

# T<sup>o</sup>gether

Summer 2021 **Issue 28**

## Managing Mental Wellbeing

How to recognise the symptoms

## Engaging Your Employer

Your experiences in the workplace

## Preventing Skin Problems

Avoid painful tissue issues

## When Andrew Met Maria

Bridging the generational gap

Plus lots more exciting **Shine** news inside!



**I cannot believe that more than a year has passed since we first learnt about the emergence of a world-wide pandemic.**

At the time, we all knew very little about Covid-19, and even less about how it would affect our lives in so many different ways. Yet, Shine realised very early on how quickly we needed to act if we were to continue to support you and your families through these times. As a community connected through spina bifida and/or hydrocephalus, anencephaly or encephalocele, we have supported each other through challenges and sadness this year; we have also found time to celebrate achievements and the sparks of happiness which have given us some hope and light at the end of the tunnel.



We have continued to listen and learn from you. As a result of successful Spina Bifida and Hydrocephalus Awareness weeks, and increased involvement in our work from so many of you, we have produced yet more useful guides and information leaflets, specifically designed to help you talk to, and tell, your GPs, other health professionals, care providers, employers, teachers and many others about your condition(s) and what it is you need and want from them. Our employment feature on pages 8 and 9 is a prime example of this work.

**I hope you enjoy this latest edition of Together – packed full of your stories, insight, experiences, knowledge, peppered with useful snippets of information. Something for everyone.**

Kate Steele  
Chief Executive

## Shaping Shine's services for the future

Shine is in the final year of our 5-year Corporate Plan. Whilst our quest to improve lives and futures for so many people living with spina bifida and hydrocephalus will continue for many years to come, significant progress has been made through the lifetime of the current plan, despite the ongoing challenges of funding, investment in staffing and the pandemic over the last 12 months.

Work on the new Corporate Plan 2022 and beyond will begin in the coming months.

Opportunities to contribute to the development of the Plan will be open to everyone, to ensure we capture your areas of priority for our work, and the range of views from across our membership.

Look out for further information on how to get involved via email and Shine's social media, or register your interest on 01733 555988 or email [firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk)



## Join Shine's Board of Trustees

Shine is looking for volunteer trustees, especially individuals with spina bifida and/or hydrocephalus, to represent the interests of our members and contribute to the good governance and management of Shine.

Trustees need to have a knowledge and understanding of:

- Spina Bifida and Hydrocephalus, or disability in general
- Statutory strategy and policies that shape the health, social care and/or education agendas
- Charity governance and management

This is a voluntary, non-paid position.

## Seeking our next Chair of Trustees

Shine is also seeking a new Chairperson as Shine's current Chairman, Mark Noakes, will be stepping down in 2021. Could it be you?

For further information about the roles, or to arrange an informal discussion with our CEO, Kate, please email [firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk) or call 01733 555988



## The Multicath Trial

Do you use intermittent catheters? Are you interested in government-funded research to try out new catheter options?

All intermittent catheters in the UK are for single use only, but catheter-users have told us that there are advantages from single-use and multi-use catheters. It is possible that using multi-use catheters some of the time and single-use catheters at other times (mixed use) would offer the flexibility and advantages of both types, including a reduction in single-use plastic waste.

The aim of the Multicath trial, led by the University of Southampton, is to find out if mixed use is safe and acceptable to users. If you are over 18 years old and use intermittent catheters, then you may be eligible to take part and we would like to hear from you.

Please contact the research nurse for an informal chat on 07960 136241 or email [multicath@soton.ac.uk](mailto:multicath@soton.ac.uk)

Find out more at <http://www.soton.ac.uk/multicath>

## Keeping in touch!

Please remember to let us know if your contact details change so we can make sure you continue to receive 'Together' and other important information about Shine's services and support.

If you're unsure whether we hold the correct details, or would like to update them, call 01733 555988 or email [firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk)

## Delivering on our promises.

Shine Health Direct, the home-delivery service exclusive to Shine members, is going from strength to strength following a recent change in delivery partner.

In a recent survey, 95% of Shine Health Direct users said they would recommend the service to a friend and many customers have told us about the service they value from our local delivery drivers.

We take your feedback very seriously, and on the rare occasion we receive a complaint, a theme has been the delivery provided by our third-party delivery partner, Parcelforce. In response, we are delighted to have entered into a new contract with the award-winning DPD, noting an immediate improvement in our customer-satisfaction scores. Wherever possible, we use our own local delivery drivers, but any other deliveries will now be handled by DPD.

To re-join Shine Health Direct, or register for discreet and efficient delivery of your stoma and urology products as well as prescription medications, contact Shine Health Direct today on 0800 023 8857.



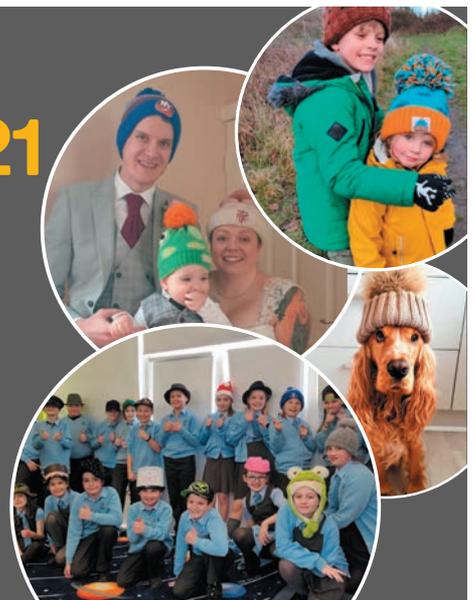
## Hydrocephalus Awareness Week 2021

In March, we celebrated Hydrocephalus Awareness Week. This year we focused on making sure you, and those around you, know more about your condition so that you can get the support you need, where you need it, when you need it.

Shine, in partnership with Codman, developed a range of resources to help.

We also delivered useful online sessions on living with hydrocephalus, from tips for managing headaches and fatigue, improving sleep, memory and concentration, to understanding shunts and the condition more.

We saw even more supporters taking part in 'Hats On for Hydrocephalus' online, having lots of fun whilst raising money and awareness of hydrocephalus.

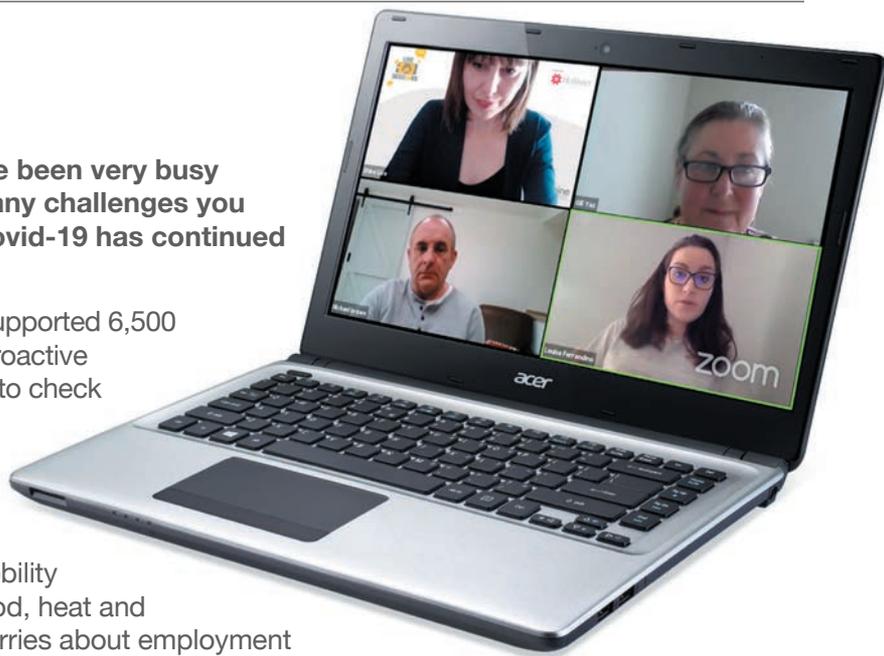


# Services Update

Since our last Together Magazine, we have been very busy supporting you, our members, with the many challenges you have all encountered, particularly since Covid-19 has continued to dominate our lives.

From 1st April to end of December 2020, we supported 6,500 members with 9,500 issues. We made 5,800 proactive contacts with members we hadn't heard from, to check how you were and if you needed help.

Many of you did. We found that you were facing problems such as reductions or cuts in external care hours, inappropriate housing, delayed NHS treatments, delays in getting mobility or sensory equipment, difficulties affording food, heat and basics, inappropriate educational support, worries about employment security as well as problems with mental wellbeing and your physical health.



**Our Support and Development Workers and specialist teams have spoken to you by phone or Zoom, and we have also been engaging with you digitally in a range of ways. We:**

- Set up 19 WhatsApp Groups with 395 members and a further 6 are ready to be established.
- Ran over 60 Facebook Live Events on a range of topics which focus on keeping healthy with spina bifida and/or hydrocephalus, mental wellbeing, equipment and adaptations, finances and benefits, etc. and we are continuing to add to these every month. You can find the recording of sessions we have run and new sessions we are going to run here <https://www.shinecharity.org.uk/national-events/shine-events>. You can also contact us to request a session if there is a topic we have not yet covered that you want to explore.
- Offered one-to-one or small group Zoom video sessions from our occupational therapist, physiotherapist, sleep specialist, benefits advisors and health professionals, as well as social groups where adults with the conditions or parents/carers can meet virtually for social get-togethers with like-minded people going through similar challenges.
- Created three videos for parents to use with schools or support workers to explain the support needs of children who walk full time, walk part time or use a wheelchair full time.
- Kept in touch with our 600 members on our 40+ Facebook Group and 670 members on our Little Stars England Facebook Group, as well as 541 members of Shine Cymru Facebook and 1,237 members of Shine Northern Ireland Facebook.
- Ran successful Spina Bifida and Hydrocephalus awareness weeks, where many of you shared your stories either by writing a case study for us or by recording your own Shine Voices Videos.
- Distributed over 350 hard copies of the 'My Child and Hydrocephalus' book to parents, and made it available to download.

We will continue to offer you the support you need throughout 2021. We haven't been able to meet you in person, but we will be there for you by phone, email, video link, social media, letter or any other way that you want to communicate with us.

We are planning ways in which we will utilise the information you gave us via the 1,000 Voices survey for adults with spina bifida and how this will inform the work of our frontline teams, Adult Engagement Officer and professional engagement.

We are continuing to keep in touch with all of the specialist multi-disciplinary children's clinics across the three nations and we are working on developing e-modules to use so that we can train the professionals you interact with on the conditions and how best to support you with them.

We are always looking for ways to enhance our services so if there is something you need that we don't currently provide, let us know.

**Our phone lines are open 9-5 Monday to Friday, so please do call us if you need help or support on 01733 555988 or email us at [firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk) and we will put you in touch with the right Shine Team Member to help you.**

# Developing and Maintaining Emotional and Mental Wellbeing

Mental health and wellbeing is now frequently talked about in the news and in other mainstream media sources. We are being encouraged to be proactive in looking after our emotional and mental health and, thankfully, there are a lot of practical things we can do to increase our wellbeing.

Survey responses to our Adult Survey: **1000** Voices showed that:

**40%**

of members with spina bifida say their mental health has worsened over time

**56%**

of members with spina bifida reported experiencing feelings of anxiety

**Only 25%**

of our members said they had no concerns with their mental health

**53%**

of our members with spina bifida reported having feelings of depression



Also, a small survey amongst our members who watched our Facebook Live sessions on Mental Wellbeing showed us your feelings of anxiety and depression have worsened during the pandemic. We can clearly see from these findings, and from the many conversations with members, that mental health support is important.

Since the start of the Covid-19 pandemic, Shine has been providing support to promote mental wellbeing via Facebook Live sessions. These sessions have covered a variety of topics including tips on how to manage anxiety relating to Covid-19 and how to live well during lockdown. We talked about the importance of routine and shared ways to find fun things to do when spending more time at home.

Our members shared creative ways they were staying busy, including joining online choirs, gardening and doing online exercise classes. We looked at how to manage when feeling overwhelmed with all the change and fear that the pandemic brings. This included learning how to acknowledge our emotions and pay attention to our thoughts. We discussed the importance of limiting our social media and news content and finding someone who we could talk to. We explored how learning skills like mindfulness and cultivating gratitude can have a big impact on our emotional wellbeing.

**As the sessions progressed, we began to consider what anxiety is and ways to manage and cope with the symptoms. Sessions included:**

- Understanding what happens in our bodies when we feel anxiety symptoms
- Grounding techniques
- Practising mindfulness
- Progressive muscular relaxation
- How our thoughts impact our feelings

Our members were able to share their experiences and coping strategies with each other and also ask the presenters questions. This interaction with our members has been a vital part of shaping our sessions

and a source of peer support and encouragement during what has been a very difficult time for many.

**In the final sessions we considered what the signs and symptoms of depression were, and we explored ways to manage and cope with the symptoms, including:**

- The link between how we feel, what we think and what we do
- What are automatic negative thoughts?
- 10 most common automatic negative thoughts
- How looking after our bodies can help with feelings of depression: diet, exercise, sleep, sunlight, connecting with nature and engaging in purposeful activity.



If you missed these sessions and you think they might be useful to you, they are available to watch at any time in the video section of our Shine Facebook page: <https://www.facebook.com/ShineUKCharity/videos>



You can also see a summary session on the Shine website: <https://www.shinecharity.org.uk/find-support/video-library/9-shines-live-session-archive/az01JEC-xkQ>.



**We regularly run new Shine Facebook Live sessions.** If there is a session which we have not yet run and which you would like us to deliver, please do let us know.

# Jim's story...



Whether you're living with spina bifida or hydrocephalus, or caring for someone who is, it's not always easy to get the help you need, where you need it, when you need it.

In his story, Jim tells us how life changed when he discovered Shine, and how his Support and Development Worker gave him the confidence and tools to talk to others about his condition.

"Life wasn't bad but I was hit with bad bouts of illness and for a long time, it was passed off and treated as vertigo.

"I used to be very active, refereeing Gaelic football matches etc. but all of this stopped when I ended up having to have surgery for hydrocephalus. There was not a lot of knowledge on hydrocephalus at that time and it was quite scary not knowing anything about your condition.

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**"...Shine has made a difference to my life as, without them, I'm unsure that I would have been given the knowledge and understanding that I have now..."**

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"People around me knew that it was 'fluid on the brain' but not how it can affect you in day-to-day life. I ended up having emergency surgery while on holiday in Cork. However, upon returning home, I felt like I was not being listened to or taken seriously. This was before I got involved with Shine.

"After reaching out to Shine and meeting my local Support and Development Worker (SDW), things were a lot different, for the better. I could talk to my SDW about concerns or health issues.

"It felt good to speak to someone who understood my condition and if my SDW was not available to speak, I was always pointed in the direction of someone else within Shine who could help.

"When I was sick, they provided me with information on different treatments and where I could get the help I needed. My SDW informed me about a centre in England that specialised in hydrocephalus, and helped me to get in touch with them and eventually travel there for multiple surgeries.

"Shine has made a difference to my life as without them, I'm unsure that I would have been given the knowledge and understanding that I have now. My SDW checks in with me regularly and I can ask for help with things like benefits or attending meetings."

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**If you'd like to tell your story in a future edition of Together Magazine send us an email to [voices@shinecharity.org.uk](mailto:voices@shinecharity.org.uk), or for tips on how to create and share your own video story, visit <http://www.shinecharity.org.uk/voices>**



# Carl's story...

I was born in 1962 with spina bifida and the doctors advised my mam and dad to leave me in the care of the hospital and told my parents to go away and start another family. My mam and dad, both fuelled with the exhilaration of their firstborn and their sheer love for one another, meant they would never agree with the so-called professionals and they took me home.

Thanks to Mam and Dad I've led a very happy and fulfilled life. Although I am a wheelchair user, I've worked all my adult life and I am currently a team leader for a young men's support service.



I also founded and manage the most successful and highly decorated disabled football club in the country, the Skem

Menaces, who back in 2017 were awarded the Queen's Award for Voluntary Services at Buckingham Palace.

In 2013, the club achieved an incredible accolade by winning a Silver medal at the Bath Special Olympic National games, and that same year I received the Volunteer of the Year with the Sunday Telegraph.

In 2015 I was the recipient of the BBC North West Unsung Hero Award, and in 2016 I was awarded the Point of Light Award from the then Prime Minister David Cameron.

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**“...I've led a very happy and fulfilled life. I've worked all my adult life and I am currently a team leader for a young man's support service...”**

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In 2017 I was awarded the Freedom of the Borough of West Lancashire.

When I was a teenager, doctors told me that I would never father my own children, and now I am married with two beautiful children, and a proud grandad to my granddaughter Harriet Eva, who I fondly refer to as 'curly'.

Late last year I decided to try and write a book to raise much-needed funds for the Skem Menaces.

Initially I was going to write about my daily struggles of living with a disability as I really do not get on with it at all, despite me giving the impression that I am fine with it, but decided in the end to look at disability through the innocence of a child's eyes as I believe that disability is under-represented in children's literature.

**My Gan-Gan's pram** is a heart-warming book of a granddaughter Harriet Eva (Curly) and her grandad, me, (Gan Gan). It's a story of the very special bond between a little girl and her disabled grandad and their wonderful exploits, with lots of laughter.

Curly loves to visit her Gan-Gan because he has the best toy in the world, Gan-Gan's pram. Together, with the wheelchair that Curly calls a pram, they have many adventures, from sailing the seven seas as pirates or riding on a big red bus racing against each other, to speeding down hills as fast as they can go.

One of Curly's first ever toys was a little yellow duck, 'Quack Quack' that she adored, so with that in mind there is a test for readers. On each page of the book, a little yellow duck is hiding and it's the reader's job to find where they all are.

Look very carefully as they are clever little ducks and they are very good at staying out of sight.

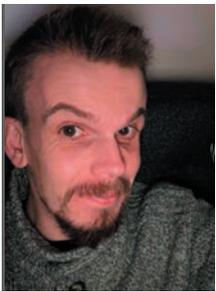
For more information please visit <http://www.curlyandcarl.com>

# You and Employment

Whilst employment isn't possible for everyone, many Shine members tell us that their job, whether paid or unpaid, is a big and rewarding part of their lives.

In this edition, we invited Shine members to tell us about what they do, what support they've had from their employer, and what advice they'd give to other people who need extra help in the workplace.

## ROBERT



"I'm a peer mentor for Bournemouth YMCA, support others as a member of Access Dorset and make monthly contributions to Shine. I like to make a difference and give others the support I had growing up.

I spoke to my employer and did a presentation on hydrocephalus last month during a session with Access Dorset - they were fascinated to learn all about shunts and how they work.

I've often felt discriminated against because of my condition, but I say NEVER be afraid to ask for help or be honest. Hydrocephalus is an 'unseen disability' and can affect people in different ways. Don't be afraid to talk about it.

I find it comforting to get familiar with the work pattern, whatever it may be. Take a notebook and keep it with you, jot things down, so if you find yourself forgetting things, you can refer to it to jog your memory. Once you establish a good routine, eventually it will stick with you, and always take short breaks if you feel you need to.

## MATTHEW



"I work for South West Water. They've been very accommodating and made sure I got help when I needed it, allowing me short breaks where necessary and offering one-to-one support. With Covid-19 I've been able to work from home if I didn't feel safe at work, or if

anyone has symptoms. My favourite thing about the job is that nothing is ever the same and I get to chat to a variety of people.

Don't be scared to talk about your condition. Most employers are really understanding and likely to ask questions if they don't know much about it. Good employers will take time to make sure that support is there if you need it, but don't hide it. Tell your employer as soon as possible. The sooner they know how to help you the more you will benefit.

...and don't over do it, it can make you even more tired! Drink lots to keep yourself hydrated and if things are getting on top of you, make sure you talk to someone.

## ANDY



"I'm a national sports development officer at a small charity.

My role is to encourage people to become more active. I give advice on inclusivity for disabled people, organise events, develop resources, manage a number of projects and present at

conferences, engaging with a variety of sport, health and education providers.

I love my job, every day is different and I get to work with some amazing, inspirational people - encouraging someone to become active and watching them grow in confidence is a great feeling.

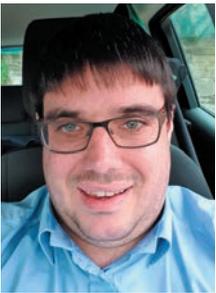
After leaving school, I started as an electrician in a factory. At my interview we discussed my condition and I was able to educate them as to how it might affect my job. They were very helpful. Working in sport I have found there are no restrictions, in fact, I've found my impairment an advantage, as I can speak from personal experience having been unable to access many sporting opportunities when I was younger.

My job involves lots of sitting at a desk, but prior to COVID I was travelling a lot - in both cases

it's important to plan carefully and take regular breaks. I'm always honest with my employers. If I need time off for appointments, or because I'm ill, I let them know as soon as possible. Try to make appointments at the start or end of the working day, and offer to make up the time – by making my colleagues feel supported, they are willing to help me when I need it.

If you're ever worried, speak to your employer as soon as possible. They aren't the expert, an honest discussion helps both parties – in my experience, most challenges can be overcome without too much expense.

### KEITH



"I'm a bus driver. I enjoy driving and meeting new people. The job allows me to combine both passions whilst drawing a weekly wage.

I told my employer about my disability and they asked me about adaptations to vehicles and buildings. I'm lucky because

I can drive a standard automatic vehicle and access everything I need without having to go upstairs.

It's your employer's responsibility to make all reasonable adjustments so they comply with the Disability Discrimination Act and Access for All regulations. Don't be afraid to talk to them about your disability. They might not know the ins and outs of your condition, but don't let that put you off. It's a chance to educate your employer, and let them know what support you need. They can't make you redundant because of your condition. You will be fine. Trust me.

Everyone has their own way of dealing with their conditions. I carry spare sanitary pads and catheters with me, and my employer issued me with a RADAR key which can be used to open many disabled toilets internationally. If you work at a PC and the screen gives you hydrocephalus-style headaches ask your employer for a screen filter. Most will also help you pay for an eye test if required.

### MARGARET



"I'm Manager of the Flying Start department in a nursery for 0-12-year-olds.

After being diagnosed, I took medication, but it didn't help. Lumber punctures were not sufficient to alleviate the pressure and 4 years ago I had a VP shunt fitted.

The operation was in March and I was back at work by September.

My employer was really supportive, allowing me time off when I needed it and adjusting my working hours. They also got voice-recognition software so I could speak into the computer rather than type out my paperwork. I still take medication and it's hard going, but I love my job and take each day as it comes.

Last year I won 'Early Years Practitioner of the Year Award Wales', it was lovely to read in the local press that my colleagues felt 'blessed' to have me as part of their team.

# 1000 Voices

Our '1000 Voices' study found that 59% of working-age people with spina bifida were out of work.

Whilst for some this was due to changes in their health, others reported feeling 'forced out' due to a lack of support from their employer. The Covid-19 pandemic has caused further anxiety for people in work, but please rest assured whether you're currently employed, or looking for a job, Shine is here to help.

We also have advice on our website about overcoming barriers to employment if you have a disability <http://www.shinecharity.org.uk/employment>

For further advice and support, download our 'Advice for Employers' leaflet at <http://www.shinecharity.org.uk/employertips> or call us on 01733 555988

# Preventing skin problems

Last year, we surveyed our adult members with spina bifida to see what health challenges arise as time goes on, so we can inform our members on living well with spina bifida and prevent some of the effects that can impact health and quality of life.

**Pressure sores (also known as pressure ulcers or bedsores) are areas of the skin and underlying tissue that are damaged by prolonged or recurrent pressure, or friction, on the skin.**

Skin issues, such as pressure sores or cellulitis, are a major health issue for our members which can have serious consequences if not picked up early and treated effectively.

Risk factors for pressure sores include lack of skin sensation (not feeling when the skin or tissues are being damaged), reduced mobility (not changing position frequently to allow blood to replenish areas under pressure), continence issues, (urine and faeces can damage the skin) and being overweight or underweight, so many of our members with spina bifida are vulnerable to skin issues.

When we asked our members about their skin and tissue health in the survey, over half had had a pressure sore at some point in their lives, with 16% having multiple sores since childhood (some had had so many they'd lost count).

The first sore often occurred between ages 11-20, a time when young people tend to have more privacy and less parental supervision in bathing, dressing etc. than early childhood.

It is also a time of rapid growth, where wheelchairs or orthoses may be outgrown and begin to rub, and a

time when symptoms of tethered cord can begin, with reduced skin sensation and reduced mobility.

People with reduced sensation may not be aware of the severity of the damage they have sustained, even though it can be serious or even life threatening.

Pressure sores and tissue problems were the most common reason reported for unplanned admission to hospital, with 57% of people who had had a sore needing to stay in hospital for treatment.

Most stayed in for two or three weeks, but some people had needed to stay for several months. Shockingly, 23% of members with pressure sores said they'd developed sores in hospital.

Once home, community treatment can be lengthy, and often bed rest forms part of the treatment. Isolation, boredom, and inadequate social care can cause difficulty with following the treatment plan, as well as severe anxiety and depression. Clearly, prevention is far better than cure.

**Get involved:** Shine is setting up a virtual focus group for adult members and parents of children with spina bifida to develop a range of information and resources to help members of all ages recognise and manage early signs of serious skin issues.

If you are interested in being involved, contact Katie Hall on [katie.hall@shinecharity.org.uk](mailto:katie.hall@shinecharity.org.uk)



## TIPS for pressure sore prevention

(from the UK government's "Stop the Pressure" campaign which uses the acronym SSKIN)

- 1 SKIN** Check it regularly, are there any red marks or open, broken areas?
- 2 SURFACE** Check the surfaces you are sitting and sleeping on. Are they providing the correct level of protection and support for you? Does your wheelchair still fit you? Do you have a pressure cushion? Do your orthoses fit well?
- 3 KEEP MOVING** Move regularly. Stand if you're able to otherwise shift your position in your chair.
- 4 INCONTINENCE/MOISTURE** Keep the skin dry and healthy.
- 5 NUTRITION AND HYDRATION** Keep up your fluids and have a good, balanced diet. Avoid smoking if possible.

**! SPEAK TO YOUR GP AS SOON AS YOU NOTICE REDDENING OF THE SKIN.**

 "Stop the Pressure" is a YouTube video which explains the importance of and key points of the campaign: <https://youtu.be/QRyxmWKE-PI>

 "It's SSKIN" is a YouTube video with a song to help professional and family carers remember the key points of prevention: <https://youtu.be/smcN7MMDAjK>

# Sara's story...

We are a family of four from South Wales - Paul, Liz and our daughters Sara, 9 and Alis, 5.

## Here's our story.

Our eldest daughter Sara came into our life with a bang on 5th November 2011 and as with all new arrivals, there was the normal baby whirlwind, but after a few weeks, we noticed her right foot turned inwards. This was raised with our Health Visitor before self-referral to our GP. Sara was referred to a consultant and specialist physiotherapist who diagnosed Talipes (Club Foot). She was treated using the Ponseti method and was put into boots and bars worn every night until her 5th birthday.

As Sara became older, we tried to no avail to potty train. Even though Sara knew what to do she was unable to control her bladder and bowel. Our gut feeling was that something wasn't right. After querying several times with our Health

Visitor we again went to our

GP who referred Sara to a paediatrician who arranged a MRI.

In March 2016 we had the MRI results. We were advised that Sara had a rare form of spina bifida known as Anterior Sacral Meningocele. This was a total shock to us, as to the untrained eye, there were no other outward signs.

By now Sara was four and a half. Throughout our pregnancy nothing was noted as unusual on the scans and no medical professionals had previously raised any concerns.

Coming to terms with the diagnosis was difficult enough without the added worry that our second daughter, Alis, was three weeks away from being born.

We were referred to Noah's Ark Children's Hospital, Cardiff, where Sara still remains under care.

Due to the rare condition Sara was referred to Great Ormond Street (GOSH), and in July 2019 she was diagnosed with Currarino Syndrome, a very rare condition of which the meningocele was a feature.

Just before Christmas 2020, Sara had successful surgery to detether her spinal cord.

We contacted Shine soon after diagnosis and were put in touch with Sian who talked to us to advise us of the services and support Shine provides, and to answer any questions. To be honest, up until then we'd not heard of Shine.

Having the late diagnosis meant the treatment Sara should have had from birth has been much later. She had to learn self-catheterisation and to also come to terms with daily bowel washouts, which she particularly dislikes and can be a challenge for the whole family.

We have had fantastic support from Shine and wouldn't be where we are today without it. From Brenda guiding us through continence issues (if you want to talk "wee and poo", speak to Brenda), to Sian who facilitates the Wales Little Stars group known as "Ser Bach" where we meet other members and families to talk and share experiences.

Since finding Shine, we've become Shine Ambassadors, active members and fundraisers.

Sara walked Pen-y-Fan (South Wales' highest mountain) for Shine. Our support has been enhanced by family and friends who have organised a sponsored fishing event, short-wearing events and Chepstow Rugby Club organised a fundraising dinner. Sara's uncle has completed the Cardiff Half Marathon and is planning to run again in October 2021 with Sara's aunty.

Sara herself is an active girl attending mainstream school where she has a dedicated one to one. She loves gymnastics and is a member of Valleys Gymnastics Academy (VGA) Disability Squad. Her ambition is to become a Paralympic gymnast. We may be biased but we think she may just do it!

**You can find a short film on YouTube called 'Born To Tumble' about VGA Disability Squad**  
<https://youtu.be/uEEKjgokZAA>

Welcome to  
Great Ormond  
Street Hospital



“...We have had fantastic support from Shine and wouldn't be where we are today without it...”

# BBC Radio 4 Appeal bridges the generation gap

BBC  
RADIO



by Maria's story, including Andrew, a 74-year-old former ASBAH (Shine's predecessor) member who, upon hearing the appeal, was reminded of his own mother's story, and how hard she fought for him in post-war Britain.

Having drifted away from the charity some years ago, Andrew got back in touch to re-state his support, signing up to become a regular donor, re-joining the organisation and even going as far as to pledge a gift in his will.

So moved were we by Andrew's story that we decided to connect him with Maria, with the pair recently meeting via Zoom to discuss their shared experience.

Back in October, Shine partnered with BBC Radio 4 to deliver a national appeal as part of Spina Bifida Awareness Week. It was an enormous success, helping us reach brand-new audiences and raising a massive amount which helped us continue to deliver vital services throughout the pandemic.

The appeal focused on Maria, whose daughter Delilah was diagnosed with spina bifida at her 20-week pregnancy scan. Like so many before her, Maria's experience was less than desirable as she and her partner were left feeling helpless as they were handed a leaflet on termination before being sent home.

Fortunately for Maria, she found Shine, and our expert knowledge of her situation provided valuable insight which helped the couple to make an informed decision. They continued with the pregnancy, and now, aged two, little Delilah is doing amazingly well, with mum Maria describing her as 'the boss of the house'.

But whilst the appeal went on to raise a large amount of money, its impact has been so much more. Many people got in touch to tell us how moved they were

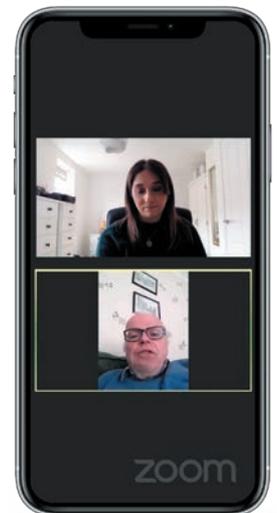
## Maria on Andrew...

“Hearing about Andrew and his amazing parents was wonderful, I'm so grateful to him for reaching out, it's given me a real spring in my step! Thank you to Shine for making this happen.”

## Andrew on Maria...

“I was so proud to be invited to 'meet' Maria. I have no doubt that Delilah will grow up with the same affectionate memories of her mum and dad as I have of mine. They always encouraged me to be independent, as Delilah's parents are doing for her – it's that which really hit home.”

Whilst you might not have regular contact with us today, Shine is here for you and your loved ones pre-birth, and throughout life, whenever you might need us.



## Get in touch

If, like Andrew, you'd like to become a Shine supporter, find out more about the many options available at <http://www.shinecharity.org.uk/donate>

If you missed the appeal, or would like to listen again, visit <http://www.shinecharity.org.uk/maria>

Shine would like to say a big thank you to BBC Radio 4 listeners for raising an astonishing £24,192.93!



## Shine launches new legal service

Back in November we launched our pioneering new legal service, giving Shine members immediate access to some of the country's top clinical-negligence experts.

Living with conditions as complex as spina bifida and hydrocephalus, you constantly place your health in the hands of clinicians, and whilst we sincerely hope that you'll never experience a problem, occasionally, things can unexpectedly go wrong.

It's where this might have been avoided that our service comes into its own, offering expert advice and support to help you identify whether there are grounds to make a claim, and to pursue it on your behalf.

It's not a quick or easy process, and can mean having to revisit painful memories, which is why it's important you take advice from specialist, reputable solicitors, as Oluma\* did after learning that three years of persistent pain and headaches could have been prevented.

Oluma was diagnosed with hydrocephalus when she was 20 and had a shunt inserted. She had no problems until she was 35 and started getting severe headaches which woke her up at night. In 2016, she had monitoring in hospital of her intracranial pressure and the readings showed levels above the limit of her shunt valve. The neurosurgeon felt that her shunt was

working fine, and she was referred to a neurologist for headache treatment.

The headaches got worse and worse and Oluma was only getting about two hours sleep a night. It was affecting her work, which involved a lot of driving and eventually, in 2017, she felt she had no choice but to leave her job because she felt unsafe on the road.

Eventually she got a second opinion from a neurosurgeon at a different hospital who told her that her shunt was not working properly. She had surgery to revise her shunt in 2019, three years after the previous pressure monitoring. After surgery, her headaches resolved.

Oluma came to us to investigate her claim. Our experts considered that the pressure monitoring in 2016 showed raised pressure and that shunt dysfunction should have been diagnosed. We were able to secure a settlement for her loss of earnings for the two years since she resigned and for the pain she had suffered since 2016.

With her compensation, Oluma was also able to access a vocational rehabilitation course to help her understand her transferable skills for employment, prepare her CV and obtain work in a new field that does not involve driving.



### Get in touch

To find out more information about clinical negligence and the legal options available to you through Shine's Legal Service, and to read more success stories like Oluma's visit: <http://www.shinecharity.org.uk/legal>

\*Name and image changed to protect the identity of the individual

The solicitors delivering Shine's Legal Service are members of the Law Society Clinical Negligence Panel, Association of Personal Injury Lawyers or the patient safety charity, Action against Medical Accidents (AvMA).



# Fabulous fundraisers!

Thank you to each and every one of our fabulous fundraisers who have continued supporting Shine over the past few months.

Many of Shine's services are funded by the generosity of the general public.

Want to get involved? Whether you know what you want to do or need inspiration, we would love to hear from you so that we can help you make the most of your fundraising.

Get in touch with our friendly fundraising team by calling 01733 555988 or visiting our website <https://www.shinecharity.org.uk/get-involved/fundraising-enquiry>



After a difficult year, we are excited that our fundraising events will start to return to continue to raise much-needed funds. As lockdown restrictions lift, we will plan our fundraising events in accordance with the latest Government safety guidelines. Should an event be cancelled or postponed, we will work with you to find an alternative way for you to fundraise for Shine.



## Our Shine superstars!



Hayley, Ross and their son Carson raised £620.00 by wearing their Christmas jumpers for Christmas Jumper Day



Jack took on the Lockdown Challenge and walked one hour a day for a week to raise £230.00



Colleagues at Prestige Telecom took on a weight loss challenge and gained £600.00 for Shine!

Thomas took part in the Great Solo Run and raised £1,080.00



Michael raised £40.00 by playing his clarinet for donations



Melissa donated £150.00 from sales of Scentsy candles and is still going!



Christopher completed the 4x4x48 running challenge and raised £540.00



If these superheroes have inspired you then join #TeamShine for Superhero at home this summer.

We're looking for people to take part in this fantastic family event!

It's the UK's one and only disability sport series and this year you can take part from home!

Find out more at [www.shinecharity.org.uk/superheroeseries](https://www.shinecharity.org.uk/superheroeseries)

## Fantastic Facebook Fundraisers

A big thank you to everyone who has set up a Facebook fundraiser in support of Shine. Here are just a few of our fantastic fundraisers:

**Hannah** has now held two different Facebook fundraisers, one general and one for her birthday, in support of her daughter, Ella, and has raised over £1,600.

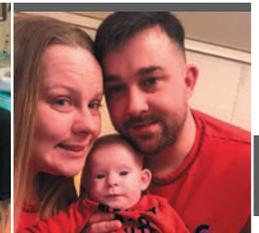
**Frank** held a Facebook fundraiser for his birthday and raised £400.

**Paige and Wesley** both held a birthday fundraiser and have raised over £280, inspired by their son, Harrison.

If you're inspired by our Facebook fundraisers, why not create your own celebration fundraising page?

Whether you're celebrating a birthday, anniversary or any other event, asking for donations to be made to Shine instead of receiving presents is a thoughtful and generous way to celebrate.

Find out more and set up your Facebook fundraiser at <http://www.shinecharity.org.uk/giftsincelebration>



## HYDROCEPHALUS AWARENESS WEEK 8th-14th February 2021



New Leaf Catering held a Hydrocephalus Awareness fundraising day and raised £295.00



8-year-old Lexi took on her own challenge for Hydrocephalus Awareness Week and rode 47 miles on her bike, raising £3,018.00



Annie took on a 10,000 Steps a Day challenge in Hydrocephalus Awareness Week and raised £1,539.50



The McCann Family supporting HatsOn during Hydrocephalus Awareness Week.

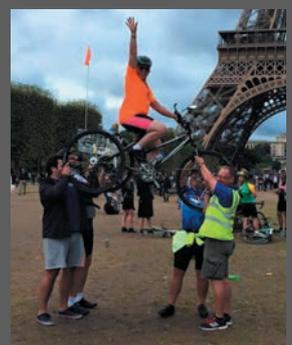
## CONGRATULATIONS SOPHIE!

In January Sophie received the Baroness Tanni Grey-Thompson Para-athlete Trophy at the Annual Guernsey Sports Achievement Awards 2020. Sophie has hydrocephalus and has raised over £3,000 for Shine by taking part in the 2019 Superhero Tri and Winter Wonderwheels and the London to Paris bike ride in 2015.

Later this year Sophie will be taking part in the Virtual London Marathon with many other Shine supporters in her racing wheelchair. Thank you for your continued support Sophie!

If you've always wanted to complete the London Marathon, but never thought you'd be able to, then 2021 could be your year. Shine has a number of charity places for the virtual event available on a first-come, first-served basis so act fast to avoid disappointment.

You'll have 24 hours to complete the route and can take as many rest stops as you need, making this the most accessible London Marathon ever.



For more details visit <http://www.shinecharity.org.uk/virtuallondonmarathon>

# Book an Occupational Therapy or Physiotherapy appointment with Shine



Many of our members are experiencing delays in accessing NHS Occupational Therapy and Physiotherapy appointments.

That's why we're now offering appointments online with our own Physios and Occupational Therapists, who can provide expert advice on splints, equipment and exercise - and if you need them too, they can also liaise with your local health professionals.

Appointments are usually available on Tuesdays between 9am and 3pm\*. Sessions take place using Zoom or Microsoft Teams, and can last up to an hour. Telephone support can also be given if preferred.



\* some flexibility can be offered if days/times do not suit.



To book an appointment, or if you have any questions, please contact our Services Admin team on **01733 555988** or email **firstcontact@shinecharity.org.uk**

Please let us know if any of your contact details have changed



Here to help...  
Please do send any comments or enquiries to us:  
P: Together Shine, 42 Park Road, Peterborough PE1 2UQ



01733 555988  <http://www.shinecharity.org.uk>  ShineUKCharity  [Twitter.com/SHINEUKCharity](https://twitter.com/SHINEUKCharity)

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