



dhg

down's heart group

Newsletter Spring 2016

Issue 57



*In this edition -
Members Stories
Fundraising Update
News And More!*

Chair's Report

Hi,

Welcome to our spring 2016 edition of the newsletter. I am not sure where 2015 went and 2016 seems to be going the same way!

Once again we are on track for the London Marathon and we have five runners competing for us this year. You will find their "*biographies*" on the DHG website and the easiest way to donate is via the runners' individual fundraising pages.

I am always amazed at the enthusiasm the runners still have at the end of the marathon. It is a marathon feat for them to get themselves out of London and home again!

Our AGM this year will be held in June, venue to be announced! I look forward to seeing you there. This will be my last AGM as Chair as I will be retiring from this post then.

Regards

Chris Stringfellow

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Challenging Behaviour Standard

NICE has released a quality standard focusing on caring for children, young people and adults with a learning disability and behaviour that challenges.



It highlights that behaviour that challenges is often considered a result of a person's interaction between environmental and personal factors. The expectation of the standard is that it will contribute to the following outcomes of: safeguarding, personal dignity, experience of care, premature mortality and patient safety etc.

The standard provides eight quality statements all focusing on the care people with learning disabilities receive. One of the statements – named 'diversity, equality and language' – explains that good communication is essential. Therefore, the support, care and treatment information provided should be both culturally and age appropriate.

Families and carers are recognised as having an important role in supporting those with a learning disability and behaviour that challenges and where it is appropriate the health and social care practitioner should make sure they are involved in the decision making process when caring, investigating and treating the patient.

The standard explains that carers often have insufficient support from professionals who do not help early enough and don't have the necessary expertise. Therefore, this can lead to overmedicating people with a learning disability. However, the standard focuses on how to ensure that assessment of these people will lead to them receiving personalised care planning. The standard also makes a range of statements which are aimed at ensuring that the approaches used by staff involved with people with learning disabilities support them, while following the least restrictive practice they can.

www.nice.org.uk/guidance/qs101

Working Together 2



Public Health
England

Working Together 2 is an update of the Working Together guide published in 2008 to help hospital staff, family members and support staff work jointly before, during and towards the end of any hospital admission (unplanned or planned) so an individual with learning disabilities can receive good support and treatment.

tinyurl.com/wt2dhg

Emma

Emma was due on New Year's Eve 2014, but being keen to meet us, arrived via emergency C-Section two weeks early.



Three days later, Emma was diagnosed with Trisomy 21. Just as we were starting to adjust to this news and find support, we received another blow in January when Emma had a heart scan. She had a moderate to large VSD requiring open heart surgery. This news was heartbreaking. No parent wants to see their child go through surgery, especially so young and with possible complications of Down's Syndrome.

Emma had her surgery on the 18th May at the Evelina Children's Hospital in London. She sailed through her surgery and the recovery with flying colours with the wonderful support of our family, friends and the whole team at the Evelina. She even got to meet Daniel Craig (007) whilst she was a patient!

Your family is only as strong as the support of friends around you

Whilst recovering from her surgery Emma was also diagnosed with Congenital Glaucoma of her right eye, so once again all the stress of surgery was upon us. Emma had successful surgery by the Evelina Ophthalmology team in July. Despite having two surgical procedures before being seven months old, Emma has shown great strength and resilience and has made healing and recovery look relatively trivial.



Emma continues with a great love of life shown by the amount of smiles she shares throughout the day, especially for the family and friends who have supported throughout this difficult period and beyond. But most importantly, Emma saves the best smiles for her big brother Matthew, who has become a very supportive little five year old.

*Pete, Tersia and Matthew Tame
London*

Helen

Helen was born in 1996 and immediately diagnosed with Down's Syndrome and the following day with an AVSD. The diagnosis came as a complete shock. I will not go into detail about her surgery at eleven months nor the worries over her impetuous behaviour at primary school but write about a particular achievement as a young adult.

After mainstream school, Helen started full time college, but in her second year, the course was cut to three days. I felt strongly that this would not be constructive for Helen or good for her social life and it was likely to put strain on our relationship too, so I put out feelers for some work experience for her.

Some people were disappointingly negative, one refusing to even meet Helen! Others were more open-minded and the deputy head of an infant school soon arranged an interview for her. Helen found herself working one morning per week with a class of five year olds, listening to the children read and they loved the attention.

As the weeks went by and the children got to know Helen, she was asked to help with opening snacks, peeling fruit or doing up coats. She was then invited to help with a trip to Bristol Waterside, when the theme was Pete the Pirate and everyone dressed up.

The children loved the one to one attention from Helen



The wonderful class teacher, who had made the whole experience so positive for Helen, wrote reports for Helen and college praising her strengths, indicating areas of progression and making suggestions for more challenging aspects. Helen kept a Work Experience Diary and in answer to the question *“What is the most useful thing you have learned?”* Helen has written “Realising not all work is interesting but it’s necessary and having to be patient all the time”. How true!

If I had been told during Helen’s first ten years that one day I would be writing about Helen’s work experience helping in a Year 1 class, I would not have believed it. To other parents who may be a few years behind us, I’d like to say that with realistic expectations, positive and supportive people behind you, some perseverance and a bit of luck, your son or daughter could have a happy and rewarding introduction to the world of work.

*Mary Lennox
Gloucestershire*

Alfie



Alfie had successful heart surgery at four years old to rectify an ASD - I remember the date so well, Bonfire Night 2003. We only had four days notice for his surgery and I remember thinking *"oh no I can't put him through this as he is so well"*. A wonderful lady at The Freeman Hospital in Newcastle explained to me that it was perfectly normal to feel like that but in time he would become poorly.

I have two other children, Sam who is slightly older and Helen who at eleven years older, I was very concerned about. She was at an age where I didn't want her to feel left out whilst I cared for her two younger brothers. She was kept in the picture and understood clearly the procedure and the care needed post surgery.

I thank the surgeon for enabling Alfie to live an amazing healthy life

Those four pre-op days passed very quickly for Mark and I as we had so much to organise. Alfie was a text-book patient, had his surgery on the Friday and was up and running around on Sunday lunchtime! I must admit that following his surgery, with all the tubes and wires it was scary. I wondered if he would ever wake up. He did and was full of his usual energy, the only thing we had to be careful of was how we picked him up. The surgeon was so gentle in his manner and I can't thank him enough for enabling Alfie to live an amazing healthy life.

Alfie is endearing, cheeky and a typical teenager



Alfie has also had other surgery - grommets fitted, eye squint correction, inguinal hernia, extraction of ten baby teeth. He is now sixteen years and has such an exciting and happy life - some days have not been easy for family members if I am honest.

Quite soon following heart surgery, Alfie was diagnosed with autism. This dual diagnosis presents in him being non-verbal, double incontinent and needing 1:1 care and support at all times. He is endearing, cheeky and a typical teenager preferring to sit on park benches rather than climbing trees and seeking out water!

Linda and Mark Dickinson, Redcar and Cleveland

Mia

I had no idea during pregnancy that Mia had Trisomy 21, as the blood tests showed low risk. She was born eight weeks premature, weighing 3lbs 8oz. Mia was beautiful and I was over the moon thinking everything was OK.

A couple of days later as I stood over Mia's incubator, treasuring motherhood, her paediatrician asked me if I had noticed anything on my daughter's face that appeared to be "wrong"! I told him no, as I thought she was absolutely gorgeous! The doctor then steered me to the comfy area and explained that my girl had lower set ears, a skin fold under her eyes which were slightly far apart. He was going to perform tests to find out if Mia had Trisomy 21.



Days passed like weeks and I noticed signs that Mia did have Down's Syndrome, she would often stick her tongue out and for a premature baby had super human strength. I had already begun to come to terms with all the things flying around in my head.

Whilst sat cuddling my beautiful Mia another doctor assured me that she was nothing more than premature and that the tests would reveal that Mia was 'normal'. I told him I didn't agree and there is no such thing as normal, because I certainly wasn't it, for sure!

Tests would reveal that Mia was 'normal'!

The next morning the paediatrician said "I'm afraid I have some news" I knew what was coming and finished his sentence, "Mia has Down's Syndrome, I know" He said 'I am so sorry' to which I replied 'what are you sorry for? She's the best thing that's ever happened to me!' I held everything together until I stepped into the lift and burst into tears. How was I going to tell everyone, knowing they would reply with sorry and condolences which isn't what I wanted at all.

A week later, Mia was diagnosed with an ASD and a VSD, all I wanted to know was would she survive. She has just had the full repair at Glenfield and after a rough time with several setbacks and eight days in PICU she is doing really well. Hopefully, by the time you read this she will be home.

This has all been a lot to take in but I realise I need to be the best support for Mia. I will never give up the fight for my beautiful daughter!

*Alex McColl
Lincolnshire*

Laura

My name is Laura, I'm 28 and I have Down's Syndrome with a congenital heart defect. I'm also partially sighted and have no 3D vision but I don't let this stop me from having a life! I live with my mum, Yvonne and step dad, Julian and I also have two sisters.



When I was five the paediatrician told Mum my heart was too bad to operate on but my mum didn't give up on me, she went to Great Ormond Street hospital for a second opinion. After some tests they agreed to operate but there was an 80% chance I wouldn't survive surgery. Mum thought long and hard and decided she would take that chance, the operation went well and we can't thank GOSH enough. I have since had further surgery to correct my main artery and to replace a valve.

Through all of this I have been busy getting on with life

Through all of this I have been busy getting on with life. I attended Cavendish school for people with additional needs and they taught me how to be successful running my own business. All schools in our area were offered the chance to start their own business - we had to show a panel of judges what our business was and how we achieved it - I won the Young Achiever of the Year for this. This got me thinking, when I left college, about setting up my own business.

I got a part time job at Halton Speak Out, a self advocacy group for people with Learning Disabilities. I have worked for them (paid) for eight years. They helped me think about how I could move my life forward as I didn't just want to be a volunteer in Asda. I was worth more than that! I had a person centred review to identify what I wanted to do. I have a passion for fashion so my PA suggested starting a business selling fashion accessories. We went to the warehouses with £60 of my own money and bought some jewellery and fashion items. When I got back my work colleagues were very impressed with my purchases and I sold them for a profit, so I knew I was on to a winner!

I'm also travel the country to tell professionals my story

My company Serendipity has now been going for five years, it is a CIC company, any money I make goes back in to the community to help other people with additional needs. I hold house parties and get invited to events across the country. I'm also a public speaker, travelling around to tell professionals my story. Two years ago I was nominated for Entrepreneur of the Year and got through to the final five.

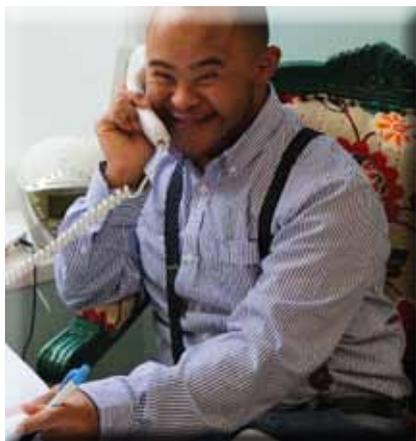
Another big part of my life is the ELLA Performance Group, an inclusive group that encourages everyone to reach their potential through performance and gives the

message that people with disabilities can achieve and lead a productive life and should be fully included in their communities. I recently played the part of Nancy in Oliver and am currently working on my new role as Smee in our production of Peter Pan.

Outside of all this, I like to meet with my friends for a glass of wine (or two!) and a meal to relax and catch up with them. So all in all I lead a full and interesting life despite my disabilities.

*Laura Green
Cheshire*

SP1 Haircare



Elizabeth Stewart has recently opened a hair salon for people with additional needs. It is called SP1 Haircare and is located in Rhiwbina, Cardiff.

Delroy left college in 2015 and as we could find nothing available in the working environment, I felt the only option was to create a work placement for him. I married his situation up with the knowledge I had regarding people with additional needs and sensory issues and from sending out questionnaires and getting an overwhelming response, I knew that so many of our young people and adults found a trip to the hairdressers traumatic, so SP1 was born!

Delroy is now Manager (with supervision) and we also employ another three part time paid employees plus two work experience staff (all with additional needs), who work alongside Petra, our Head Stylist and Paul, our apprentice barber. The facility includes a sensory room with calming lighting, music and textured items on the walls to help its clientele and they use low vibration equipment and distraction techniques when needed. They are wheelchair friendly, have an accessible wash basin, a disabled toilet and changing facilities and the staff have knowledge of Makaton Sign Language.

Delroy had major heart surgery at three months old. He was born with a complete AVSD. He has made miraculous strides since this stage in his young life. He may at some point need more surgery to correct a leaky valve, but for now, his life is on the up.

*Liz Stewart,
Cardiff*



Hi, everyone. Happy New Year!

Tell us your plans and dreams for this year and the future.



Have you left school or college?

If you are aged between 19 and 23

can you help Corinne with her research?

See page 15 for details.



Baby Emma met Daniel Craig.

He plays James Bond.

Have you met anyone famous?

Send us your photos to put in the newsletter.



Are you famous?

If you perform on stage

please tell us about it.



Write about exercise and sport that you do.

It can give other people good ideas.



We would like to know about good places to visit.

Have you been somewhere fun?



The weather forecast is for very cold weather.

Look after yourself by wrapping up in warm clothes, hats and gloves if you go out.



You may prefer to be indoors.

What do you do to keep happy?

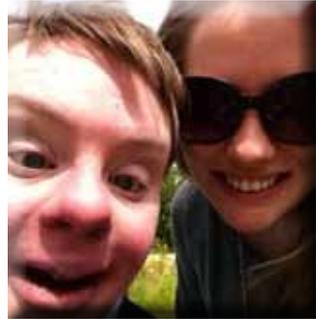
London Marathon 2016

Down's Heart Group has five runners in this year's London Marathon, which takes place on Sunday 24th April. This is DHG's biggest single fundraiser of the year, so please support our runners if you can.

Talulla Barrow featured with her brother Barnaby in a recent newsletter. She ran the Richmond Half Marathon in September for DHG and hopes to achieve a great time on her first full marathon.

Talulla and Barnaby are very close, Barnaby has beaten all the odds and is doing really well despite heart and lung problems.

uk.virginmoneygiving.com/TalullaBarrow



Lorraine Kent is mum to twins, Kaylen and Lola, and used to be a keen club runner. Unfortunately, running was put on hold until Lola's health became more stable. Lola is now doing quite healthy so Lorraine decided to run for DHG.

This will be Lorraine's second Marathon, the last one being ten years ago!

uk.virginmoneygiving.com/LorraineKent



Mark Bickell will be running his third (and last!) Marathon where he hopes to beat his best time of 3:40, although he isn't very confident about that!

His daughter had successful heart surgery at six months old, so Mark is running for other parents who have not been quite so lucky and need DHG's support.

uk.virginmoneygiving.com/mark-bickell-SAVMLMBONDS3332



Pascha De Souza and Vicky Ross are also running and can be sponsored through the DHG website, where all the runners information will feature in more detail. (A 6th runner had to drop out recently due to illness, but as we go to print we are in the process of allocating it to another runner.)

www.dhg.org.uk

Give A Gift

Do you have gift cards that you aren't going to use? Give A Gift will swap it for a gift card of your choice when you donate a percentage of your unused gift card to DHG.



Simply enter your details on the website and either donate or exchange your gift card. Select how much value of your gift card you would like back, select DHG as your chosen charity to receive the rest and follow the instructions on screen.

So, check drawers and folders for those forgotten gift cards and put them to good use by donating to a very worthy cause.

giveagifhq.com

DHG Heart Superhero T-shirts

Positive Choices (a learning disability nurses organisation) and Down's Heart Group have joined forces to spread the message that by working together, everyone involved with Learning Disability can make changes to improve lives.

The Positive Choices conference which has encouraged support of DHG over several years, has the theme of superheroes this year and falls shortly after World Down Syndrome Day, so designer Lyndsay Weir has kindly designed this stunning heart superhero T-shirt to jointly celebrate the occasions.

These wonderful awareness raising T-shirts come in various sizes and styles, from children's to XXL and are available in three colours - white, grey or blue. They cost from £11, plus postage and packing and all proceeds from sales will go to Down's Heart Group.

Orders for more than one colour are currently treated separately on the website, so chat to your friends and order together to save on postage and packing.

Available only from tboom, follow the links below and wear your DHG t-shirt with pride!

White - www.tboom.co.uk/pc-dhg-4-wdsd-white
Blue - www.tboom.co.uk/pc-dhg-4-wdsd-blue
Grey - www.tboom.co.uk/pc-dhg-4-wdsd-grey



Front of T-shirt

Holiday Ideas

As part of an innovation assignment, Craig Bell, a third year Learning Disabilities Nursing Student at the University of Nottingham, discovered a lack of local and national support around activities and holidays for people with Learning Disabilities, so he has developed a resource to help families and care providers.



This is available through DHG, as it is quite an in depth guide but we have highlighted some holiday ideas to share here:

- Revitalise** a national charity providing short breaks and holidays in centres at Chigwell, Southampton and Southport, each offering their own set of holiday packages.
www.revitalise.org.uk/respite-holidays
- Caravanable** a website providing resources on caravan sites throughout the UK. The website also advertises the 'Landeez', an all-terrain wheelchair purposely built for use on stones, sand, snow and water, than can be hired or borrowed.
www.caravanable.co.uk
- Calvert Trust** outdoor adventure in Northumberland, Devon and Cumbria, all with specially trained instructors. Families or individuals are welcome.
www.calvert-trust.org.uk
- Kerry Farm Holidays** set in ten acres of Welsh countryside providing accessible cottages and equipment for hire,
<http://tinyurl.com/kerry-farm>
- Hesley Cottages** located on the Lincolnshire coast
www.helsey cottages.co.uk
- Mitchelland Farm** self catering, fully equipped cottages in the Lake District close to tourist areas.
www.lakedistrictdisabledholidays.co.uk

For the full resource contact Sarah at DHG on

0300 102 1644 sarah@dhg.org.uk

Cake Stall

Phil Thorn, DHG Treasurer, has been holding cake stalls as fundraisers for DHG for the past 25 years. This year was, sadly, the last one. We asked the former maths teacher to calculate the sum he and his team of helpers have raised over the years but he was unable to provide an answer!

Phil wrote:

We raised £200 for DHG this year. In the picture are my sister Marian Hudd, my daughters Katherine and Jo, Katherine's partner Becky and ex-student Lawrence Walker, who asked if he could help. Marian has helped for many years and Katherine and Jo were at the first stall which was held at Blaise Castle Fayre 25 years ago. I've enjoyed it.



*Phil Thorn
Gloucestershire*

Support After Education

Hello, my name is Corinne Girling and I am currently in my second year of my social work Masters at Keele University. I'm doing my dissertation on young people with Down's Syndrome and their perceptions of their support leaving compulsory education.

I would like to interview people between 19 and 23 years old individually or as part of two focus groups. For the practicality of my research I am looking for young people with Down's syndrome who have verbal communication and have capacity to understand what is being asked of them and to give consent. I would also like their parents or carers to complete a questionnaire.

I am based in Keele but would of course be willing to drive and make it as convenient for people as possible! I would be happy to drive up to an hour for each interview or further if necessary.

Thanks in advance for any help you can provide! Please contact Sarah at DHG on



0300 102 1644
sarah@dhg.org.uk

Evelina Sibling Project



ECHO and the Rainbow Trust Charity are running a pilot project to employ a Cardiac Family Support Worker who will support around 25 families directly either within the hospital or in the community. Many more families in the hospital will also benefit from the project and the support resources which are also being developed.

The eligibility criteria for families includes having a child with a heart condition and must live within London and the M25 area. Families may have a sibling exhibiting signs of distress or behavioural problems, a heart child requiring constant supervision or showing challenging behaviour, be a lone parent family or have no extended family for support. Those with long hospital stays or crisis within the family are also included.

The Family Support Worker will work with families to help them improve their ability to manage stress, maintain normality of family life and enable quality time between parents and siblings.

For more information about the project and how to be included, go to:

www.echo-evelina.org.uk/information/cardiac-support-worker/

Do Siblings Matter Too?



A new report from Family Fund and the University of Portsmouth, 'Do Siblings Matter Too?' reveals the impact a disabled sibling has on a child. It highlights a number of key themes for siblings, ranging from elements of a typical sibling relationship to issues of lack of time, experience of aggression, violence and emotional upset.

Siblings often have fewer choices, are unable to take part in the same activities as their friends, experience challenging behaviour, along with elements of social exclusion, and find it hard to get parental attention.

The needs of these siblings are often overlooked by policy makers and service providers. Siblings are not identified by local authorities and schools and few siblings are being supported by agencies such as Child and Adolescent Mental Health Service (CAMHS) or Young Carer groups.

www.familyfund.org.uk/news/new-siblings-report

Creative Breaks

Down's Syndrome Scotland has launched the Creative Breaks scheme. This scheme offers grants of up to £300 to parents or unpaid carers who have a significant caring role for an adult with Down's Syndrome living with them. It is only open to people living in Scotland or The Highlands.



The Creative Breaks Fund can be used for short breaks for the family, overnight stays away from caring responsibilities, tickets to events, taxi fares to social clubs or activities, annual cinema passes or day trips.

For more information on the Creative Breaks Fund and how to apply, please email or call

0131 313 4225
louise@dsscotland.org.uk

Molly's Dolly

Children's Heart Federation have a selection of male and female rag dolls with surgical scars available to any child with a cardiac condition.

A Molly's Dolly can be used prior to surgery to introduce the idea of scars and help prepare a child for a hospital stay. They can be given after surgery to show that having a scar is OK. However these lovely dolls are used they are bound to become a firm favourite in the toy box and can be played with for years.



CHF can provide a Molly's Dolly for free if the order is endorsed by a healthcare professional, such as a Cardiac Liaison Nurse. They can also be obtained by giving CHF a donation of £20 plus postage if you are outside the UK.

Application forms to be completed by a healthcare professional, if you're claiming a free doll, can be downloaded from the website, or to request an application form through the post, call or email:

020 7422 0630
info@chfed.org.uk
www.chfed.org.uk

Stories 4 Life



Stories4life is an online voice recording service currently offering over 50 children's stories. There is also the option to create your own recordings so parents or relatives can record stories to be played to children for when they aren't able to be there. A book of the story is provided with the CD for children to read or flick through whilst listening.

All recordings are professionally edited so mistakes are taken out and wonderful, fun sound effects are added throughout the story, bringing the story alive, encouraging the child to engage in the story and also improve literacy and listening skills.

www.stories4life.com

Bag Books



Bag Books provides multi-sensory books and storytelling for people with severe learning disabilities. Bag Books are very different to conventional books. Each story contains a number of un-bound A3 boards, as pages, each comprising a different multi-sensory experience. These pages are brought together by a simple but captivating storyline of just a few short sentences.

Listeners are encouraged to explore the different sensory experiences, often hand over hand with the storyteller. Each of the 25 Bag Books stories takes the listener on a journey to discover new textures, sounds, smells and movements. The books are all handmade from scratch by a team of skilled craft artists and volunteers and take an average eight hours to make.

Bag Books is a registered charity and also provides multi-sensory storytelling sessions at a range of venues throughout the UK. Training in storytelling techniques is available for parents, carers, teachers, day centre staff and librarians.

020 7627 0444
www.bagbooks.org

Sensory Stories

Joanna Grace is a special educational needs and disabilities consultant. She would like to introduce us to sensory stories, which were originally a resource used with individuals with Profound and Multiple Learning Disabilities. Sensory stories are now being used in both special and mainstream settings and for all age groups. They really are great for everyone, as with any story it is just a case of finding one to suit your audience.



Sensory stories are concise narratives told through spoken language and sensory experience. The meaning of the stories is carried in both the language and the experience. They can be used to support cognitive development, memory, concentration, mental health, readiness to learn, understanding and communication.

For individuals with naturally jumpy attention spans a sensory story offers the listener something to jump their attention to at every stage: something to touch, something to smell, something to hear and so on. As their attention jumps their concentration stays on the same topic.

Concentration is a multilayered skill; we often focus on just the final two layers: look this way and listen to me. But underneath are skills such as being able to sit still and cope with how your foot feels as it falls asleep, or being able to screen out the sound coming from the electric lights above you. If you can wrap someone in a wonderful story, and offer them something for their attention to skip to as they concentrate then they get to practice all those underpinning skills, which like a muscle, grow stronger with exercise.

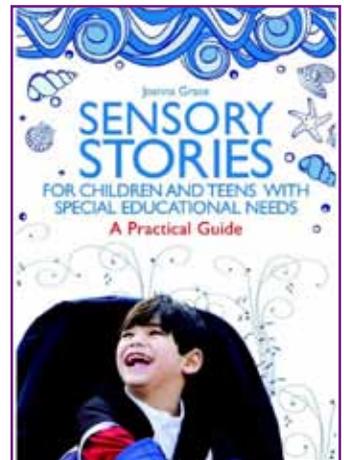
I sell a selection of stories on my website, they're £12 and come with instructions on how to tell and resource them as well as ideas for activities to do to compliment them. The website also contains a page of free educational resources on a variety of topics and a series of summary guides about things to do with sensory stories which can come in handy.

The most important thing to remember about sensory stories is that they are terrific fun!

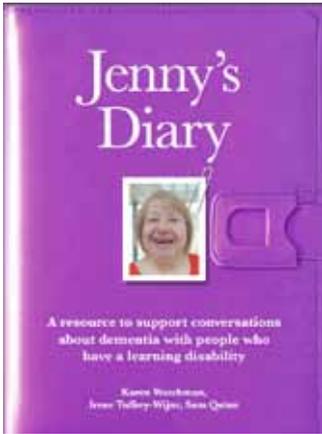
Joanna Grace

Find Jo on Facebook or connect with her on Twitter:

[@jo3grace](https://twitter.com/jo3grace)
jo.element42.org/



Jenny's Diary



Jenny's Diary is a free booklet and set of postcards aimed at supporting conversations about dementia with people who have a learning disability.

All dementia strategies in the UK state that everyone is entitled to know of their diagnosis, not only as a human rights issue but as part of developing appropriate and individualised post-diagnostic support. Currently there is limited guidance on how to explain dementia to an individual with a learning disability.

Conversations about dementia are never easy, there is typically a fear of what will be understood, what words to use, and how to cope with the response.

Jenny's Diary takes a three-step approach to address this:

Part 1 - opens dialogue about why Jenny is behaving differently, and how she can be supported to live as well as possible with dementia.

Part 2 - suggests how to have a conversation with Jenny about her diagnosis of dementia.

Part 3 - contains guidance to talk about dementia with George, Jenny's partner.

Jenny's Diary has been developed at the enhanced dementia practice level of the Promoting Excellence education framework in Scotland by Karen Watchman and Sam Quinn from the University of West Scotland and Irene Tuffrey-Wijne from St Georges University of London and Kingston.

www.uws.ac.uk/jennysdiary

Get Online

getonline@home

Get Online @ Home is an initiative to provide low cost refurbished desktop and laptop computers. It is part of the Go On UK digital inclusion programme.

A desktop computer costs £99 and a laptop costs £149 for purchasers who are in receipt of eligible benefits. Those not qualifying for the cheaper price can buy a desktop computer from £119 or a laptop from £169.

03719 100 100

www.getonlineathome.org

Up Down Man

Salisbury Playhouse presents Up Down Man, starring Nathan Bessell as Matty. The play runs from Wednesday 24th February to Saturday 12th March 2016.

Up Down Man is the sequel to the internationally acclaimed Up Down Boy, and asks the question that faces every parent of an adult with a learning disability.... What will happen if I'm not here? Written by award winning Brendan Murray, Up Down Man is a funny, provocative and moving show.

Shows include a relaxed performance on Thursday 3rd March and on Saturday 5th March there will be a family post show talk, where families can discuss topics raised in the play.



01722 320 333

www.salisburyplayhouse.com

Kidz Exhibitions

Kidz Exhibitions are free for people with disabilities, their families and carers. There are hundreds of stands and displays regarding every aspect of life: gadgets to make life easier, care providers, supported holidays and benefits advice are just a few examples.

The 2016 dates for the Kidz and Kidz to Adultz exhibitions, including a new venue in Wales are now set and free tickets can be ordered by emailing or calling Disabled Living. All venues are accessible and have plenty of free parking.

Midlands - Thursday 10th March at Ricoh Arena, Coventry CV6 6GE

South - Thursday 9th June at Rivermead Leisure, Reading RG1 8EQ

Wales - Thursday 7th July at National Indoor Athletics Centre, Cardiff CF23 6XD

Scotland - Thursday 15th September at Royal Highland Centre, Edinburgh EH28 8NB

North - Thursday 17th November at EventCity, Manchester M17 8AS



0161 607 8200

info@disabledliving.co.uk

Funeral Advice



Down To Earth is a small team that's part of the charity Quaker Social Action (nothing to do with Down's Syndrome). Helping those struggling with funeral costs, with kindness, friendliness and clarity they work hand-in-hand with people to:

- * Find funeral directors to provide an affordable service
- * Check if you can receive benefits or charitable funds
- * Support you to add meaning and dignity to a simple funeral

"I've never had anyone stand up for me like that in my whole life"

People save an average of £2,237, but for many talking to someone who will listen, free advocacy and practical support are more important. Down to Earth also understand that everyone has different needs and values when it is time to say goodbye, they endeavour to provide a speedy, appropriate and empathetic response to grieving people.

Support ranges from quick calls to weeks of painstaking research and Down to Earth are experienced in supporting carers and people who have lost a carer.

020 8983 5055 10am-4pm weekdays
downtoearth@qsa.org.uk
<http://tinyurl.com/qsa-d2e>

Child Bereavement UK



Child Bereavement UK supports families and educates professionals when a baby or child of any age dies, is dying, or when a child is facing bereavement.

It is a UK wide organisation offering confidential support, information and guidance, either through the website pages or through arranged telephone calls.

0800 02 888 40
support@childbereavementuk.org
<http://tinyurl.com/childbereavement>

Further information about Down's Syndrome is available from



Down's Syndrome Association
Langdon Down Centre, 2a Langdon Park
Teddington TW11 9PS

0333 1212 300
www.downs-syndrome.org.uk



Down Syndrome Education International
6 Underley Business Centre
Kirkby Lonsdale, Cumbria LA6 2DY

0300 330 0750
www.dseinternational.org



Down Syndrome Ireland,
Citylink Business Park,
Old Naas Road, Dublin 12

00 3531 426 6500
www.downsyndrome.ie



helping people realise their potential

Down's Syndrome Scotland
158 - 160 Balgreen Road
Edinburgh EH11 3AU

0131 313 4225
www.dsscotland.org.uk

Further information about heart related issues is available from



British Heart Foundation
180 Hampstead Road
London NW1 7AW

0300 330 3311
www.bhf.org.uk



Children's Heart Federation
Dragon Enterprise Centre, Cullen Mill,
Braintree Road, Witham, Essex CM8 2DD

0808 808 5000
www.chfed.org.uk



The Somerville Foundation
Saracen's House, 25 St Margaret's Green
Ipswich IP4 2BN

0800 854 759
www.guch.org.uk



PHA UK
Unit 2, Concept Court
Manvers, Rotherham S63 5BD

01709 761450
www.phassociation.uk.com



dhg

down's heart group

charity 1011413

Tel:
Email:
Write:

0300 102 1644
info@dhg.org.uk
PO Box 4260
Dunstable, LU6 2ZT

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The Information Standard



Certified Member

Down's Heart Group are certified members of Information Standard, ensuring all our information is accurate and current. The standard applies to any articles within this newsletter which contain treatment or diagnosis information.