

Anya is the face of the new CHAS appeal

Four year-old Anya Behl from Edinburgh is the face of the new Children's Hospices Across Scotland (CHAS) appeal.

The wee girl and her family have been shielding since the pandemic began, with some support from CHAS during the last 16 months.

Anya needs round the clock care from her parents Abhishek and Katherine. The family has been able to take emergency respite stays in Rachel House hospice in Kinross, with regular assistance from CHAS family support services and frequent visits from CHAS at Home's nursing support workers.



The Behl Family

Katherine says: "Early on in Lockdown, our support network had stopped due to Covid and we were beginning to struggle, so we got help from CHAS at Home. We're lucky to have them. We

didn't want anyone coming in at first, then realised that the team would be wearing full protection, taking every precaution and it would be a huge help. We get a rest, a good natter with other adults and Anya has really thrived from seeing people.

"CHAS at Home come very early morning and take over, to give Anya her meds, breakfast, get her outside for fresh air and have a play. It gives us an opportunity to catch up on sleep. Anya's condition makes her vulnerable but we have seen some cognitive developmental leaps. Try as we might to teach her, it's the CHAS at Home team who have her memorising new nursery rhymes! They've really got to know her and they've become a big part of helping us in this journey.

"CHAS at Home came to us so that they could understand her condition more closely and built us up to our first stay there. They were the ones who suggested that Rachel House might be right for what we were going through. Amanda and Julie timed it so that they could be there to welcome Anya to Rachel House, to get her used to the place. She relaxed straight away and took to everyone else because she knew they'd be Amanda and Julie's friends.

"Amanda taught Anya "the girls on the bus go kiss, kiss, kiss." Anya's eyes light up when she sees her. It's lovely to see. Amanda obviously has all these years of experience, so the connection she was able to make was immediate. They've been a great help, not just to Anya, but to us too.

"Come May last year, Anya's symptoms were worsening and we were a bit broken with fatigue, so we brought her into Rachel House because it is controlled, safe and they have "zones" that families can live in safely. We needed somewhere to go and knew that the right place would be Rachel House because they could manage her symptoms and give us the break.

"It was far less scary than we thought it was going to be. We didn't think we would have much living space and that social

contact would be impossible, but it was the perfect setup for Anya. We get use of the quiet room while Anya is able to play in the snoezelen sensory room, have access to the garden and there's a lovely bedroom full of toys.

"Having one to one care from staff is also wonderful. Sure, things have changed a little but it's not this maze of rules we had feared. The care, the rest and the food are all the same. The cleaners, the chef, the doctors, nurses, family support – they've all been brilliant. They link up with the community health team at the hospital too, so Anya's care is all joined up.

"There's only so much you can do when you're shielding, if you haven't got the support. Having this homely environment where everything can be kept safe means the world."



Anya Behl (4)

Anya has a one-in-a-million condition called alternating hemiplegia of childhood (AHC). This causes a neurological complication causing numbness or full loss of feeling or

movement. AHC can result in whole body paralysis which lasts for weeks at a time. Triggers include heat and dehydration to pain and lack of sustenance, and the condition can mean that Anya stops breathing as her neurological system shuts down. This requires being ventilated in ITU which has happened six times already.

CHAS is the only charity in Scotland that provides hospice services for babies, children and young people with life-shortening conditions. The national charity offers palliative care and respite for the whole family via its two hospices, Rachel House in Kinross and Robin House in Balloch. The CHAS at Home service supports families in their own homes across the whole of Scotland and has teams working in communities and hospitals across the country.

Like many other charities left reeling from the COVID-19 pandemic, CHAS has had to dramatically transform the way in which it provides its increasingly important services. They have set up Scotland's first ever virtual hospice to support children and families who are having to completely self-isolate.

The virtual hospice has now been operational for a year, offering families extensive assistance, whether it relates to clinical guidance, financial advice or bereavement support, by video and phone. CHAS family support teams are also offering an expanding range of interactive activities, art clubs, storytelling and conference calls to children and parents, with more in the pipeline.

Although safeguarding is very much in place as lockdown measures continue to ease, children needing urgent physical and end of life care are welcomed at both Rachel and Robin House, where staff continue to work tirelessly to provide palliative assistance to them and their families in a comfortable environment.

Iain McAndrew, Director of Fundraising and Communications at CHAS, said: "Over the last year, our supporters have stood by CHAS families giving them strength and showing love in what has been an incredibly tough time for all. It's certainly not been an easy journey but without that support, and our amazing staff and volunteers, we simply could not have continued to evolve and adapt our services, helping those in greatest need. CHAS was a lifeline for so many.

"Our summer campaign is continuing our ask from Christmas 2020 – that everyone who can, supports Scotland's most vulnerable children and helps us keep the joy alive even in the face of death."

www.chas.org.uk