INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

LIVING WITH SBH

Stories of Lived Experiences

IF INTERNATIONAL ADULT WORKING GROUP SBH

2026 EDITION

Different journeys.

Shared strength.

Why this catalogue?

The International Federation for Spina Bifida and Hydrocephalus (IF), through its International Adult Working Group SBH, has brought together stories from adults living with spina bifida and/or hydrocephalus (SBH) across the world.

Each contribution offers a unique perspective on growing older with SBH, reflecting different life journeys, challenges, achievements, and aspirations. Together, these stories highlight both individual resilience and the barriers that continue to affect the lives of adults with SBH worldwide. By sharing them, we hope to strengthen understanding, support advocacy, and encourage more inclusive and responsive systems of care and support.

How to read this catalogue

The stories in this publication explore a wide range of themes, perspectives, and stages of adulthood. While some experiences may resonate with many people, each article reflects the author's own journey and should not be seen as representative of everyone living with SBH.

This publication is not a medical or scientific report. It is a collection of personal narratives that aims to raise awareness, encourage dialogue, and amplify the voices of adults living with SBH.

STORIES OF LIVED EXPERIENCES

IF INTERNATIONAL ADULT WORKING GROUP SBH

Images

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STORIES AT A GLANCE

A collection of lived experiences reflecting different paths, perspectives, and realities of life with SBH.

Vanessa Caraveo
"Defying the odds together"

Theme: Community and peer support

Stijn Calders
"Working, adapting and breaking barriers"

Theme: Employment and professional life

Su Xiao Vin
"Finding strength in everyday life"

Theme: Mental health and wellbeing

Catherine Nakanyiga
"Rebuilding strength and redefining wholeness"

Theme: Resilience and strength

Gerry Maguire
"Beyond disability, towards potential"

Theme: Identity and self-acceptance

Kevin O'Donnell
"From silence to self-acceptance"

Theme: Mental health and belonging

Vanessa Caraveo

USA

Living with SBH:
Defying the odds together

> *While these conditions bring unique adversities, we also cultivate strength, adaptability, and perseverance.*

Vanessa Caraveo

Living with SBH:
Defying the odds together

My background

Birthdays are often full of fun and celebration, but given the immense odds those of us with Spina Bifida and Hydrocephalus (SBH) face from birth, they can also become moments of profound reflection and gratitude. Each year reached is a milestone truly worth cherishing. After all, many in our community were not expected to survive into adulthood.

When I was diagnosed with spina bifida shortly after birth, the prognosis was grim. The doctor told my mother that I might never walk, likely would not survive past adolescence, and could face significant learning disabilities. Being born into a low-income, single-parent household with limited resources added further challenges from the very beginning. It was a difficult starting point, yet I chose not to define my life by those limitations.

Defying expectations

With a strong foundation of faith and my mother's unwavering support, I was fortunate to overcome many of those early expectations. Despite the bleak prognosis, I began walking at ten months old and lived well beyond adolescence. Although spina bifida often meant a demanding medical schedule and multiple surgeries throughout my school years, I remained committed to my education, graduating from high school early at sixteen and later completing college with honours.

Walking across that graduation stage was more than an academic achievement. It was a deeply emotional moment that defied the assumptions placed on my future and reminded me that these challenges did not have to define what I could accomplish.

That perspective shaped the way my mother and I approached every obstacle. In the face of surgeries and ongoing treatments, we chose to focus on what was possible rather than what was predicted. The simple fact of still being here today remains something I am deeply grateful for and never take for granted.

From lived experience to advocacy

My journey has shown me that medical predictions do not determine a person's future. Living into adulthood with spina bifida brings both purpose and responsibility, especially when it comes to helping create a better world for others facing similar challenges.

One way I contribute to this change is through mentoring younger generations via initiatives with the International Federation for Spina Bifida and Hydrocephalus. By sharing lived experiences and offering guidance on daily life, employment, and independence, we help others see that fulfilling and independent lives are possible. These exchanges also ensure that the progress achieved today becomes a foundation for future generations.

Addressing the gaps in adult care

Advocacy is equally important, particularly in securing the care, accessibility, and long-term support that adults with SBH need. By joining our voices, we can help raise awareness of the barriers that still exist within healthcare systems.

While medical advancements have significantly increased life expectancy for adults with SBH, the availability of specialised, long-term care has not kept pace. This gap contributes to poor health outcomes, increased hospitalisations, and a lack of structured, age-appropriate care. As more people with SBH live well beyond adolescence, it is essential to recognise this new reality: adults with SBH are not only surviving, but increasingly thriving.

Efforts to help address these gaps have included collaboration with organisations such as the Spina Bifida Association of America (SBAA). By sharing my story with congressional offices, I contributed to advocacy that helped secure increased federal funding for the National Spina Bifida Program. In addition, the SBAA has launched several initiatives specifically focused on improving support for adults living with SBH.

Building community and collective strength

As these issues affect people globally, partnerships with IF help foster a supportive international network and drive meaningful change across diverse communities. This work spans local and global levels, empowering individuals to create lasting impact.

Engagement with mission-driven organisations has fueled my commitment to advancing health equity and systemic reform, while also building meaningful connections. Meeting members of the SBH community who share similar lived experiences offers invaluable support rooted in collective wisdom, encouragement, and solidarity. The scars on our lower backs are a shared legacy that unites many of us across the world and reminds us of the resilience we carry.

Belonging to this community is transformative, turning individual struggles into collective empowerment. These spaces help people grow, thrive, and recognize their potential. While this journey is not one any of us would have chosen, the fortitude developed through it can shape purposeful, compassionate, and determined individuals.

Looking ahead: a message to others

To younger and future generations living with SBH: having walked this path myself, I know that while these conditions bring unique adversities, we also cultivate strength, adaptability, and perseverance. Every surgery, setback, and challenge builds a foundation of discipline and self-advocacy that carries into adulthood, teaching us how to communicate our needs and navigate complex systems with confidence.

I encourage you to embrace your voice and connect with the SBH community to foster belonging and lasting impact. Your circumstances do not define your potential. As you transform barriers into personal breakthroughs, you rewrite what is possible and make each milestone a true testament to your growth. Celebrate your journey with pride, knowing that support, guidance, and inspiration can always be found within the SBH community.

Together, we will continue defying the odds.

Stijn Calders

Belgium

Living with SBH: **Working, adapting and breaking barriers**

> *Explaining individual needs helps create better opportunities and makes working life more sustainable.*

Stijn Calders

Living with SBH: **Working, adapting and breaking barriers**

My background

I was born in Belgium in 1981 with spina bifida. From an early age, I realized that many things in daily life would take more effort than for many of my peers. Still, my parents encouraged me to study, work, travel, and live as independently as possible.

As a child, I was fascinated by astronomy and space. When the first Belgian astronaut, Dirk Frimout, travelled into space in 1992, it made a strong impression on me. Later, I studied electronics engineering and started working in space research.

When I began studying at college, I decided to obtain my driving licence. This reduced the time and energy needed for commuting and helped me continue my studies successfully. Experiences like this taught me early that practical adjustments can make education and employment more sustainable.

Today I work full time. This is possible mainly because my work is intellectual and because I have a high level of independence in organizing my tasks. At the same time, this type of working environment is not accessible to everyone with SBH. People in more physically demanding or less flexible jobs often face additional barriers, which highlights the importance of inclusive employment policies across all sectors.

For many people with SBH, the combination of physical limitations, inaccessible workplaces, and inflexible employers makes employment much harder to access and sustain, regardless of motivation or ability.

Living and ageing with SBH

When I was younger, I tried as much as possible to hide the impact of my disability. I wanted to do the same things as everyone else and avoid drawing attention to SBH.

This approach helped me complete my studies and start my career. But over time, it became clear that working long term with SBH requires more than personal effort. It also requires understanding from employers and colleagues, and a work environment that allows flexibility.

Ageing with SBH means learning how to manage energy, health, and expectations over time. For example, on the days when commuting for work is required, there is significantly less energy left by the end of the day. Since the COVID-19 pandemic, more flexible working arrangements, including working from home several days per week, have become widely accepted. This flexibility makes it much easier to continue working full time in a sustainable way and shows how small organisational changes can remove important barriers for employees with disabilities without affecting productivity.

Challenges and adaptation

Living with SBH means that many daily activities require extra planning and effort. During studies, this meant organizing work carefully and persisting even when things are more difficult.

Many workplaces are designed for people without physical limitations. This can make full participation harder, even when someone is highly motivated and capable. For many years, I tried to manage these difficulties on my own. I preferred not to ask for adjustments and tried to adapt quietly. Later, it became clear that this approach is not always sustainable.

Learning to explain what I need at work was an important step. For example, when your job sometimes requires travelling abroad. This includes asking colleagues for support with practical aspects, such as carrying luggage during work travel. Small forms of support like this make it possible to participate fully in international collaboration.

What I have learned over time

Ageing with SBH has also brought important strengths. One of these is persistence. **Living with a lifelong condition teaches you how to continue even when things are not easy.** This is a useful skill in both research and everyday life. Another strength is self-knowledge. There is now a clearer understanding of what I can do, what costs extra energy, and what helps me continue working in a sustainable way.

My view on disability has also changed. When I was younger, I mainly tried to hide its impact. Today I see that talking about disability is important. It helps create understanding and makes it easier to remove barriers in employment. Advocacy has therefore become more important to me, especially in a professional context.

Because of this growing awareness of the importance of advocacy, there is now active involvement in the “gender & diversity” working group at my workplace. Each year, we work on improving accessibility for employees with disabilities in at least one concrete way. Contributing to these improvements is important, as it helps make the workplace more inclusive not only on an individual level but also for others.

Looking ahead: a message to others

Education and employment are possible for many people with SBH, but opportunities differ from person to person. Not everyone can follow the same path. This makes it even more important that workplaces are flexible and accessible at all levels of employment.

It is natural to try to fit in and minimize differences, especially at a younger age. This is a common experience. Over time, however, explaining individual needs helps create better opportunities and makes working life more sustainable. At the same time, inclusion in employment should not depend only on individual effort. Employers and policymakers also have a responsibility to remove barriers.

By removing barriers in employment, people with SBH can participate fully in society and build sustainable careers over the long term.

Su Xiao Vin

Malaysia

Living with SBH: **Finding strength in everyday life**

> You do not need to become someone else to live fully, you just need to learn how to live as yourself.

Su Xiao Vin

Living with SBH: **Finding strength in everyday life**

My background

Although I'm the eldest of 3 siblings, I'm naturally reserved, preferring to observe and listen to the world around me. I am most at ease moving quietly, often choosing to step back rather than seek attention.

Beyond my professional role as a pharmacist in the local civil service, I am deeply committed to serving the community through various ministries in church. For over a decade, I have been involved in children's ministry, while also supporting the sick through hospital visitations and helping to welcome church attendees. In addition, I lead a small group for working adults and a local support group for individuals with spina bifida.

Growing up, much of my energy was spent adapting, learning how to get through each day, managing pain, instability and a body that did not always cooperate. Movement and physical activity felt distant, belonging to bodies that seemed more predictable and easier to manage than my own.

Learning to move differently and rebuilding trust

In my late thirties, a shift began to take shape. I realised that if I wanted to preserve my mobility, independence, and sense of self, I needed to learn to work with my body, rather than simply around it. This realization, however, came with its fears, uncertainty about stiffness and imbalance, doubts about physical capacity and concern about how I might be perceived in new environments.

Swimming became a turning point. In the water, for the first time, there was less focus on limitation. It became possible simply to move, breathe, and exist without constant negotiation with my body. This experience gave me the confidence to explore something new: Pilates. Initially, it was intimidating. The focus on controlled movement, precise alignment, and core strength made me more aware of how differently my body responded. Yet, with persistence, attention to my limits, and the support of understanding instructors, I continued.

Over time, my perspective shifted. This journey was never about perfection. It became about showing up for my body in a way that had not been possible before. Building strength, cultivating trust and discovering that I could move, learn and take up space in environments I had once assumed were not meant for me.

Living with daily challenges

For much of my life, I have understood my body in terms of its limits. From the outside, I may appear no different from any beginner. Yet internally, there is a constant process of calculation, what feels stable, what may cause strain and what signals my body is giving before discomfort turns into pain. At times, my efforts may be misinterpreted as a lack of initiative, when in reality, every movement and decision is guided by careful awareness and deliberate effort.

As my body changes with age, each new phase demands continuous learning and adjustment. This ongoing adaptation can take a significant emotional and mental toll. My days are shaped by constant planning, balancing hydration with self-catheterization schedules, anticipating access to clean and available restrooms and preparing for the possibility of unexpected leaks or soiling incidents. Managing these daily routines while balancing professional responsibilities, church ministry and family commitments requires constant planning and can often feel overwhelming.

Living in an environment where medical services and support are limited has meant navigating much of my condition through trial and error. Chronic abdominal cramps and persistent constipation have long been part of my reality and are particularly challenging during classes, social gatherings or travel. In addition, foot deformities contribute to frequent pain and back strain due to postural imbalance and an unsteady gait.

The need for multidisciplinary medical care is not always easily understood by colleagues or superiors. Limited accessibility within healthcare facilities further compounds the stress, especially when I must remain responsive to work responsibilities while attending medical appointments.

Amid these challenges, maintaining a positive outlook is essential. Choosing to see life through a lens of gratitude helps me preserve a sense of balance and resilience. The support of close church friends, my family and a handful of understanding colleagues brings light to the complexities of my daily journey.

Strength, identity, and adaptation over time

With age, confidence has become less about visibility and more about quiet consistency. The repeated choice to allow myself to be seen, step by step. Living with spina bifida does not diminish identity. Instead, it has shaped a deeper sense of patience, awareness and understanding.

There is a growing recognition that a voice does not need to be loud to be meaningful. It is not necessary to move at the pace of others to have value. Stepping forward is not about allowing authenticity to exist more openly. There is still ongoing learning in how to respond to the world. Some days call for calm expression and clarity. Other days require silence and energy preservation. Both responses are valid forms of adaptation.

What has shifted most is the sense of self. Worth is no longer measured against external expectations or assumptions. Understanding now comes from lived experience, not comparison. There is awareness of the effort behind what others may consider “ordinary”. There is also recognition of the resilience required to navigate environments that are not always accommodating.

In moments of discomfort or misunderstanding, there is a quiet reminder that external perceptions do not define identity.

Looking ahead: a message to others

You do not need to become someone else to live fully, you just need to learn how to live as yourself. Not everyone will understand what you are experiencing, especially when disability is not visible. Some assumptions will be inaccurate. These are reflections of limited understanding, not of your worth.

Do not let assumptions become your truth. Your experience is valid, and your way of living has value.

Catherine Nakanyiga

Uganda

Living with SBH: **Rebuilding strength and redefining wholeness**

> *Identity is not defined by what is taken away, but by what is built from what remains.*

Catherine Nakanyiga

Living with SBH: **Rebuilding strength and redefining wholeness**

My background

I am Catherine Nakanyiga, a 34-year-old woman living with Spina Bifida, and I have spent much of my life navigating challenges that began long before I could fully understand them. From childhood, my life was shaped by frequent hospital visits, strict routines and quiet, personal battles that often went unseen by others. While this condition affected me physically, it was the incontinence associated with it that drew the most attention from the outside world. In school, this became a source of stigma and ridicule. Classmates mocked me and although some teachers tried to help, they often lacked the tools to protect my dignity fully. Instead of being recognized for who I was and what I could become, I was reduced to a label, “the girl with problems”.

Despite this, I developed resilience early in life. Even without the language to describe it, I clung to small victories: succeeding academically, forming even a single meaningful friendship and finding brief moments of belonging. These moments became the foundation for my identity and strength.

Living and ageing with SBH

Today, I am a clinical psychologist working in a pediatric surgical hospital, where I support children and their families through some of the most difficult moments of their lives. My work is deeply informed by my own experiences, allowing me to connect with patients on a level that goes beyond professional training. I am also a mother to a healthy baby boy, a role that has brought profound joy and a renewed sense of purpose to my life.

For me, ageing has not represented decline, but transformation. As a child, I viewed my body as unpredictable and limiting. During adolescence, I became painfully aware of how others perceived me. However, with time came a shift in perspective. I began to see my body not as something broken, but as something that had endured and survived, carrying me through surgeries, infections, and countless challenges.

Challenges and adaptation

A defining moment came ten years ago when I developed gangrene, a severe and life-threatening condition. The infection spread rapidly and to save my life, doctors had to amputate my left leg. This loss was not only physical but also deeply emotional and psychological. I grieved not just the loss of a limb, but also the version of myself I had once imagined. It forced me to confront a profound sense of loss and re-evaluate my identity.

Throughout my life, I have faced multiple layers of challenges. The stigma surrounding incontinence left emotional scars, instilling a sense of shame that I later recognized was never mine to carry. Managing this condition required constant adaptation, both practically and emotionally. After amputation, I had to relearn fundamental aspects of daily life, such as how to move, balance and trust my body again. Yet beyond physical rehabilitation, the more difficult task was rebuilding a sense of self.

What I have learned over time

Over time, however, I gained perspective. I came to understand that loss did not diminish me; instead, it expanded my capacity for growth, awareness and compassion. I realised that identity is not defined by what is taken away, but by what is built from what remains.

Education played a key role in this journey. Studying psychology gave me the tools to better understand both myself and others, to process my experiences, and to transform pain into something meaningful. Instead of being defined by my struggles, I began to use them as a source of insight and connection.

In my work with children facing medical challenges, I bring not only professional expertise but also lived experience. When I sit with a frightened child or a worried parent, I offer more than reassurance. I offer understanding. My presence becomes a source of comfort because we share a similar path.

Motherhood introduced another dimension of growth. Becoming a parent while living with a disability came with doubts and external judgments, yet it also strengthened my confidence and sense of capability. Caring for my son has become one of my greatest sources of purpose.

With age, I have gained clarity about my worth. I no longer measure myself against societal expectations or ideals of perfection, but instead I embrace authenticity and self-acceptance. My confidence is quiet but steady, rooted in what I have lived through.

Gratitude has also become part of this perspective, not as a denial of hardship, but as an ability to recognise value alongside it.

Looking ahead: a message to others

My message to young people living with Spina Bifida or Hydrocephalus is one of hope and empowerment. Your journey may include moments of pain, exclusion, and self-doubt, but **your identity is not defined by your condition.**

Speaking up, seeking support and pursuing education can play an important role in navigating challenges. Education is a powerful tool not only for building a career but also for understanding yourself. Dreams should not be abandoned, even if the path looks different. **Different does not mean less**. Progress may take time, but it remains meaningful. My own life stands as evidence that it is possible to build a fulfilling, purposeful life despite adversity.

My story is one of resilience, dignity and transformation. I have learned that wholeness is not about physical completeness, but about identity, strength and the ability to keep moving forward. **What remains can always be rebuilt with courage, meaning and hope.**

Gerry Maguire

Ireland

Living with SBH: **Beyond disability, towards potential**

> *My parents saw my potential, not my disability and that changed the course of my life.*

Gerry Maguire

Living with SBH: **Beyond disability, towards potential**

My background

When I was born many decades ago, my parents were unaware that the child they were expecting would be born with spina bifida. At that time, prenatal screening was not available and the birth of a child with a disability often came as a complete surprise to families and medical professionals alike. When I was born, the medical staff realised that there was something amiss.

After giving my mother time to meet her newborn son, they explained that I would face many challenges throughout my life. They even suggested that her best course of action would be to focus on her other children rather than on me. While such advice seems shocking today, it reflected attitudes that were common at the time. Many parents received little encouragement to believe in the future of a child born with a serious disability and institutional care was often presented as the preferred option. Thankfully, my mother ignored their advice and was determined to focus on my potential rather than my disability and believed that I could grow into an independent adult, despite what the clinicians predicted.

Looking back, I like to think that together we proved many of those predictions wrong and that my achievements justified the faith she placed in me from the very beginning.

Defying expectations

Throughout my childhood and adolescence, my parents were repeatedly told what I would never achieve. They were told:

- I would not attend mainstream school: I did.
- I would receive minimal education: I wrote and published my own book.
- I would never find employment: I built a successful career.
- I would remain dependent on state services: I achieved an independent lifestyle.
- I would never drive a car: I learned to drive and maintain my independence.

I attended mainstream school, although support was often limited. I secured employment, developed an independent lifestyle and today own my own home. I also learned to drive, something that has been central to maintaining my independence throughout adult life. Many of these achievements would have seemed unimaginable to those who made predictions about my future at birth.

From 2016 to 2021 I was a special advisor to the Minister for Disabilities in the Irish Government not because of my disability but in spite of it. Following the end of that government, I successfully competed for the position of Chief Executive Officer of Spina Bifida Hydrocephalus Ireland.

Ageing with SBH: adapting to new challenges

Ageing with spina bifida can be very challenging. I often say that spina bifida is “the gift that keeps on giving”. Small issues can rapidly become large and minor irritations can sometimes become life-changing. As we grow older the independent lifestyle that you fought so hard to achieve can become more difficult to maintain. Over time, I have learned the importance of adapting rather than giving in to these challenges. My approach has been to face challenges directly and focus on practical solutions wherever possible. Small adaptations, assistive tools and creative problem-solving may not eliminate difficulties, but they can often make daily life more manageable and help preserve independence.

What I have learned over time

For many years, I spent a great deal of energy trying to minimise or camouflage my disability. Looking back, I realise that disability cannot truly be hidden, either physically or emotionally. Constantly trying to appear unaffected took a significant psychological toll and eventually contributed to unhealthy coping mechanisms, including alcohol misuse. While alcohol provided temporary relief, it came at a considerable personal cost.

One of the greatest lessons that age has brought me is the ability to see myself as a whole person rather than through the lens of disability alone. I have learned to see myself as Gerry first, not as "the disabled man". I see myself as valuable, as a good friend, a much loved member of family, as someone who has always worked hard and someone who can be relied upon in difficult times.

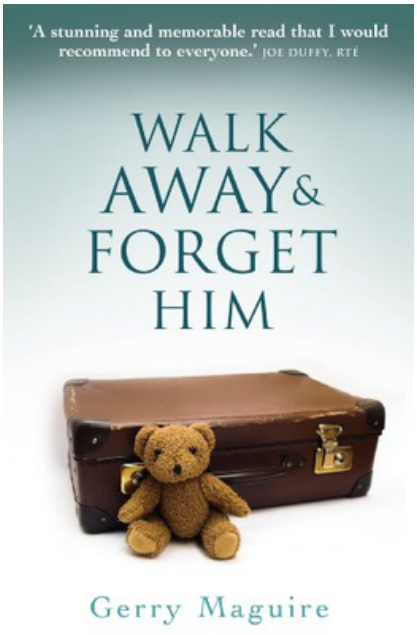
Looking ahead: a message to others

My message to younger people living with spina bifida and/or hydrocephalus is simple: **do not allow your disability to become your entire identity.** It is important to acknowledge the physical challenges that disability can bring, but it is equally important not to allow those challenges to define who you are. The psychological impact of disability is often overlooked, yet it can be just as significant as the physical impact. At times, my difficulty accepting disability led me towards unhealthy ways of coping, such as alcohol misuse, which ultimately taught me the importance of looking after both physical and mental wellbeing.

So if there was one strong message I, as an older person who has lived all of his life with a serious disability, would share, it is this: **take care of both your physical and psychological health.** Managing the physical aspects of disability is important, but so is recognising and addressing the emotional and psychological challenges that may accompany it. You do not have to love your disability or pretend that it is easy. What matters is not allowing it to define your entire sense of self. Disability may always be part of your life, but it does not have to dominate your future.

Each person's journey is unique.The strategies that helped me may not be the same ones that help someone else. What matters is finding the approaches, supports and coping mechanisms that work for you.

Life with SBH may be challenging, but it can also be fulfilling, meaningful, and full of possibilities.



Kevin O'Donnell

Scotland

Living with SBH: **From silence to self-acceptance**

> *The greatest challenges were not always physical, but the way I learned to see myself.*

Kevin O'Donnell

Living with SBH: **From silence to self-acceptance**

For much of my life, I believed that the most difficult part of living with spina bifida was the physical impact of the condition. As I grew older, however, I came to realise that the greatest challenges often lay elsewhere: in the way I saw myself and in the messages I received from others about what it meant to live with a disability. Looking back, I now understand how deeply stigma, exclusion and a sense of being different can affect mental health. My journey has taught me that building self-acceptance and finding community can be just as important as managing any physical condition.

My background

I was born with a myelomeningocele in 1962 and underwent surgery shortly after birth. Like many people with spina bifida born in the United Kingdom during that period, I was baptised in hospital because it was thought that we might not survive. I grew up in a small town near Edinburgh, Scotland. I didn't know anyone else with spina bifida or have any real understanding of what it actually was. However, I was always conscious of being 'different' and at school this led to bullying, something which I know now has lasting effects on our mental health. Certainly, I had low self-confidence and low self-esteem, which lasted well into my adult years. I also struggled because I missed a lot of school due to hospital stays; in my early teens I had a series of orthopaedic surgeries. This meant that I was always struggling to catch up and increased my sense of being different and at that age I viewed being different as something negative.

Turning point

A major turning point came when I went to university, which felt like an opportunity to start again. I never told anyone that I had spina bifida. I had internalised much of the stigma surrounding spina bifida and carried it as a form of shame; it was a secret that I did not want anyone else to know because I believed that they would then treat me badly. This belief wasn't something that I was conscious of but I now realise that it shaped my life and not in a good way.

Meeting the woman who became my wife was a real turning point for me, someone who accepted me as I was. I eventually left university with a PhD and worked as a scientist. I married and had a family of my own and didn't think much about spina bifida until I began to experience the physical decline that we now know is typical of ageing with spina bifida: pain, fatigue, loss of balance, declining mobility and more.

At the same time, I realised that I had become more interested in people than in plants and left science to retrain as a counsellor. This made me look again at spina bifida and the way it had affected my mental health and I decided to pursue this through doctoral research, interviewing other people with spina bifida about their own childhood experiences. I realised that other people had experiences similar to my own and with similar effects on their mental health.

Ageing with SBH

Spina bifida is a big part of my work as a counsellor; part of the week I work for Spina Bifida Hydrocephalus Scotland, which provides a counselling service to people with SBH. In that role, I draw not only on my professional counselling and psychotherapy training but also on my own lived experience. I understand the effect on our mental health of being made to feel that spina bifida means that you are not as good as everyone else. That can take a lot of time to unpick because some people have been made to feel like that for decades.

My passion is to help with that, not just as a counsellor but as an active part of the spina bifida community. For example, during my research I discovered that during the 1970s in the UK, babies born with spina bifida were, in some cases, denied treatment and effectively encouraged not to survive. That this happened without legal challenge undoubtedly contributed to the stigmatisation of spina bifida. I found that the UK professional body for paediatricians actually had an award in honour of the man who was the architect of this policy. I felt that this was an injustice that needed to be changed and that award has now been dropped.

What I have learned over time

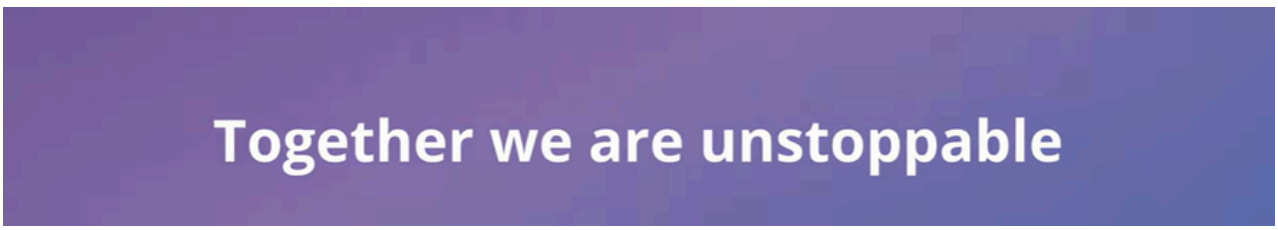
My view is that the most harmful effects of spina bifida do not always come from the physical impairments associated with the condition but from the impact on our mental health and the way society can make us feel about ourselves.

Counselling is one way of addressing this. Another is being part of a strong spina bifida community, united in the belief that we are just as valuable and capable as anyone else. I am hugely cheered and impressed by the attitude of the younger SBH generation. Many are growing up with a stronger sense of self-worth than my generation had. They have higher expectations of accessibility and inclusion, and they are confident enough to advocate for those rights. This gives me hope for the future and every day I try to be more like them!

Looking ahead: a message to others

My message to younger people living with SBH is to **remember that your wellbeing matters just as much as your physical health**. Seek support when you need it, connect with others who share similar experiences and do not underestimate the value of community.

Living with SBH may bring challenges, but it should never determine your worth. **Your voice matters, your experiences matter and you have every right to expect inclusion, respect, and opportunity.**



Acknowledgements

This publication brings together the lived experiences and personal journeys of adults from the global SBH community.

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- Spina Bifida and Hydrocephalus Association of Uganda (SHA-U)
- Spina Bifida and Hydrocephalus Ireland (SBHI)
- Spina Bifida Hydrocephalus Scotland (SBHS)

STORIES OF LIVED EXPERIENCES

IF INTERNATIONAL ADULT WORKING GROUP SBH

CONTACT DETAILS

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