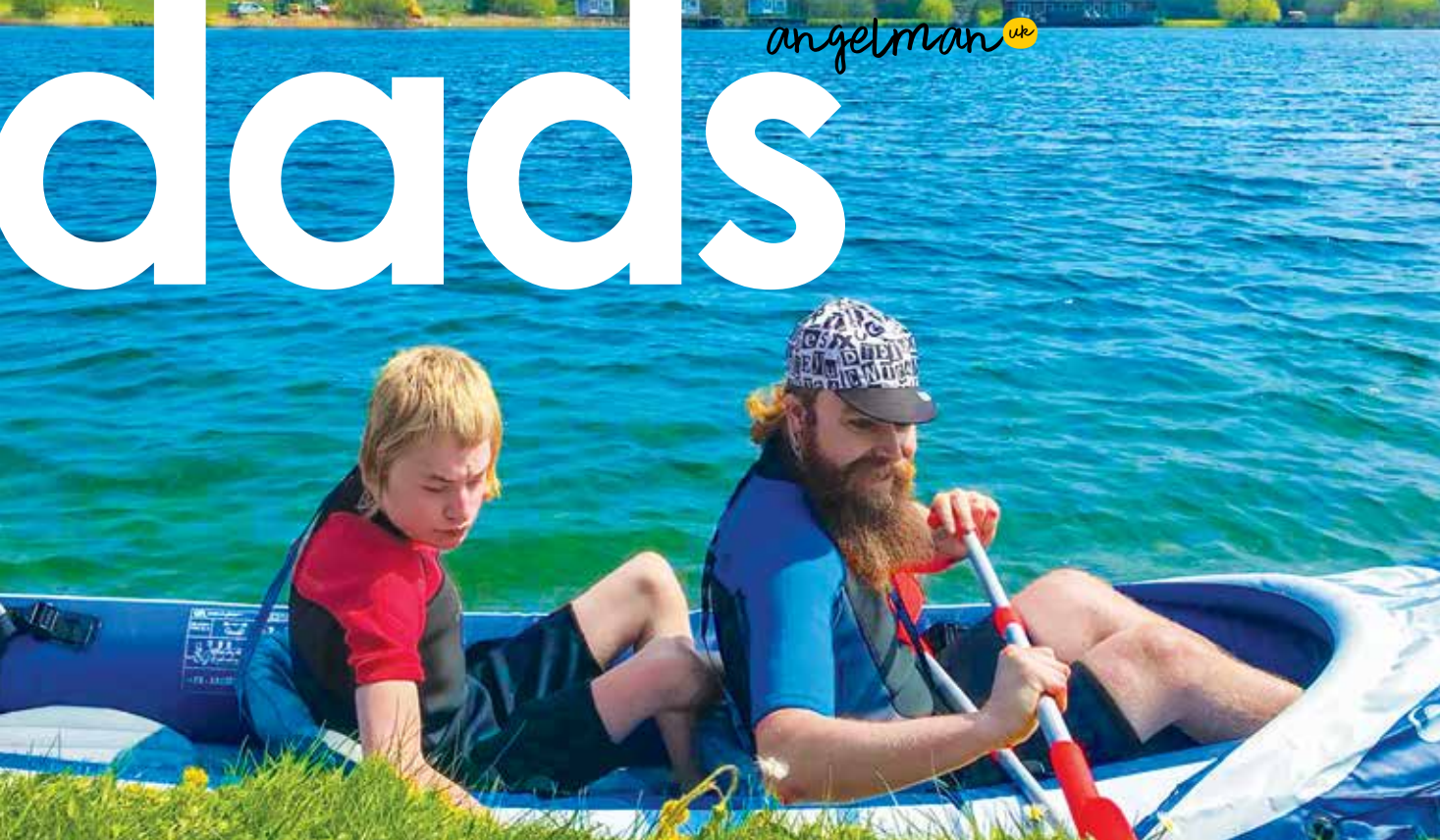
## Special educational needs

- Special Needs Jungle

## Information on benefits

- Entitledto.co.uk (benefits calculator)





Is it really the Spring newsletter already? Back in September I wrote about our family and how having a child with Angelman Syndrome has changed our life (or not) and about flexible working. How timely that I am sat writing this now whilst working indefinitely from home. Last time I wrote I mentioned other Dad's coming forward and sharing their experiences too, the offer stands, please do get in contact and share your experiences. You will get very bored of me otherwise.

When Jenn and I first met I was a very keen golfer, I would happily spend most of my free time in and around the golf course. So obviously when Alastair came along I always expected that he would do as I did and follow me around the course from the moment he could walk. This never happened but that doesn't mean that we haven't had the chance to play golf together! On a recent family holiday, Alastair was still taking tentative steps with some assistance. I saw a crazy golf course and well, we had to play we were on holiday after all! We had a great time, Alastair managed to play along each hole walking, not stuck in his wheelchair! Success! There is a short video on Alastair's Vimeo page of the holiday...stick it out to the end. (vimeo.com/smilingandwaving)

Thing is, just getting around is hard enough let alone trying to enjoy a hobby. You will all likely have experienced the NHS standard wheelchair and all its foibles. It serves a purpose, providing



you are on perfectly flat and smooth tarmac with appropriate drop curbs to cross the street. Anything else, and well they are just not going to work. This sucks. We are an active family who like to be outdoors. I don't mean we like to climb up rock faces all day and jump off a cliff, but we do like to be able to go to the beach or take the dog for a walk. For this we discovered the Hippocampe (see video) and it completely changed our life! That chair literally opened up the world to us. He has been up mountains in Switzerland, explored the wilderness in Yosemite National Park and has been in two oceans! Oh and we are able to walk the dog and all of us enjoy it, not just the dog!

Golf isn't a quick sport to play or indeed practice, I haven't stopped playing I just don't play 4 times a week anymore. Things come and go but cycling really took over to the point where we have 6 bikes littering the house and a few more in the shed. Alastair has 2! Well, 1 but it works as a tagalong behind me – which he peddles only when I stop at the lights and as a trike for him to ride himself. Without this trike we don't think he would ever have walked! It was a fight to get the physio to sign off a recommendation on the trike but the look on her face when the rep came and Alastair calmly rode the trike around in circles was priceless. She promptly signed off on the trike to take to a charity for funding. I rode with a local bike shop and they put events on to bring cycling to a wider audience. Alastair was very quickly included and all rides were then made suitable for



us with the tagalong. To feel included like this was amazing. Alastair's tribe grew once again and we were able to continue doing something we enjoyed without causing a fuss.

Turns out Alastair loves water, who knew right? Jenn and I haven't ever been around water sports really, not to the point of trying it anyway. Alastair now has a 3 man kayak and we are a kayak family. I can barely swim. Well, I can swim... just! We must look a right sight traipsing down the beach all 3 of us and the dog, all terrain wheelchair, kayak, tent...pitch up the tent (shade on that 1 day the sun shines) blow up the kayak, wetsuits on and the dog stays to guard (!) the wheelchair. All 3 of us head down to the sea and mess about in the kayak for a bit.

So, what is the message here? Well, I didn't think I would be taking my son on a 75-mile bike ride just for fish and chips. I didn't expect to kayak in the sea, or anywhere for that matter. And I certainly didn't expect to push a wheelchair up the side of a mountain. I have done all of those things and so have Jenn and Alastair. Anything is possible if you put your mind to it. People look and people stare, but mostly, they are in awe of what we are doing, because they can't/won't do it and they don't have all the extra stuff to think about that we do!

Smile, it confuses people.

Adam Smith



## angelman community ambassador

AngelmanUK is very proud to announce our Community Ambassador Programme for 2020. We are inviting applications for the position of Community Ambassador from parents and siblings of and including, those who have Angelman Syndrome.

- You must be over 16 yrs old.
- You must be happy to promote AngelmanUK and awareness of Angelman Syndrome in a positive way in your local community, on social media and in your local news media.
- You will be responsible for arranging or attending regional events on behalf of and with the full support of AngelmanUK.
- We ask that you are willing to commit for a period of one year.
- We would like you to contribute to at least one edition of the AngelmanUK newsletter - this could be an article about an activity that you have organised or a photograph of you in your community etc.

This is a voluntary position but reasonable expenses will be covered and you get a FREE T shirt! Obviously those with Angelman Syndrome who are chosen as a Community Ambassador will need the full support of a parent or carer whilst representing AngelmanUK. Community Ambassador applications will be considered by the Board of Trustees and their decision is final. **Applications for 2020 close on Monday 1st June.**

We are very proud to introduce our first Community Ambassador **Souzie Mackay**, United Arab Emirates UAE.

*"Having lived through the diagnosis of a child whilst settled far away from the support of family I am well placed to empathise with those who find themselves in a similar position. I have worn the path of connecting*

*medics and educators and support groups with our daughter and can facilitate some comfort and context to those who feel mistakenly alone. With the unswerving support of AngelmanUK I have the confidence to challenge authority figures into bolstering fine words with meaningful action. We have not shied away from trying to increase public awareness of Angelman Syndrome here in the UAE and have purposefully challenged schools and authorities to improve the recognition and facilities for children of determination. I am looking forward to assisting in anyway I can."*



## Kidz-to-Adultz

Disabled Living has an excellent reputation of organising the very prestigious Kidz-to-Adultz event since 2001 and now hold five of the largest FREE UK exhibitions totally dedicated to children and young adults up to 25 years with disabilities and additional needs, their parents, carers and all the professionals who support and work with them.

Keep an eye on the Kids-to-Adultz website for updates and cancellations  
[www.kidzexhibitions.co.uk](http://www.kidzexhibitions.co.uk)

### Save the date for our future events...

SOUTH	WALES & WEST	SCOTLAND	NORTH	MIDDLE
Thursday 7th May 2020 Farnborough International Exhibition & Conference Centre, Farnborough	<b>NEW VENUE!</b> Thursday 2nd July 2020 The International Convention Centre (ICC), Newport	<b>WE'RE BACK! (held every 3 years)</b> Thursday 10th September 2020 Royal Highland Centre, Edinburgh	Thursday 12th November 2020 EventCity, Manchester	Thursday 18th March 2021 Ricoh Arena, Coventry





# IAD international angelman day

15 February 2020



## A round-up of some of the events across the UK

*This annual event on February 15th is supported by over 30 international not-for-profit charitable organisations around the world, supporting people with Angelman Syndrome, their families, care givers, and service providers.*

*AngelmanUK organise regional events throughout the UK to give our families a chance to get together, share stories and have fun.*

### Central: Lisa Court Green Towers, Hinckley

We had a lovely few hours in Hinckley catching up with familiar faces. The kids had a blast with the bouncy castle and soft play, and the siblings enjoyed playing football and a competitive game or two of snooker! It's always great to meet up and swap stories, share advice and just hear what's happened since the last meet up. It was lovely to have such a broad age range as



well, ranging from pre-schoolers through to Bonnie who is about to celebrate her 50th birthday!

### South Central: Andrea Baines 'Swings and Smiles', Thatcham

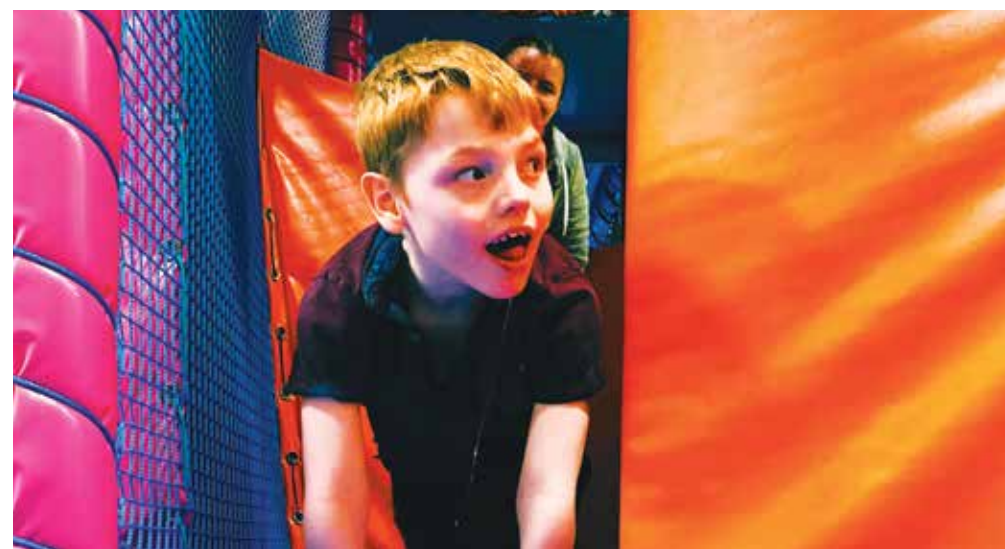
The South Central IAD event this year was held at Swings and Smiles in Thatcham - a former children's centre that has been converted into an inclusive play centre. Eight individuals with Angelman Syndrome attended with their families, ranging in age from 4 to mid-30s. The venue has a sensory room, ball pit, soft play and a large outdoor area (although as storm Dennis was well in progress on the day of IAD, only a few intrepid souls ventured outside!). The ball pit and sensory rooms were very popular, as was the cake and it was lovely to see so many familiar faces and some new ones.

### N.Wales & N.West: Rachel Martin Warrington Sensory Play Centre

As usual we had a fantastic turnout for our IAD2020 event this year. Warrington Play and Sensory Centre ([www.warringtonsensorycentre.org](http://www.warringtonsensorycentre.org)) are



always perfect hosts and the facilities for our families are great. The needs of most people are met from babies right up to adults and the more physically disabled. The equipment is designed with adults and Carers in mind and there are no age or height restrictions on anything. Our younger families particularly love the sensory room and quiet ball pit - I'm sure more balls end up on the floor than in the pit itself! We also have a feast fit for royalty and this year was no exception. Kumar's Singapore



Noodles and his Special Rice are always the stars of the show with people queuing up for more! Attending the AngelmanUK events in Warrington is always something our North West families look forward to and we can't wait for next year!

### Surrey: Diane Fox-Jones Burview Hall, Walton-on-Thames

The South East IAD meeting was held at Burview Hall once again. It was very well attended and it was good to meet some newly diagnosed families as well plenty of old friends. The weather was poor so we couldn't make use of the extensive play area and woods, but the children were able to play with all the toys provided in the hall while everyone chatted over tea and snacks or made use of the large sensory room.

### Yorkshire: Jenn Smith Leeds Mencap Centre

The Yorkshire IAD meet was held at Leeds Mencap. This is such a safe and well equipped centre that meant everyone in attendance had a really chilled out afternoon in great company. It was great



to meet Dylan and Caitlin and their families and share some wonderful food. Special mention to all the siblings in attendance, as always they were super helpful, kind and playful and all got along great.







When I gave birth, it was the most beautiful thing I have ever experienced. What I didn't realise was something more beautiful could have happened – the day James met Benjamin.

The afternoon of Benjamin's birth, James came to the hospital to meet him. As soon as he walked in, he saw the baby in my arms and James' face lit up. He came and sat next to me and hugged me whilst stroking Benjamin's head so gently.



Never did I think James' reaction would be the reaction he gave. He was so gentle and happy!

Whilst being pregnant there would be numerous times James placed his hand on my bump whilst we told him there was a baby inside, but we never knew if he fully understood the concept of being pregnant. As soon as he met Benjamin, he clearly showed he knew that the baby was mine! It was simply beautiful!

Alexandria Edgar

# my son James

My son James turned 19 in January. He has Angelman Syndrome, but we lived the first 12 years without any diagnosis. After being referred to GOSH we received the news he has AS. The Geneticist said he has a very rare mild case of AS and they were interested in using us as a case study.

James has trouble sleeping, he has learning difficulties and he is delayed in all areas of his development. He can walk, talk (though not age appropriate), bathe, cook etc but he cannot go out of the house alone.

James excels at sport and has very good hand eye co-ordination. He has been playing cricket since the age of 8 and loves it. James' skill lies in bowling – he has played cricket for mainstream local teams and now plays for Essex Ability team at Chelmsford ground. He will be joining a local cricket club in the summer. and James was awarded Bowler of the Year 2019 as he took so many wickets in different games.

He loves all sports and also plays darts for Essex (this is a huge step as it involves playing on stage in front of an audience and having walk-on music etc, as on TV).

We are super proud of him as you can imagine!  
Pauline Whale



Stormy Chamberlain  
Ph.D, Associate Professor,  
Genetics and Genome  
Sciences, UConn Health.

angelmanUK



## angelman subtypes

*Angelman syndrome (AS) genetics can be confusing and overwhelming, even for the most Angelman-savvy people. In an effort to make sure everyone can understand their loved one's diagnosis, below is a brief explanation of the different genetic subtypes of AS. All of the percentages are approximate.*

### 15q11-q13 Deletion

Approximately 70% of individuals with AS are missing a large chunk of chromosome 15q11-q13. This large deletion, which includes 4-7 million DNA basepairs, is the most common cause of AS. Type 1 deletions are larger and involve a few more genes than Type 2 deletions, but there really does not seem to be a lot of differences in the severity of AS between these two types of deletions. Compared to other genetic causes of AS (UBE3A mutation, UPD, ICD—see below), individuals with deletions are often more strongly affected because there are other genes missing in addition to UBE3A. One of these other genes causes individuals with deletions to have fair hair and blue or light-colored eyes compared to their parents.

### UBE3A mutation

Changes in the DNA sequence of UBE3A can also cause AS. These changes are referred to as mutations. Mutations in the maternal copy of the UBE3A gene cause AS in approximately 10-15% of individuals with the disorder. We know that UBE3A is the most important gene

in AS because of these individuals UBE3A mutations. Mutations can either be de novo (from new) or inherited from mothers. Because of this, it is important that biological mothers of children with UBE3A mutations be tested to see if they also carry the mutation. Females who carry a UBE3A mutation have a 50% chance of having a child with AS.

### Uniparental disomy

Paternal uniparental disomy (UPD) is a mouthful of words to mean that a child has inherited both copies of chromosome 15 from their father. Since the paternally-inherited copies of UBE3A are silent, individuals with paternal UPD have no UBE3A protein in their brain cells. UPD accounts for approximately 3-5% of AS cases.

### Imprinting defect

Some individuals with AS have a copy of chromosome 15 from their mom and a copy from their dad, however, the copy inherited from their mom behaves as if it were inherited from the father. This results in two silent copies of UBE3A. This genetic subtype of AS is called "imprinting defect" or "ICD", and accounts for approximately 3-5% of individuals with AS. This genetic subtype is very similar to UPD.

### Mosaicism

Some individuals with AS have cells in their body and brain that have AS and some that do not. This phenomenon

of mixed cells is called mosaicism. The percent mosaicism – or the amount of typical versus AS cells – can be estimated, but only in the blood. This does not accurately reflect what the percentage is in the brain, where it impacts the abilities of the individual. Individuals with mosaicism are often less strongly affected than others because some of their cells have UBE3A. Some mosaic individuals may even speak in sentences and/or have nearly typical motor skills. Most individuals who are mosaic for AS have the ICD genetic subtype of the disorder, although there are a few rare examples of individuals who are mosaic and have other genetic subtypes. In fact, there are likely many more individuals who are mosaic for AS than we know. Many individuals who have been diagnosed with ICD are likely mosaic, but the tests cannot detect their typical (non-AS) cells. Conversely, there are likely individuals who have mild learning or speech disabilities who have the mosaic form of AS, but haven't been tested for AS at all because their disorder does not "look" like AS to their doctor. It is exciting to consider that the presence of some typical cells amongst other AS cells can improve many features of AS – especially in light of the many therapeutic approaches being developed.

Stormy Chamberlain Ph.D is part of the



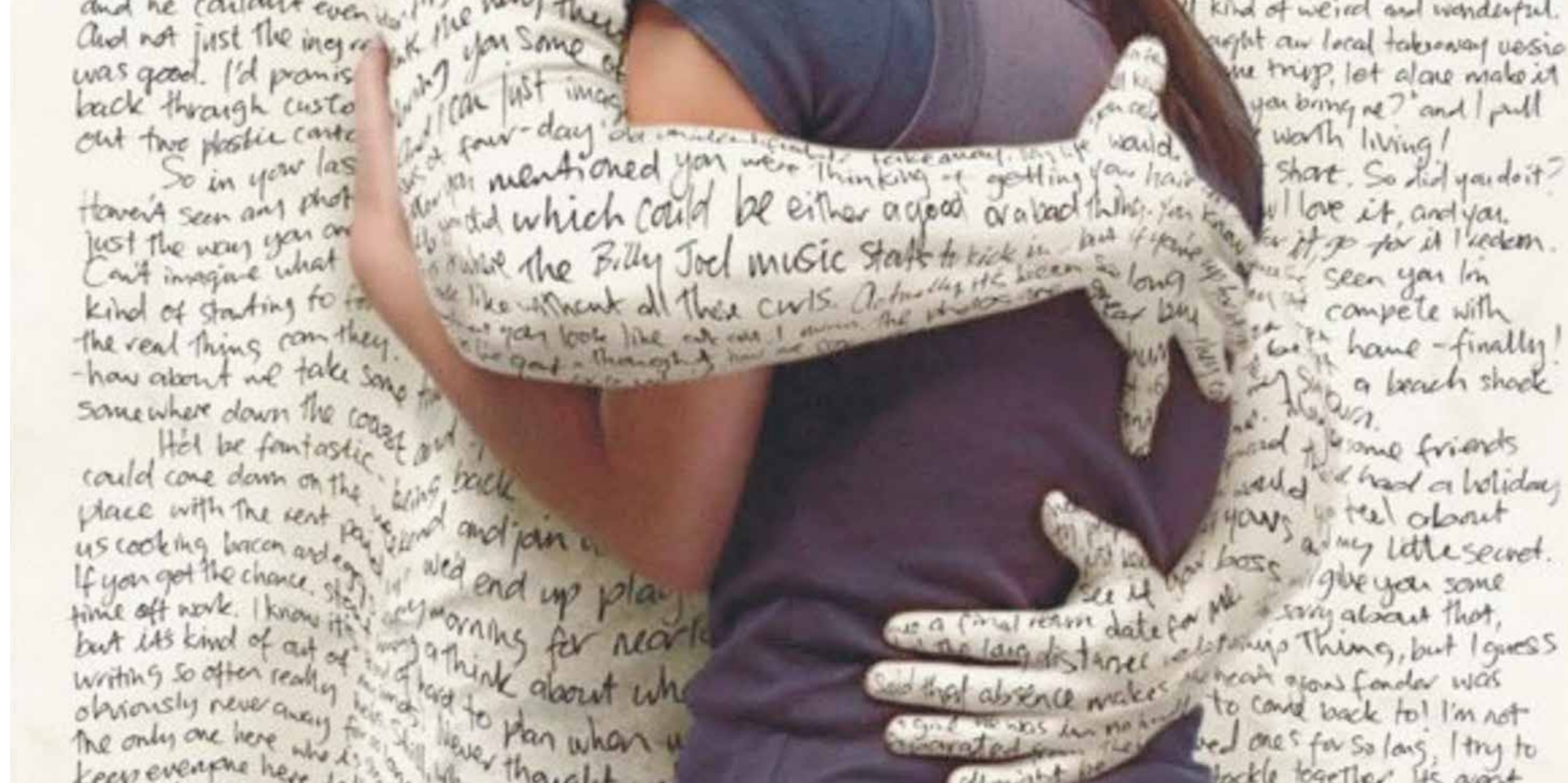


# the power of positive language

We recently found this article and it struck us that the message it contains is also relevant to us as individuals who may feel negative or 'stuck in a rut' because of our caring roles and the restrictions or social isolation that may be imposed up on us.

Caring for someone is hugely worthwhile and the majority of us do it willingly because we love our family members – be they someone with Angelman Syndrome or some other disability. But it is very easy to fall into the trap of using language which affects us negatively.

Caring for ourselves has to be a priority in order for us to care for others to the best of our ability. Mental wellbeing and taking positive steps to change the way we think can play a big part in the way we feel about ourselves and our role as carers... hopefully you will find the following article empowering and encouraging.



## The power of positivity

Using more powerful language can make a big difference to your life, reawakening your confidence and boosting your happiness.

How do you feel right now? Think for a second and observe the words that come to mind. If you replied along the lines of 'fantastic thanks, everything's going great'... then well done – you are more likely to have lower stress levels, better health and more success in life, love and just about everything that any of us more pessimistic souls. If, on the other hand, your reply was more in the 'Alright I suppose/can't complain/mustn't grumble' camp it might be time to start reframing some of those responses. As inconsequential as they might seem, negative thoughts and words can have a huge impact on almost every aspect of our lives.

These are the findings of neuroscientists Dr Andrew Newburg and Mark Waldman, whose book, *Words Can Change Your Brain*, available from Penguin, expounds the power of the words we use and how they can shape our lives – for better or worse. 'A single word...such as 'peace' or 'love'...has the power to regulate physical and emotional stress,' they wrote. Conversely, negative words such as 'No',

'I can't', 'I'm useless', 'terrorism', and 'drought', stimulate the amygdala, our brain's fear centre (hard-wired to react as if faced with a physical or existential threat) to release stress hormones. "These chemicals immediately impair logic, reason, language processing and communication," they write.

It's not just the words we say out loud that affect us either. The voices inside our heads that cheer us on – or more likely criticise our every move, can be incredibly potent. And while the odd negative thought or phrase might not do much harm, they have an alarming propensity to breed. Consider how many of the following apply to you: have you moaned about your boss today? Have you checked in on Instagram or Facebook, and felt that you weren't pretty/thin/happy/clever/successful enough? How many sentences have you started with 'sorry'? Chances are you will have done one, if not all, of these things – and therein lies the problem. The more houseroom we give to negativity, the stronger its effect and the harder it becomes to escape its influence.

But if we can silence our inner doom-monger and think and speak more positively, the benefits are manifold.

A recent study by Harvard School of Public Health found that people who look on the bright side have fewer heart problems and lower cholesterol levels. Research from Duke University found that MBA graduates for whom the glass was half full were more likely to find jobs than those who believed it was half empty. The same study also found that optimists tend to earn higher starting salaries than pessimists and are also promoted more frequently.

In part, this is because if we sound happy and confident, others respond more positively towards us, something its especially important for women to remember. How often have you sat in a meeting and noticed yourself, or a female colleague, saying something along the lines of 'I don't know much about this, but...', or 'This is just my opinion, but...' According to Dr Judith Baxter, linguistics expert and author of *The Language of Female Leadership* (Palgrave Macmillan), these are typical examples of Double Voice Discourse and Out-of-Power Language – language that self-deprecates to avoid appearing arrogant or argumentative. But they give the impression of being less powerful, confident, or decisive and devalue our opinion. And why would we want to do that?

## Breaking the pattern

So how can we break the pattern of negativity? Happily, It's easy to do. The trick is to simply replace those negative words with more positive ones. So stop saying 'fine' – and start thinking 'great'. Replace 'should' with 'could'. Don't just try to do something, do it! And cease labelling yourself as too anything and start celebrating your strengths and achievements. Do it now to see how simple it is.

For the more reserved among us, such wholesale positivity seems at best unfounded and naive and, at worst, like cheating or even lying. If this is how you feel, some of the tactics used by Cognitive Behavioural Therapy (CBT) practitioners can help. First, for every negative thought you have about yourself, ask yourself if it's true? Are you really a 'failure'? Think about all the times you have succeeded in life. Are you really 'unqualified' for your job, or do you in fact have a lot of relevant experience? Then try to turn your negative thoughts into positives, so 'I'm too quiet' becomes 'I'm a good listener' and 'I'm too loud' becomes 'I'm gregarious and enthusiastic'. Soon you'll start to see that everything depends on the lens through which it is viewed. The only people we are cheating by maintaining relentless negativity is ourselves.

## Talking yourself up

The joy is that it doesn't matter if the positive things you tell yourself are true or not – the mere act of saying them lifts your mood. You might consider yourself the world's worst singer or dancer, but tell yourself you're good – or better great – and not only will you start to believe it, but others will respect you too. It's not so much about pretending, more about acknowledging that all value judgements, yours included, are ultimately no more than opinions.

"The longer you concentrate on positive words, the more you begin to affect other areas of the brain, changing your perception of yourself and the people you interact with," write Newburg and Waldman. "A positive view of yourself will bias you towards seeing the good in others, whereas a negative self-image will incline you toward suspicion and doubt."

"The limits of my language are the limits of my world," said philosopher Ludwig Wittgenstein. Or, as American businesswoman Mary Kay Ash once said "if you think you can, you can. And if you think you can't, you're right."

The truth we believe is that which we tell ourselves, so go on, tell yourself – and the world – a happy story, and watch as it comes true.

## Happy talk

Say positive things at every opportunity. Say thank you, give praise, pay compliments. Focus on your strengths and write three affirmations that begin 'I am...' They needn't be true (yet). Monitor your speech over a day. Note the patterns you fall into and start rephrasing.

## Try some simple switches

I'm hopeless at...I'm learning to.

It's impossible...It's a real challenge.

No problem...You're welcome.

I messed up...I can do better.

I'm stressed...I have a lot on.

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angelman<sup>uk</sup>





# communication

## how to make a PODD book

### Templates and Boardmaker

In order to print a PODD book you need the appropriate template. Disks with the files are available from Inclusive Technology, make sure you get the Windows or Mac disks as appropriate. There are also alternative access templates available which are suitable for people who require eye gaze, partner assisted scanning or coded access books. You will also need access to Boardmaker; three versions are available - Boardmaker V6 and Boardmaker Studio (both available as memory sticks) and Boardmaker Online. There are free month long trials that should be plenty of time for customising a PODD. There are features of Boardmaker Studio and Online that should make printing easier, however they are not currently compatible with the PODD construction manuals. Therefore, Boardmaker V6 is still recommended for PODD books, especially if you are new to the process.

### Useful videos

Mary-Louise Bertram recorded this video for anyone getting started with PODD as part of the ASF communication series:

[youtu.be/smc6AWQOM0](https://youtu.be/smc6AWQOM0)

She discusses the PODD disks including reference to the information files that help you decide what book to choose, as well as how to customise the books using Boardmaker.

"We Speak PODD" have three videos that discuss making PODD books. Alternative access templates are now available since these videos were made:

[youtu.be/DFswtsvZDrY](https://youtu.be/DFswtsvZDrY)

...is the first one and discusses software,

customising and printing PODD books.

[youtu.be/HVSIrdusa-k](https://youtu.be/HVSIrdusa-k)

...discusses the paper, laminate and binding used to construct PODD books.

The third video is about actually using PODD at home and is outside the remit of this article, but still worth watching for those at the beginning of their journey.

### Laminate or Waterproof paper?

Traditionally PODD books were printed, cut, laminated and cut again and many people still use this method. This does make a thick book so it is advisable to use 80 micron matt laminate if you can which is more expensive but worth it. For one thing, matt laminate generally eliminates glare but it is especially essential that a non-gloss finish is used for those who have vision impairments as light refraction will distract the user. A number of careful considerations will need to be addressed for those users who have CVI, as they will need significant adaptations to templates. Alternative access, including Partner Assisted Scanning books, high contrast symbols and/or black background will need to be considered when selecting a template. My advice would be to reach out to other users in the community who have specialised knowledge regarding CVI and alternative access. Websites such as "Little Bear Sees" and "CVI Scotland" will have a symptom checklist - these are worth visiting, as CVI behaviours are subtle, but are unmistakable once they are known. I have used Q-Connect (stationery providers) in the past who charge approximately £15-£20 for 100 pouches.

We now use Xerox Nevertear 195 µm waterproof paper to make our books. There

are other papers available, but we have not had any problems with this one so have used it for our last three books. It is usually about £50-£60 for 100 A4 sheets but as we only use A5 we cut it to get 200 sheets. This makes it not only less labour intensive but cheaper too (A5 laminating pouches are comparatively more expensive than A4). However, for books requiring A5, the material costs are probably higher than laminating. The books are considerably lighter and thinner when using waterproof paper and we have found that they last just as well as the laminated books. (Note: printing to laminate paper requires a laser printer.)

Most people who use waterproof paper do laminate the pages that they use most often. For one-page books this would be "chat" pages, "branch starters", "opinions" and "categories". In the two-or-three-page books, "chat" and "opinions" are commonly used. We first began laminating the "people" page too, but haven't with the last few and that has been successful.



### Size of book

Many people asked about the size of Jane Farrell's book. She prints it at 70%, but you can print any of the books to whatever size you like, however remember the compromise

between how transportable they are and how accessible the size of the symbols. I have been asked about doing a 3-page book in A4 but it wouldn't be practical in my view. A one-page book could be printed on A5 paper, but some people would struggle to access the symbols due to their motor or visual difficulties. Remember that the most important factor of any book is that it is accessible to the AAC user, not that it is convenient to carry.

### One-page books

The lists on the one-page books should be attached to the back of the page above. If you are using waterproof paper it is best to print double sided. To save costs, we practice using ordinary paper to ensure the alignment is ok before printing on the finishing paper.

The binding on one-page books should be done so that the book can fold back on itself. It is recommended that you use a stand for these books. Mary-Louise demonstrates making one in this video:

<https://www.youtube.com/watch?v=IJUKepEX4Xk>

Materials required for this include a lever-arch folder, 4-hole punch and cable-ties.

### Two and three-page opening PODD books

Rosie Clark has made a video on printing two or three page PODD books:

<https://www.youtube.com/watch?v=kWkCN5vy3XY>

Since this video was made the plastic covers that Rosie used have changed quality. I have used flexible chopping mats very successfully for the past few PODD books.

Binding for two-and-three-page books should stop the books from folding back on themselves. The official advice is to use comb binding, although I have never found this to be successful. I now use a binder to punch holes in the book but then put cable ties through every second hole, pull the cable ties to an acceptable tightness, cut the ends and then burn them so they are not sharp.

### Straps and harnesses

Here is a handy blog post on straps and harnesses: <https://www.nwacs.info/blog/2019/10/carrying-straps-for-aac-devices> For books, we have used old ties and dedicated straps we bought from Jules Whicher. For devices, camera harnesses including OP/Tech and Bushnell are good.



Article by Tracey Campbell





# angelman<sup>uk</sup> fundraising

## Victoria Moralee – Great North Run

The day Lola was diagnosed was the most surreal moment ever! I knew deep down there was something going on but was hoping there wasn't. Lola has Angelman Syndrome, she may never walk or talk... the list goes on! Our hearts sank! The news sunk in and the dust began to settle and we made a point of saying we are no good to anyone if we mope around. How can you be miserable when you're around any Angels anyway? I've always wanted to do everything I can for Lola to help her in any way so I'm always researching how to help her wellbeing to ease epilepsy and constipation which is most Angel's norm!

When I found out about the charity AngelmanUK I instantly wanted to fundraise in some sort of way... so we did. Me and my wonderful friends did a few things to raise money, my sister and her work - TNT - organised a huge raffle, bake sale etc. and raised an amazing amount of money. Then we all did the Great North Run. It was THE HARDEST but MOST AMAZING thing we've ever done, the crowds as we ran were simply the best and the encouragement really got me round. Meeting Lola at the end and giving her the biggest cuddle of all time was really the cherry on the cake.

By working together, me, Helen Moralee, Marianne Peters & Shelley Richardson raised the brilliant amount of £5,717. Thanks to my friends and family for all the effort and donations for this amazing cause!

## Nicola Moore – Hell Fire Half Marathon

I have done several half marathons in the past but haven't always done fundraising. I applied to do the 'Hell Fire Half Marathon', as it's in my local town and the route had recently changed and I hadn't yet attempted the new course (known to be very tough). This half marathon was formerly known as the 'Wycombe Half Marathon' and the name change occurred this year, to better reflect the history of West Wycombe Park; which the race runs through, and its association with the scandalous 'Hell-Fire Club'. I thought I should take the opportunity and raise money for Angelman UK after all the help and support they have given our family over the years. The half marathon took place on 14 July.

The course was gruesome (hill after hill) and I took longer to complete the race than I had wanted but it was worth it. I had great support from my family: Malcolm and our three children (Elliot, Oliver and Natasha (AS), as well as my Mum (Margaret) and mother in law (Jean) cheered me at the 4th, 5th and 9th mile points, which was very welcome as I had just climbed steep hills prior to these points! I raised just over £1,200 which was £700 more than I had aimed for – all thanks to very generous family, friends and work colleagues.



## Mark Newbold – Fantha Tracks

Fantha Tracks have raised funds for AngelmanUK for a couple of years now.

The latest donation was raised by selling Star Wars posters signed by our patron Gareth Edwards at various events. The latest batch of merchandise raised the excellent sum of £1,430.



## Sunny Braitch Birmingham Half Marathon

Sunny, Jas and Chan ran the Birmingham Half Marathon earlier this year and raised the wonderful sum of £758.69.

## Mark Hughes Manchester 10k

Mark ran the Manchester 10k and raised the excellent sum of £675.31.



## Darren Keighley Great North Run

I started running when my aunt died of cancer. I ran the marathon that year. Shortly after my cousin gave birth to

Holly Stone who was diagnosed with Angelman Syndrome. My focus immediately changed and I directed my charity work to AngelmanUK. Holly is a beautiful little girl with a smile to die for. This time I raised £400 and completed the race in 1h 47. 28. I look forward to more running challenges in the future.

## Ruth Curbishley Basingstoke Circle Dancers, Tadley Circle Dancers & Basingstoke Folk Dancers

These 3 dance groups from the U3A have made donations for surplus allotment produce each year since 2013. This year's total was a splendid £290.



## Danny & Jade Bates Wedding

Danny, Jade Bates and their family have this charity close to their hearts. Lexi Bates is now 7 and has knowingly lived with Angelman Syndrome for roughly 5 years. She has a large family around her and fantastic support from Hope House School. Seeing her progression and always with a smile on her face makes daily life a joy.

Over the years there have been two evening charity balls, two music festivals and now our Wedding Wishing Well, all in Lexi's honour, and have been able to raise a fabulous £2268. Thank you to everyone who helped arrange these events and of course all donations. AngelmanUK please keep up the good work.



## Sue Taylor – The Ladies of Dukinfield Golf Club

The Ladies of Dukinfield Golf Club held two fundraising events – a car boot sale and a cheese and wine afternoon.

The total amount raised was a fabulous £1,662.60.



## Martha, Jennie, Rayner, Indio, Joe, Jessica and friends in class 6M

We live on the South Coast of England and have been blessed with a beautiful little niece called Holly aged 5, who lives in Perth W. Australia. Holly has Angelman Syndrome. My brother (Holly's Dad) and his eldest daughter were aware that my daughter Martha along with her friends had arranged a cake sale at school but we hadn't realised until we attended that they had decided that they wanted the proceeds to go to an Angelman charity to help Holly. They raised a total of £85. It was an emotional afternoon for my family. **Andrea Rabuszko**



## Tracey Shelbourn Lincoln 10k

We had a great day and all finished the run, raising a total of £385.







We had 7 runners in the 2019 London Marathon. 5 ran on one of our Golden Bonds and 2 runners ran on a ballot place.

**Golden Bond**  
Gareth Edwards (our patron)  
Sharon Speers  
Hannah Mensah  
Jessica Hall  
Mathew Hendery

**Ballot Place**  
Paola Noto  
Danni McCormack

Between them, our 7 runners raised the phenomenal total of £27,637.26! Such an amazing amount of money, well done guys!

The Golden Bonds for 2020 have been taken, if you would like to be considered for one of our golden bonds in 2021 please email [lisa.court@angelmanuk.org](mailto:lisa.court@angelmanuk.org)



I'm Paola Noto, Mum of two (Luca aged 5, Alessia aged 2). I work full time at Haven House Children's Hospice in Woodford, Essex as their PR and Communications Manager. I completed the marathon the day before my 34th birthday. I secured my place in the ballot and decided to run for AngelmanUK. Running the London Marathon was always on my bucket list of things to achieve in life and crossing the finish line was one of my proudest moments (aside from having my two amazing children) yet. I decided to run for AngelmanUK as I had heard about the incredible work the charity does to support families whose children have the condition. One of my dearest and closest school friend's Felicity and her family have had immense support from the charity since their little girl Ruby was diagnosed with the syndrome.

I know how invaluable fundraising is to the charity – a charity that relies solely on donations and volunteers to continue its vital work in supporting families and I really wanted to make a difference. Felicity often tells me how the charity was there when she had nowhere else to turn and that both her and her husband Dean have found much needed support at the family conferences and through the telephone help line. AngelmanUK help families to not feel alone.

I started my marathon journey having run no more than 5km and I was so proud to have crossed the finish line 26.2 miles later representing the Angelman's Running Team at London 2019. Training was hard and a massive commitment - juggling two children and full-time work but Ruby was my determination and inspiration to getting there. Whenever I was struggling her beautiful smile and strength got me through. Ruby has come such a long way and we are extremely proud of her. This would not have been possible without the unwavering support and love of her parents, family and AngelmanUK. Seeing her at mile 23 on the marathon day gave me the biggest boost.

A special thank you to all my family and friends who helped me surpass my target of raising £5,000 and helped me achieve £6,910 for AngelmanUK and who supported me throughout my training. I really could not have done it without everyone behind me and believing in me from the off.

**Paola Noto**

Running the London Marathon for such a great charity was a once in a lifetime experience that I will forever cherish! I thoroughly enjoyed the day and the atmosphere. I appreciate all the support that I have received over the months leading up to the event and on the day!

I decided to apply to run the marathon as I have an older brother called Kodwo with Angelman Syndrome. Kodwo was diagnosed with AS at the age of 3. He is a very big part of my life and he has helped shape the minds of myself and my other siblings. He has taught us great value around patience, acceptance and helping others with special needs. We are eternally grateful for this. Many of the experiences that I have shared with him influence many of the decisions that I make today.

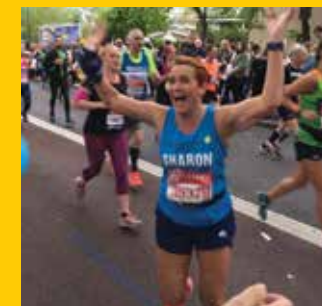
Deciding to run the marathon, was my way of attempting to give back to not only AngelmanUK but also to Kodwo for everything that he has taught me. I will forever be grateful as his sister, and for this opportunity that I had to raise money and awareness for such an amazing charity!

**Hannah Mensah**



**Golden Bond runners (L-R)**  
Jessica Hall  
Sharon Speers  
Mathew Hendery

angelmanUK



## a word from our patron...

I hope everyone is staying safe from the Corona virus! I kept myself busy last year training for the London Marathon where we managed to raise over £10,000 for AngelmanUK. I kind of caught the running bug after that (although you wouldn't be able to tell from the size of my belly) and ran a half-marathon in Death Valley, as well as

another by Area 51 through the middle of the night. Sadly we didn't see any aliens though. Talking of which, I also officially started development on a new sci-fi movie for New Regency. I can't talk much about the storyline just yet as it's under wraps, but we did get to go on a crazy location scout across Asia at the end of last year. Obviously the Corona

virus has hit everyone hard since, including the film industry where all productions across the board have been put on pause until this all blows over. Fingers crossed we still get to have the AngelmanUK conference later in the year as (unless the new film starts shooting) I will hopefully will see you all there! Stay safe! **Gareth Edwards**

*Gareth Edwards competing on a Golden Bond place in the 2019 London Marathon and with his niece, Ella Court*





help us to help you keep

# smiling



## donations

Without your contributions there would be no AngelmanUK to offer support for your family. Whether big or small, every penny really does make a difference. A very big thank you to...

<u>Hazel Tait</u>	<u>Mrs J Clark</u>	<u>Catherine Rust</u>	<u>Elizabeth Ferris</u>
<u>David Roberts</u>	<u>Carol Lee</u>	<u>Alan Bailey</u>	<u>Kim Flaxman</u>
<u>Gail Whisker</u>	<u>Mrs Eveline Knapp</u>	<u>P Flannery</u>	<u>Ali Dalton</u>
<u>Heather Forrest</u>	<u>Janet Hall</u>	<u>Leigh Leslie</u>	<u>Emma Streatfield</u>
<u>REC Ltd</u>	<u>Basingstoke and Tadley Circle and Folk Dancers</u>	<u>Julie Atkins</u>	<u>Karen Jones</u>
<u>KKL</u>	<u>Mr A J Taylor</u>	<u>Elaine Hill</u>	<u>Annette Robinson</u>
<u>Amy Johnson</u>	<u>Rachel Haston</u>	<u>Siobhan Martin</u>	<u>Ian Wright</u>
<u>Kendal South Westmoreland Rotary Club</u>	<u>Danny &amp; Jade Bates</u>	<u>Fran Childerhouse</u>	<u>Jill Haston</u>
<u>Mr &amp; Mrs Capen</u>	<u>Molly Bartlett</u>	<u>Daniel Schroeck</u>	<u>Julie Callaghan</u>
<u>Helen Polat, Jo, Skel and everyone from The Rabbit</u>	<u>Pete's Plaice</u>	<u>Kate Fox</u>	<u>Miranda Jenks</u>
<u>Wedgewood Cricket Club</u>	<u>Ladies of Dukinfield Golf Club</u>	<u>Jane Streatfield</u>	<u>Craig Brown</u>
<u>Viasat World</u>	<u>Sue Taylor</u>	<u>Sheila Scott-Wright</u>	<u>Clare Garland</u>
<u>Parklands Primary School</u>	<u>Stagecoach Performing Arts</u>	<u>Theresa Brockington</u>	<u>Charles Meyrick</u>
<u>In memory of Mr. Alan Spencer</u>	<u>Anna Marshall</u>	<u>Marie Brockington</u>	<u>Gregor Campbell</u>
<u>Jan Moir and The Longhouse Quilters</u>	<u>Gwen Elliott</u>	<u>Peter Williams</u>	<u>Sarah Brown</u>
<u>In memory of Michael Wong</u>	<u>David Cook</u>	<u>Christine Manley</u>	<u>Adam Mee</u>
<u>Martha, Jennie, Rayner, Indio, Joe, Jessica and friends in class 6M</u>	<u>Stephen Roberts</u>	<u>Clare Streatfield</u>	<u>Max Williams</u>
<u>Stu-Nique</u>	<u>Charlotte Walker</u>		
<u>The Old Portmuthian Chapter Bar</u>	<u>Elize Lomas</u>		
<u>In memory of Maggie Mobsby</u>	<u>Robert Brashier</u>		
<u>In memory of Mrs Gwendoline MacFarlane</u>	<u>Maria Moralee</u>		
<u>Mrs Brenda Page</u>	<u>Nicola Stephenson and Lily Reid</u>		
	<u>Susan Wheatcroft</u>		
	<u>GoCo Group</u>		
	<u>Ethelwyn Owen</u>		

## fundraisers

You've read about the efforts of our fabulous fundraisers elsewhere in this issue. Why not get involved yourself and organise an event to raise money for us?

Contact [lisa.court@angelmanuk.org](mailto:lisa.court@angelmanuk.org) and she'll send you a fabulous fundraising pack with all the details of how you can get involved.

<u>Jimmy Deighan</u>	<u>Great North Run 2019</u>
<u>Darren Keighley</u>	<u>Great North Run 2019</u>
<u>Andrew Bell</u>	<u>Great North Run 2019</u>
<u>Victoria Moralee, Helen Moralee, Marianne Peters &amp; Shelley Richardson</u>	<u>Great North Run 2019</u>
<u>Chan Sangha, Jas Sangha &amp; Sunny Braitich</u>	<u>Birmingham Half Marathon</u>