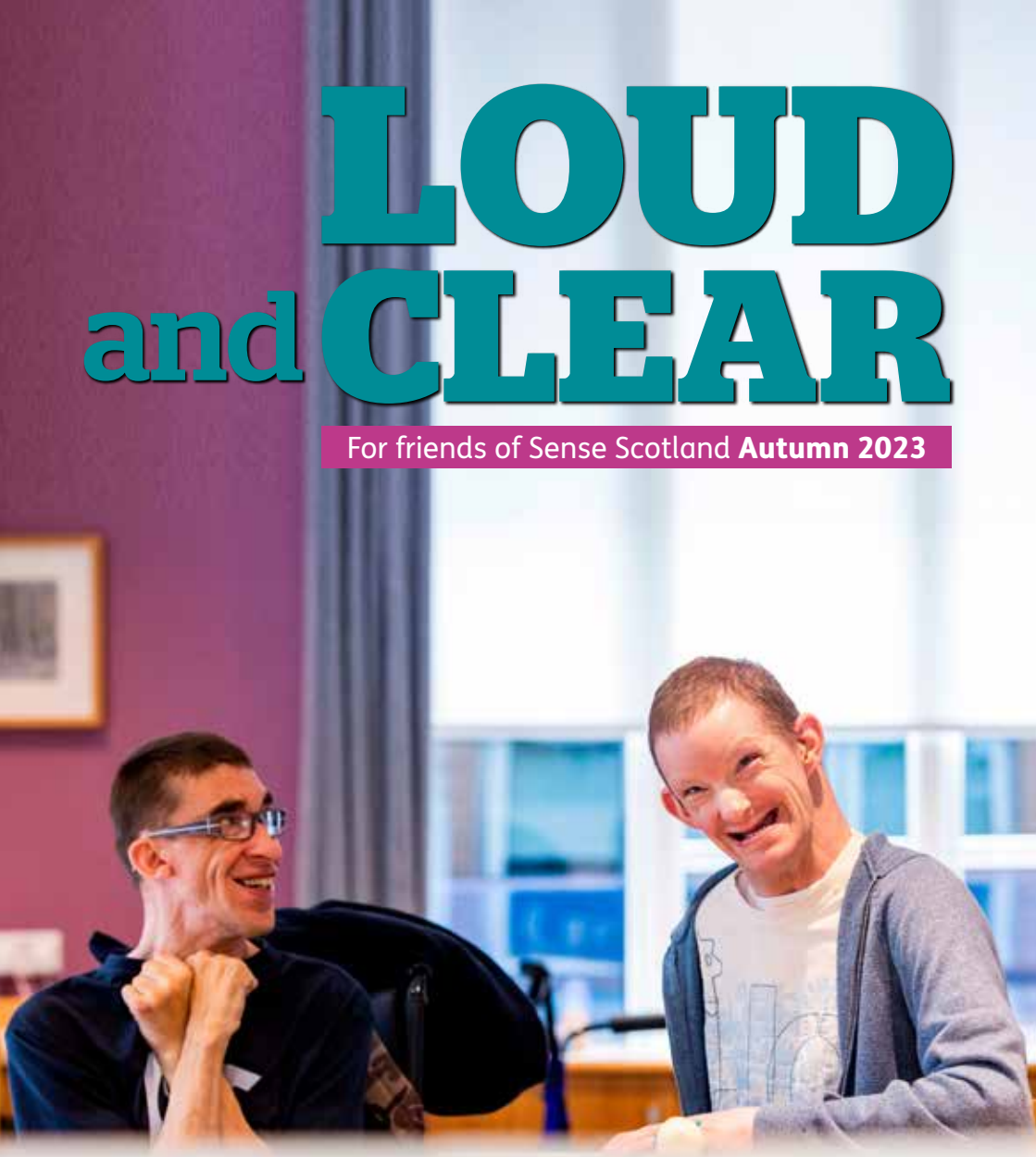
LOUD and CLEAR

For friends of Sense Scotland **Autumn 2023**



We care.
We connect.
We communicate.

LOUD and CLEAR

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Head Office:
Sense Scotland
TouchBase Glasgow
43 Middlesex Street
Glasgow, G41 1EE.

Tel: 0300 330 9292
www.sensescotland.org.uk

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sense Scotland

Sense Scotland is a Scottish charity and specialised care provider supporting people with communication support needs associated with complex and sensory disabilities, and their families, where individual needs and choices come first.

Sense Scotland now supports hundreds of families all across Scotland. We are recognised as leaders in our field and still hold true to our family values, caring for children through adolescence and into adulthood whilst supporting them through all the challenges and opportunities along the way

We provide registered care services to people with communication support needs associated with complex and sensory disabilities. Every service is tailor-made and designed with individual wishes, potential and independence in mind.

Your donations fund all the things that make Sense Scotland unique: music, art, social groups, play and communication sessions – fun, fun and more fun. But serious stuff too – making sure people we support are included in decisions which affect their life, are able to choose where they live and how they spend their time.

UPCOMING EVENTS

A NIGHT AT THE MUSEUM

Join us for our biggest fundraising event of the year on Friday 17 November at Kelvingrove Art Gallery and Museum. Tickets are £100 per person or a table of 10 for £950.

GINGHAM AND GLITZ

A fun night out at the world-renowned Grand Ole Opry in Glasgow on Sunday 28 January 2024. Saddle up for a toe tapping, line dancing, crazy night of country. Tickets only £25 and selling fast.

Breaking Point

Caring for a son or daughter with complex disabilities, healthcare and communication needs is exhausting - it can wear you down physically, mentally and financially. Being able to step away from the responsibility, for a few days or even hours, can quite literally be life-saving, but getting that break these days is increasingly difficult. **Many parents and carers are at breaking point.**

At Sense Scotland, we have provided residential respite at three locations for over 20 years, a critically important part of our service delivery: "hotels" for the people we support, where we offer safe, high-quality, personalised care, and fun! A break both for those who stay, and for their families at home, who can relax, secure in the knowledge that their loved one is in good hands, with people they trust.

The level of care and support needed to allow both the respite "guest" and their family to relax and fully benefit from the break requires committed, skilled staff available 24 hours/day and comfortable, fit-for-purpose accommodation. This costs money, and even more so at the moment as bills rise. Yet, despite increasing demand and the increasing cost of providing residential respite, funding from Scottish Government and local authorities has been slashed, and the hourly social care rate of pay (set by Scottish Government) is inadequate. **Our staff and services are at breaking point.**

But Sense Scotland is not alone. You may have seen and heard the ongoing media coverage of the struggles in social care: years of underfunding, false promises, an apparent disregard for some of the most vulnerable in our society, and a workforce who don't feel valued are all contributing factors to a precarious situation. Many providers are now withdrawing from residential respite provision, and families can afford fewer nights' stay at a reduced choice of facilities. **The social care sector is at breaking point.**

Despite the challenges, the good news is that I want Sense Scotland to be famous for respite, and for continuing to provide much-needed breaks for families and carers. And our Trustees agree; continued respite provision is a key objective within our new strategy, and we are already working with Scottish Government to find solutions to the difficulties we face.

I'm delighted to shine a spotlight on our respite services in this issue of Loud and Clear, and to tell you more about some of the fabulous people we support in them and their families. I hope you enjoy their stories and, after reading, agree with me about the importance of respite and share our ambition to be famous for it.

Your support and donations are appreciated more than ever at the moment. Thank you for helping us avoid breaking point.

Angela Bonomy,
Chief Executive Officer

Wish You Were Here?

The emotional and physical demands faced by parents and families who have a loved one with complex disabilities are significant. It's really important that they are able to take time out to focus on their own wellbeing to allow them to continue in their caring role - and that is why respite is so important.

At Sense Scotland we provide short break residential respite care in three locations – Dundee, Helensburgh and Blantyre.

Blantyre Short Breaks

Up to seven adults can enjoy a short break in this purpose-built home from home. Guests come from far and wide, but all have complex disabilities and healthcare needs which can't be met in traditional holiday accommodation. Staff go to great lengths to ensure that friendship groups are able to enjoy stays together, and to co-ordinate stays for guests who share similar interests so they can socialise together if that's what they choose.

Ardlui Respite House for Children and Young People, Helensburgh

Our Children's Respite Centre welcomes children and young people up to age 25. Five young people at a time can enjoy their own personalised holiday. For children coming from very rural areas or the islands, Helensburgh is full of exciting activities such as bowling, trampolining and the cinema. For children coming from more urban areas, activities including beachcombing, forest walks, picnics and den building are very popular.

Dundee Respite

Set in the heart of Dundee, this three bedroom bungalow was designed to accommodate adults who have learning disabilities and/or autism, complex communication needs and require positive behaviour support. All guests are referred via Dundee City Council, who commission the service in its entirety. In addition to enjoying activities and visits to places of interest, the service is also able to prepare people for independent living, helping them learn key skills like housework and cooking!

We care.

Defying the Odds

As a baby, Stuart was never expected to live. However, now 36, he was one of our first guests at Blantyre Short Breaks, aged 16, and has been enjoying 4–5 day stays on a regular basis.

From the moment Stuart was born, he was very poorly and constantly stopped breathing. Doctors in his Isle of Man hospital were flummoxed and he was sent to Alder Hey Children's Hospital in Liverpool. He had every test possible, but with no definite diagnosis.

Mum Lorraine and Dad Stuart soon realised that they needed additional family support to help them with Stuart and his older sisters Karynne and Michelle, so moved back to Scotland when Stuart was two. Over the years, Doctors and researchers from Yorkhill Children's Hospital genetics team studied and learned from Stuart, resulting in his many mentions in medical journals. However, it was not until he was 18 that he was finally diagnosed with the very rare Kabuki syndrome. Although not a life limiting disease, Kabuki syndrome has a range of health implications including cleft palate, intellectual disabilities and immune deficiencies. His many essential medications

are meticulously sorted out and dispensed daily by Dad.

When Stuart was 25 he suffered a massive heart attack and was extremely lucky to survive. However, he developed aspiration (when food enters the airway or lungs) and his mobility reduced drastically. He now needs a wheelchair when outside and is on a special diet. Stuart has no formal verbal language – he uses Makaton sign language and can speak a few words - but according to mum *"likes to babble like a child and thinks people can understand him"*. But when he does go quiet, this is often an indicator that he is experiencing pain.

Despite his challenges, Mum Lorraine describes him as the happiest person she has ever known – *"he is never in a bad mood, never shows a temper and is the type of boy you can take anywhere - he always behaves."*

Both parents are now retired and full-time carers at home for Stuart. During COVID he was classed as medically vulnerable and so the whole family endured additional restrictions and felt very isolated. Now that Stuart is able to attend services again, Mum and Dad are able to get some respite from their caring roles.

Lorraine explains *"Respite is extremely important to us, especially as we are getting older. We get 28 days a year and are grateful for that.*

It gives us the opportunity to go out for dinner, go on holiday and, most importantly, spend time with our daughters and grandchildren. Just to be able to do normal things without having to be home for 3pm, when Stuart comes home. Having his day centre and respite certainly helps make life easier. There is not a lot of help nowadays for disabled people and it is worse since Covid."

Stuart loves his respite visits at Blantyre Short Breaks and all the outings they take him on. *"It's very important for him as it's a holiday with people he knows and who care for him. It's a happy atmosphere and the staff are exceptional. I walk away knowing he is secure and well cared for."*

So what does the future hold for Stuart and family life? Lorraine's response is typical of many parents: *"As long as I can keep going and be at home, Stuart will be at home! I'm not ready for him to go anywhere. I can't think into the future. I'll keep going as long as possible."*

Home from Home

Stuart's stay at Blantyre Short Breaks

MONDAY

Mum and Dad dropped me off. Heather made me a cup of tea and gave me a bit of swiss roll whilst I watched to see who else was staying. It was Fergus' first time so I made him feel very welcome and let him hold my baby dinosaur egg. I chatted to the staff, most of whom I knew, and stayed up late to see who was on night shift.

TUESDAY

Woke up nice and early as I didn't want to miss anything! Went on the bus with my new friend Fergus as well as Niamh, Stuart, and Craig to Cloybank Fishery. Didn't fish but did see goats, alpacas, turkeys and highland cows which I loved. Was quite tired but still managed to stay up late and chat to the night staff.

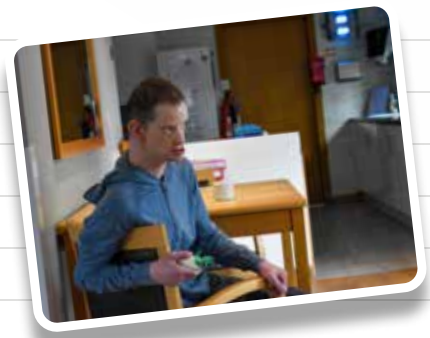
WEDNESDAY

Up early again. After breakfast I built a jigsaw. Went to the Blantyre Miners Welfare Club for lunch with Niamh, Jamie and Sharon and had lasagne. Later I had a few cups of tea and my favourite Barney biscuits whilst people watching from my usual spot in the kitchen. Kept an eye on the night shift for a while to make sure they were doing their work properly, before heading for bed.

THURSDAY

Another early rise to see what was going on. Was a good day watching what everyone else was up to in the house and outside in the garden. Mel was showing me her artwork and I enjoyed watching Craig playing ball with Martin. I love being part of the group but don't usually join in. It's more fun to watch. Thursday night is always take-away night so tonight I had chicken curry and rice.

I've had a great stay but am ready to go home in the morning so early to bed for a wee change.



A Vital Break

By Kathryn, Mum of Greg, Lewis and Niall

Greg is 29 years old and has a genetic condition called Tuberous Sclerosis, first diagnosed when he was 10 weeks old, when he took his first tonic colonic seizure. He has many small, non-cancerous tumours on various organs, mainly his brain and kidneys. These have resulted in him having difficult-to-control epilepsy, a profound learning disability, visual impairments, no speech and some challenging behaviour. It sounds a lot and we have had some moments over the years, but at other times, he is a lovely, smiley young man.

Caring for Greg is a full time, tiring occupation. Greg needs all aspects of personal and medical care carried out. We are always on alert watching for seizures, which, in some form, happen daily. He takes night seizures as well and wakens frequently. He likes to throw things and loves a loud crash. He eats anything which has been left lying, so we have very tidy work surfaces! For someone with no speech he can be very loud and dominates at home.

Greg has two older brothers – Niall and Lewis (who has autism and a learning disability). The combination of trying to find time for the older two and tiredness were the main

reasons we asked for respite. It's also the only way we can do certain things. As a family, we view respite as a vital tool which helps us to carry on our caring roles.

Blantyre Short Breaks has been our lifeline for over 10 years. It is a safe, fun place for Greg to spend time away from us, and for us to recharge our batteries. It has allowed us to sleep, go to the cinema, have quiet, calm meals out without worry of upsetting other diners, visit our middle son, go on holiday or to social occasions, get a new kitchen fitted - all things which to many are normal. We can't be spontaneous - everything needs to be planned well in advance.

Greg appears to cope well with staying - he goes in willingly, which is a good sign. Greg knows the staff and they know him and his ways - ie they know to clear the surfaces and not leave breakables! He is looked after well, has plenty to eat and takes part in activities and outings. Greg always has disturbed sleep, probably related to his seizures, and likes to wander at night. However, waking night shift staff are employed and so he is well supervised and regularly checked in on.

As a carer, I think you always worry about leaving your loved one with others and think no one can look

after them the way you do. I always still feel very guilty every time I leave him. However, at times, when he's been really difficult and challenging, I just focus on getting through each day until respite starts. Once he's gone, it's a real mix of emotions - but I can relax and recharge. His brother Lewis doesn't miss him!

We don't get any respite support for Lewis. We were never offered it and Lewis's autistic anxiety is so severe we can't even consider it even if we had the budget. And after Covid, it was a total shock when Greg's respite budget was severely cut without warning. We felt very unsupported and penalised by Social Work. Hearing from other carers, unfortunately, we are not alone.

Changing Lives in Malawi

Our project in Malawi, funded by the Scottish Government, challenges stigma and discrimination against disabled children and ensures they are able to access education.

Karen Goodman-Jones, Project Co-ordinator, has recently returned from Malawi and sent this report:

What an amazing but exhausting visit! Over the last 5 years, the team, led by The Church of Central Africa Presbyterian, have engaged with almost 40,000 people – children with disabilities, their siblings, teachers, parents and community leaders. And behind these staggering numbers, are individuals whose lives have changed forever.

I met Daniel, who has a visual impairment and struggled to learn at school. However, after his teacher received training on how to recognise and support learners with additional needs, he was moved to the front of the class, and his educational experience was transformed! Supported by his peers, he not only passed his Primary Certificate of Education but was then one of the few selected to attend Secondary School. Daniel's goal is to now become a teacher himself.

I met so many amazing Peer Educators - children with and without additional needs - who are taught about everyone's right to an education. They raise issues with teachers and support other children not only to learn, but also to get to school every day. Schools are now more inclusive - bullying and drop-out rates amongst learners with additional needs has reduced, whilst their confidence has grown and, all importantly, they have friends.

I met Agnes whose son Wilson has additional needs. She kept him at home, where he had no friends. After learning about the project and meeting teachers and other parents, she finally sent Wilson to school. She said *"He's changed. He's playing football with friends. He couldn't speak before, and now says "Mama". It makes me so happy."*

I met parents who openly admitted that they originally didn't like the idea of all children (with and without additional needs) learning together, but now they are very happy with it.

I met parents who have come together to form Parent Support Groups. They raise funds to support the educational needs of any child who is vulnerable; has additional needs; is orphaned; or just temporarily struggling. The funding purchases essential items such as uniforms, books, pens and bags.

I met parents at Mlale Primary School in Karonga, who had big dreams for inclusive education. They initiated a huge community fundraising effort to construct new, disability-friendly latrine blocks to ensure that all children who attend school can do so with dignity.

I met enterprising parents who funded the construction of two concrete blackboards as well as purchasing books and uniforms for children at the Lwakwa Primary School in Chitipa, by growing soya beans and raising goats and chickens for sale.

The people of Malawi showed their gratitude for our support by bestowing on me the great honour of a gift of a chicken. In return, I left behind a little bit of Scotland – author Forrest Wilson kindly donated signed copies of his iconic SuperGran book which will take pride of place in the newly-built Karonga School for the Deaf library.

Lives have been changed forever and I have no doubt that the impact of our project will continue for many generations to come.

Behind the Scenes at our TouchBases

We were delighted to welcome supporters to a VIP Tour of our TouchBase Glasgow and Lanarkshire centres earlier this year.

Guests were able to meet staff and people we support, take part in fun storytelling, music and art activities, ask lots of questions and see for themselves the difference their donations make.

We also have TouchBases in Ardrossan, Bishopbriggs and Kirkcaldy and plan to host similar events throughout the year.

"The young man who presented his artwork was a highlight. As was music."

"I really enjoyed my visit. The facilities are wonderful and the staff were all so friendly and enthusiastic".

"It is great to know that my small donations help to provide such a great facility and service for the people who attend."

If you are interested in coming along, please contact the Fundraising Team.

Tel: **0300 330 9292**

Email: **fundraising@sensescotland.org.uk**

Making a Difference

During the month of June we welcomed the absolutely amazing, hands-on support of 133 volunteers from financial institutions Barclays and Morgan Stanley.

IT experts, accountants and human resource professionals gladly stepped away from their desks to help out at our Bellahouston allotment, TouchBase Glasgow Children's Service, TouchBase Dunbartonshire and Ardlui Children's Respite Centre gardens. Over eight days, they painted, sanded, scrubbed, weeded, trimmed, mowed, cut and planted till their fingers were sore, pink, blue, dirty and/or green.

In addition to our volunteers, we also received fantastic support from local businesses – Mather Hire of Helensburgh provided lawnmowers and strimmers, whilst Crown Decorating Centre in Glasgow provided paint.

Susie Stevenson from Morgan Stanley shared *"The feedback from the volunteers has been very positive and they have really appreciated the chance to support such a brilliant charity and see first-hand all the work that goes on behind the scenes to help deliver such an invaluable service to the local community."*

Rhona Smith from Barclays said, *"all of the volunteers had such an amazing experience at TouchBase Dunbartonshire. Supporting the revamp of the garden in time for their Summer Fayre and seeing the transformation unfold was just incredible."*

Could you volunteer?

Whether it's a few hours a week or just when needed, we have lots of opportunities for volunteering!

- In our charity shops helping sort items and on the shop floor
- At our respite centres, as a minibus driver
- With our Children's Services, helping children have fun
- In our Group Services, bringing your skills and knowledge
- Keeping our outdoor spaces looking blooming lovely!

To find out more contact the Fundraising team: 0300 330 9292 or email fundraising@sensescotland.org.uk

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