


Helping children with upper limb differences live life without limits

Within Reach

Winter 2023 | ISSUE 154

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Front cover stars Meghan and Summer


Reach

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NEW 'Your Reach Story' with Reach Mum Emma Gilpin



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Events

DEC • 10th - Berks & Wilts Branch | Steam Train Ride | Didcot Railway Centre, Oxfordshire
• 17th - West Midlands Branch | Christmas Party | Hatchford Brook Golf Course, Birmingham

JAN • 27th - Southwest Branch | Sheep Trekking in Taunton

FEB • 11th - East Anglia Branch | Soft Play & Skating | Curvemotion, Suffolk

MAR • 30th - Northern Ireland Branch | Reach Charity Gala

APR • 1st - 30th - Limb Loss & Limb Difference Awareness Month
• 19th - 22nd - 18 - 25s Reach Retreat | Violet Fountain Farm, Devon

MAY • 25th - 26th - South Wales Branch | Family Weekend | YHA Swansea

AUG • 4th - 11th - Reach Activity Week (RAW) | Calshot, Southampton

OCT • 25th - 27th - Annual Family Weekend | Portsmouth
For details contact reach@reach.org.uk or your local branch coordinator

Hello!

From the Editor & Designer of withinReach

We're celebrating 45 years of Within Reach Magazine. When it began it was written on a typewriter and photocopied to send out to members, so Tom and I are very pleased for the invention of Word, InDesign and the Internet! We hope you enjoy this issue; we always welcome comments, requests, or suggestions for future issues, **so please feel free to email us at withinreach@reach.org.uk**. Your Within Reach Creators, Max & Tom



Reach Membership

Membership is open to parents of children with upper limb difference, and individuals of 18 years and over who are interested in furthering the work of the association. The UK and Ireland subscription is from £36 (£35 via direct debit) and the International subscription is £40.

Views expressed in withinReach are not necessarily those of Reach and are not intended to reflect or constitute Reach policy, or in any way portray an official view.



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Meet our Wonderful Branch Coordinators

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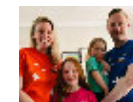
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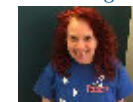
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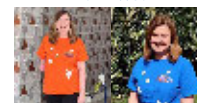
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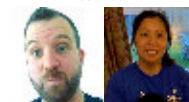
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Stay up to date

All event news is on our website www.reach.org.uk and facebook page www.facebook.com/reachcharity.

How YOU can help Reach!

Know of a local venue, sports club or hall that would be perfect for a private meet-up for our Reach families? Or perhaps you're keen to help but can't commit to being a branch coordinator, no problem! Help your local Branch Coordinator by simply making that first contact with a venue or getting a quote for an event. Every little really is a BIG help. Don't underestimate your impact. Get in touch with your local Branch Coordinator or the Reach team at reach@reach.org.uk.

"Thank you Reach for being a constant support and family to us"

Navdeep (Branch Coordinator) & Abnaas - Reach parents

Despite a yellow weather warning 326 people came together at the Delta Hotel Gateshead to enjoy AFW 23

- 93 families attended in person

- 75 people watched online

For many of the families with us it was their first time coming to a Reach event. The event had a big buzz and a constant energy from the get-go, with Scott the magician and Dawn the Face painter welcoming families in and out of the rain. There were quite a few firsts at the event; it was the first time Lou Hawkins and Owain Beesley (age 13) had spoken at an event, Lou spoke with honesty from the heart and earned a standing ovation, Owain talked of his journey and aspirations as a young musician, the support he has, and what he's having to work out for himself as a musician, and as a young person. Briony Matthews gave a cooking demo whilst being 'grilled' by Alastair Greener, and Alex Brooker sat on the sofa and shared, almost shyly, a story board presentation of his journey from a boy in a wheelchair with his mates, to a Channel 4 Presenter and comedian. Another first: Our first ever Young Influencers Panel: Chaired by Alex Brooker, Young Influencers Jesse, Gemma, and India came together with Reach Trustee, and Writer, Emily Tisshaw, Reach Young Peoples Ambassador, Ella Dickinson, Influencer in her own right, Megan Bacon-Evans and Owain on the panel, to share their journeys and aspirations. The voice of young people was a constant at AFW 23 and next time we'd like to make it bigger.

Ideas for next time include a Young Influencers workshop for 11-17-year-olds! Thank you to all those who gave us feedback, your ideas are with us as we turn our sights to AFW 24, 25-27 October, at the Portsmouth Marriott.

I am just back from our Strategy Weekend in Birmingham, where Trustees came together with local Branch Coordinators, Tracey and Jason, the Reach Team (myself and Ashley) and our Social Media Manager, Megan, to map 5 years ambition, which includes: working on our articles of association, our governing documents, to bring them up to date and make sure they reflect the work we do now and exciting plans for the future, a new 18-25's project, for which we've just received funding for a Pilot in 2024, a Performing Arts Summer School akin to RAW (subject to funding), increasing access to Reach with the publication of a new booklet for new parents, and a steady build to a national celebration of 50 years of Reach in 2028!

I am so enjoying meeting and listening to Reach members, young and old(er), a few weeks ago I was at an event in Kent with families making cupcakes and friends all at the same time, next week I'm holding coats for ice skaters at Hampton Court. These amazing events are only happening because of the commitment of very special people, our volunteer Branch Coordinators, thank you all for enabling, since I've been in post, a massive 694 members over 24 events, amazing!

Wishing all a relaxing festive season and looking forward to meeting some of you in the New Year. In the meantime, if you want to reach me please email: sarah-janel@reach.org.uk



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"I'M WITH MY PEOPLE"

The Reach Annual Family Weekend began on Friday as members arrived despite stormy conditions, long drives, train delays and cancellations, their enthusiastic reception starting a palpable 'buzz' - the excitement contagious and the expectations astronomical. A meet-and-greet buffet invited people to get to know each other and renew old acquaintances, assisted by Scott & Dawn Cuthbertson with magic and face-painting, while children did what children do - they played, oblivious to each other's limb differences.

On Saturday children were placed in the care of Tinies Crèche, guided to Activity Rooms, or transported to Whickham Thorn Activity Centre, whilst relaxed parents were welcomed into the conference room with tea, coffee, and chat. (The buzz builds.)

Alastair's introduction only raised the anticipation, introducing Bill Basford, a Reach veteran from 1979 to 2023 (following the birth of daughter Alice), tracing the progression of a small group of committed parents, demanding support and services for their children.

Louise Hawkin's emotional story of childhood experiences, leading her to become a creative and highly motivated adult/ Mum/Life Coach with steely determination, really moved the members.

Dom Hannett's (Opcare) presentation discussed the role of prosthetics as a tool to enable us to do what we want to, a reminder of Captain James Thompson's video demonstrating the adaptations to his prosthetic arm that empower him to fly a jet aircraft. Wow!

Dr Dorothy Cowie's (BOLDkids) confirmed that our children are thoughtful problem solvers that can keep up with, and often compete with, children with both arms - exceeding our expectations constantly.

Owain Beesley (13) demonstrated his progress on his specially modified Trombone (OHMI), and shared his goal to join an orchestra.

Reach Chairman Chris delivered the AGM Report to whet our appetites for lunch, and then into the afternoon...

Briony May Williams showed us how to create our very own Bake Off making detailed pastry animals.

World Champion Matt Phillips told us of his Paralympic career in swimming and then in climbing; focusing now on coaching and mapping out courses for athletes and centres.

Alex Brooker (Channel 4: The Last Leg) was his inimitable, hilarious self with his comfy couch delivery of his childhood to adulthood escapades - life lessons which he generously shares with 'our people.'

The panel of young influencers and the roles that they're creating for themselves impressed upon members that Reach children can do what they want to do - and they are doing so.

Time to prepare for the Gala Dinner. (The anticipation builds to a crescendo!) With children fed and moved to activities for the evening, adults can get their 'glam' on. Pre-dinner fizz and sax encouraged mingling before heading into the Banquet Hall where the Marriott's dinner courses surpassed each other, and in between we were entertained by the children's Play in a Day (Twisting Ducks Theatre Company) performance - our own little thespians, and DJs in our midst (DJ Workshops).

The Auction, arguably the most entertaining part of the evening, saw vigorous tit-for-tat bidding duels, raising the excitement whilst also raising money for Reach. Thank you to all for both the entertainment and the funds.

By now, the only way to dissipate this 'buzz' was with a few drinks and dancing. Rachel Francis sang her heart out, and rumour has it the party was a late night into-morning session.

Sunday, bleary-eyed parents and children enjoyed a hearty breakfast before the visit to Shiremoor with Reach Mentors, where the children were challenged by new activities - a taster for Reach Activity Week (RAW).

Owain's consoling comment to his anxious Mum, departing for RAW for the first time, has proven to be uncannily accurate, "I'm with my people."

Chris

Chris Creamer
Reach Board of Trustees
Chairman
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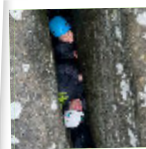
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SAVE THE DATES!

Annual Family Weekend

Portsmouth Marriott Hotel | 25th – 27th October 2024

We're still buzzing after the 2023 Annual Family Weekend, but that doesn't mean we can't look forward to the next! Save the dates for next year's AFW conference in Portsmouth.



Reach Activity Week (RAW)

Calshot, Southampton | 4th – 11th August 2024

Reach Activity Week – a water-based week of confidence building, connecting, trying new activities, making new friends and creating unforgettable memories with Reach buddies! To find out more, email reach@reach.org.uk

18 – 25s Reach Retreat!

Violet Fountain Farm, Devon | 19th – 22nd April 2024

Coast, connection and camping: an opportunity for Reach young adults to get away with like-minded people to build confidence, friendships and memories.

"I'm excited to announce that next year we will be introducing our first ever 18-25 Reach Retreat thanks to successful National Lottery Funding. We will be glamping for 3 nights and taking part in seaside outdoor activities, wellbeing workshops and enjoying a pizza night with the campsite's outdoor pizza oven!"

- Trustee and Mentor, Emily Tishaw

"I struggled with anxiety and low confidence at the age of 18. I think a retreat like this would have helped me to connect with people my age who understand what I might be feeling, to figure out my insecurities, and boost my confidence."

- Max, Within Reach Editor

To register your interest please get in contact with the team, email reach@reach.org.uk - spaces are limited



Feather Down
Escape to a simpler life



Northern Ireland Reach Gala Dinner

A three-course meal at the beautiful Stormont Estate, with games and raffles to offer attendees countless opportunities to walk away with amazing prizes, hosted by TikTok 'CEO of One Hand Humour' India Sasha and Mum, Tracey.

"I recently got the ballot through the Northern Ireland Civil Service Athletics Club for the London Marathon 2024. What better reason to fundraise - I've done a few local marathons but thought if I get the opportunity to race in a big one like London then I'd do it for Reach."

I really feel that many people in Northern Ireland are still not aware of Reach. I'm hoping by holding a Gala event that it will help get the word out there. I'm blessed to have the support of my three daughters. India Sasha having her influencer experience, Asha Dionne is a singer and will be singing at the event and my youngest Tiana Mya also works with brands. I have a great team. This is also a great learning experience for them. For us personally, having Reach we know there is support, families to meet and experiences to share."

Buy your Gala Dinner tickets here: <https://www.eventbrite.co.uk/e/reach-charity-gala-tickets-752786273007>

The warmest welcome to new trustee Steve

Steve Haynes | steveh@reach.org.uk

"I'm absolutely delighted to have been elected as a trustee; thank you for your support!"

I was a member of Reach as a child, when the charity provided invaluable support to my parents, and to me; I was an early recipient of a one-handed recorder. I went on to become a professional trombonist, performing on over 20 West End shows during ten years in the music industry.

I have always been passionate about equality, diversity and inclusion, especially when related to disability. This led me towards a second career as a trade union official with expertise in employment and equality law.

I still fondly remember the branch meetings I attended as a child, where I felt safe amongst friends. I am keen to ensure Reach continues to thrive for generations to come."



Walking 3000km for Reach!

On the 5th November Ellie left Ireland to hike the 3000km Te Araroa trail in New Zealand - raising money for Reach as she goes.

"Between aged 6 - 12 Reach events were the only time I showed my arm. Like most kids growing up with a limb difference I experienced all the usual isolating probes, aghast faces, pointing fingers, long stares and the classic 'where's your arm?' This told me I was different and more importantly made me feel different. Reach was a safe haven, I was normal and would never be called out there. In my mid-teens I learnt to take pride in my limb difference, I learnt to appreciate being different and the tenacity it inspired within me. Despite this growth being a solo journey, I knew the community at Reach were in my corner if I needed them."

The Reach Bursary Panel awarded Ellie funding for an adapted canoe paddle to help her on her adventure! The Reach Bursary Scheme helps individuals up to the age of 25, cover the cost of specialist equipment, adaptations or additional training. Find out more. <https://reach.org.uk/apply-reach-bursary/>

<https://www.justliving.com/page/elmarie-obrien-1695586346780>



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The 2023 Reach Annual

Family Weekend & AGM

My AFW

by Emily Tishaw

I was excited for the family weekend this year because it meant reconnecting with old friends, seeing faces I had been following online and getting to meet all the new families that would be attending for the first time.

Having spent time planning the event in our trustee meetings this past year, after I was elected onto the board at last year's family weekend, I had an idea of how the weekend would be run but with the team in place and all the work being done behind the scenes from the board, our staff members and the rest of the dedicated volunteers, of course, it exceeded all of my expectations.

The buzz of the first night mingling with everyone as they arrived was the perfect way to relax before the commotion of the next day, although it was saddening that the weather restricted some of the guests who had booked to come from getting to the location. I was receiving updates of the storm's progression and the cancellation of trains which delayed a number of our members from getting to the hotel, although I was glad to see them when they finally arrived—a bit later than planned and a little discombobulated from the weather outside, but still with beaming smiles!

Saturday morning arrived and our first conference speaker was Lou Hawkins, who told me before her slot that it was her first time speaking on stage. I was deeply touched by her story; she was a natural at captivating an audience. One moment she had everyone laughing, the next minute I was crying and when I turned around I noticed that almost everyone was reaching for tissues and had tears in their eyes too.

It is always interesting to hear researchers, scientists and prosthetic technicians in between the talks of lived experience and I was drawn to the work that BOLDkids are doing with the developing brain of limb different children. The research is new but the findings will hopefully greatly benefit our community in understanding how we as limb different individuals evolve and grow in our own unique ways.

I had the pleasure of being part of the young person's panel hosted by Alex Brooker where we were asked about our experience of growing up with a limb difference. I want to emphasise the point I made about the importance of the change in representation of disabled people and more limb different people within the media—it's amazing to see and fills me with so much hope and excitement for the future of fairness and equality for our community.

There's something quite magical about being in a room full of people who look similar to you and this is exactly how I felt at the evening's dinner dance. Seeing everyone dressed up smart and even watching the kids perform and take turns on the decks really lit me up! I rarely stay awake past 10pm—as I've gotten older I've realised that 8 hours sleep is non-negotiable—but I danced and chatted and danced some more, right until the music stopped playing at 1am and I enjoyed every last minute of it!

I brought my best friend along as a guest this year and she told me that she had never been around such a supportive welcoming group of people before; that is the gift of navigating a world where you are different, you know what it feels like to be left out so therefore creating a loving, welcoming community is a natural side effect of your personality. Reach does this really well, whether you are a parent of a child with a limb difference, a young member, an older Reach adult, researcher, prosthetic technician or friends and family of Reach members; we gather to celebrate the uniqueness and diversity of our community. We show love, compassion and demonstrate a stubborn resilience to life's challenges. We have support for our members that continues to reach out to an audience of thousands. Our volunteers, staff, fundraisers and stakeholders continue to amplify their dedication and I am beyond proud to be part of this fantastic team.

I cannot wait for next year already!

The buzz of connection

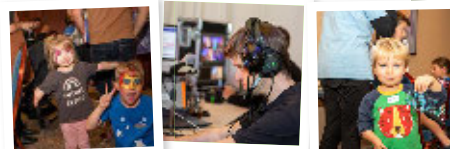
by Max Swincoe

The word that seems to have been most associated with this year's family weekend is 'BUZZ' and what a buzz there was. I felt it, on the stormy drive I was excited, apprehensive and buzzing to see my fellow mentors, to meet new parents and members, to spend a weekend unencumbered from self-consciousness.

But what is this buzz and where does it come from?

This is the buzz of Reach. The magic of being among people who might just get it. The journey you're on, the feelings you're experiencing, the conversations, the stares, the highs and the lows... Someone has walked the path before you.

On this one weekend a year you know that the people surrounding you...the parents, adults, children and guest speakers, only look out of love, chat for the connection and listen out of interest.



For me, this year I wore the badge of Reach Mentor with honour. Just a couple of months before I spent a week at RAW witnessing, for the first time, the incredible 10 – 17-year-olds challenging themselves, surpassing their own expectations, making new friends and supporting each other on their wonderfully exhausting week of activities. So, heading to the AFW with this new insight I wanted to speak to parents more than ever. To reassure them, support them and be an example for their children.

The welcome buffet on Friday evening was a fantastic opportunity for people to mingle in a relaxed and open space. I know from my first AFW I was really nervous to start conversations or know how to approach parents as a Reach adult, but this year it was different. We know why we're all there, to celebrate difference and create a safe space for anyone who wants to share or connect.

On Saturday, Tom - Within Reach designer and my husband - and I were recruited to chaperone the off-site activities, so while the conference took place, we accompanied the 10 – 17 year-old Reach children and siblings to Wickham Thorne Activity Centre where we played laser tag and problem-solving games; hopped onto snow-tubes, climbed and tackled some muddy orienteering. It dawned on me then just how important it is too for the children's siblings to feel welcome and involved in our community and I truly hope they do, because they're on this journey too – and some of them will grow to be guardians, supporters and confidantes for their Reach brothers or sisters.

On Sunday morning some Reach mentors and families had the wonderful opportunity to head to Shiremoor Adventure Playground... A chance to play, of course, but also a great time to talk to some parents about RAW, about how special it is for the Reach children to spend a week together, bonding and forming friendships, building their self-confidence, seeing lots of different upper limb differences and watch how others do, try, adapt!

The Reach Annual Family Weekend isn't just a conference and workshops, it isn't just an AGM or dinner; it's a wholesome, utterly unique gathering of individuals all living completely different lives coming together because they have a very special thing in common, Reach.



Welcome to Reach

Ada



Brodie



Elle



Harrison



Imogen



Hayley



Isabella



Indie



Melita



Rian



Ruby



Sienna



Tommy



Toby



Make it Monthly

Did you know you can set up monthly donations to Reach via PayPal?

Visit [Reach.org.uk](https://www.reach.org.uk), click on 'Donate', then select 'Make this a monthly donation' and follow PayPal's instructions.



Fundraisers

£4000

Elizabeth & Prince Zaiger
Charitable Trust

Sharon Stuart
Football charity day

£500

£3065

Family on behalf of Jo Neal
Fundraised for Reach in memory of Jo

Theo Natarajan
Instead of having gifts from friends and family

Theo asked for donations to Reach to say thank you for all the support they've given Ru. He still got an awesome paintball party and some video games as well as raising £800!

£730

£1319

Max Swinhoe
The Big Brutal Swim 2023

Joanne Taylor
In memory of Alan Gozzard
and Beatrice Taylor.

£250

£8

Rose Walker

£10

J Tabbah

Navdeep Kalsi
Ran a 10km race

£382

£20

John & Leigh Cox

Steven & Dawn Davies

£20

£500

CMS Foundation

★

Suzanne Parker
Coast to Coast Challenge

£589

£500

Sharon. Donation from Sandra in
memory of her cousin Terry. Funds also
raised by family & friends

UltraTile

£3000

£1000

Morgan Lewis's London office

Stephen Callaghan

£30

£15

Nicholas Matthews

Janet Graaff

£10

Legacy Donations

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Sylvia Dorothy May Freeman

Russell Edward Artherton

£120

£250

Valerie Jean Bastian

Antony Palin

£207

£2000

Marie Tarrant

Monthly Donations

★
£10

Heather Nash

Annette Gabbedey Goldsmiths

£5

£61

Durray Zeb

Jonathan McGee

£10

Our Reach journey, tackling bullying & finding support in the Reach community

By Emily Wilkinson

I initially found out I was pregnant with Charlie very early on as I'd developed hyperemesis (extreme nausea and vomiting) which ultimately landed me in hospital at 6 weeks pregnant as I'd gone days without being able to keep anything down and even the smell of water was making me sick. Aside from this, my husband and I thought the pregnancy was going fine, initial scans looked good and my sickness, although never fully settled, did become manageable.

Before we knew it, it was time for the 20-week scan - we were so excited. Going into the scan we were adamant we wanted to keep baby's gender a surprise. During the scan the nurse didn't say much and took an unusually long time going over and over my stomach with the probe. I didn't think much of it until the nurse said she needed to get a doctor to look. My heart sank to the ground, I started panicking, I instantly knew something was up. My husband held my hand and said everything would be ok. The doctor came in and told us that baby's left arm appeared not to be developing at the same rate as the right. I just broke down and wondered what on earth I'd done wrong in my pregnancy for this to happen. It was at this point that I decided I needed to know baby's gender and be able to start planning for their future. When we found out it was a boy my husband and I were overjoyed, and it provided distraction for a little while. I rang my mum straight after the appointment, she reassured me everything would be ok and reminded me to take each day at a time, "whatever will be, will be."

We were sent for more scans, and I was offered a procedure which would determine whether Charlie had Down's syndrome, but we refused, to us it wouldn't matter whether he did or not, he was our baby and we would deal with things as they came.

The day Charlie entered this world was incredible and a huge relief that he had arrived safely. Our perfect precious baby was in our arms and he was perfect. I will never forget looking down at his little body and thinking how lucky we were to be his parents. A week later we found out from the health visitor that Charlie had been diagnosed with Poland's syndrome; he had a shortened left arm with fused bones in his forearm and a boxed webbed hand, and a missing left pectoral muscle.



When it was time for Charlie to go to nursery, I was a little concerned how other children would interact with him and whether they'd tease him because of his arm. Charlie's childminder, Jayne, has looked after him since he was a baby and she's been amazing at building his confidence, taking him to plenty of toddler and tots' events etc. Charlie has such a strong character I thought he'd have no bother dealing with any nastiness, and being confident enough to tell an adult if anything were to happen. I had nothing to worry about, we'd never had any incidents and Charlie was the daredevil of the class, always loving to have a carry-on with everyone!

September of this year Charlie started primary school and, like most children, was rather shy the first couple of weeks. I had a chat with him before he started, telling him if anyone teases him because of his appearance he needed to tell myself and the teacher straight away, but I was hoping things would be like nursery. Within the first week some boys were laughing at him in the bathroom in school and at afterschool club another boy said his hand was "creepy", and at his first week at rugby training, more laughing.

I found out about the incidents at school either by Charlie telling me or Jayne which was very frustrating, as soon as I heard I contacted the school to find out more. The instances at Kids Club I was told about on the day, and at rugby I was present. Charlie has been upset over the bullying but after having little pep talks, he soon puts it to the side and is back to being himself. I ask him every day how school was, and this is the time when he tells me if something has happened.

Kids Club chatted to the children and explained that Charlie has Poland's syndrome and that he is just like everyone else and can do all the same things.

The incident at rugby really put Charlie off joining in, but I talked to the coach, and he sent a message into the training group chat which explained Charlie's limb difference and asked if all the parents could educate their children. Since then, we've had no more issues at training and Charlie's getting fully involved and loving it!

Charlie and I filled in the Reach booklet "My Story" and we sent this into school for Charlie's teacher to read to the class. The children were fascinated, and Charlie was proud as punch, standing up by his teacher while the story was read out loud which explained how his little body developed! I'd recommend anyone in a similar situation to take advantage of this resource, it's a fantastic informative tool.

We're still dealing with instances of bullying from some older children at school, so I'm in discussion with Charlie's teacher about an assembly to address this and hopefully bring an end to any incidents.

"Our perfect precious baby was in our arms and he was perfect."



Ask for help Parental support, advice & resources

Young Minds - Parents Help Line

'Call our Parents Helpline for detailed advice, emotional support and signposting about a child or young person up to the age of 25.'

<https://www.youngminds.org.uk/parent/parents-helpline-and-webchat/>

YOUNGmINDS
fighting for young people's mental health

NSPCC

NSPCC Bullying advice

Bullying and cyberbullying

'Advice for parents and carers to help keep children safe from bullying, wherever it happens.'

<https://www.nspcc.org.uk/what-is-child-abuse/types-of-abuse/bullying-and-cyberbullying/>

Bridge the Gap

Child mental health & emotional literacy support.

'Bridge the Gap are here to help children, young people and adults understand their emotions and feelings, to empower you with knowledge and tools to support your child.'

<https://www.bridgethegap.com/free-resources-1>



A journey of grief, acceptance, and joy.

When did you first find out about Miles' limb difference?

Miles' limb difference was discovered at our 20-week anomaly scan. I'd been so nervous leading up to the scan but the sonographer was amazing at putting me at ease, after all the checks she told us she was unable to scan our Miles' left arm properly, that for some reason he wouldn't 'unfold his arm,' but she never once sounded panicked. I don't remember much else from that appointment.

We were seen in Foetal Medicine the following day and the Consultant explained that Miles' lower left arm had a single bone and two, maybe three, fingers. We even got to see a 3D scan of Miles' hand. He explained that they needed to investigate further but that the worst-case scenario was that our baby had an un-survivable condition.

We were devastated. However, he told us the likely diagnosis was radial aplasia (it was actually ulnar aplasia, revealed on an X-ray after Miles was born). If it was as he expected, he explained it was likely to have been caused by an isolated vascular event during very early pregnancy, for no obvious reason. He reassured us that I or we didn't do anything to cause it, and he didn't expect there to be any further complications, but would refer us to genetics. After some tests the results all came back clear and after some time processing we were ready to move past this hurdle and enjoy Miles' pregnancy.

How did you feel when you found out?

At the time it was all quite overwhelming. I know now that I went through a period of loss. I grieved for the baby I thought I was having, a baby like everyone else's, that 'perfect baby.' My denial was hoping that at the next scan they would count ten fingers but that wouldn't happen.

Then I was angry; angry that I had worked hard for our NHS looking after other people's poorly children - why wasn't I getting my perfect baby? What did I do wrong? This led to bargaining; what if I had done 'this' differently, would it have changed things? Why can't I go back? Then I was sad. I had two weeks off work while we waited for results and I mostly cried; I was just so sad and couldn't enjoy our pregnancy. And then I found acceptance; our baby was loved and healthy and we would overcome any challenge his limb difference would throw at us.

I look back at that period and know that I had to go through all of the emotions to come out happy at the end, if I hadn't I would have just been burying how I really felt and that wouldn't have been good for any of us.

Finding out about Miles' limb difference in pregnancy meant we had time to process and accept and move on before he arrived. I was so excited to meet him and to see if his arm was how I had pictured it - it almost made it more exciting. And when Miles was born, he was perfect. He was our Miles. I realised that we really didn't need to worry about him.



Did your role as a Paediatric Nurse impact the way you dealt with the news?

I don't know if being a nurse affected my feelings initially. I found it difficult in a selfish way, thinking at first, 'hadn't I done enough already nursing other sick children, couldn't I just have a healthy baby, it wasn't fair.' As I processed and realised we were having a healthy perfect baby I think the fact I have looked after very poorly children gave me perspective. Miles' limb difference wasn't going to be an issue and it isn't an issue, it really has little to no impact on his life.

Interview with Reach mum Emma Gilpin



What resources did you find helpful to you in the beginning?

Before Mile's was born we attended an appointment at Leeds Children's Hospital, one of the UK's leading children's hand clinics. Sitting in the waiting room was surreal. I looked around at the children waiting, desperately trying not to stare at their arms and hands, but really just looked in awe. Seeing them playing, using games consoles and phones without a problem, it was so reassuring and just what we needed. I think that appointment really helped comfort us, knowing that Miles would be absolutely fine.

We also had the opportunity to speak with the psychology team and something they said has always stuck with me, and it's something I now say to others. "Not all children are bullyable." It gave me confidence and it feels true to me.

We were also told about Reach at that appointment and I immediately made contact with our local branch coordinator. She was so supportive, saying all the right things. I think I made her cry on the phone with the things I was saying because it was how she had felt. Knowing that, made it feel ok to feel down at times but I also told me it would be fine in the end.

We became members of Reach and joined the relevant Facebook groups. We didn't go to any meet ups beforehand but that wasn't really a conscious decision. I know we did some reading online, but once we'd had the appointment at the hand clinic I felt like we had the right information and concentrated on enjoying the pregnancy. We met up with the branch coordinator after he was born - it was lovely to meet another family just like us.

How did you find sharing your news with friends and family?

We told them straight away; I think it was important to have that support network and to share the worry. And just like us, it gave everyone the time to process that Miles would be a little different. And ultimately however he was going to be, he was loved and wanted by us all.

At the time Dan and I worked for the same team so before returning to work and after the initial news about Miles' difference, we sent an email to our colleagues. We found it easier to let the team know in one go, that our baby would be born with a limb difference, it was still something we were managing our feelings about but would talk about it if anyone had questions. Everyone was super supportive which made everything easier.

What has Miles taught you about limb difference?

Never to underestimate him, not that I ever really do. But also, not to try and teach him how I think he will do something. I don't know how his little hand works but he does. He knows what feels natural and right, we just need to be there to assist him if he asks. He has taught me that having a limb difference is not a problem, especially in the world we live in.

As Miles has grown, have you found any adaptations helpful for everyday life?

When Miles was a baby I adapted his babygrows and tops but now he's older he's happy to just roll back his sleeves. When he started school he had Velcro fasten t-shirts so he didn't need to do buttons but we found that when he undressed the Velcro would scratch his forehead, which he obviously didn't like. Also, he didn't need them, no one in his class could do buttons either. Going into his second year of school he asked for 'normal' t-shirts and at age 6 he can fasten his t-shirt buttons one-handed.

He has the Koala Paw to help him grip his bike handlebars. I don't think he would have learnt to ride without it, it's been invaluable. He no longer needs it for his bike but he's hoping for a guitar for Christmas and he may use his Paw with the plectrum holder.

What would be your one piece of advice for parents who are concerned about their child being bullied?

I would say talk to your child and try and find out if there is anything you can do to make things better. Talk to the school and see if there could be an assembly that celebrates difference without shining a light on them.

It's important to try and keep communication open with your child. Although for me this is just theory, we've been good so far, Miles hasn't encountered any unkindness. He's very confident with his limb difference and I think that works in his favour.



How much do you think knowing other Reach children impacts Miles' own feelings about his limb difference?

I would have said it's too early to know, however we recently attended the Reach Family Weekend and Dan my husband pointed out how Miles was instantly confident. From the minute we walked through the hotel door he was running around and playing with the other children. It usually takes him an hour or so to warm up to a new environment and people. Maybe it's coincidence, maybe it's because he felt comfortable enough to just join in. I think only time will tell.

Do you have any other advice for new Reach parents?

My message to any new limb different family is, feel all the feelings, good and bad, you need to feel them to work through them, the storm WILL pass and before you know it you'll be wondering what you were worrying about. Most importantly, enjoy your little new family member, they are going to teach you so much and amaze you in so many ways.

We're yet to find anything that Miles can't do; he loves to climb, ride his bike and scooter, play football, build LEGO, draw, and show us nothing will stop him.

And finally, on those days where the worried thoughts creep in or something has happened that's upset you or your limb different little one, never forget Reach is there to help, I am here to talk to if you want to.



What does the Reach community mean to you and your family?

It's a safe place to get support and advice from people who truly understand. And a place for Miles to meet children and adults who are like him, and can share stories and challenges as they grow. I also feel it is important for siblings. Miles has a younger brother Seth, and I think Reach events are a great place for siblings of limb different children to meet each other. They are a support network of their own, they understand each other too.



A True Trailblazer



Jacob Pickering is a rugby-loving 14-year-old from Blackburn and one of Land Rover's Trailblazers as part of their Defender campaign. We were grateful to Jacob and mum Kathryn for their time, as they chatted to Within Reach about attending the launch event in Paris, how rugby became a huge part of their lives, developing inner strength through sport and finding confidence as a new mum.

Jacob, the 'Sydney Morning Herald' front page, that's very cool!

You're a Land Rover Trailblazer, and 1 of only 6... I have to ask, how did that come about?

My parents received a telephone call out of the blue to see if I would be interested in taking part in an advert by a sponsor for the rugby world cup, we didn't know who it was or anything but I agreed and then we found out it was Land Rover! Which was really exciting. I think they found me through Blackburn Rugby club and a previous article in the paper.

What was the launch event like? Kano and other Trailblazers were there, and that massive statue of YOU! How did it feel to be there representing limb difference? (And do you get to keep your statue?)

It was really cool and quite surreal. When we got to the Palais De Tokyo in Paris we walked along a black carpet into the venue. I remember seeing the big posters of me outside and when we got inside it was such a great place. I felt like a celebrity, lots of people talking to me and taking photographs. I felt very proud to be there. I'm not sure about the statue it's 7 feet, not sure where we would keep it!

The Defender campaign talks about 'overcoming any obstacles', have you faced obstacles on your rugby journey, or maybe in other areas of life?

I don't think I have been treated any differently to anyone else, I learnt to tackle in exactly the same way as my team mates and I don't feel any different to any of the other lads. Even in primary school and now secondary school I have never felt different. The only thing I get away with is not having to wear my PE socks but that's me being lazy and not wanting to change them!

Have you had role models growing up that have boosted your self-confidence?

I don't really know; I feel that's a hard question. My mum and dad have always encouraged me to do things, I've done rock climbing, snowboarding, archery, swimming, and rugby so I think sports have boosted my confidence. I always looked up to my grandad and I was very close to him, he took me on lots of adventures growing up but he passed away to MND in 2019. I would love him to see me now. He was always so proud of me. He was in the Army and I love anything related to this. He would tell me lots of stories and I always wanted to join the army. I think that's probably the only thing that won't be possible!

The Defender campaign mentions 'inner strength' – does Rugby give you that strength? Would you recommend Reach members give it a go?

Yes, I love playing sports, especially rugby. I have so many great memories over the years and have made some brilliant friends. It's a team sport and you have to work together, I would say if it's something you would like to do - give it a try, nothing will hold you back and you won't feel any different to anyone else. I never have.

Kathryn, you must be very proud! How did it feel to see him on the front page of a newspaper, on Land Rover's website... Everywhere! And representing limb difference?

I am immensely proud! When we see him on the TV it still seems a bit crazy and even though we have watched the clips over and over we love it! A friend in Australia messaged me after walking into the staff room to find Jacob's face looking at him on the front page of the The Sydney Morning Herald.



How has rugby impacted your lives? Has it given Jacob self-confidence and that inner-strength the campaign talks about?

Rugby was something Jacob LOVED from a young age. He was welcomed into the team from the very first day he joined and has grown with them. They were unbeatable for a few years which was amazing! There have been lots of highs, before covid they had started to do tournaments - First was in Bristol and then second Cardiff, we are hoping to go to Spain next year! Without a doubt it has given him confidence. I also believe they have never treated Jacob any different which has 100 percent given him inner strength. It's such a great family sport, no shouting on the sideline etc, well not at Blackburn anyway. We have also been very lucky to go down to Twickenham and watch a few games, that is a brilliant family day out with such a good atmosphere.

Have you faced any negativity or prejudice towards his difference during the campaign or when he started playing?

During very early days when Jacob had just started playing, we went to a Rugby festival at Blackburn, one of his coaches was talking to me and asked, how do you think Jacob will be able to play as he gets older. I was honestly quite shocked, this does stick in my mind, I simply replied, it's not something I have even thought about for now he's playing something that he loves and that's good enough for me, as long as Jacob is enjoying, he will continue to play for as long as he wants. There have also been a few comments on socials but the only thing I can say regarding this, is it's impossible to understand some people! On the whole it's been great and I have received some really encouraging messages. Jacob too!

In 2009 just a few weeks after my 20-week scan and being told about Jacob's arm there was an article in the paper about Carrie Burnel. I was already an emotional wreck and cried every day, reading that was tough because I remember comments about her scaring children, it was awful to be reading this. Months later when he was born there was another article in the paper about a girl working for Abercrombie and fitch, again similar to Jacob - she was made to work downstairs because she did not fit with their look. This all added to my pain, when he was born I felt I had to cover him up, protect him from people until one day, I went to the coast with my mum and sister - it was a beautiful sunny day and we were all talking. Jacob was about 6 weeks

old, my mum and sister said you know you must not hide or cover Jacobs arm because if you do as he gets older he will, from that day on I didn't. I knew I had to teach him confidence even though I don't have much myself so that was my mission! Jacob isn't overly confident but I definitely see a change in him when he's playing rugby.



You fundraised for Reach a few years ago (thank you), why do you think charities like Reach are important for parents and children?

Because they bring people together to share experiences and to help one another. To see what is possible for the younger ones. I am sure over the years there have been some great friendships made from this charity. I would be happy to give advice to anyone, I was very lucky to have that because during my pregnancy it felt like a very lonely place until I was introduced to a parent who had a little boy just like Jacob. I am forever grateful for that. Preston Rehabilitation, Sharrow Green has been great for us also and Dr Fergus Jepson along with his team have always gone above and beyond, we could not have asked for a better place to take Jacob.

What would your advice be for new Reach parents or expectant Reach parents that might be feeling anxious or worried about their child's abilities with a limb difference/s?

My advice to expectant parents would be, you are going to be amazed! Once your baby arrives all your worries with disappear, I promise you. Don't hide away from anything, as they grow you will learn and see just how they adapt, there is nothing they cannot do or find a way around. Don't hide away from anything, I wanted to when I had my baby but that was not protecting him. Again, if anyone has any questions they would like to ask I would be happy to give advice. Jacob just started doing something he loved and now he's showing the world he's doing something he loves!

Follow Jacob's journey on Instagram @jacob_pickering_



Tony's #10for100 Transformational Challenge

By Tony Addison

Everything changed in the summer of 2023. The chance to feel a type of happiness – a happiness I'd never known – was there right in front of me; all I had to do was take it.



I peer over the edge and my breath is taken. The view is mesmerising, the hairs on my neck are standing on end and I need to capture this moment forever. Thrill and excitement have won out against fear and trepidation.

I feel a tap on my shoulder and suddenly I'm falling. My gloveless hands are out to the side as the ground races up towards me. I gasp to fill my lungs with ice-cold air. I'm struggling to breathe and then I remember what to do – in life, and this moment – I stop struggling and let go. My head lifts to meet the horizon and I can see a thousand miles in front of me. I close my eyes and this is what I will see forever.

A sense of freedom washes over me as this life-changing skydive cleanses blocked emotions of the past. I'm content, at peace, and happy.

It wasn't always like this though.

There was a time that I hid a part of me – a part of me that may be familiar to you. This was a time that I felt ashamed. A time that lasted 27 years too long.

Here's where I tell you that I was born with missing fingers and thumb on my right hand and my life splintered horribly off track when I was ten. My hand was the source of bullying and fighting. I fought back hard but then it all became too much for me to handle. That magical era of silliness, of playing football like Asprilla, of dancing like Michael Jackson and imitating those Ninja Turtles was over; that part of me withdrew and felt lost forever.

All I wanted was to be liked, but now there existed an insurmountable fear of rejection, which led to a lot of mistakes,

a lot of embarrassments and a lot of missed opportunities throughout my teenage years. Running away from home was a particular low-light, trials for Newcastle United weren't grasped, being humiliated on stage in front of my school-peers, quitting the basketball team, ending relationships before they started, dances avoided at prom, messing up my exams – these were just some of the stories that should glow with a different light; and a different ending.

It took until my early twenties to take accountability for my actions and begin to turn things around. A first-class honour's degree, promotions, senior leadership roles, meeting my partner, and having our adorably crazy children. A house by the Coast and the sand between my toes. Mentoring for REACH. All reasons to feel happy, content and at peace.

But I wasn't truly happy. I wasn't content, and I certainly wasn't at peace.

A time for reflection arrived to understand why. I delved into my personal values and recognised that making a difference in the world is how I'm driven – to act with honesty, integrity and trust, to be creative, and to work with like-minded people.

Only, I wasn't doing any of that.

I stepped to the edge and looked around. The career I'd made was now in the past. 19 years. 12 roles. 5 promotions. I said goodbye to the Civil Service and hello to Macmillan Cancer Support – a place I could make an impact. Only, the real impact was the difference that Macmillan had on me.



Working for Macmillan meant working in a psychologically safe environment – where I felt comfortable to be myself and show my hand. By bringing my whole self to work, I wasn't just living, I was thriving. I was producing my best work and I was happier.

So, what was the problem?

I still wasn't content or at peace.

Those two fingers on my right hand were still a source of shame. I was still hiding my hand in all other areas of my life, and for many people that knew me – most for over 10 years, some for over 20 – they still didn't know anything about it or the impact that it had on me. I wanted to feel that freedom everywhere, and not just at Macmillan.

Not only that, I wanted my kids to be proud of their father, and I never want them, or anyone else, to feel that they can't be comfortable in their own skin; something that I had done for so long. I want Noah to embrace his Autism and ADHD, and I want Aoife to embrace her Raynaud's, and find their sense of belonging.

For that to happen, I needed to hold my two fingers high and shine a light rather than cast a shadow.

The question was, how? How could I undo a habit of 27 years?

The answer: #10for100. I decided to structure a challenge that was personally meaningful and allow me to create a long-term positive habit whilst also keeping myself accountable. This moment of inspiration woke me in the middle of the night at 2am and I knew I needed to act on it straight away or I'd regret it.

I spent the following 100 days showing my limb difference – at all times – whilst undertaking some extreme physical, emotional and psychological challenges. I provided daily updates via Social Media of my experiences, warts and all, to raise awareness, whilst also donating £10 each day to both REACH and Macmillan Cancer Support, which inspired others to contribute too.

I was extremely nervous to begin with – at this stage I was more worried about what other people thought. I was fighting against a tsunami of old habits and behaviours; all trying to push me back to shore – and back to 'safety'. Once I started the relief I felt was incredible. Truly embracing my uniqueness was what I had always wanted and needed to do, and the positive response to my story was amazing.

The real high moments were my Sky Dive (no pun intended), a Mighty Hike, the Great North 10k, and learning to swim. The most challenging was speaking to 600 people about unhiding my hand at an event for Macmillan. My anxiety – that tightness in my chest – was at its peak and almost broke me. It felt great afterwards and I went on to repeat the process on a Podcast and at a Book Launch, which helped build the resilience needed when creating new habits.

The most enjoyable moments were going to watch Newcastle beat Man Utd with my hand showing the whole time – we also won 2-0 so that may have helped! I also loved going to gigs (Sam Fender), taking the kids to Disney World, Rock-Climbing in public and playing football with friends – all with my hand showing for the first time in over two decades.

There were so many positives to this process of unhiding, but a fundamental part was working through the psychology behind my need to hide my hand in the first place. I was conscious that those behaviours might come back, so I experimented with different types of therapies, including EMDR (Eye movement desensitization and reprocessing), to reframe early life experiences that I'd blocked out and not dealt with.

I also adopted a few Coaching practices and I'd wholeheartedly recommend trialling all types of personal development to see what works for you. Trying to be the best version of yourself should always be your priority, and the world might just be a better place if everyone had help to re-shape the narrative in their heads into a more positive light.

The fulfilment of my 100-day challenge is the best thing I ever did. I now fully own my disability – previously I would never associate myself with the word disability

due to the negative connotations. I'm able to talk about my experiences of ableism and the importance of psychological safety in being the best version of yourself.

I've successfully created a habit that I've continued – I've never hid my hand since – and I've stretched my boundaries in ways I didn't think possible. I also managed to raise over £2,000 to go towards future Reach Activity Weeks, which I'm really proud of, and it's inspired me for my next challenge; writing a book in 100 days!

For many people who read this, you too may be fighting your own personal battle to show the world exactly who you are every day and I know it can be exhausting. Please know that you are not by yourself and the world deserves to see the best of you. I want to empower people living with a difference to embrace their uniqueness and maximise their potential. You are capable of so much more than you think. I know the very first step can be the hardest but by being a little bit brave and showing that vulnerability – embracing every part of who you are – it might just be the best thing you ever do.



“
I needed to hold my
two fingers high and
shine a light
”

“
My anxiety – that tightness
in my chest – was at its peak
and almost broke me.
It felt great afterwards
”

Satyadasa

The Sound of One Hand



What is the Sound of One Hand Clapping? It's a famous 'koan' - an apparently unanswerable question posed by the Zen Buddhist Master to a student. Give a clever clogs answer and the fierce Master might bash you with a broom handle, so the old stories say. Instead the student must answer authentically, from the depths, and rise to a new level of understanding.

My 'little hand' or stump has been a kind of koan or riddle I've had to live with and which has forced me, sometimes against my wishes, to grow in directions I may never have taken. I've written a memoir about it called *The Sound Of One Hand*, because it also involves a Buddhist journey.

As a child I didn't want to discuss it much. I didn't even want a prosthetic because I didn't want to make any concession to it at all, not even covering it up. My parents gave me a good cover story: you are no different to anyone else. At school I competed hard; winning stuff gave me recognition and helped me feel equal to my friends.

This story persisted well into adult life. If anyone asked (which they rarely did) I told them the hand hadn't affected me much. 'A little bit of course...' for practical stuff.' I pushed to one side lurking feelings of being different or awkward or weak. What was the point of exploring such ghastly feelings? I'd still have one hand missing and I'd be miserable as well. I was doing okay thank you very much.

“ I returned home less struck by what was missing, than by how beautiful the children were. ”

In my early twenties I went on a ten day silent meditation retreat. My grandfather had been a meditation teacher and purveyor of Eastern religion. Soon after I moved into Buddhist community, meditating every day (okay not every day) and going on longer and longer retreats. Buddhist practice is the systematic cultivation of awareness of oneself, of others, of nature and even of something deeper than that, which goes beyond ordinary awareness. Call it Buddha Mind. Call it the Sound of One Hand Clapping. Sounds good, and Buddhism is a popular thing to get into. We imagine being calmer, spending hours in lotus position and appearing rather spiritual. But it's not really like that.

One day I was on the way to work on the Central Line when I saw a guy with a missing hand. I was 29 and I'd been practising meditation for nine years. A banker I thought. (We were at Bank station.) I quickly hid my little hand under my book, hoping he hadn't spotted it. I didn't want a friendly chat with him on that theme. Later on this episode set me thinking. I've done all these hours of meditation so surely I can face these feelings a bit better? Why don't I want to meet anyone like me? I never had.

A week later I was booked on a volunteer training weekend for the

REACH activity week. Six adult helpers met at a station in mid-Wales. There were little hands galore: claw like things, little buds, foreshortened arms. I felt an instant, happy bond with everyone as walked up Cader Idris together. At the pub that evening though I felt deep discomfort. On my own I could pretend I was unnoticed and normal, but with six of us there was no chance of that - counting out coins with our stumps and clutching drinks in various odd ways. Part of me wanted to run away, but it was too late for that.

There were forty or so children on the Reach Activity Week. In every one of them I could see myself. That's how I look carrying a tray or opening a jam jar. Some were more confident than me in how they related to their missing digits and foreshortened arms. I would have recoiled from all this as a child, but it would have done me a lot of good. What surprised me most was how the inability to hide the fact and the shared bond gave us the opportunity to genuinely forget about it. I returned home less struck by what was missing, than by how beautiful the children were.



In my thirties I started to talk about it more. An inner shift in me allowed others to ask how it happened. 'I was born like this.' I wished for a longer, more heroic explanation. I also started to breathe and pause when I felt the instinct to hide, to tuck the stump up a sleeve or under a book. It's okay to want to do that and I still do sometimes, but it also helps to lean into the feelings about it and sometimes resist habitual urges. It opens things up in all sorts of ways.

Through writing the memoir I've been able to reflect on how much my little hand has shaped my life. It's been a grain of suffering

in an otherwise happy and fortunate life, a pinch point around which my growing self had to form and defend itself. As I approach 50 years old though, I realise that how our lives unfold is a mystery. There are so many causes and conditions for what has happened to me and the hand is just one. Maybe not even the main one. I probably wouldn't have been a rock star, even with two hands!

I feel a great gratitude to REACH for the two activity weeks I did all those years ago, and I'm delighted to be sharing my memoir now with members. I hope you enjoy it, have a good laugh, find things to relate to and more besides.



Books



The Sounds of One Hand

<https://www.amazon.co.uk/Sound-One-Hand-Buddhist-Life/dp/B0BYFBJ23L/>

Anything You Can Do, I Can Do Too

<https://www.amazon.co.uk/Anything-You-Can-Do-Toolbox/dp/B08RR8K0NM>



Born just right

<https://www.amazon.co.uk/Born-Just-Right-Jeter-Publishing/dp/1534428380>

Different Is Awesome

<https://www.amazon.co.uk/Different-Awesome-Ryan-Haack/dp/1631772155>

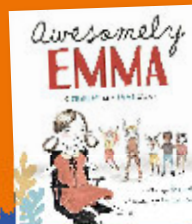


Emmanuel's Dream: The True Story of Emmanuel Ofosu Yeboah

<https://www.amazon.co.uk/Emmanuel's-Dream-Laurie-Thompson/dp/044981744X>

Aven Green Sleuthing Machine

<https://www.whsmith.co.uk/products/aven-green-sleuthing-machine-aven-green/dust-bowling/paperback/9781454941804.html>



Awesomely Emma: A Charley and Emma Story

<https://www.amazon.co.uk/Awesomely-Emma-Charley-Shirley-McCarthy/dp/1506464955>

My Big Brutal Swim

By Max Swinhoe

On the 10th September I took to the waters of Llyn Padarn in Eryri (Snowdonia) in North Wales to swim 2.5 kilometres. But it wasn't all smooth sailing...

I began training around a year before the event, knowing that my swimming fitness was non-existent and that the only way I was going to be able to complete that distance was to get my fitness and swimming confidence up to scratch.

At first, just heading to the pool on my own was nerve-wracking; I watched YouTube videos to help improve my technique and I even started a 'Swim Club' WhatsApp group with a few friends because I knew it would help me to hold myself accountable. We kept each other updated with our swimming progress, week-by-week the lengths started mounting and confidence was growing.

But even going to the pool on my own at first challenged me, I didn't know which lane to swim in, I felt like everyone was staring and like the life guards must be waiting at the edge of their seats ready to have to save me.

But I pushed through the discomfort and soon the feelings of worry shifted to feelings of empowerment, as I felt fitter, and grew stronger, I stopped caring so much about people staring and just concentrated on getting the lengths done.

I was proud of myself, previously I wouldn't have even attempted front crawl, for fear of people looking at my arm, let alone going to the pool on my own. For me, fitness has always been a confidence-builder, so I knew the more I went the better I would feel.

As spring came round though I realised I had to start training outside, in a lake, if I were to tackle this challenge.

Tom and I popped down to the lake for my first dip, just to get used to it. Wetsuit, cap, booties, goggles and go, I felt apprehensive but keen... Oh how I had underestimated it.

It was terrifying, I felt panicked by the green murkiness of the water, by the cold water on my face, the brain-freeze taking over – I tried a few strokes of front crawl but just felt like I was splashing inefficiently, unable to keep my face in for very long, for fear of the cold and the fear of seeing... anything in the darkness.

From then on I joined the group for lots of dips, and I arranged several lake dips and training swims with Jackie, and in between the wild swims I continued my fitness training in the local pool. I still felt nervous and very unsure, especially by the reeds and plants that seemed to be growing from the depths of the lake as summer arrived but I had discovered that swimming with others made me feel much more at ease.

Over time in the pool, my 30 lengths become 45... then 55, soon I was happily swimming 65 lengths, 70, 80... but I still had lots to go. And I'd have to cover the distance in open water – a whole challenge in itself.

Finally though, after extending our distance a little with every lake swim and working out that swimming in the middle meant no reeds, we were getting close to the 2k mark. And on the weekend before the 'Big swim' we swam 2.5k. "Yes, I can do it!"



The big day! Wetsuit, goggles, booties and bright green 'Brutal Swim' cap on, butterflies in the stomach and we were off. What a day; from the shore our SARDA Wales (Search and Rescue Dog association Wales) friends cheered us through the start line, the water was reasonably warm and the swim was smooth, undeterred by the other swimmers splashing around, Jackie and Tom swam along next to me and we smashed it. My training had paid off!

It was only then, as I hundreds of pairs of arms 'splashed' past, around, before and behind me, that it dawned on me - my limb difference does give me a disadvantage. All the videos I'd watched on 'perfecting your stroke' and being efficient in the water, I had simply applied it to my right, and left my little arm to do what it can, but I hadn't recognised how much faster, or more effective I'd be if I could replicate the actions of my right arm on my left. But I can't, and I'm OK with that.

Instead of this being a negative thought, I was only filled with the greatest pride. I was proud and empowered by all the training I had achieved, by the distance I had managed, the challenge I had just overcome as I stood there on the bank surrounded by able-bodied people – I didn't care at all about anybody looking at my limb difference – I had just nailed it, despite all my fears.

I was also so grateful for the amazing and wonderful support I had received from not only my friends and family but from friends of friends and family members, and I was absolutely delighted to raise over £1000 for Reach.

So, what did I learn... I learned that despite its asymmetry my body can do amazing things.

I have been asked on many occasions *if* I can swim or *how* do I swim... Well, I can assure you, yes, I can swim - I completed The Big Brutal Swim 2023.

Here's to the next challenge!

<https://www.bigbrutal.org.uk/max-swinhoe-1688555262605>

Ashley Young
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What does representation mean to you? (Did you have any limb different role models growing up?)

Representation to me means everything! I believe that everyone deserves to see themselves in all forms of media. This has certainly stemmed from the fact that when I was a kid I didn't necessarily have any role models. It made me grow up feeling extremely isolated from society and all of my peers where I had the belief at one point that I was the only one in the world with a limb difference. All body types, races, abilities, and genders deserve to be seen and to take up space in every industry.



Have you ever faced people saying that things are 'going too far' in terms of representation and if so, how do you respond to that?

Well, I have, but mostly behind a keyboard and in random comments from YouTube or Facebook. I don't really pay too much attention to it because I believe that the work I am doing is unaffected by the comments, and I will still continue regardless.



You were in the Barbie movie! How did it feel to be a role model and to know you're normalising difference by being there for all to see on the screen?

Yes indeed! It felt like a complete full circle moment for me to be in Barbie. I grew up without a doll that looks like me and to be the doll I always wanted I will cherish for life. I had a lovely conversation with some of the cast of Barbie where we talked about how important it was to see such a variety of people in the movie. Not necessarily using their difference as a plot point, but to have us just exist and be included is a great step towards the future. Every step of the way I had the next generation of limb different kids in mind, even getting emotional at some points because I couldn't wait for them to see me in this and see themselves in the character.



The modelling industry is notoriously challenging, how have you found navigating it? Are things actually changing for the better?

I have had a few instances in 2019 where I have been emotionally hurt by being the token person and treated as such by professionals in the industry. On a particular job I was the only person who didn't have individual shots or interviews but was used right at the end for the group shot. It was extremely disappointing to be in such a situation. I do believe that the industry is moving in the right direction for advertisement and film and TV but high fashion labels are stuck in the early 2000s and I really feel like it isn't talked about enough. When you see big brands not representing all body types you can't help but think that they are doing it very much knowing the rest of the industry is changing but they simply do not care.

Why do you think the high fashion industry or some brands refuse to progress in terms of inclusion?

I would say that they refuse progress in inclusion because they probably don't have the knowledge or education about people with disabilities.



What Reach Does

Find out more by visiting: www.reach.org.uk

The UK & Irelands Upper Limb Difference Charity Supporting families and individuals with community, information and more.



Reach Activity Week

For Reach children aged 10 – 17 years, it's all about fun together and plenty of action; from climbing, abseiling and canoeing to problem solving, archery and coastering.

Welcome Pack

A special care pack for new parents with information about what to expect, the support available to them, and how Reach can help along the way.

Annual Family Weekend

Our annual conference is all about sharing experiences, inspiring stories, invaluable resources, and reconnecting the Reach family.

Within Reach Magazine

The Reach publication sharing the voices of our upper limb difference community; real stories, celebrations, events, inspiration and representation.

Social Media Community

Public platforms focusing on representation and awareness, and private groups providing a safe space for sharing and celebration within our community.

Branch Meet Ups

Helping Reach families make meaningful connections through our 19 Branches across the UK by organising meet ups and events.



Helping children with upper limb differences live life without limits