



# Take a Break

*Scotland's Short Break Fund for disabled children, young people and their families*

## Outcome Report 2019/20



Administered by:



## Introduction

Take a Break is part of a Short Breaks Fund programme, funded by Scottish Government. It was set up, and has been subsequently administered, by Family Fund since 2011/12. Family Fund has over 47 years' experience in providing grants and services to families raising disabled or seriously ill children and young people across the UK. Other elements of Scottish Governments Short Breaks Fund are operated by Shared Care Scotland. These programmes provide grants to third sector organisations to support carers access short breaks.

This report provides a review and analysis of the Take a Break programme for 2019/20. It presents the performance of the programme against aims set for Take a Break and its alignment with the aims of Getting it Right for Every Child (GIRFEC). The report covers:

- Aims, outcomes and indicators
- 2019/20 performance
- Family-wide outcomes
- Added value
- Summary of 2019/20
- Take a Break next steps
- Family stories.



## Aims, outcomes and indicators

Take a Break aims to support carers, including kinship carers, and their families to take a break. Grants enable families caring for disabled or seriously ill children or young people to have the opportunity to choose how they would like to take that break, with a view to improving the quality of life, health and wellbeing of the whole family.

The programme supports the achievement of Scottish Government's strategic Health & Wellbeing outcome through targeted grant support: "People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing".

The agreed outcomes and indicators for Take a Break in 2019/20 were:

Outcome 1 Families and carers of disabled children are supported to have the same opportunities as other families to take a break and spend time together.	
Indicator and Target	Achieved
70% of carers report that the grant enabled them and their families to take a break they would not have otherwise been able to take.	78%
70% of carers report they had been able spend quality time together as a family.	90%
90% of carers report they were able to tailor their break to their needs.	98%
750 applications gathered from carers who have not received support from Take a Break Scotland before.	1,030
Provide information to professionals and carers during four promotional events prior to the end of the application window.	✓



**Outcome 2 Families and carers of disabled children are aware of the variety of short breaks available, providing them with choice and control over their breaks.**

Indicator and Target	Achieved
Access to information about the type of short breaks available in Scotland provided to 100% of carers as part of the application process. Examples of short breaks taken by other families caring for disabled children and young people made available to all on the Take a Break website.	✓
90% of carers report they were able to tailor their break to their needs.	98%
90% of carers report experiencing a positive impact as a result of receiving a Take a Break grant.	100%
Eight case studies completed evidencing variety of short breaks experienced using Take a Break grants, to share ideas with new applicants.	8

**Outcome 3 Families and carers of disabled children can undertake a short break which meets their personal outcomes, improving the quality of life, health and wellbeing of the whole family.**

Indicator and Target	Achieved
70% of carers report that the grant enabled them and their families to take a break they would not have otherwise been able to take.	78%
90% of carers report experiencing a positive impact as a result of receiving a Take a Break grant.	100%
90% of carers report a positive impact for their disabled child or young person in line with GIRFEC approach to wellbeing.	98%
750 applications gathered from carers who have not received support from Take a Break Scotland before.	1,030

**Outcome 4 Families and carers of disabled children from all across Scotland will benefit from a short break and support with their caring role, and in particular new families and carers.**

Indicator and Target	Achieved
2,000 grants provided to carers of disabled children across Scotland.	2,156
750 applications gathered from carers who have not received support from Take a Break Scotland before.	1,030
Provide information to professionals and carers during four promotional events prior to the end of the application window.	✓

## 2019/20 performance

A total of 2,156 grants were provided to help parents/carers and their families through Take a Break in 2019/20. This is the highest number of grants made in one year since the scheme started in 2011. Application numbers were higher than last year, at 3,150 compared to 2,834. The number of grants to first time applicants increased from 708 last year to 726.

### Applications received

Total applications	3,150
First time applications	1,030
Online applications	2,825

### Grants made to carers

Total grants	2,156
First time applications	726
Average grant value	£273
Total grant spend	£587,780



The highest number of applications received were from carers raising an eligible child aged between 6-10 years old, followed closely by carers raising an eligible young person aged 11-15 years old, which is similar to previous years.

Out of the 2,156 carers helped, 108 were raising more than one child eligible for a grant.

### Age of child

Age at application	No of children
0 to 5	274
6 to 10	845
11 to 15	749
16	92
17	101
18+	184





## Most prevalent conditions

Autism Spectrum Condition has been the most prevalent condition in a child or young person from applications received over the past three years.

The full list of conditions reported on Take a Break application forms can be found at Appendix A.

Condition	2019/20
Autism Spectrum Condition	938
Learning disabilities	336
Mental health condition	120
Facial or skeletal	79
Cerebral palsy	77
Communication/hearing	69
Named syndrome	64
Down's syndrome	60
Behaviour disorders	56
Undiagnosed condition	48



## What did carers need the most?

The short break support that carers need is consistent with the position in previous years, with a family break away remaining by far the most popular request and days out being the second most popular.

1	1,937 breaks away
2	132 days out
3	40 bikes, sports equipment and activities
4	32 supporting a break at home
5	14 clubs and activities

**132** Days Trips

**40** Bikes, sports equipment and activities

Supporting a Break at home **32**

Break away

**1,937**



## Reach to carers

Take a Break has a large reach to carers of disabled or seriously ill children or young people across Scotland through dual promotional activities with Family Fund.

Family Fund's network of relationships across the voluntary and statutory sectors supports the delivery of Take a Break, and are developed and nurtured on an ongoing basis. Throughout 2019, the following promotional activity took place:

- Targeted social media promotion across the Highlands and Islands, including those within Comhairlie nan Eilean Siar.
- Promotion via existing networks such as the Scottish Children and Young People's Palliative Care Network and Scottish Transitions Forum.
- We attended Fraserburgh school's cluster parent engagement events, and the National Managed Clinical Network (NMCN) for Children with Exceptional Healthcare Needs conference.
- Meetings with professionals and organisations such as the East Renfrewshire Social Work Request for Assistance Team, Dumfries & Galloway Community Children's Nursing Team and Fife Tourette's Scotland Group.
- Contact with a wider range of organisations including: Comhairlie nan Eilean Siar Family Support Service, PLUS Forth Valley, National Deaf Children's Society Family Support Service, Fife Health & Social Care Partnership, Dunoon Grammar School, Care & Learning Alliance Highland and North Ayrshire Branch National Autistic Society.
- Family Fund hosted Information Days in Aberdeen, Motherwell (in partnership with North Lanarkshire Council Community Learning & Development) and Glasgow (in partnership with the Office for Rare Conditions) where families and participating support organisations were informed about Take a Break.
- Our digital channels had a reach of 23,241, with 15,164 visitors to the Take a Break website, from 1 May to 31 August 2019, and 8,077 followers across our social channels. This is a 42% increase in digital reach compared to the equivalent period in 2018.

*"I couldn't really take part in many activities as I get very tired very easily since my heart attack, but it's great to meet up with the rest of my family and seeing our boys having such a blast. We're so thankful for the opportunity to have had a good time and bond as a family."*





## Joint work with Shared Care Scotland

Through joint work with Shared Care Scotland, geographical areas were identified that required targeted activity. Between the two organisations, promotional activity was focused in Lanarkshire (North & South), Comhairle nan Eilean Siar, Dumfries and Galloway, and Fife.

This promotional activity proved effective with:

- over 100 more grants awarded in North and South Lanarkshire than in 2018
- over 50% growth in grant activity in Dumfries and Galloway
- 9% growth in grant activity in Fife
- after having received no applications in 2018, three grants were awarded in Na h-Eileanan Siar.

In July the initial data was reviewed and a further plan established for the launch of Better Breaks in September 2019. Quarterly meetings now take place to support future joint working.

In 2019 Shared Care Scotland exhibited at Family Fund Information and Support Days across Scotland. Family Fund have also contributed to the advisory group overseeing Shared Care Scotland's Holiday Activity Provision research.

The data exercise is currently being repeated, taking into account applications made for the recent round of Better Breaks funding. This will inform promotional activity in relation to the 2020/21 Take a Break funding round.

*"There are many challenges that my daughter overcomes. Sometimes the hardest thing is how isolating it can be; people don't understand how a child can be so intelligent and yet can't dress or shower without reminders or support."*



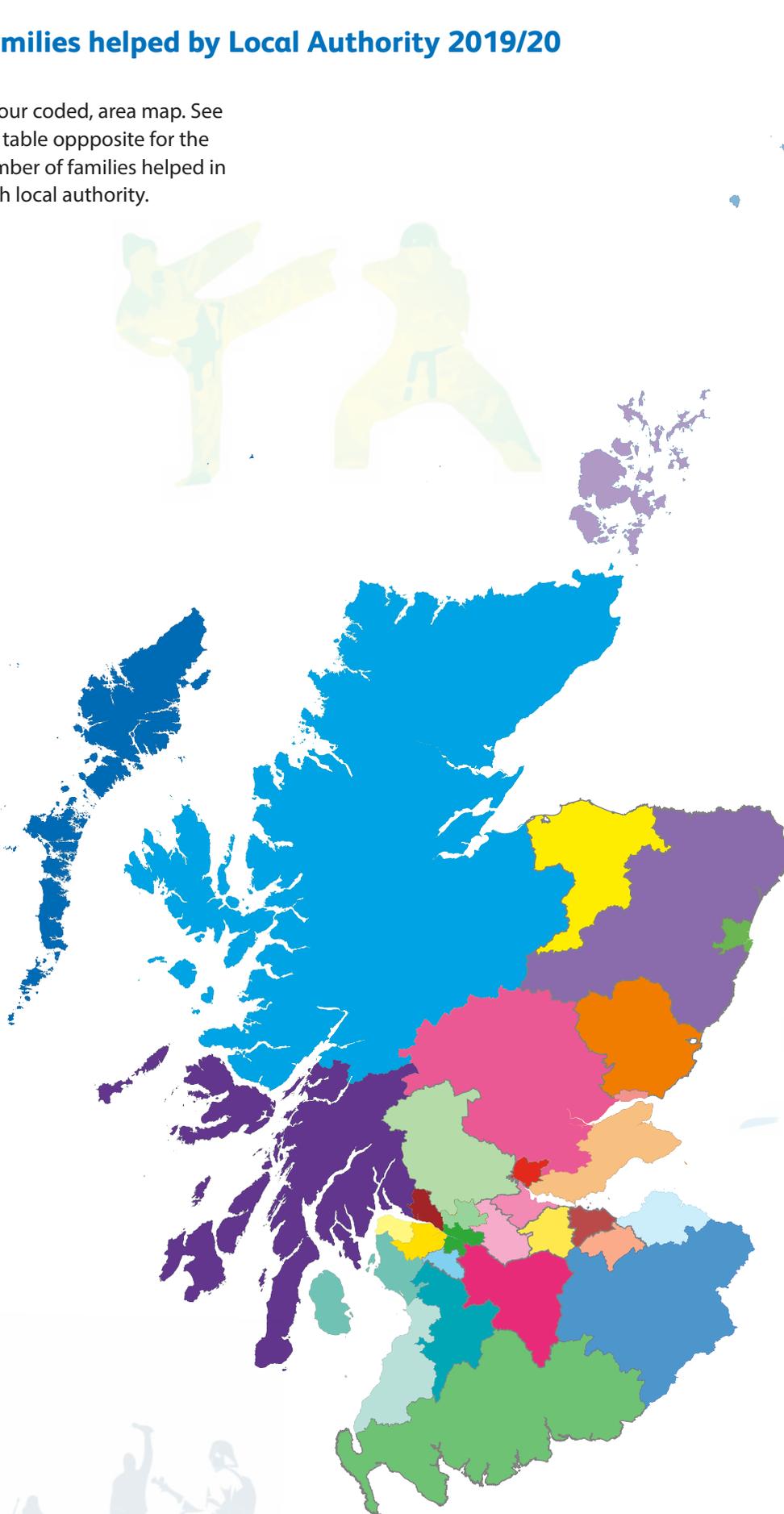
## Families helped by Local Authority

Local Authority	2018/19 families helped	2019/20 families helped
Aberdeen City	64	37
Aberdeenshire	69	63
Angus	38	41
Argyll & Bute	18	20
City of Edinburgh	155	157
Clackmannanshire	14	16
Dumfries & Galloway	33	53
Dundee City	34	33
East Ayrshire	46	45
East Dunbartonshire	38	33
East Lothian	31	35
East Renfrewshire	59	37
Western Isles	0	3
Falkirk	51	76
Fife	108	118
Glasgow City	293	312
Highland	83	90
Inverclyde	37	26
Midlothian	70	61
Moray	30	28
North Ayrshire	39	45
North Lanarkshire	225	284
Orkney Islands	1	1
Perth & Kinross	58	47
Renfrewshire	46	49
Scottish Borders	24	35
Shetland Islands	3	3
South Ayrshire	36	41
South Lanarkshire	207	251
Stirling	11	13
West Dunbartonshire	35	38
West Lothian	72	64



## Families helped by Local Authority 2019/20

Colour coded, area map. See the table opposite for the number of families helped in each local authority.



## Family-wide outcomes

During 2019, over 500 Take a Break grant recipients responded to our outcome survey. When asked “to what extent, if at all, has the Take a Break grant affected you and your family”, 100% responded that it has affected them positively, with 95% saying that it had affected them very positively. The following further demonstrates the impact of the grant on the family.

### How has your Take a Break grant affected your family as a whole?

	Response %
It has given us quality time together as a family	90%
We have made some memories we wouldn't otherwise have had	78%
We were able to try something new	56%
Relationships within the family have improved	48%
Don't know	0%
No effect	1%
Other	5%

Take a Break supports flexibility and a personalised approach, enabling carers to access short breaks that may not otherwise be available to them. It supports the personalisation agenda and enables both carers and families to try new things without the fear of losing vital family income. When asked whether they had been able to tailor how they spent the Take a Break grant to their own family's needs, 98% of respondents agreed that they had, with 90% strongly agreeing.

### How has the Take a Break grant affected you personally?

	Response %
I've been able to relax	72%
I've been able to have some one-to-one time with my child/ren	69%
I've been feeling cheerful	47%
I've been feeling more optimistic about the future	40%
I've felt close to other people	38%
I've been thinking more clearly	24%
I've been feeling confident	21%
I've been dealing with problems better	17%
I've been able to have some time to myself	17%
Don't know	0%
No effect	0%
Other	11%



Wellbeing is at the centre of Scottish Government's Getting it Right for Every Child approach to supporting children and young people. The approach provides a shared understanding of wellbeing and the various aspects of wellbeing in relation to children and young people. Take a Break grants support children and young people's wellbeing as demonstrated below.

## Safe

40% of carers reported their disabled child's self-confidence has grown, with 27% of non-disabled children growing in self-confidence too because of the Take a Break grant.

"We were lucky enough to receive a grant that we used to buy camping equipment. We had a few nights away sleeping under the stars."

"The last few months have been a real struggle for my son with him basically living in his room 24/7! So for us to get my son not only out his room, but outside was a massive achievement, he even tried a bit of kayaking."

## Healthy

21% of carers reported that their disabled children were better able to cope with the normal stresses of everyday life, with this rising to 28% for non-disabled children. 14% of disabled children and over a quarter of non-disabled children were more optimistic about life following the grant.

The grants not only enable carers to support their own wellbeing and make appropriate provision for their child or young person's physical support needs, but also that children and young people's mental health is positively impacted by the opportunity for a short break for, or with, their carer. Examples often included comments about being included socially or having the opportunity to experience the outdoors.

"We went to Hungary to see our disabled child's grandparents and all his cousins, uncles and aunts who rarely see him. With your support, it means the whole family travels together and Misi got lots of sunshine and was in the waters at Lake Balaton too. His grandparents were overjoyed to be with him and he enjoyed more love and attention than he's had before."



## Achieving

Almost 30% of carers reported their disabled children had the chance to develop life skills such as responsibility, leadership, decision-making and social skills.

"The Take a Break grant was a lifeline for my family this summer. It allowed my son to continue Judo, which was the first club that he had the confidence to join after years of being too anxious to try anything new. We had insurance, a new judo suit and membership fees to pay all at once so this made life much easier. We were also able to try new activities throughout the long summer holidays which took my son outdoors and away from his games console. We were so grateful for the support of the grant. Thank you so much!"

## Nurtured

A third (34%) of carers said that their disabled children had felt supported by the carer themselves and a network of family or friends. 43% of carers also indicated that this was the case for their non-disabled children.

"We are just back from our break at Homelands Trust in Lundin Links, Fife. This is a fully adapted holiday house which caters completely for our two severely disabled children. The house has ceiling track hoists, a wet room and height adjustable profiling beds among other things. It is a fantastic place in a beautiful setting. We were able to explore Fife and access beach wheelchairs in St Andrew's, Deer Centre in Cupar and Play As One park in Dunfermline. It was a lovely week and quality time spent as a family. It is over £1,000 for a week so we can only afford this with the help of your grant."

## Active

Three quarters of parent carers (76%) told us that their disabled children had the chance to play and have fun, with 70% of non-disabled children having the same opportunity.

Carers reported almost three in five disabled children (57%) and almost half of non-disabled children (49%) had been more physically active. More than two thirds of carers said that their disabled child had a chance to try something new.

"We attended a family summer camp in Shrewsbury for visually impaired children and young people. The grant helped towards travel and accommodation allowing Samantha to meet old and new friends and families who are also registered blind. Having the opportunity to access all the activities while having the necessary support from staff there, was amazing. From kayaking, gladiator wall, disco, family quiz to toasting marshmallows around the camp fire, these family and friend times are so important to Samantha as she has struggled with her mental health due to trying to accept her sight loss."

## Respected

Over a third (34%) of carers said that their disabled son or daughter had had a chance to develop their independence/autonomy, which was the same level for their non-disabled children.

"Our Take a Break grant was used to provide my daughter with horse riding lessons. These lessons have been therapeutic for her to manage her Post Traumatic Stress Disorder (PTSD) and have really helped her physically and emotionally. My daughter's support worker have seen huge differences in her as a result of the block of lessons. Due to PTSD, Autism Spectrum Condition and Hypermobility my daughter needs a one-to-one riding lesson and without the Take a Break grant we couldn't have accessed that. It has genuinely made a phenomenal difference to every aspect of her wellbeing."





## Responsible

Over a quarter (27%) of carers told us that their non-disabled children had grown in self-confidence.

"We are very grateful for our Take a Break grant which we used on days out to the cinema, for milkshakes and the climbing zone. As a single parent with three children, we can't afford these things very often and this has brought us together as a family. We've been communicating better and I can see it benefiting all the children, not just my daughter. They get to do fun things, socialise and learn new skills, giving them confidence, it has brought us closer together.

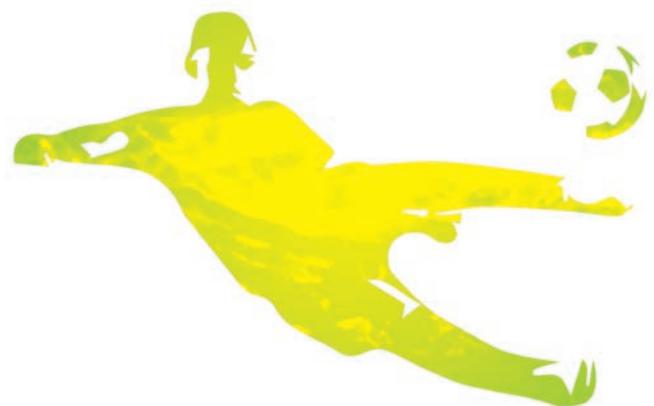
"I also enrolled Alex in a gymnastics club with the help of the grant. It's the first time she's shown interest in a sport since her accident. It has helped her with the social side of things too, so thanks again for your help and support from one happy family."



## Included

16% of carers said that their disabled children had developed new friendships, with a quarter of non-disabled siblings doing the same.

"I'm a full time carer for my severely disabled 21 year old son. He lives at home and needs 24-hour care. Getting help from Take a Break means so much to me, I took my son to Craig Tara caravan park where it's an environment he is used to, he is familiar with the surroundings. It takes away the stress of daily life of doctors and hospital appointments. We were able to go on long walks, explore, visit different places, go for lunch and meet new people. Social interaction is a big deal for him as he is a recluse at home. I'm so happy you could help as I don't have a life outside of my caring role."



## Added value

We always look for opportunities to expand the help provided to those supported by Take a Break, and aim to provide wider support to carers raising disabled or seriously ill children and young people across Scotland. Additional support provided via our wider charitable activity includes:

- During 2019/20, six digital skills training events were held where carers in Scotland received in-depth support on using iPads to help their child or young person with additional needs. At the end of the sessions carers were able to create iBooks, videos, iCalendars and much more to help day to day life. Family Fund has also secured funding working with Good Things Foundation to support a further 110 carers of disabled children and their families in Scotland with digital skills specifically to support their financial health. Power Up will deliver its support between April 2020 and March 2021.
- Parents and carers received access to help and information related to sleep through our single online resource Tired Out. This online 'hub' aims to keep all information and support relating to sleep issues of disabled and seriously children and young people in one place for parents and carers to access 24/7. This includes details of local and national support events, latest research, top tips from professionals, and parents giving their first hand experiences of dealing with sleep deprivation.
- All carers that apply to the Take a Break scheme are also made aware of Family Fund's grants and services so that they can access other forms of support. This includes our helpline and services over the phone. Our team support families who call us with a range of services including grant searches to identify more support, benefit checks to ensure families are aware and in receipt of funding available and wider signposting to local and national support.

## Summary of 2019/20

This report highlights many of the valuable outcomes experienced by parent carers and the positive impact of accessing direct short break grant support upon them. The positive impact of this vital support often extends to their disabled child or young person and the wider family, including siblings. It provides the opportunity for parent carers to look after their own health and wellbeing and have a life alongside caring, which in turn enables them to be sustained in their caring role, thus supporting the wellbeing and developmental needs of their children and family.

Take a Break has continued to support carers in this way. The breaks carers choose are often taken with their whole family, allowing everyone to benefit from a little time away from the challenges and demands of their normal routine.

Take a Break's primary objectives have again been met in 2019/20.

Positive outcomes for carers and disabled children aligned to the Scottish Government's GIRFEC approach have been delivered as highlighted in Family-wide Outcomes section of this report.

Carers have been given more opportunity to be at the centre of planning and decision making about their short breaks through this grant scheme, and in greater numbers than ever before. Over 2,000 carers and their families have received support.

For the first time, we received over 3,000 applications from carers for this support, including over 1,000 first-time applications, showing that awareness of the scheme, and the need for this support, continues to grow.

Since 2011, Take a Break has in total given over 15,500 parents and carers access to a short break through direct grant support. Each year the need for this help continues to grow and, despite changes to the scheme to enable more parents and carers to access a break, there is still a significant number of parents each year that we are unable to support – over 900 this year.





## Take a Break next steps

### Support more carers in Scotland

In addition to continuing to work with Shared Care Scotland to ensure that parent carers across Scotland have the opportunity to access short breaks support via the Better Breaks and Take a Break Scotland Short Break Fund programmes,

Family Fund, Shared Care Scotland and MECOPP will work together to begin to explore the reach and outcomes of the Time to Live and Take a Break Scotland Short Break Funds for ethnic minority carers and families and to identify possible activities to reduce barriers to access funds.

Furthermore Family Fund will continue to work with Scottish Government and the National Carers Organisations to ensure that the support is responsive to the changes needs of unpaid carers, including parent carers of disabled and seriously ill children and young people in light of the current COVID19 outbreak.

This year saw an 11% increase in applications from the previous year, even with targeted communications outlining our focus on carers who were applying for the first time.

Take a Break has predominantly focused its limited outreach activity on under-represented groups and geographic areas to ensure those carers get an equal opportunity to access this support. Wider awareness-raising has not been required given that we are already receiving high numbers of applications that cannot be fulfilled.

In future years, we would like to support more carers with grants through Take a Break and build further upon our awareness-raising activities.



# Rufus

## Background

Rufus is 15 years old and lives with his mum Kate, dad Nick and sister Freya in North Ayrshire. Rufus has cerebral palsy. As mum Kate explains, *"He is on the severe end of that spectrum – he uses a wheelchair, he needs a profiling bed and requires a hoist for all transfers. He is non-verbal, and is fed using a percutaneous endoscopic gastronomy (PEG) tube. He uses his eyes to signal 'yes', or 'no', when he responds to simple questions."*

Rufus is deaf, and currently wears cochlear implants, a surgically implanted device to aid his hearing. Kate also tells us that Rufus has a diagnosis of Type 2 Respiratory Failure. *"It means, in practice, that he sometimes struggles to breathe and can go 'blue', which obviously means there needs to be a quick response from those around him."*

Though life for Rufus can be difficult, Kate says that he has *"a fantastic sense of humour. He's utterly gorgeous and loves his little sister Freya who is 12 this month. She is a fantastic help, and is brilliant with her brother and with his disabled friends too."*

## Daily life and challenges

*"Day to day life is impacted by Rufus' condition. The logistics of his personal care mean that as a family we tend not to be terribly adventurous – even a trip to Glasgow takes some planning. Routine-wise, we run to a clock for feeding, medication and bedtimes. But after 15 years, we only really notice when we're with 'normal' people who don't have to plan everything."*

Kate explains that one of the main challenges they face as a family is when *"things go wrong unexpectedly. Last October Nick broke his kneecap, which made us face the horrible reality of how fragile our life is, especially when someone who is part of our team – our family, suddenly isn't there. We're on the mend now, but I think we were all – except Rufus – traumatised by the event."*

*"It can also be difficult juggling the different needs of Rufus and Freya, especially as Rufus can't be left alone during waking hours. It makes life very stressful at times."*

## How we helped

Kate and the family used their Take a Break grant to go to the Calvert Trust in Kielder. The Calvert Trust is a charity that specialises in outdoor activities for families with disabled adults and children. *"They provide inclusive holidays, and crucially for us they have beds and hoists that are suitable for Rufus. They are also fabulous at making sure that anyone can participate. We love it there."*



*"It can also be difficult juggling the different needs of Rufus and Freya, especially as Rufus can't be left alone during waking hours. It makes life very stressful at times."*





The climbing wall is a favourite for Rufus and Freya. *"Using their hoist system, Rufus can reach the top of the wall and uses motor hand movements to ring the bell. His sister can climb next to him – it's serious heartmelting stuff as a mum."*

## Rufus

*"They also enjoyed the King Swing and going on the boats. Archery was a particular favourite, and we took the opportunity to visit Alnwick Gardens too."*

### How it's made a difference

*"Sadly accessible accommodation is scarce, and tends to be expensive. The grants have enabled us to have a break as a family and do things together. Without the break Rufus wouldn't get the opportunity to go somewhere like the Calvert Trust, which would be a huge shame. It has enabled us to make memories."*



# Logan

## Background

Logan is nine years old and lives near the north coast of Scotland with his brother and parents. Mum Fiona tells us that *"Logan has learning disabilities and sensory issues, and what I'd describe as a lot of autistic characteristics."*

*"It was obvious to us from when Logan was a young age that he wasn't meeting the usual developmental stages – he didn't speak until he was four and half years old. Now, he's mostly operating at the level of a four year old. He can't write and he's limited in his reading and understanding. He has no concept of danger at all, so road safety is a big issue. He can fixate on certain things – water especially. He could sit in the bath for hours."*

*"Parenting Logan can be really tough, but he is the light of my life. He sees things in such a different way. He still has that little dinosaur he made in his room looking down on him. I honestly think he'd go back every weekend if he could."*

## Daily life and challenges

Fiona explains that Logan "can find the normal world very frustrating and stressful. Sounds cause a lot of sensory overload for him, and he is very isolated. At school he doesn't connect with the other children and it's impossible for him to find friendships. He is in mainstream school at the moment but it causes a lot of anxiety, so that's currently under review."

*"The experience of parenting a child with additional needs is incredibly stressful. What parents with neurotypical children don't realise is that on top of everything your child does, there's also a large amount of professionals who come into your life and dissect every element of what's going on."*

Logan

*"They all have a different opinion and you have to constantly justify why he needs this or that and it can be exhausting. I actually had a heart attack a few years ago due to the pressure I was under. It still affects me now and leaves me very tired and drained."*

Fiona tells us that due to Logan's needs, both she and her husband have made the decision to work for themselves. *"Unfortunately it can mean that my husband is working a seven-day week. Having a holiday results in both of us being off work at the same time, which is hard to juggle."*

## How we helped

Fiona used the Take a Break grant to go to Center Parcs. *"The boys absolutely love it, and we could never have afforded it on our own."*

## How it's made a difference

*"The chalets are perfect for us and we meet family there, which means Logan gets to see his Uncle, which is a massive draw. They spent loads of time with their dad playing and exploring. Logan can't ride a standard bike, but they have tandem bikes you can use, so he went off on the back with his dad pedalling through the forest."*

*"He loved the huge swimming area – obviously – and the pedal boats on the lake. He also went to a pottery place and made a small dinosaur. He painted it himself and that's now a lasting memory of the trip for him."*

*"I couldn't really take part in many activities as I get very tired very easily since my heart attack, but it's great to meet up with the rest of my family and seeing our boys having such a blast. We're so thankful for the opportunity to have had a good time and bond as a family."*

*"Parenting Logan can be really tough, but he is the light of my life. He sees things in such a different way. He still has that little dinosaur he made in his room looking down on him. I honestly think he'd go back every weekend if he could."*

*"Despite both working, we're on a low income, so to book a trip and take time off is almost impossible without Take a Break."*

## Background

One of the young people Take a Break has helped lives in Scotland with her mum. She has Autism Spectrum Condition, obsessive compulsive disorder (OCD), hyperacusis, which refers to a condition that affects sensitivity to sound, hypermobility and post-traumatic stress disorder (PTSD).

## Daily life

Her mum explains that, *"At home it's just myself and my daughter. A few years ago I took a break from work to care for her full-time; as she got older some of the challenges she faced in terms of schooling and peer relationships were overwhelming."*

Anonymous



## Anonymous

*"She currently attends a specialist provision for one-on-one teaching for a few hours a week, and she completes the rest of her school work at home. She is very bright but finds social situations, the unpredictability of daily life and living with the memories of her trauma too much."*

*Due to her condition, she has a "very structured life. We use visual timetables and fairly rigid routines. Most of her week is spent with adults at appointments. We go to her occupational therapist appointments and Child and Adolescent Mental Health service (CAMHS) appointments weekly, as well as her one-on-one teaching. All her time is supported by myself."*

*"She is an incredible child, with so much to offer the world. She loves animals and she works really hard in everything that she does, but it's difficult for her to make connections with others. At times, when memories of her trauma come to the surface, or when she starts feeling overwhelmed by the world, we have to shut off completely. We unwind and recover until we are ready to face the world again, otherwise she can turn to coping mechanisms that aren't healthy or safe."*

*"The grant has made a phenomenal difference. It has helped her mental and physical health. Her occupational therapist has seen improvements in her leg strength and her posture, but more importantly I've seen how much her confidence has grown and the sheer enjoyment of riding."*

## Challenges

*"There are many challenges that my daughter overcomes. Sometimes the hardest thing is how isolating it can be; people don't understand how a child can be so intelligent and yet can't dress or shower without reminders or support."*

*"The hardest thing for me personally is seeing her struggle every day and wishing I could make things better for her. I try and ensure that between all the appointments and the coping strategies, there is also fun and time for us both to unwind."*

## How we helped

*The Take a Break grant was used to purchase a block of private horse riding lessons. "The lessons have been so therapeutic for her."*

## How it's made a difference

*"The grant has made a phenomenal difference. It has helped her mental and physical health. Her occupational therapist has seen improvements in her leg strength and her posture, but more importantly I've seen how much her confidence has grown and the sheer enjoyment of riding."*

*"The rhythm and movement of the horse has helped to regulate her and there are definite improvements in her mood and ability to cope after her lessons have finished. The difference was so positive that we have kept up with the lessons – not every week, but as and when we can afford them. She is benefitting, and has benefitted, so much."*

# Ellie & Jack

## Background

Ellie is 13 years old and Jack is 18 years old. They are brother and sister and live with their family in Midlothian, Scotland. They both have Pontocerebellar hypoplasia type 2. As mum Lynne explains, *"The condition affects the development of the brain. They both need 24hour care for all their needs. They can't walk or sit unaided, they require specialised seating and wheelchairs to get around."* Ellie and Jack are also tube-fed through their stomach.



For Ellie and Jack, communication is difficult, as they are both unable to talk. *"Ellie is very good at eye pointing. She is a really happy child and you know how she is feeling by the sounds she makes and the expressions on her face."*

*"Jack is also really happy. You know what he wants through his vocalisations and facial expressions."*

Lynne tells us that two years ago, Jack's health took a turn for the worse. *"At the age of 16 he suffered a cardiac arrest whilst in hospital for a chest infection. It left him fighting for his life and unfortunately he suffered further brain damage as a result. Life is much more difficult for him now. He requires chest physio and has a nasopharyngeal airway to help keep his airway open."*

## Daily life

*"Life is pretty full on. We have the daily routines for washing, dressing, hoisting Ellie and Jack in and out of chairs and their beds, physio programmes, feeding, medicines and getting out and about as much as possible."*

Ellie currently attends school, whilst Jack attends a day centre once a week. *"We get some help in the house with our daily routines and Ellie and Jack both go for respite eight nights a month. We try and live life as normally as possible."*

As Lynne says, *"every day is a challenge, and no two days are the same. Jack needs more specialised care than Ellie and it's a constant challenge to keep his chest as clear as possible. Looking after two children with complex needs is physically demanding but it's also mentally challenging at times as well. Routine is definitely the key. They are amazing children and they bring us so much joy."*

*"Life is pretty full on. We have the daily routines for washing, dressing, hoisting Ellie and Jack in and out of chairs and their beds, physio programmes, feeding, medicines and getting out and about as much as possible."*



## How we helped

Lynne and the family used their Take a Break grant to go to Homelands Trust, a charity based in Lundin Links, Fife, which provides wheelchair and disability accessible holiday accommodation.

For many families, finding fully accessible accommodation can be incredibly difficult. *"When we look for accommodation we need to look for something very specialised. Having wheelchair access is not enough for us. The accommodation needs to have specialised facilities for two – we need ceiling track hoists, electric profiling beds, a shower trolley and a wet room. Usually this type of accommodation is limited and really expensive. However Homelands Trust is absolutely fantastic and has everything we need. It's like a home from home."*



## How it's made a difference

*"The Take a Break grant has been fantastic. It's made it possible for us to spend quality time together as a family."*

Whilst fully accessible, Homelands Trust accommodation is also expensive. *"One week can cost anything from £1,100 up to £1,500. There is no way we can afford this so receiving a grant from Take a Break helps make this possible, especially as I only work 10 hours a week. My husband had to go from working full-time to part-time when Jack had his cardiac arrest, so our income is very limited now."*

*"Quite simply, the Take a Break grant helps us spend quality time together. We made precious memories and without it we would not be able to afford the type of accommodation we need."*

Ellie & Jack



# Aaron

## Background

Aaron is 10 years old and lives with his family in Ayrshire. Aaron has autism and Attention Deficit Hyperactivity Disorder (ADHD). Mum Nicola also tells us that Aaron *"has high blood pressure, due to his anxiety."*



## Daily life and challenges

*"Family life is extremely challenging on a day to day basis. Our routine has to be exactly the same each day, even down to what Aaron eats for dinner. He has no social skills and he is very reluctant to leave the house unless it has been planned beforehand. Trying to stick to routine can be difficult, and it's not always possible either. Unfortunately when Aaron's routine is changed, it can cause huge meltdowns."*

Aaron also struggles with sleep. *"He only manages around three hours a night. His lack of sleep has had a massive impact on all of us. Bedtime is hugely challenging, as he is unable to sleep without the help of medication."*

Nicola explains that until very recently, the family were living in a flat. *"We had no garden where Aaron could run around and burn off his energy, which was hard for all of us. The fact that he has so much energy he couldn't get rid of, tied with the fact he struggles to sleep, was torture at times."*

Due to Aaron's needs, Nicola had to give up working. *"I've had to give up my job of 15 years to care for him full-time. I've been the only parent since Aaron was born and it's been hard, especially being sleep deprived. Thankfully I met my partner just over four years ago who is amazing with Aaron. They get on so well."*

*"Aaron is the most funny, caring child you could wish for. In the comfort of his own home he is amazing and so full of love."*

## How we helped

Nicola tells us that she first heard about Take a Break through her local autism group on Facebook. The family used their grant to book a week away at Wemyss Bay on the coast of Inverclyde. *"It was our first ever family break. We went to a caravan site and had the most amazing time."*

## How it's made a difference

*"The difference it has made is almost indescribable. We have made memories that will last forever. We had a safe space beside the caravan where Aaron could run around and it meant we didn't have to worry about the dangers we face in everyday life."*

Nicola reveals that one huge difference was that Aaron went swimming. *"We managed to get him to use the pool, and we have never been able to do that before. In fact, he has started to learn how to swim."*

*"My partner's two children came with us and Aaron wanted to be 'the same as them' – his words."*

*"We went when we were still living in our flat, and after having to spend time confined and without a garden, to have a break where Aaron could run around and be a child for a few days meant so much to him."*



Aaron

*"The difference it has made is almost indescribable. We have made memories that will last forever. We had a safe space beside the caravan where Aaron could run around and it meant we didn't have to worry about the dangers we face in everyday life."*



*"Thank you  
- I want you to know how truly grateful we are for the Take a Break grant."*



## Appendix A: Breakdown of child/young person's condition – two year comparison

2019/20		2018/19	
Alimentary tract disorders	13	Achondroplasias	1
Arthritis	3	Alimentary tract disorders	29
Arthrogyposis	4	Arthritis	16
Asthma	10	Arthrogyposis	4
Autistic spectrum conditions	938	Autistic spectrum conditions	1316
Behaviour disorders	56	Behaviour disorders	402
Blind or impaired vision	36	Blind or impaired vision	106
Blood or circulatory disorders	7	Blood or circulatory disorders	19
Bone condition	24	Bone condition	48
Bowel/Urogenital disorders	17	Bowel/Urogenital disorders	73
Cancers & tumours	15	Cancers & tumours	27
Cerebral palsy	77	Cerebral palsy	163
Chromosome-genetic	36	Chromosome-genetic	100
CNS disorders	34	CNS disorders	82
Communication/Hearing	69	Communication/Hearing	184
Cystic fibrosis	5	Cystic fibrosis	11
Diabetes	5	Diabetes	22
Digestive system disorders	6	Digestive system disorders	16
Down's syndrome	60	Down's syndrome	134
Dyspraxia	4	Dyspraxia	51
Endocrine, metabolic or storage disorders	10	Endocrine, metabolic or storage disorders	48
Epilepsy or convulsions	22	Epilepsy or convulsions	221
Facial or skeletal-genetic	79	Facial or skeletal-genetic	110
Failure to thrive	1	Failure to thrive	4
Foetal/environmental defects	11	Foetal/environmental defects	33
Haemophilia	1	Haemophilia	2
Heart disease	31	Heart disease	49
Hydrocephalus	18	Hydrocephalus	33
Kidney or renal diseases	2	Kidney or renal diseases	25
Learning disabilities	336	Learning disabilities	604
Leukaemia	11	Leukaemia	9
Lung or respiratory diseases	21	Lung or respiratory diseases	51



Appendix A: Breakdown of child/young person’s condition – two year comparison (continued).

2019/20		2018/19	
Meningitis	1	Meningitis	5
Mental health condition	120	Mental health condition	130
Microcephalus	1	Microcephalus	24
Muscle disorders	5	Muscle disorders	43
Muscular dystrophy	7	Muscular dystrophy	17
Named syndrome	64	Physical abnormality/malformations	14
Not known	3	Premature baby	9
Physical abnormality/malformations	3	Skin conditions	24
Premature baby	8	Skin/hair/connective tissue-genetic	7
Skin conditions	4	Spina bifida	27
Skin/hair/connective tissue-genetic	4	Spinal injury	20
Spina bifida	10	Spinal muscular atrophy	3
Spinal injury	3	Transplant	4
Spinal muscular atrophy	3		
Undiagnosed condition	48		

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