

# journal





## Letter from the Chief Executive



Carol Boys

We have worked hard to keep you up to date throughout the Pandemic. We have produced an enormous amount of accessible information and tried to bring you the very latest as we received information from the Department of Health and Social Care.

We were able to influence some of the decisions about the addition of people who have Down's syndrome to the CEV (clinically extremely vulnerable) list and we campaigned hard to get them moved up the queue for the vaccine. Our free weekly update webinars have been extremely popular. The updates will continue for as long as there is a

demand. If you would like to receive information from us via email, please do let us know your address.

Our inclusive participation programme, **Our Voice**, launched last summer. The group's contribution to the development of our resources, planning and awareness raising has been first rate. The new look Journal is a reflection of our commitment to inclusivity; it should be as relevant to our members who have Down's syndrome as it is to their parents and carers. We also plan to send out short summer and winter 'Updates' to all our members to ensure you have the most current news, information and resources.

Thank you once again to all of our members for your continued support. The response to our appeal last year was unbelievable and the increase in our membership during the year has been quite overwhelming. We have great strength in our numbers!

Carol Boys, Chief Executive

### Information for Contributors

The Down's Syndrome Association publishes The Journal every September and March.

We are interested in publishing general articles, news, letters, academic papers, book reviews, arts/exhibition reviews and conference reports, all of which should be specifically related to Down's syndrome.

We include human interest stories on any aspect of life with Down's syndrome. Previous articles by parents have covered all stages of life from birth to adulthood. If you have an interesting story we would like to hear from you.

### How to submit

Our document Information for Contributors gives full details on submitting an article. If submitting photographs, you will also need to complete a DSA photo and film permission form. See [downs-syndrome.org.uk/about-us/dsa-journal/](https://downs-syndrome.org.uk/about-us/dsa-journal/)

Articles submitted for consideration should be sent to: Ian Jones-Healey, DSA Journal Editor [ian.jones-healey@downs-syndrome.org.uk](mailto:ian.jones-healey@downs-syndrome.org.uk)

### General Notes

We cannot always publish articles as space is limited; articles may be published at a later date if the next issue is full; we reserve the right to edit articles; the Editor may alter articles wherever necessary to ensure they conform to the stylistic and bibliographical conventions of The Journal; authors are responsible for all copyright clearance for any third party material/references/images included; if using references please use the Harvard system; photocopying single copies of articles contained in this journal for the purpose of private use is permissible; for multiple copies and reproduction, permission must be sought from the DSA/author(s); copyright is retained by the author(s); if authors use the same material in subsequent publications, acknowledgement should be given to this journal.

## Letter from Kate Powell



Dear readers,

You may be wondering why you haven't got a copy of Down2Earth? Last year we decided that it is important that **The Journal** should have more content in it by people who have Down's syndrome.

That's why you haven't got a copy of Down2Earth...it's now part of The Journal!

We'll still be sharing all the wonderful stories, art, photos and poetry so please keep them coming. Send them to [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk) and mark with 'FAO Kate Powell'. Or you can post them to Kate Powell, Down's Syndrome Association, Langdon Down Centre, 2A Langdon Park, Teddington, Middlesex TW11 9PS.

We'll also be adding extra articles we think you'll be interested in and enjoy reading. Catch up on my weekly blogs at [downs-syndrome.org.uk/kates-blog/](https://downs-syndrome.org.uk/kates-blog/)

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### Disclaimer

The Journal is designed to provide a communication forum for members of the DSA through which to facilitate the exchange of information on topics related to living with Down's syndrome. Unless indicated otherwise, the views expressed in The Journal are those of the authors and do not necessarily reflect the official positions or policies of the Editor or the Down's Syndrome Association.

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**On the Cover:** Isaac visited Bewilderwood in Norfolk whilst on a camping holiday and enjoyed the zip wire.

# News

## Coronavirus (Covid-19)

We are hopeful that by the time you read this, many adults who have Down's syndrome will have received their first vaccination shot.

The advice and guidance regarding how to stay safe and healthy is changing all the time. We are working with Government departments in England, Wales and Northern Ireland to make sure we know the latest.

You will find all the latest news and relevant resources on our website –

[downs-syndrome.org.uk/coronavirus-covid-19/latest-coronavirus-news/](https://downs-syndrome.org.uk/coronavirus-covid-19/latest-coronavirus-news/)

You are also very welcome to join our free regular, online update sessions. Find out more here – [downs-syndrome.org.uk/about/training/online-training/dsa-update-on-covid-19-and-people-who-have-downs-syndrome/](https://downs-syndrome.org.uk/about/training/online-training/dsa-update-on-covid-19-and-people-who-have-downs-syndrome/)

Our Helpline team are also available to answer your questions. Email [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk) or call 0333 1212 300 (Monday to Friday, 10am-4pm).



## DSEngage – online activities for people who have Down's syndrome



We are all doing different things to keep busy and active at the moment. That's why we created DSEngage. Each weeknight there's something to try...videos to follow at home including relaxing yoga, fun dance routines, motivating exercise challenges, simple arts and crafts, as well as downloadable colouring and activity sheets to do at the weekends.

We're developing new activities all the time and are also really happy to hear or see how you've been inspired.

You can find out more about DSEngage here – [downs-syndrome.org.uk/dsengage/](https://downs-syndrome.org.uk/dsengage/) – and see all the videos we've already shared on our YouTube channel – [youtube.com/c/DownsSyndromeAssoUK/](https://youtube.com/c/DownsSyndromeAssoUK/)

## Responding to the Work and Pensions Committee on the disability employment gap

The Work and Pensions Committee, a group of Members of Parliament (MPs), are holding an inquiry on why so many people who have disabilities find it difficult to find jobs. This is sometimes called the 'disability employment gap'.

At the end of last year we wrote a report that told the MPs on the Committee why we think it doesn't

work as well as it could at the moment for people who have Down's syndrome. We also told them about our WorkFit programme and how successful it has been.

After the MPs on the Committee have read our report and all the other reports that were sent in, they will also listen to some people talk about what

they think. After the MPs have thought about all of this, they will publish their ideas on how to make things better.

We'll make sure to let you know when the report is published.





## Our Voice

### *Lindsay is a member of the Our Voice programme...*

I'm Lindsay. I look forward to the Our Voice Weekly Check-In on Zoom because I'm meeting other people who have Down's syndrome.

We get to chat about what we have been up to, how we are keeping busy and we plan things we can do together. I like hearing all the things that the others have been doing and their ideas of what else we might do.

I don't belong to any other groups and because I went through mainstream education I don't regularly meet with other people who have Down's syndrome. When Our Voice first started I was a little bit nervous and wasn't ready to speak up and so just listened but now I have found my voice and enjoy taking part and contributing my ideas and making new friends.

Being a member of Our Voice has made me more confident and I look forward to doing more with them.



## New online support sessions

### *We are now offering regular free support sessions via Zoom as well as a range of online training events.*

**Well-being Wednesdays** happen every fortnight and offer an opportunity to unwind and relax in a friendly and non-judgmental group with people who understand.

Each session is facilitated by Jane Mitchell who is a Learning Disability Nurse and Mindfulness Teacher and will include guided mindfulness practices as well as other well-being activities with time to share and reflect.

The **Sharing Positive Support** sessions offer the opportunity to share your experience around

behaviour in children and adults who have Down's syndrome. Each session will be facilitated with a focus on collaboration and sharing rather than an 'ask the expert' format. Each session is free and they will be run twice a month.

We are also now running a regular online session for expectant parents and those with babies up to 18 months old. The sessions will provide

an opportunity for everyone who is at the start of their journey to ask questions, share experiences and relax with people in a similar place.

Our online training events cover a wide range of subjects and we're adding to the list regularly.

Go to [downs-syndrome.org.uk/online-training/](https://downs-syndrome.org.uk/online-training/) to find out more and to register for a place.



## Catch up with DSAActive programme manager, Alex Rawle



It has been a really challenging year for all grass root sports and leisure activities and our DSAActive sessions have experienced difficulties alongside the rest of the sector.

Alex caught up with Richard Bailey in an episode of our Shifting Perspectives podcast to reflect on the year and highlight ways that everyone can still keep active and healthy.



You can find all the Shifting Perspectives podcast episodes on our website at [downs-syndrome.org.uk/ShiftingPerspectivesPodcast/](https://downs-syndrome.org.uk/ShiftingPerspectivesPodcast/)

## WorkFit film starring social media stars Ollie and Cameron wins Charity Film of the Year



One of the highlights of last year was hearing that our WorkFit film 'When I Grow Up...' had won the Film of the Year Award from Charity Today. In the film, Ollie and Cameron tried out a variety of different jobs and their mum, Elaine, explained why it's important to think about working, even at a young age.

While things have been difficult for many of our WorkFit candidates and their families, WorkFit continues to provide them with support and information. WorkFit is supporting employers to ensure that, as things start to return to normal, candidates can get back to work as safely as possible. We are also exploring exciting opportunities with new partners to offer even more candidates the prospect of accessing employment opportunities.



You can watch Ollie and Cameron's film on our YouTube channel. Go to [bit.ly/OllieAndCameronWhenIGrowUp](https://bit.ly/OllieAndCameronWhenIGrowUp)



## Our 50th Anniversary

*We're very happy that our anniversary celebrations will be continuing into 2021.*

We have shared some amazing stories from people who have Down's syndrome who are over 50, including five oral histories.

We are so grateful to everyone who has been involved in this project... your stories are fascinating, moving and full of joy.

The Memories and Stories photography project, led by Richard Bailey with contributions from some of the leading lights of British photography, will be launched this summer.

We look forward to sharing the stunning images with you. To find out more go to [downs-syndrome.org.uk/about/our-50th-anniversary/](https://downs-syndrome.org.uk/about/our-50th-anniversary/)



CELEBRATING  
**50**  
YEARS  
1970 - 2020



## World Down Syndrome Day and Down's Syndrome Awareness Week 2021 – #CONNECT

We will be celebrating all the different ways we're connecting with each other...particularly to share and amplify the experiences, knowledge, creativity and achievements of people who have Down's syndrome.

We'll be sharing lots of fantastic stories... visit [downs-syndrome.org.uk/about/campaigns/awareness-week-2021/](https://downs-syndrome.org.uk/about/campaigns/awareness-week-2021/) or check out our social media channels for all the latest updates.

The **#LotsOfSocks** socks are the same popular design as 2020 and you can buy them at a special price for 2021!

There's still time to get a Fundraising Pack too. It's full of lots of great ideas to inspire you as well as advice on how to make your fundraising as fun and successful as possible. You'll find a link to the pack here [downs-syndrome.org.uk/about/campaigns/awareness-week-2021/](https://downs-syndrome.org.uk/about/campaigns/awareness-week-2021/)

## There's still time to take on a #Challenge21 this spring

*There's loads of ways you can get involved in #Challenge21.*

It's a great way to raise awareness and some money for the DSA this year.

The challenges can be super simple or really tough. There's something for everyone whether you're sporty or crafty; want to try new things or to perfect a hobby you love; want to get friends involved or take on something on your own.

Visit our website for loads of inspiration, ideas and resources. Go to [downs-syndrome.org.uk/challenge-21/](https://downs-syndrome.org.uk/challenge-21/)

For all the latest news from the Down's Syndrome Association go to [downs-syndrome.org.uk/news/](https://downs-syndrome.org.uk/news/)



## Bryony

I live in Morecambe which is a seaside resort in Morecambe Bay with breathtaking views of the Lake District. It had its heyday in the mid 20th century. It attracted visitors from all over the north. It had two piers which have since burned down. Also many theatres and dance halls. My own grandmother who is 93 can remember dancing the night away at the Pier Ballroom. In the 1930s a big new hotel called the Midland hotel was built in an Art Deco style and it is now quite famous.

Nearby the Midland hotel is the Stone Jetty which used to bring in by rail and sea, all the holidaymakers. It is now a quiet little jetty. Next to it used to be a huge outdoor swimming pool where 'Miss Great Britain' was televised from every year. It was the largest outdoor pool in Europe, but was demolished in 1975.

Eric Morecambe was an English comedian, who together with Ernie Wise formed the award-winning double act Morecambe and Wise. Eric Morecambe took his stage name from his hometown. There is now a

statue to commemorate him and most people like to have their photo taken next to him (like me).



The promenade is five miles long and I have walked along it nearly every day since I moved here. I like to watch all the different kinds of seabirds like oystercatchers and curlews. The tide comes in twice a day and when it's out people can walk across, but I've never done that. You need to have a guide because there is lots of very dangerous quicksand.

There is so much more to tell about (Morecambe), and I will tell you more later.

Ps. I took a photo recently of a fantastic rainbow over the bay, hope you like it.



## Aidan

I have supported my local team, AFC Bournemouth (AFCB) since I was little. AFCB won the Championship against Charlton Athletic at the Valley and were promoted to the Premier League. AFCB is a good team and have scored lots of goals in their Premier league history.

I was excited when I heard I had an audition for an AFCB Product Ambassador. I had to do a video for the audition and my brother Niall helped me. The AFCB staff chatted to my mum on the phone and asked her lots of questions about me.

I got the role of Product Ambassador and I felt happy and important.

Me and my family were delighted.

Me and mum went to the stadium and met the other Product Ambassadors and staff there and said hello to them all. I had food to eat with the other Product Ambassadors. I put on new AFCB clothes and had this photo taken in them.

I was sad when the virus came to England because it means that I can't be a Product Ambassador at the moment because of the lockdown.

I am looking forward to watching AFCB play again and being a Product Ambassador again.





## Catherine



My name is Catherine and I am 23 years old. I am writing to you about my life. My hobbies are: sailing, horse riding, cycling, kayaking but my passion is: dancing.

I have a big family with my parents, my brother and sister who are married to their partners, and my grandparents and my aunts and uncles and cousins.

I love celebrating parties with my family. The family weddings were fun especially as I was a bridesmaid for my sister and I was proud to do a speech at my brother's wedding.

Early in my life I had Portage and they helped me towards my adult life. I went to mainstream schools and I had the best teacher assistant and a best friend at Saint Peters school in Hammersmith. Learning more was

difficult at my secondary school but I had lots of fun with my best friend.

Then I moved from London to Norwich where I went to City College Norwich and I did four courses there. I finished my Project Search placement at the hospital.

Over the last few years I have done various volunteering roles at hospitals, cafes and church. I have also been searching for my first paid job.

My dream job would be a dance teacher so I have to take work experience teaching the juniors when I go to my dance lessons. I enjoy performing with my friends and I have participated in lots of public performances. I go to dance classes like contemporary, street dance, ballet, tap, modern and jazz. I am flexible through dance and I can do gymnastics in dance as well. All those dance classes that I did in the past I have improved myself into my dancing.

My dog Liaka, who was 14, was a lovely friend to me, but unfortunately last year she was poorly and had a stroke. In May she passed away. This year we got a new puppy and now she is getting to know the rest of my family and friends.

Now it's about time for me to be independent and I have been going to one of my independence courses. I have a P.A which is personal assistant

who helped me to be independent. I like to be independent because I would like to live in supported living flat. With my P.A I have learnt meal planning, time management, budgeting, and housekeeping.

I am trying to be independent being in the house on myself without parents during the day, but I can't do it by myself in the evenings and now that is my aim.

I have a boyfriend who helped me and is supporting me. I would like to have a house with my boyfriend but I have to be independent by myself first and then also need a paid job. I would like to have a future with my boyfriend.

I have a mentor who helped me apply and go for interviews and prepare towards a job. I am starting my first paid job at my local hospital as an Apprentice Assistant Housekeeper very soon. This is a big change going to work after life of education. I am very proud of myself but I am nervous and also excited and happy about it. I have had lots of help in my life from my family and friends and my schools.

My advice for people with learning difficulties out there is to be the best you can be, be yourself to be independent, find jobs for yourself and find hobbies. Also believe in yourself and enjoy yourself. I hoped you have been inspired!!

## Kathryn

Hello. My name is Kathryn. I am a very sporty person.

I like to learn new things. I swim for Team GB, I snow ski, I tap dance, I play the violin and I water ski.

I water ski with the Access Adventure on Heron Lake in Wraysbury. I first started two years ago. Now I go fast behind the boat and cross the wake.

I enjoy it. I'm starting to do the slalom course.

I like meeting new people. Everyone is helpful and gives me tips. They know about your disability and special needs.

They have BBQs and other things. Water skiing makes me confident. When I fall down I get up again. It is fun. You should try it.



## Blue Sky actors by Lauren

Hello Journal readers!

I am going to talk about my drama group that is run for people with learning disabilities and difficulties.

It's a way to have fun, get some acting experience and to gain confidence in yourself.

We put on plays at the end of each term, we did a recent play on Pinocchio but we twisted the play and called it Pantocchio and I played a judge as part of the game show we hosted, there were five judges and my talent was a dancer.

We all enjoyed it and everyone said it was the best play. There was a lot of people there watching us this was my second time doing this and I felt confident and more relaxed and now

I know everyone there very well I made a lot of friends.

I'd recommend it to people with learning difficulties and disabilities, it's every Saturday and we are there from 3pm until 6pm and it's only 20 pounds per term. If there is anyone who wants to join they will have the best time of their life, the staff are brilliant and the teacher is really excellent at his job. We have fun that's the main thing.

We warm up by dancing to music as we come in and give a handshake. We learn performance and theatre skills and you have to wear loose fitted clothes that you are comfortable in and they give you a Blue Sky Actors t-shirt when you join. We are based in Stratford Circus Arts Centre, East London.

Thanks readers for reading my article.



## My Costa Rica holiday by Rebecca



My name is Rebecca and I went on holiday with my parents in February before the virus affected everyone, and we went to Costa Rica we went to Tabacon. Our room had views of the volcano and the views were magnificent and we had a mix of wet and hot weather. We spent a week there and me and mum went to the spa and we had a Swedish massage and it was a nice and relaxing and it was near to the hot springs and the waterfalls. They were so beautiful and magical and we all went into the hot springs, it was lovely it was like a nice hot bath.

In the rain forest we went to see the sloths and different animals. We saw a turtle move up close and also saw it trying to give birth to her babies. We went to different zoos to see the frogs and then we went to see the snakes, and went to see the birds of prey and we had a tour guide to see all the wildlife, it was wonderful to see it and we loved it. The weather was fantastic.

The following week we travelled near the Pacific Coast to the beach and it was hot. The entertainment was good, me and mum saw a show based on Costa Rica with the history and the big, bright colours with the America side and also the other side was Spain it was a very interesting story. My mum did a class of all the *Strictly Come Dancing* moves and me and mum did a masterclass of cooking. We had a cabana on the beach and we went into the pool and also swam to the pool bar and had a drink. The fruit and food in Costa Rica was lovely and very exotic. There was great views outside the room, the sunset in the evening was so bright and the colours were so vibrant as we went across the sky I loved watching it. In the nighttime we saw different shows and what was on at the bar at night. We had a good time there was a disco as well and I danced and I danced gracefully like a swan and we also sang along with the music as well.

We made great memories.



# Our story: how Jenny learnt to ride

Martin Whittle and Julie Grafton

*Our daughter triumphantly rode a bike for the first time just before her 18th birthday. She was elated; we were possibly more elated. It was the culmination of many months of work driven by the hope that she would one day ride on two wheels. She was wearing one of her favourite t-shirts; pink, inscribed with 'This girl can' and, yes indeed, she could!*

There is a freedom about cycling that has always been a big part of our lives. So we were keen that Jenny might one day be able to enjoy a ride with us. We started as most parents do by putting her on a back seat at about 18 months and doing some short rides in quiet places. On holidays we sometimes hired a covered cycle trailer.



When Jenny was seven, we got her a tricycle. This had a single 1:1 low gear fixed wheel drive and came with toe clips and straps to prevent the feet slipping off the pedals. Jenny was visibly ecstatic the first time she rode her new trike in the park. We think she got a taste of that freedom that we enjoy from cycling. It is also empowering, here was something new that she could do. We took that trike to playgrounds and parks at every opportunity.

We thought the next stage might be a bike with training wheels, but Jenny was very averse to the wobble, so unless these were set very close to the ground she would not ride. We had the same problem with a hired tag-along; she found the side-to-side wobble caused by the coupling

immediately unacceptable. We became doubtful that Jenny would ever ride a bike and concentrated on tricycles for several years. Trikes enable the family to enjoy a ride together; they provide great exercise and give a taste of that outdoor freedom. Foldable, transportable trikes are available and provide a solution to accessing traffic-free trails and holiday rides.

Jenny enjoyed riding and developed the pedalling strength and skill to ride for miles on traffic-free trails. The missing element was balance. We eventually thought we would give two wheels one more shot. Like most kids, Jenny listened better to someone other than her parents, so we hired a trained cycle instructor for the first few lessons. He took the pedals off her bike, lowered the saddle so that her feet touched the ground, and transformed it into a 'balance-bike'. This is what she needed to develop the missing element. She started on a very gentle grass slope in the park, which is less bruising in case of tumbles, and then progressed to the pathways. Weather permitting, we practised several times a week and very gradually the glides got longer.

It was several months before Jenny could sustain a glide even to the count of three. Jenny persevered brilliantly but we still had our doubts that she would ever do it. Then one of Jenny's friends learnt how to ride. This was very motivating for Jenny. She could see for herself that something once so apparently impossible can be achieved. Gradually, over several months, the glides got longer, straighter and more consistent. Learning to balance takes a lot of concentration and it is important to not do too much in one session. Better to do shorter sessions more often.

When she could glide confidently for about 10 seconds without putting her feet back down, we experimented by putting one pedal on. Jenny was already a good peddler from years of riding a trike, but balancing at the same time is different. Starting off is particularly hard because that first push on the pedal puts the bike off balance. So learning to use one pedal to set the bike in motion, then raising the other leg to get balance and glide is a key stage. Jenny had a few weeks of one-pedal balancing with lots of encouragement. Then it was about putting the other pedal on, repeating the balance technique, and gingerly trying to get the other foot on the pedal as well.



There came a day when she seemed to know she could do it, and she did! With a few more weeks of consolidating practice improving steering and braking skills, Jenny was soon riding confidently with us on traffic-free trails. It is clear that she really enjoys being outside with the wind in her hair. It is hugely empowering for her and emancipating for us.

# Oliver's story

*Oliver was special. He was a real character with impeccable manners and a great sense of humour who loved life. His smile would light up a room.*



He enjoyed playing computer games, listening to his extensive music collection and surfing the net. He was happy to entertain himself but he really came alive when he was with his friends. He enjoyed going to the pub and he loved a party. He also enjoyed concerts, being a frequent visitor to Download, Bloodstock, Rock City and other venues showing a band he liked.

He was fiercely loyal and protective of family and friends, especially his brother Jack. If Oliver had the slightest inkling that Jack was about to get a telling off he would intervene with one of his classic phrases... *'Now now, calm down yourself'*.

Oliver was a creature of habit and liked to know what was planned for the coming day, week and month. Every Sunday morning he would sit down with the Culture section from the papers so he could plan his television viewing for the coming week, though he actually already knew when his favourite programmes were on. *Pointless*, *House of Games* and *University Challenge* were essential viewing and his colleagues on the village quiz team will know of his astonishing knowledge in the most surprising areas. When watching *University Challenge* Ollie would always get a few questions right on a range

of topics. He would mark his success by punching the air and we would look at each enquiringly as if to say 'How on earth did he know that'?

Ollie exuded a calmness and serenity that was in total contrast to his entry into the world. Oliver was born on 5 February 1988. Immediately after he was born he needed the urgent attentions of the maternity crash team to get him breathing and his heart going. This emotional roller coaster... the elation at his birth, then terror at the thought of immediate loss and finally relief when he cried... served to form an unbreakable bond between us and the pale little bundle that was Oliver.

A few days later a consultant confirmed that Ollie had Down's syndrome and possibly a number of other medical conditions that would require further tests to confirm. He 'reassured' us that in time *'he may be able to feed himself and possibly even dress himself'*.

Then he asked us a question that, at the time, caused an unrepeatable reaction: *'So, are you keeping this baby? You can leave him if you want.'*

The doctor wasn't to know that Ollie was already an accepted and loved member of the 'Mat' clan (who had also been signed up as a Nottingham Forest Junior Red) and any suggestion that we would walk away and abandon our son was unthinkable.

We left this meeting somewhat shell-shocked, clutching a piece of paper on which had been scribbled the name, address and phone number of the Down's Syndrome Association. In 1988 there was no world wide web and no informative website dispensing advice to new parents. Instead we had an agonising wait for the DSA info pack to arrive by post; to fill what we realised was a huge gap in our

knowledge about Trisomy 21.

The crash team at birth was, it turned out, the start of an up close and personal relationship with the NHS that continued to the end of Oliver's life. Being told in the first few weeks of his life that Ollie would be lucky if he made his first birthday was devastating. It was however, instrumental in determining our approach to his upbringing. We decided not to live every day as his last but to make life as 'normal' as possible while he was with us.

In the early days Ollie was very poorly with an AV canal defect that we were told was inoperable. Oliver's medical issues increased as time progressed but we were blessed with a series of fantastic consultants, doctors and clinics over the years at the Nottingham QMC, Nottingham City Hospital and, in recent years, in the pulmonary hypertension unit in Sheffield. We owe a lot to the various medical teams we have had over the years. We can honestly say that we never felt that the quality of Ollie's care was compromised because of his condition.

We should also mention that Oliver did do his bit to help medical education. Oliver's heart condition was unusual and we were often asked if he would mind if student doctors could examine him. Ollie never objected and, as he got older, he positively seemed to enjoy the experience particularly if the student was female and blonde.

We made the decision to use mainstream schools wherever possible for Ollie's education. Ollie went to a local nursery before joining the village primary school. We think he was the first pupil to attend who had Down's syndrome. He learned to read and developed a real interest in history and music to go with his love of sport, passions that stayed with him throughout his life.



While Oliver was not particularly academic, the supportive and inclusive atmosphere at school meant that, as well as leaving school with several qualifications, he also had a curious, enquiring mind and a thirst for knowledge that stayed with him throughout his life. His many interests would sometimes leave us surprised and induce amazement in people that did not know him.

We still laugh at the memory of a trip to Hardwick Hall when he was about 10 years old. On entering the main hall, the curators started to tell him about some of the room's highlights. Oliver listened and thanked them...then scanned the paintings on the wall and correctly identified the subjects of several portraits, leaving the curators open-mouthed. It was on occasions such as this that we would say to each other 'Are we keeping him then?' before dissolving into helpless laughter.

Oliver enjoyed reading. Although I don't think he ever read a novel he loved books about the subjects that interested him. Oliver loved second hand bookshops and enjoyed exploring to find the music and sport sections. He would always find something of interest and a book of *The Best Rock Albums* he found on holiday one year was a particular favourite. This particular book may explain why he was unbelievably accurate in his answers to *Planet Rock Radio's* 'Guess the year' quiz which was compulsory listening on the journey to his drama group and day centre.

Ollie was a committed Nottingham Forest and England fan although his sporting interests were not restricted to football. He loved cricket and enjoyed regular visits to Trent Bridge for the 20:20 games. Ollie would watch every Formula 1 Grand Prix on television and really enjoyed his visit to Silverstone for the 2018 British Grand Prix. He would cancel all engagements for Wimbledon fortnight and spend it sitting in front of the television watching the tennis...even after Maria Sharapova had been knocked

out! On Saturday evenings during the football season Ollie always watched *Match of the Day*, accompanied by a bag of wine gums. Although he was in control of the bag of wine gums, he would generously give you as many of the sweets as you asked for, plus one more. Ollie was totally selfless and he would have given you his last Rolo if you asked him for it.

Ollie was a big fan of *Strictly Come Dancing* and watching him, totally entranced by the show and dancing round the lounge, was delightful. He also loved live theatre. He was a loyal attendee at all the local pantomimes each Christmas but Ollie also loved Shakespeare, especially Macbeth and Richard III.

Oliver was an active member of a couple of clubs, Mencap and Panthers, where he had many friends. His last attendance at Panthers was as presenter of a quiz that he had put together himself... it proved to be a great success with all participants.

On 12 February 2020, shortly after his 32nd birthday, Oliver died. He was a special person and we feel blessed to have had him. One of the things we learned over the years was that somehow Oliver managed to connect with people and people liked him. He had a real twinkle in his eye, a ready smile, an infectious chuckle and a warm handshake when you met him. That he is no longer with us has created a huge gap in our lives and the house is strangely quiet.

We take great comfort in our memories of the years he was with us. Even through our tears, we can smile at the memory of the joy he brought. Of course, every parent thinks their child is special, so I shall close with the words of one of Oliver's headmasters who attended his funeral:

*'Oliver knew what was right and wrong, important and unimportant, good and bad and how to tell the difference. What a pity there aren't more Ollies around.'*

## This is me... Sophie



My name is Sophie and I am 13 years old. I live in Schaffhausen, Switzerland, with my mother, father and younger brother.

I like to play football with my brother. Here you see me playing the accordion.



I am in 5th grade at the regular school. I've been studying English for three years at school with my special education teacher. My mother language is Swiss-German.

I've been dancing since I was four years old. I dance in three dance classes in Schaffhausen and in a group with other dancers with Down's syndrome ([www.enea21.ch](http://www.enea21.ch)).

I am looking for a penfriend my age.

# Christopher's cardiac operation

By Chris Williams

In the Spring/Summer 2020 edition of The Journal, my attention was caught by Dr Gerry Coghlan's article, 'A milestone in cardiac care'. What particularly stood out for me was the reference to the independent inquiry into the paediatric cardiac surgery service at the Royal Brompton and Harefield hospitals, brought about following whistleblowing and parents' complaints about children who have Down's syndrome not being valued and parents being persuaded that surgery was not in their child's best interests. The reason it stood out was because it most definitely was not the experience I had with my son Oliver in the early 1990s. What I have come to realise is that there was a significant difference between the experience of parents whose children were treated at the Royal Brompton compared with what happened at Harefield Hospital. And that difference may well have been due to one man – Prof Sir Magdi Yacoub.

Oliver was born with a heart defect in 1987. Oliver's mother and I knew about his heart condition – an AV septal defect – from his earliest days. We knew that without treatment Oliver's life expectancy would be twenty years or so. And it never occurred to us to do anything other than ensure he had the necessary treatment.

We were fortunate. We lived in Teddington, in South West London; Harefield, near Uxbridge, was our closest specialist hospital. I have to admit that, at the time, I did not fully appreciate just how fortunate we were.

I do recall, however, going through a period when an appointment for Oliver had to be postponed a couple of times, and when I did get to see Prof Sir Magdi Yacoub's consultant, Rosemary Radley-Smith, I did ask her if Oliver's appointments were being postponed because he had Down's syndrome and therefore wasn't seen as a priority. I can very clearly recall Dr Radley-Smith being obviously upset that I could have been led to think that and promised me that Oliver was most definitely seen as a priority

for surgery, that the fact Oliver had Down's syndrome did not make Oliver any less deserving of the operation he needed as far as Prof Sir Magdi Yacoub was concerned.

In due course, Oliver went in for his operation. Those seven or so hours seemed like an eternity for Oliver's mother and me; we knew there was a possibility Oliver would not survive, and we could not help hearing the inevitable voice in our minds that asked us if we thought we had done the right thing. Our worries were not necessary – the operation was a complete success. And I still remember the time when, a few days after the operation, when Oliver was still in intensive care, Prof Sir Magdi Yacoub came in to see how his patient was doing and spoke with us for a little while. After he had gone, one of the nurses looking after Oliver commented that it was very unusual for Prof Sir Magdi Yacoub to do that. I didn't fully understand the significance until later, when I learned about his charity Chain of Hope and how important it was for him to ensure correctable heart defects in children – all children – could be operated on.

What I know about other parents' experiences I have gleaned from reading about the inquiry that took place almost a decade after Oliver had his operation. And it does appear that the issues identified by the inquiry were much more relevant to the Royal Brompton Hospital than Harefield – although the Department of Health was criticised in the report for failing to provide adequate funding for the development of paediatric cardiac services at Harefield Hospital. I have no doubt, from the evidence in the article, that there was discrimination against children who have Down's syndrome among some senior doctors at the Royal Brompton Hospital. But that is not what I experienced at Harefield.

Looking back now, I am not sure how much I knew about Prof Sir Magdi Yacoub at the time Oliver had his operation, and how much I learned

soon after. I knew that Oliver's operation was conducted by one of the most eminent surgeons in the world, but I certainly did not fully appreciate just what an extraordinary man he was.



Oliver is now 33. He has a profound learning disability. He has limited speech. But he makes his thoughts and wishes known. He loves animals and zoos. And I cannot imagine the world without him.

We are delighted to hear that Oliver had successful heart surgery at a time when so many babies, children and adults who have Down's syndrome were not so fortunate. At the time of The Brompton Inquiry, we did receive accounts from families about Prof Sir Magdi Yacoub and how generous he had been with his time. Families told us that in some cases, Prof Sir Magdi Yacoub had performed surgery on their loved ones when other surgeons had said no.

Thankfully, all of that is behind us now and cardiac services are very different for people who have Down's syndrome. It's important to note that the DSA is working with Down's Syndrome International and cardiac professionals from the U.K. and the rest of the world who have come together to produce a consensus statement about the surveillance and management of cardiac conditions in Down's syndrome. We look forward to the publication of this statement!



# Our Voice interview with Sarah Geiger

*Sam and Zoe interviewed Sarah about her education research. We filmed the interview and thought you would like to see the questions Sam and Sarah asked and what Sarah said.*



Sam



Zoe



Sarah

## The interview

**Sam - What was your research about and what did you find out?**

**Sarah -** Okay. Thanks, Sam. So what was my research about? And what did I find out? My research was about three things. Firstly, what are the views of children and young people who have Down's syndrome about their school. So that was the first thing. And then what schools do people go to and are there any patterns. That was the second thing. And then the third thing was, what works to make school successful.

So, there was those three things that I was wanting to find out about. I'll give you an example. When I interviewed young people, I found out that they liked lessons with some activity and something creative. They really liked their class group. And they liked friends and special adults. And if there were things that made school a bit difficult, one of the things that made schools difficult was too much adult talking. I don't know if you remember that when you were in school. That was what they said, sometimes it was just too much adult talk, or too much running about. They were things that made school difficult.

### The research questions:

What are the views of children and

young people who have Down's syndrome about their school?

What are the educational histories of children and young people who have Down's syndrome and are there patterns?

What works to make school successful?

**Sam - Why is it important to involve people who have Down's syndrome in your research?**

**Sarah -** That's a good question, Sam, I think there are different reasons. I think it's important for people to represent themselves. It's better to speak for yourself. And we don't know how it is for somebody, unless we try and find out, unless we ask them. So I think that information that people tell us about themselves, it's important for schools and parents to know. And it's important for schools and parents to be able to know what people who have Down's syndrome are saying about their schools so that they can make changes and take notice of what they say. I think it's even better for people who have Down's syndrome, to do the research together with other researchers, I think that'd be great. And that would be a good next step.

So for example, why it's important is when I was researching and doing the interviews with some young people who have Down's syndrome, they told me about things that otherwise

I wouldn't have known. So there were the reasons, I'll give you an example. They talked about breaks, having breaks. Firstly, lunch breaks, and at break time, but also, sometimes in a lesson, it can get a bit much, it can be important to have a little break, to get your concentration back and get your attention back and your strength back. So that was one of the things that they mentioned.

**Why involve people who have Down's syndrome?**

It's important for people to represent themselves.

It's better to speak for yourself

It's even better to do the research together with researchers

**Sam - I loved doing different subjects, like numeracy, literacy, history, and going on school trips. How is the best way to teach these subjects?**

**Sarah -** Oh, Sam, well that must have been very nice for your teachers at school, that you like the subjects, especially the subjects that people often want to teach in school, like literacy and numeracy. And interesting that you talk about school trips, because some people in the research, some young people also talked about school trips.

So I suppose what you're talking about

fits in with the part of the research about what works, what's the best way to teach those subjects. And what came out, especially was keeping it visual, so that people can see what you're talking about. Support for communication, keeping it real and active, building up learning in small steps, they were the sorts of things, and all those practical thoughts and things about what works, I have put together and some guidelines for schools to share that information. But I suppose there were two very important things about the best way to teach, and very important things for making school a success. One was about belonging.

So, it was very important for somebody in school, a child or young person to know that they fit, where they fit in school, that they've got a place that school is for them, and that the school enjoys them and allows the difference. And then if we're thinking about learning that you were talking about, Sam, I suppose it what came through is knowing what to teach, knowing how to teach it, and knowing the child or the young person very well and understanding their needs. They were the sorts of things that came out.

### How is the best way to teach subjects?

Keeping it visual

Support for communication

Young people knowing that they belong

Teachers understanding the person's needs and knowing what to teach them

Sarah is writing up guidance for teachers

### Zoe - How did you include people who have Down's syndrome in your research?

**Sarah** - Okay. So, well, the first thing, including people, especially young people who have Down syndrome in my research, the first thing was to make sure that they did actually want to be involved. And it wasn't just their mum or their school that were giving permission that they gave permission and did want to be involved. That was

the first thing. So I did that by making sure they had information, that they gave their permission, and things like making sure I knew they could stop or have a break if they wanted to. And then I wanted to make sure that when they met me, they were still okay with it.

So for example, when we did our school tour, when I met the person who was coming in the school tour, if they met me, and they thought, 'Oh, no, actually not happy about coming around the school with you'. I said to them, "would you like to do the tour today or another day?". And then if they were being polite, and they didn't really want to, they could say 'another day', and they could say it politely. So the first thing was about permission. And then another thing was keeping it private for people. So people chose different names, they didn't use their own names. They chose different names to keep it private. And, and then another thing is including people who have Down's syndrome in my research, I wanted to make sure that people chose what was important to them. And I didn't just ask them about what was important to me.

So they took photographs, and they gave me a tour of their school. And we used the photographs and other cards of things, or other things that they thought about afterwards. We use them to choose what was important, what wasn't. So they take the photos. And if it was important, they put them at the top. If it wasn't, it's alright it can go in the middle, if it wasn't important, or didn't like it go at the bottom. And the photos were good actually, because the photos help people remember about things and help people take their own time and help them see what to do. And to enjoy it, and to really take the pressure off. So that was good. And another thing is people didn't have to talk, because I didn't want to only ask people who were good at talking. I wanted everybody to be able to be involved in the research.

### How did you include people who have Down's syndrome?

Sarah asked if they want to be involved

By giving information

By asking for permission

By giving people choices

By keeping it private, e.g. changing people's names

By the young person taking the photos

People didn't have to talk. Everybody was able to be involved

### Zoe - So my second one is I love doing music. Can you tell us about creative lessons for people who have Down syndrome?

**Sarah** - Yes that's interesting, because the other people that I did the research with have liked creative lessons, and they thought that was important. Like you must know as well. So Sammy for example, she loved doing art. She loved really working hard on art in a class with her friends and her peers. And she was really enjoying doing Andy Warhol art. So she liked that. And then Jonah, Jonah liked creative lessons, like what Sam was talking about with school trips. And he liked lessons like citizenship. Sarah, really, really liked a project about space arts, and they had an artist who had visited the school, and that was great. She really enjoyed that. And she loved music. She had wanted to do music for her year 10 choice, but she couldn't. But she still chose that as something important to her for her schooling. And what she really liked was dance. So she did an after school club for dance that she really enjoyed that in the school. They had raves. And she really loved that dancing in the school hall. Oh, yes.

### Can you tell us about creative lessons?

Lots of young people liked creative lessons.

Sammy loved doing art with her friends

Jonah liked creative lessons and citizenship

Sarah liked a project about space art and loved music lessons and dance

### Zoe - How are people who have Down's syndrome being supported to follow their passions when leaving school?



**Sarah** - Okay, so how people who have Down's syndrome are being supported to follow their passions? That's a great question, isn't it. I suppose we covered it a little bit in the research about what works. Because when I hear that about following your passion, following your passion is a very happy kind of a laugh-out-loud kind of happy, really, it's sort of when you're following your passion makes your heart sing makes you know, you're really happy. So I suppose I'd be thinking about connecting with people with experiences, adventures, as well as thinking about employment and volunteering. And so then I'd be thinking about schools and parents, well, really getting to know people. So in schools really getting to know people to discover their passions, taking risks. And I suppose I think about having experiences and skills, and about schools thinking, 'yes, you can do this' and building your skills and your confidence to say, "yes, I can do this". I suppose that would be what I'd be thinking.

### How are people being supported to follow their passions?

It is very important to make your heart sing

Schools should get to know people to discover their passions

Schools should give experiences to build confidence and connect people

And think about employment and volunteering

Thank you Sarah!

*Sarah Geiger is a Senior Educational Psychologist working for Barnet in north London. She chairs the Barnet Leading Edge group for children and young people who have Down syndrome. Sarah's research looked at our children and young people's views of their school, their education histories, and what is linked to successful school placement. We look forward to finding out more when Sarah's research is published.*

## All about Ava

*Last year workplace design company Oktra raised money for the DSA through their annual art show. People of all ages and experiences were invited to submit a piece of their artwork to be auctioned off for charity.*

We were put forward by Sam who works at the company, as he has a daughter called Ava who has Down's syndrome.

### Sam shared Ava's story for us...

Ava was born six weeks early on 4 October 2019, weighing a small 4lb 1oz and was diagnosed with Down's syndrome when she was just five days old. Due to a few complications, she spent four weeks in Stoke Mandeville NICU where we met some amazing and supportive people. She is our first daughter and despite her surprise extra chromosome, she was instantly loved by our family and friends! She loves playing with her mum and dad and her personality is really shining through, she is particularly cheeky in the way that she will ensure she gets our undivided attention! Musical toys are her favourite, yes the ones that she can drum and make lots of noise with, although she does have a soft spot for her knitted premie Octopus that she was given in hospital.

Recently her eating has come along in leaps and bounds with her now enjoying getting messy with a few finger foods. She enjoys her meals made and prepared by her mum Zoe, as long as they are followed by her favourite fruit...mangos! Bath time is also a highlight of her day, and she enjoys splashing around as much as possible! Her main dislikes would be avocado, coming out of the bath or having to wait for food, but all in all she is a very positive, happy little lady with a very big smile.

### Why did you suggest DSA as the charity beneficiary this year to Oktra?

Each year we ask the business (in a poll like event) who the charity should be, but this year one goal was to find a charity who may be celebrating



their 25th year anniversary like us. Obviously I would have always put the DSA forward, but the fact that you are celebrating your 50th anniversary made it the perfect match.

The DSA are obviously close to my family's heart and this has been a great way for us to raise some positive awareness of such a wonderful organisation. The DSA have been a key source of information for my family from day one. In fact, I remember an information pack given to us when Ava was first diagnosed which had a link to your website, which has now become a firm favourite.

### You mentioned that Ava submitted her own artwork too...

We always invite colleagues, friends, family, suppliers and clients to submit art, so we couldn't wait to get Ava involved this year! She loves strong colours so we prepared some bright kids friendly paint on a couple of canvases and then let her work her magic... we soon had some interesting abstract pieces of art ready for submission!

Thank you to Sam, Ava and all the staff and supporters at Oktra. The auction was a great success and we are so grateful for all your generosity.

# Staying well and healthy

Looking after ourselves has been tough over the last year...but it's really important.  
Here are some quick tips to help you look after yourself.

## GO OUTSIDE FOR A WALK



Being out in the fresh air can make you feel more positive and calmer. Stick to a familiar route or try somewhere new.

## SLEEP



Good sleep is very important for keeping well. Try to get around eight hours each night.

## DIET



The food you eat affects how you feel. Eating healthy food will make you feel more positive.

## EXERCISE



If you are feeling low, try doing a half hour home workout or going for a walk.

## KEEP IN TOUCH WITH YOUR DOCTOR



Make sure your doctor has the right information for you and remember to have your annual health check.

## KEEP BUSY



Do things for yourself and for others. Keep your space tidy and clean.

## CONNECT WITH OTHERS



Stay in touch with family and friends. Even if this is online or on the phone. Talk about your feelings. Listen to them if they need support too.

## DO SOMETHING FUN



Talk about things that make you happy and bring back good memories that you can share. Watch something, talk to someone or do something that makes you laugh.

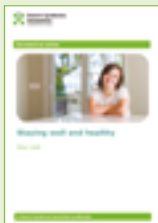
## TRY LEARNING SOMETHING NEW



Can you spend half an hour each day learning a new skill?



## Things that can help look after you.



### Staying well and healthy –

This easy read guide is full of ideas and will help you plan how to make yourself feel good.

[downs-syndrome.org.uk/Staying-Well-And-Healthy/](https://downs-syndrome.org.uk/Staying-Well-And-Healthy/)

**DSEngage** – Yoga and dance classes, fitness challenges and activities to keep you busy.

[downs-syndrome.org.uk/dsengage/](https://downs-syndrome.org.uk/dsengage/)

### DSActive healthy eating

**factsheets** – Want to know about healthy eating? DSActive's factsheet is a great place to start...and there's advice for parents too.

[dsactive.org.uk/healthy-living/](https://dsactive.org.uk/healthy-living/)



### Emotional well-being resources –

We've created a whole lot of resources that can help you think about

your feelings and how to handle difficult and stressful situations.

[downs-syndrome.org.uk/for-people-with-downs-syndrome/emotional-well-being/](https://downs-syndrome.org.uk/for-people-with-downs-syndrome/emotional-well-being/)

**Our Voice** – Our Voice is about including people who have Down's syndrome. It is an opportunity for people who have Down's syndrome to speak up and have their voices heard...and to make friends from all across the country.

There are weekly Zoom meetings, a closed Facebook group and lots of other ways to get involved.

[downs-syndrome.org.uk/for-people-with-downs-syndrome/join-our-voice-2/](https://downs-syndrome.org.uk/for-people-with-downs-syndrome/join-our-voice-2/)

# Weight management

*Johnathan Hirniak, Medical Student, St George's University of London.*

*Irene Hadjikoumi, Consultant Paediatrician, St George's University Hospital NHS Trust, London.*

*Marian McGowan, Consultant Paediatrician, St George's and King's College Hospitals, London.*

## What is obesity?

The term obese is used to describe someone who is very overweight and with a lot of body fat. Your height and weight can be used to calculate your Body Mass Index (BMI), which tells you whether you are of a healthy weight for your height. A BMI of:

- **Less than 18.5** means you are underweight
- **18.5 to 24.9** means you are a healthy weight
- **25 to 29.9** means you are overweight
- **More than 30** means you are obese

The process is different in children who have Down's syndrome, as it takes into account the height and weight centiles noted in the growth charts.

## Obesity and Down's syndrome: how are they related?

The number of people with obesity is rising worldwide, with an estimated 1 in 4 adults, and 1 in 5 children aged 10-11 currently obese in the UK.

Research has shown that men and women who have Down's syndrome are more likely to be overweight or obese compared to the rest of the population. This is possibly due to an increased risk of both physiological and behavioural factors.

### Physiological Factors

Physiological factors are factors relating to the body's biology. Research suggests that children who have Down's syndrome are at a higher risk of developing hypothyroidism and a lower

metabolic rate. These conditions make it harder to burn calories, meaning that you would have to do more physical activity than someone without those conditions to burn the same number of calories.

### Behavioural Factors

Behavioural factors are to do with lifestyle choices, particularly diet and exercise. If you consume lots of energy through food, but do not burn it off through everyday activities or exercise, then a lot of that excess energy will be stored as fat.

A poor diet involves eating large amounts of processed or fast foods which are typically high in fat and sugar. Eating portions larger than you need and drinking lots of sugary drinks like fruit juice or coke can also increase your energy intake. Unhealthy eating habits usually run in the family, so children and young adults may learn these from their parents or peers.

A lack of physical activity also contributes to weight gain. Whether it's watching the television for a long period or playing indoor games, if you are not active enough you won't be burning the extra calories.

## Risks of Obesity

Obesity can increase the risk of developing various health conditions, some of which are very serious. These include:

- Type 2 diabetes
- High blood pressure
- Coronary heart disease
- Some cancers
- Stroke
- Back & Joint pain
- Depression

Being obese can also make it more challenging to take part in physical activity. However, there is a lot of support available to help identify those at risk of becoming overweight and obese, to help people lose weight.

## Your Paediatric Consultant: how do they help?

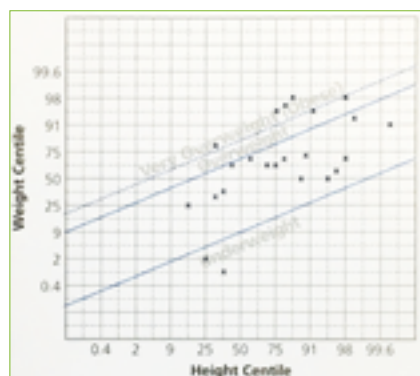
One of the most supportive people in your life will be your paediatric consultant. They are responsible for helping you stay as healthy as possible by performing various investigations, providing you with advice, and recommending treatment relevant to any conditions you may have.

### Health Check-ups

At three months old, six months old, twelve months old, and then once every year, you will probably have a health check-up with your paediatric consultant. There are a number of investigations that your doctor will want to do, including eye and hearing tests, taking a blood sample, and discussing how home and school life is progressing. The check-up is also a fantastic opportunity to talk to your doctor about any concerns you may have or to get your questions answered correctly.

### Growth Charts

As people who have Down's syndrome are shorter on average, the typical BMI calculations are not entirely accurate. Instead, a growth chart specific for children who have Down's syndrome is used.



When you go to the doctors, you will have your height and weight

measured. These will be plotted on the growth chart to find out your height and weight centiles. These centiles can then be used and plotted on a BMI graph on the front page of the growth chart to find out your BMI. This is shown on the graph illustration (each X represents plots of different people).

## Diagnosing Obesity

If you are found to be overweight or obese, the Down Syndrome Medical Interest Group (DSMIG) recommend that your paediatric consultant:

- Encourages weight loss
- Provides advice on dieting and physical activity
- Considers referring you to a specialist (e.g. Dietician)

If you have been recorded as overweight or obese for a couple of years, the doctor may want to order some more investigations to make sure there isn't a serious cause. Alternatively, your doctor should refer you to a dietician – a specialist dealing with health and nutrition. They can help streamline what foods are best to eat, portion sizes, and can help find cost-friendly solutions.

### Screening for hypothyroidism

You will be asked to have a quick blood sample taken to measure the amount of thyroid hormones in your body. If they are low, this could indicate hypothyroidism, which could be a cause of obesity.

If you have hypothyroidism, your doctor may prescribe a medication to boost the amount of thyroid hormone in your system to normal levels. This will make it easier for you to manage your weight if you have this condition.

## How can I manage my weight?

There are many things you can do to help lose weight or maintain normal weight: it's not just dieting!

### Making a plan

Planning your meals and exercises on

a weekly basis can really help provide a structure to your daily routine. Using a calendar, diary or putting a written timetable on your fridge are just some of the many ways you can plan your week.

In your plan, you can cover what meals you want to cook for breakfast, lunch and dinner, making a note of what ingredients you need to purchase from the shops. Additionally, you can write down what activities you hope to accomplish every day, whilst taking into account school, your job or going out with friends.

### Education in Childhood

Healthy lifestyles can be nurtured from early in life. By teaching your children healthy habits about food and exercise from an early age, you can help develop health foundations for your child to grow from, avoiding obesity.

### Education in Adulthood

There is a lot of information about all sorts of special diets and exercise regimes, making it difficult to figure out what is the best for you. The NHS Live Well guide is an excellent and easy to follow source that provides information on this topic. It includes details on nutrition, sleep hygiene, exercise and mental wellbeing among others.

If you are still uncertain about anything, let your GP or specialist doctor know at your next check-up as they can provide you with the best and most up to date information.

### Physical Activity

Find an activity you enjoy and stick with it! Whether it's going to the park with your friends, cycling, free-running or swimming, the best kind of exercise is the kind you look forward to doing! The NHS recommend you do some type of physical activity every day, aiming for 150 minutes of moderate intensity or 75 minutes of vigorous intensity activity each week if you are aged 19 or older. For children, it's recommended that at least 60 minutes is spent on physical activity per day.

### Group Initiatives

There are lots of groups and





Figure 1. Recommended food portion distribution from the NHS Live Well website

organisations that host activities and regimens to support healthy living. Whether this be local sports teams, Weight Watchers, fitness in the park sessions, or training for Special Olympics competitions – there is always support no matter where you are.

### Food

Eating a balanced diet ensures you get the right amount of nutrients from different food groups. Figure 1 shows the proportions of foods with examples as part of a healthy diet.

However, if you have any nutritional requirements, speak to your doctor as

they can refer you to a dietician who can give you the best information about what to eat.

Eating five portions of different fruits and vegetables every day can ensure you get all the important vitamins and minerals. For children, a fun way to do this is by trying to 'eat a rainbow', where red could be a red pepper, yellow could be a banana, and green could be broccoli!

Portion sizes are also important to consider. After a meal, you shouldn't feel hungry. If you feel bloated, it may mean you have eaten portions too big for your body.

For more information on portion sizes for your age, have a look at the NHS Live Well website.

But don't get bogged down on strict diets – it's always important to treat yourself every now and again!

### DSActive Health Swap App

The DSActive Health Swap app is available on Apple and Android products.

It has been designed to make healthy eating and exercise easier for people who have Down's syndrome. The app has a 'Food' section, where users can plan their daily meals. After selecting a health meal option, the app highlights what ingredients need to be purchased, and has cooking instructions. There is also an 'Activity' section, where you can keep track of your physical activities.

#### For more information

For more information on healthy living, I would recommend these resources:

<https://www.nhs.uk/live-well/>  
**The Down Syndrome Nutrition Handbook – A Guide To Promoting Healthy Lifestyles**  
 by Joan Guthrie Medlen  
 (Woodbine House, 2006)  
 'Nutrition Top Tips' on the DSA website



Matthew doing what he loves: going to the gym and taking part in the Special Olympics



DSMIG was established in 1996 by 17 paediatricians. It has grown to become a network of approximately 160 healthcare professionals from the UK, Republic of Ireland and further afield. Our aim is to help promote equitable provision of medical care for all people who have Down syndrome in the UK and Ireland by disseminating a wide range of information about the medical aspects of the syndrome and promoting interest in its specialist management. We are a registered charity and are the only organisation to provide this type of medical-specific service in the UK. We receive no statutory funding.



[www.dsmig.org.uk](http://www.dsmig.org.uk)

# What have we learned from research in trying to understand memory problems in people who have Down's syndrome?

## An update from Cambridge University Down's syndrome research group.

Dr Shahid Zaman, Consultant  
Psychiatrist and Associate Lecturer  
Email: shz10@cam.ac.uk

Site Principal Investigator for the Cambridge  
Site of the Alzheimer's Biomarkers  
Consortium-Down Syndrome (ABC-DS)  
[www.nia.nih.gov/research/abc-ds](http://www.nia.nih.gov/research/abc-ds)

Cambridge clinical site lead for TRC-DS  
(Trial-Ready Cohort- Down Syndrome)  
[www.actc-ds.org/projects/](http://www.actc-ds.org/projects/)

When people who have Down's syndrome start reaching the age of 40, they may begin experiencing a decline in their ability to think, memorise or concentrate. They may start to find day to day activities difficult, such as eating, drinking, and personal care, this might be an indication that they are developing Alzheimer's disease.

Scientists have known for a long time that Alzheimer's disease brain develops excessive deposits of a protein called amyloid-beta (**Aβ**), followed by deposits of another type of protein called **tau** which together cause havoc in the brain and which are probably responsible for many of the symptoms of the condition.

How is Aβ and tau relevant to the development of symptoms and the clinical diagnosis of dementia? In Cambridge we have been running a major research programme to help us answer such questions to enable us to understand the disease enough

There is lots of good news about the amount of research that is happening around dementia and how it affects people who have Down's syndrome. We now know so much more thanks to all the wonderful volunteers with Down's syndrome who have contributed to studies all over the world. This important work continues and we look forward to a time when there are effective treatments.

to start clinical trials to treat dementia.

We have been measuring the protein Aβ deposits (and tau) in volunteers with Down's syndrome who have no symptoms using brain imaging techniques called PET and MRI scans. This is a painless procedure. The person simply lays down in a scanner for about 90 minutes after a Aβ tracer has been injected into a vein in the arm. This is how we have obtained detailed images of the protein Aβ (see figures 1 and 2) in the person's brain.

In the results from our study from over 50 people we can see that there is a sharp rise in the amount of the protein

Aβ deposited in the brain as the age increases. The steepest rise occurs after the age of 45 and it levels off around 55 years. We believe that the protein Aβ may be **driving the disease**.

We also discovered that a protein that comes from the brain into the blood can be measured in the blood called neurofilament light (NFL) increases rapidly as the disease progresses, probably in line with changes in the amount of amyloid and tau deposits in the brain. These are very important findings as we may be able to use them to measure **disease activity in the absence** of symptoms for clinical trials.

We know that not only does dementia in people who have Down's syndrome occur **some 15 to 20 years earlier**, but that it behaves very much like Alzheimer's disease in the general population. The discovery of blood tests and imaging tests which monitor the disease ('biomarkers of disease') before it becomes symptomatic is key for clinical trials.

We hope to be able to use biomarkers of disease to predict when someone may get the diagnosis before they get



Figure 1: MRI scanner with a participant about to undergo a scan in our research.

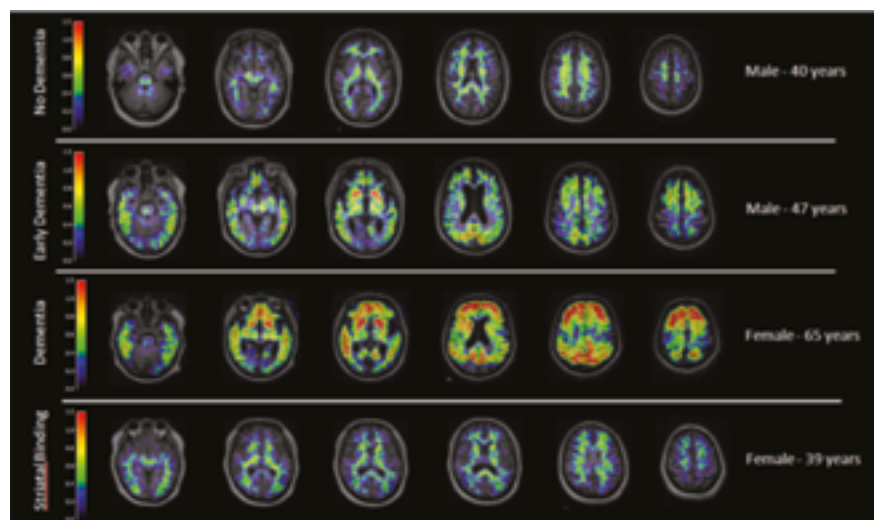


Figure 2: These panels are slices taken from brain scans using PET superimposed on MRI scans. The slices in a plane sliced are from the back of the head to the front. You can see the eyes in the images in the left column. They are of people with Down's syndrome with no dementia or early dementia or with dementia showing deposits of amyloid hotspots as red.



any symptoms. Being able to measure predictive biomarkers will help us to design clinical trials that can **prevent the disease**.

We have been fortunate to be part of a very large USA recently funded \$110 million research consortium programme (ABC-DS or the Alzheimer's Biomarkers Consortium-Down Syndrome) involving labs all over the USA and only one outside (University of Cambridge). This amount seems a lot, but amyloid and tau scans cost c. £2,500 each!

Also, very exciting is that we are part of a **clinical trial ready consortium** (also USA-funded) which is now recruiting people who have no symptoms and who are willing to trial treatments aimed at reducing the amount of amyloid-beta in the brain.

The aim of our endeavour right from the start was to **find treatments** for this dreadful disease. Targeting the A $\beta$  to reduce the amounts in the brain may prevent or delay the onset of the symptoms of the disease.

We cannot thank enough all the people who have been a part of the project in Cambridge. It has been a pleasure working with them and we hope they will continue to engage with us as we have further research planned over the next five years and beyond. I really do hope that others who read this article will contact us and help with defeating dementia in Down's syndrome.

### Recommended further reading published in the Lancet:

**Clinical and biomarker changes of Alzheimer's disease in adults with Down syndrome: a cross-sectional study by:**

Fortea J, Vilaplana E, Carmona-Iragui M, Benejam B, Videla L, Barroeta I, Fernández S, Altuna M, Pegueroles J, Montal V, Valldeu S, Giménez S, González-Ortiz S, Muñoz L, Estellés T, Illán-Gala I, Belbin O, Camacho V, Wilson LR, Annus T, Osorio RS, Videla S, Lehmann S, Holland AJ, Alcolea D, Clarimón J, Zaman SH, Blesa R, Lleó A. **Lancet**. 2020 Jun 27;395(10242):1988-1997. doi: 10.1016/S0140-6736(20)30689-9. PMID: 32593336; PMCID: PMC7322523.

## Fundraising Events

### 50 for 50 Anniversary Jump!

24 July 2021 | GoSkyDive, Old Sarum Park, Salisbury SP4 6EB

Join our brave band of jumpers and take to the skies this summer in support of the DSA and our belated 50th anniversary celebrations!

There will be food, music and games throughout the day so it really will be a day of celebration you can spend with your family and friends!

**How Much?** £50 Registration Fee (paid to GoSkyDive)

**Jump Options?** 10,000ft or 15,000ft

**Fundraising Target?** £400/£500

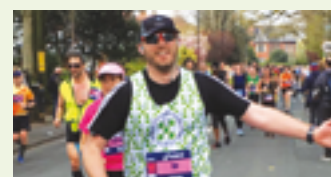
[downs-syndrome.org.uk/50-for-50-anniversary-jump/](https://downs-syndrome.org.uk/50-for-50-anniversary-jump/) | [events@downs-syndrome.org.uk](mailto:events@downs-syndrome.org.uk) | 0333 1212 300



### Sport for Charity

Through our partnership with Sport for Charity we've got places available in a range of great events all around the UK... from 5k runs to half-marathons. Visit our website to find the event that's right for you.

[downs-syndrome.org.uk/sport-for-charity-events/](https://downs-syndrome.org.uk/sport-for-charity-events/) | [events@downs-syndrome.org.uk](mailto:events@downs-syndrome.org.uk) | 0333 1212 300



### Ultra Challenge Series

Stretch your legs this summer with one of the fantastic walks or treks from the Ultra Challenge Series. Your challenge can range in distance from 25km to 100km and you can choose to walk, jog or run the distance.

[downs-syndrome.org.uk/walks-and-treks/](https://downs-syndrome.org.uk/walks-and-treks/) | [events@downs-syndrome.org.uk](mailto:events@downs-syndrome.org.uk) | 0333 1212 300





## Helpline and Information Centre

0333 1212 300

[info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

Our Information Officers are available to respond to calls and emails Monday to Friday, 10am-4pm.

Together with our team of specialist advisers, we offer advice about any aspect of living with Down's syndrome including prenatal support, benefits, education, service provision, rights, health, speech, language and communication, complex and adult needs. We also offer individual consultations and assessments.

Our information resources are freely available on our website.

People who have Down's syndrome shape our resources and help to inform our decisions through our inclusive participation activities with DSA Our Voice members. Parents, practitioners and people who have Down's syndrome can also ask us questions on our closed Facebook groups.

We work with affiliated parent support groups in England, Wales and Northern Ireland. Contact us for local support group contact details.

## Training

[training@downs-syndrome.org.uk](mailto:training@downs-syndrome.org.uk)

We offer a range of training to support individuals at every stage of their lives. From our Royal College of Midwives accredited Tell It Right® study days to conferences, webinars, workshops and online training about education and development, positive behaviour support, adolescence, support for adults, Down's syndrome and health awareness, ageing and dementia.



## Get active

[www.dsactive.org.uk](http://www.dsactive.org.uk)

Our DSActive programme aims to provide as many opportunities as possible for people with Down's syndrome to lead active and healthy lives.



## Employment

[www.dsworkfit.org.uk](http://www.dsworkfit.org.uk)

Our WorkFit® programme brings together employers and jobseekers who have Down's syndrome, providing tailored support to employers and candidates.



[www.langdondownmuseum.org.uk](http://www.langdondownmuseum.org.uk)  
[www.facebook.com/LangdonDownMuseum](https://www.facebook.com/LangdonDownMuseum)



[www.langdondowncentre.org.uk](http://www.langdondowncentre.org.uk)

0333 1212 300

[info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

Langdon Down Centre  
2a Langdon Park Teddington,  
Middlesex TW11 9PS

Office hours are Monday to Friday,  
9am-5pm. Emergency numbers  
are given outside office hours by  
recorded message.

## Founder

Rex Brinkworth MBE, BA, Cert Ed, DCP

## Patrons

Emma Barton  
Paul Bird  
Christine Bleakley  
Michael Caines MBE  
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Dame Judi Dench DBE  
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David Flatman  
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Georgie Hill  
John Humphrys  
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Liam Neeson  
Craig Phillips  
Fiona Phillips  
Nicky Piper MBE  
Professor O. Conor Ward

## Officers

Chair	Georgie Hill
Vice Chair	Sarah Leggat
Treasurer	Darren Warkcup
Chief Executive	Carol Boys

## The more members we have, the stronger our voice

To find out more about our services, campaigns, consultations, research and how you can become a member visit  
[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)



[www.ds-int.org](http://www.ds-int.org)