



Impact Report
2020/2021

Leaving No Carer Behind

About Us

Carers Worldwide works exclusively and strategically with unpaid family carers in the Global South. We act as a catalyst to achieve long term and sustainable change by promoting recognition of carers, drawing attention to their needs and promoting achievable solutions.

We do this at all levels: with families, communities, local, national and international NGOs, service providers, academics, the corporate sector and local and national Governments across India, Nepal and Bangladesh. We also interact with other carer organisations on a global scale to promote global change for carers.

VISION

Our vision is a world in which the needs of every carer are routinely met in order to achieve their physical, emotional, economic and social wellbeing.

MISSION

Our mission is to enable carers, service providers, policy makers and other stakeholders to recognise and respond to the needs of carers in the Global South, ensuring balance and equal value is given to the needs of the carer and the person receiving care.

MESSAGE FROM OUR CHAIR

CHRIS UNDERHILL, MBE
Chair



As I come to the end of my term as founding Chair inevitably I recall that I was tremendously drawn by the strong vision of Anil, our Founder, that the very poorest carers have opportunities to develop their own lives economically and emotionally. The enthusiasm of carers in both looking after someone and grabbing the opportunities offered to them is inspiring.

Our team has had to work from home during COVID-19 and I am grateful at the professionalism they have maintained throughout. Our partner organisations have overcome real challenges to provide food, medical and mental health support to carers and those who they care for, often disabled people or the elderly.

It is a joy to report that we have been able to maintain our income despite the many challenges and even though many funders have pivoted towards COVID-19 only funding or to supporting domestic causes. To have funders who believe in our cause has been enormously encouraging.

As Anil mentions in his piece, not only I but also Siân Edwards and Sue Taylor are in the process of stepping down from the Board. We took a decision some time ago to strengthen the Board overall and we have found some wonderful people to join the Trustee team. I offer a warm welcome to Jonathan Freeman who will take on the Chair role at our July 2021 Trustees meeting. He comes with fantastic expertise and experience, and I am confident that the organisation will be in very competent hands going forwards.

The organisation will end its strategic plan at the end of 2022 and over the next few months, Trustees will dig into and refine the emerging strategic vision described on page 5. This relates to our determination to earn some of our own funds through consultancy and training and the renewed Board is in a perfect position to take the organisation from strength to strength.

Recognising the strength of all the carers we serve, my warm thanks to our Trustees, past, present and incoming, to Professor Janardhan, our Indian Board member, our partners, our fantastic staff and to Anil and Ruth Patil who are the beating heart of Carers Worldwide.



MESSAGE FROM OUR FOUNDER AND EXECUTIVE DIRECTOR

DR ANIL PATIL
Founder and Executive Director

Over the last 12 months we have continued to contend with the global COVID-19 pandemic. COVID-19 has impacted carers hard. Merck's Global Carer Well-Being Index found that 39% of carers surveyed in India became carers for the first time this year. 55% of carers in our projects have reported increased stress and anxiety.

I am proud of how our team, partners and carers have navigated the challenges presented to us all, ensuring carers remain connected and supported when they have needed it most. Thank you to our donors and supporters, old and new, who have been by our side during this year of challenge and helped us to continue caring for carers and their families.

Our State Level Carers Forum in Karnataka has demonstrated its strength and effectiveness by driving forward a state-wide COVID-19 vaccination campaign to prioritise carers and their disabled family members. This is an incredible achievement, protecting lives and promoting recognition of carers. You can read more about our policy gains on page 11.

Whilst the impact COVID-19 has had on our work cannot be ignored, it has not been the sole focus of the 12 months. We have worked with our partners to make adaptations to our programmes, ensuring our core work could continue and have secured funding to scale-up our work.

The past year has thrown a spotlight on carers and the vital role they play. We have responded to this by developing a new 10 year vision. We will be implementing a set of creative and innovative solutions to one of the greatest social challenges of our time, the recognition and inclusion of unpaid family carers and together will ignite, amplify and mobilise a global carers movement. Details are on page 5, including our exciting plans for a new training and consultancy service.

After completing their maximum terms as founding Chair and founding Trustees, it is with sadness, but so much gratitude, that I announce that Chris Underhill, Siân Edwards and Sue Taylor are stepping down from the Board. I thank each of them dearly for their roles in shaping Carers Worldwide from its inception. We are welcoming to the Board five new Trustees with a diverse range of skills, who will work closely with our other Trustees as we drive forward our ambitious new 10 year vision.

I welcome your support and involvement to make our vision a reality as we seek to change the lives of 10 million carers by the end of 2030. Join our journey and together we will be stronger!

“Society today is undergoing a series of transformations that will change the way we live. How we view care and treat carers is a core part of that.” Anil Patil

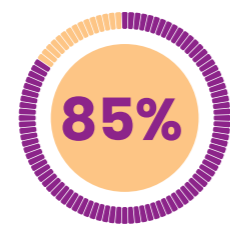
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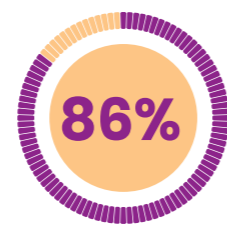
MAKING CARERS VISIBLE AND VALUED

Caring for a sick or disabled loved one can provide invaluable emotional benefits but at the same time it can take its toll on the physical, mental, social, and economic wellbeing of the person providing care. Whilst the challenges of caring are a global phenomenon, carers in low and middle income countries are particularly hard hit due to limited social protection and support systems along with inequitable healthcare provision.

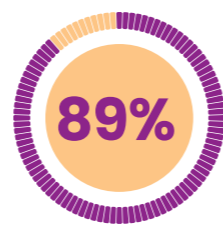
We regularly conduct surveys with carers living in the communities where we work in order to find out the level of need. 84% of the carers we have surveyed and worked with are women and girls. For many of them, this is the first time anyone has asked about the issues that affect them. The results of our surveys show the challenges that carers are living with. The picture is similar across our three countries of operation – India, Nepal and Bangladesh. Here is a snapshot:



85% of carers worry about not having enough money to meet their family's basic needs



86% of carers are concerned about their physical health



89% of carers experience anxiety or depression

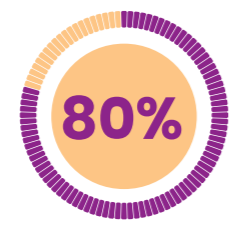
WORKING IN PARTNERSHIP

By forming strategic partnerships with local NGOs and other well established organisations skilled in delivering services to the community, we act as a catalyst to facilitate rapid changes in awareness, attitudes and service provision for carers. Our readiness to work in partnership with local communities ensures our programmes are constantly evolving and always meet the needs of carers and those for whom they care.

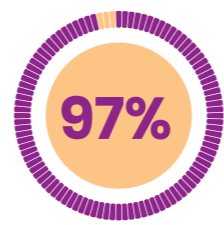
This year our network of partnerships has expanded. We have begun to work with three new NGOs in India, collaborated with government agencies in India and Bangladesh and joined forces with sector specific networks to increase our reach.

Partnership and the sharing of knowledge, expertise and creativity is at the core of our approach. Our achievements would not be possible without the belief and dedication of our partners. We thank them for their unwavering support of carers, providing a vital lifeline for them and their families during the challenging year we have all just experienced.

It is imperative therefore that carers are included and their own issues are supported, alongside those of the persons for whom they care. By creating projects that cater to the specific needs of carers, we have demonstrated the potential for positive change for carers as individuals and for whole households. This is demonstrated by data collated from our end of project surveys:



80% of carers are now earning a living, contributing to lifting their families out of poverty



97% of carers report improvements in physical and mental health

Importantly, we see these positive changes sustaining as carers join together to speak up for their rights and advocate for the support that they and their families need. Together we are making carers visible and ensuring they are valued.

"For many years I was alone, now I have a whole community, a way to earn and a chance to smile after more than 25 years."

Sarita, Nepal

OUR STRATEGY AND VISION



"Now I see my son smiling because he is now seeing me always smiling."

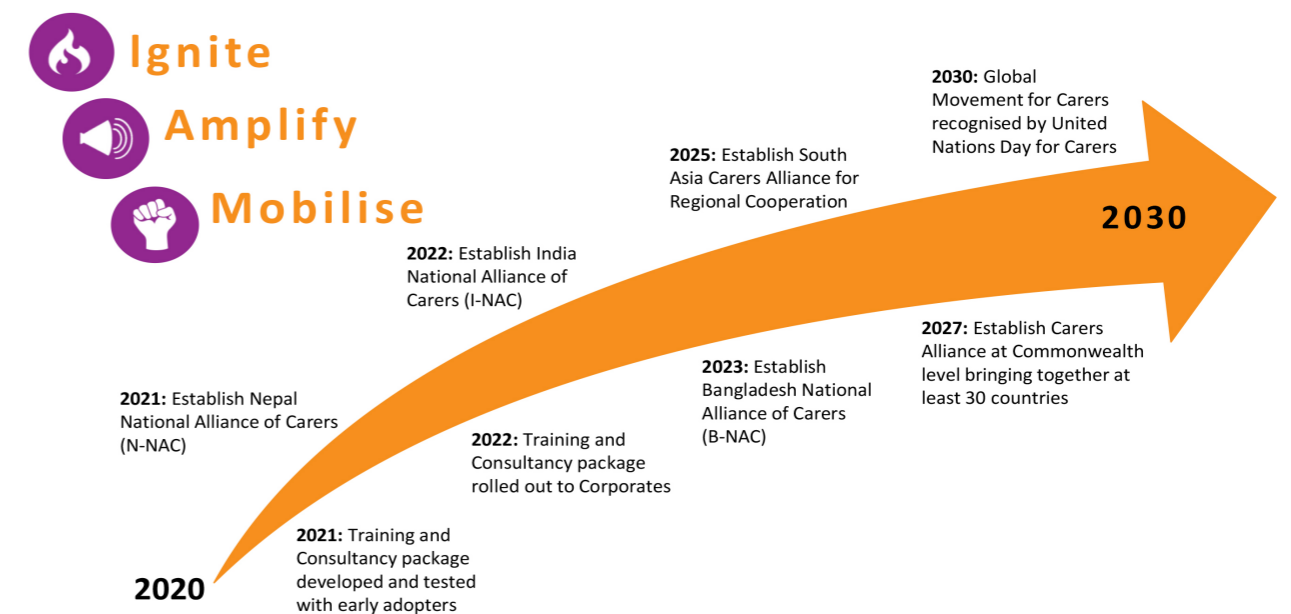
China Begum, Bangladesh

We are midway through our current strategic plan covering the period 2020 - 2022. Due to the COVID-19 pandemic, progress towards our objectives was inevitably impacted. We have nevertheless succeeded in:

- expanding the number of partners we will be working with
- increasing the body of evidence available to us for our advocacy work by carrying out and publishing evaluations of our projects
- forging ahead with our policy related initiatives in India.

As we move into a phase of 'building back better' from the impacts of COVID-19, it has been time to reflect. The result has been development of an ambitious 10 year vision for the organisation which will ultimately **transform the lives of 10 million carers by the end of 2030** through a combination of scaling up grass roots programmes, influencing policy, and training those within the NGO and corporate sectors who can impact the lives of carers through their own work. Faced with increasing cuts in funding from traditional sources, our vision also includes a paid-for consultancy programme aimed at corporates, which will improve the wellbeing of carers in employment. By diversifying our income in this way, we will be able to continue funding our work with the poorest and most vulnerable of carers.

"We will influence, re-frame perceptions, instil empathy and embed change that promotes the rights of carers within communities, workforces, and the public sphere." Anil Patil



10 million carers impacted

OUR APPROACH AND ITS IMPACT

Our core approach involves building local partnerships which implement the Carers Worldwide model. The outcome is holistic transformation of the physical, mental, social and economic wellbeing of carers and their families. This approach is cost effective and replicable, flexible to meet local need and highly impactful.



Ensuring carers are visible and valued means looking at all aspects of their lives and the community around them.

EMPLOYMENT, TRAINING AND EDUCATION
6,735 carers accessing government support
312 young carers back in education
80% of carers now earning



COVID-19

Each one of us, wherever we live, has been impacted by the COVID-19 pandemic. Our world has been changed, countless lives have been lost and we have been forced to reassess the way we live and what is important to us. As societies, we have understood more about the vulnerabilities facing many people and realised how much we have taken health, education and the opportunity to work for granted.

Carers have been impacted significantly over the last year, as have their disabled and sick relatives. Already isolated and marginalised, many of them were used to being overlooked and denied opportunities to participate in life. Together with our partners, we have worked creatively and flexibly to ensure carers were not forgotten about. We have provided practical and emotional support throughout repeated lockdowns, from the initial stages of the pandemic through to the most recent devastating wave that is still sweeping through south Asia.

Carers told us that they and their families did not have enough food, had difficulties accessing vital medicines and other healthcare and were living with no or much reduced income. Isolation, stress and anxiety were all increased and many found the number of hours they were engaged in caring responsibilities significantly increased.

72% saw their caring responsibilities increase

55% reported increased stress and anxiety

72% faced a reduction in household income

Our Actions

Over the course of the pandemic, we have supported 47,601 carers and family members across 1,830 villages in India, Nepal and Bangladesh. Staff from our partner organisations have worked tirelessly and we are especially grateful to them. Together we have implemented a range of life saving measures, keeping families fed, safe and connected:

- 4,040 families supported with regular food relief, feeding over 20,000 people
- Vital medicine supplies hand delivered to 1,663 individuals



- Handwashing awareness sessions in 1600 villages, reaching approximately 120,000 people
- Sanitation packages distributed to 2,282 families, protecting over 11,000 people from COVID-19 transmission
- Over 10,000 carers supported via telephone based group meetings, training sessions and remote counselling
- Regular online education and therapy sessions for 432 children with cerebral palsy and their carers
- Telemedicine sessions for 876 carers to provide emergency physical and mental health support



Through our collaboration with Kit4Carers, masks (made by carers and disabled women) along with sanitation packages and PPE equipment were distributed to 12,757 frontline health workers in Karnataka India, enabling them to continue safely providing their services to over 275,000 community members.



As a result of our successful campaign with state authorities to prioritise their inclusion, over 138,000 carers have been vaccinated against COVID-19 (and that figure is rising daily).

Looking Forward

At the time of writing this report, the pandemic is still overshadowing all of our lives and we find ourselves once more in 'relief mode'. However, in consultation with our partners and with carers, we are also looking beyond this current phase towards recovery.

We have expanded our livelihoods initiatives which will enable carers to regain - and in the case of many, achieve for the first time - sustainable financial security for them and their families. We are investing in training local partner staff and volunteers to provide mental health first aid in the heart of the communities where we work.

We have learned a lot this year and we are already using that learning to shape our future programmes. The successful collaborations we have forged with local government agencies and health professionals will be continuing and we are looking forward to greater creativity in how services are delivered to meet the unique needs of carers and those they care for.

We have all learned to keep connected virtually. The systems our partners have established to make use of telephone and internet based group meetings will now be used to make sure carers living in isolated locations or kept at home because of caring responsibilities do not miss out.

Together we will build back better and continue to break down the isolation, exclusion and inequities that face carers and people living with disabilities and long term health conditions.

"In taking a hard look at how the pandemic has affected the globe, carers have faced unprecedented challenges - they are undercounted, unheard and struggling. Now more than ever, governments, public entities, the private sector and all citizens have roles to play in addressing that problem. Carers should not have to face these hardships and inequities alone. They're sacrificing for us, one by one. As a society, we can help them, together."

Taken from the Global Carer Well-being Index, a global survey conducted during the pandemic by the Embracing Carers team. For the first time, experiences were gathered from carers in India. Our Executive Director Anil Patil was part of the advisory board for the survey process.



OUR POLICY WORK

Long term sustainable change for carers will not be achieved without the involvement of local and national governments. Advocating for the rights of carers and working on policy change are therefore key priorities and this remains the case even during a global pandemic. The role of carers has come to the fore over the last year and we have been harnessing this increasing recognition of their vital role by engaging with policy makers and government agencies in each of our three countries of operation.

In Nepal, our Carers Associations have approached their local municipalities to secure emergency relief for carers whose incomes were most adversely affected by lockdown restrictions, raising awareness of the needs of carers at the same time. In Bangladesh, emergency support from the Neuro-developmental Disability Protection Trust, a national government agency, has developed into a full assessment of the needs of carers and their disabled children with a view to longer term collaboration.

Our Commonwealth Foundation funded project 'Family Caregiving and Public Policy' operating across four states in India is allowing us to work in a sustained way to influence policy makers at district and state level. We are building the capacity of our four State Level Carer Forums and sharing best practice and learning between the states. Progress has been made on the implementation of the Rights of Persons with Disabilities Act, most significantly the rolling out of a carers allowance which for the first time in India recognises the contributions carers make in the care of people with complex disabilities. Our goal now is to increase the awareness of and subsequent take up of the carers allowance. We have also contributed to the Karnataka Health Vision 2021-2030, making practical recommendations that will ensure carers' health is supported and their needs systematically documented to promote further recognition. We will be taking this document to other states as an example of best practice.

Rameeza cares for her son who has multiple disabilities. The monthly carers allowance has meant she can now afford to take him to specialist hospitals for assessment and treatment. She has also been able to buy the medication and equipment he needs to improve his daily quality of life.

"This kind of financial support should be extended to all carers so that we can use the money for the immediate needs of our children and family."

CARERS WORLDWIDE INDIA

Our staff in India have been at the forefront of our COVID-19 relief activities, liaising with our partner organisations to ensure support has reached the most vulnerable of carers. Their response has been immediate and adaptive, meaning that we and our donors could be confident that funds were being used in a timely and appropriate way.

We are delighted that our expertise has been recognised by the state government of Karnataka, which has appointed Carers Worldwide India as a nodal agency on the topics of caring and disability. The Karnataka State Legal Services Authority has also recognised us as a domain expert on the topics of caring, disability and mental health. Our sustained lobbying with these two agencies has resulted in the prioritisation of carers to receive the COVID-19 vaccine. We are grateful to our network partners Disability NGO Alliance and Enable for their assistance in securing this significant policy achievement.

Strengthening the governance of Carers Worldwide India and securing ongoing funding have also been priorities. We are delighted to be expanding the Trustee Board and have received ongoing and new funding for projects in Odisha from two Indian donors.



COUNTRY FOCUS - INDIA



Life right now is challenging but Maheswari is confident that their small business will bounce back soon and their future will once again look bright.

"The carers group has given me confidence. I can share my problems and get support from my friends there. But the best thing is being able to work alongside my husband and support the family. Nobody can take this away from us and we will always be grateful."

Maheswari cares for her husband Yogesh who sustained a spinal cord injury which left him paralysed. On top of the shock of Yogesh's injury, the family were also devastated financially with the loss of his earnings combined with mounting hospital fees. Maheswari struggled to care for Yogesh as well as find ways to earn money. At times she felt that she could not go on.

When staff from our partner organisation Margadarshi heard about Yogesh, they stepped in to provide counselling, physiotherapy and practical assistance including a wheel chair and an accessible toilet. Maheswari was introduced to her local carers support group where she was able to connect with and get support from other carers in similar situations. She was also able to access counselling for herself. The family at last started to see a light at the end of the tunnel.

Before his accident, Yogesh worked as a chef. Unable to go back to work, we provided a grant to enable the couple to set up a small business cooking and selling snacks from their home. Their tasty treats became sought after in their village and brought them a steady income before COVID-19 struck and they were faced with the prospect of no income again. But this time Margadarshi were able to step in straight away, providing them with food parcels and a medical kit.

Our four state level carer forums have overcome COVID-19 restrictions by meeting virtually over the last 12 months. They have been a powerful force for action during this period, bringing together influential stakeholders who have been able to support carers directly, lobby local government to include carers and their families in COVID-19 responses and raise funds from local donors to provide emergency relief.



PARTNERS



NARENDRA FOUNDATION



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COUNTRY FOCUS – NEPAL



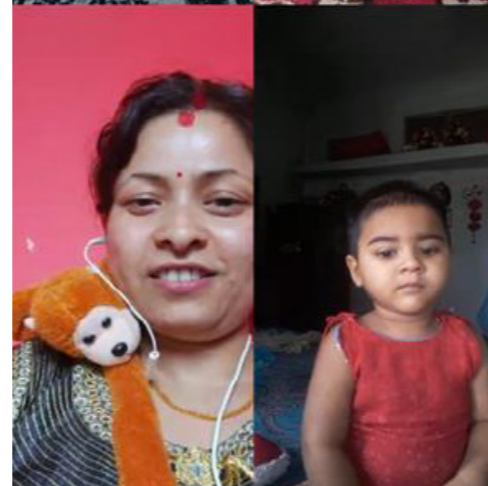
Bhola cares for his daughter who has bipolar disorder. They live in a remote part of western Nepal. Before the launch of our UK Aid Direct funded project in partnership with LEADS Nepal, he and his family were living in poverty.

We provided Bhola with two goats and training on how to rear them, so that he could start to earn a steady income. The income he generated from selling his goats meant he could purchase and raise chickens for sale as well. Bhola then attended training on fruit and vegetable production and additional support from our project helped him to set up an irrigation system on the land around his house. This has meant he can now grow more vegetables and also kiwi fruit which are incredibly popular in the local area. Bhola's daughter has also been able to access treatment and her condition is currently stable.

Bhola is now thought of as a local entrepreneur within his community. Our initial investment of just £97 – the cost of the goats and training – has enabled Bhola and his family to become economically secure and independent.

"I want to be an example to other poor carers living with poverty, stigmatisation and social exclusion that we can change our lives."

Much of our work in Nepal is with remote communities, some of them several days walk from the nearest town. This has made keeping in touch with carers during the pandemic very challenging but our partners came up with a range of technology based ways of staying connected. LEADS Nepal produced videos on COVID-19 awareness and effective handwashing which they distributed via YouTube, WhatsApp, Viber and Facebook. In this way, they reached 12,900 carers and community members with accurate information. SGCP reached isolated families with disabled children via Zoom and provided emotional support, practical guidance and even therapy sessions.



COUNTRY FOCUS – BANGLADESH



Maya Rani cares for her daughter who has learning difficulties and a physical disability. Her husband's health is poor and he is unable to work. Before getting involved in our UK Aid Direct funded project implemented in partnership with CDD, Maya Rani worked as a maid on a very low income. Struggling to feed her family on such an income, Maya Rani struggled with depression and worried for her daughter's future. *"I totally forgot how to laugh at that time,"* she says.

When project staff met her, it was obvious that she was a priority for support. She joined the carers group that was set up in her village on the outskirts of Dhaka and started attending meetings regularly. For the first time, she met other carers and she no longer felt alone. Through the group, she learned that her daughter was entitled to a disability allowance from the government and project staff helped her to apply for the certificate she needed to claim this.

Maya Rani attended one of the project's health camps and also regularly received counselling. During the lockdown imposed at the start of the COVID-19 crisis, the counselling continued over the phone, providing a lifeline for Maya Rani and her family.

By far one of the biggest impacts the project has had on Maya Rani and her family has been the support provided for her to find a new means of earning. She was one of a group of carers trained in making craft items, for which there is great demand in the markets of Dhaka. Now, she prepares beautiful paper flowers at home and then goes with her daughter and husband to sell them in the city. She is now earning triple what she was earning as a maid, enough to comfortably feed her family and save some money for the future.

"Before the support from the project, my life was stressful and I was struggling a lot. Now I am a lot happier. I can earn an income in a dignified way and my family life is better."

Our community caring centres provide education, therapy and social opportunities for children with disabilities and an opportunity for respite for their carers, usually their mothers. During COVID-19 lockdowns the centres had to close but as soon as local guidelines allowed, our partner CDD re-opened our two centres on the outskirts of Dhaka, knowing that children needed to get back to socialising and learning – and that their mothers desperately needed contact with other carers and some time off from caring. These centres provide learning opportunities for 30 children and a much needed break for their mothers.



PARTNERS



PARTNERS



Bringing hope, dignity and meaning to life

THE IMPACT OF OUR TRUSTEE BOARD

A good Board keeps a charity on track and safeguards its future. It ensures that the charity and its leaders are accountable to the people whose lives it seeks to change, its funders, its partners and all the other many stakeholders. An exceptional Board does much more than this. It debates important decisions robustly, drawing on many different perspectives, and, in the case of Carers Worldwide, keeps carers at the heart of all they do. It celebrates the charity's values and leads by example.

At Carers Worldwide we have been fortunate enough to have a truly exceptional Board that has done all this and more. This year sees us saying 'au revoir' (it is definitely not goodbye) to our two founding Trustees, Sue Taylor and Siân Edwards, and our founding Chair, Chris Underhill. Together they, and later along with Sarah Ridley, Alastair Page and Dhanya Vamadevan have guided the organisation, challenged its leaders and given freely of their wide-ranging skills, expertise and time over the last 9 years. They have been at the heart of the organisation's growth and impact, as Chris notes: "The Board have always been very committed and focused on the organisation and have been wonderful colleagues to work with. In the past we did have some very hard times financially and there were genuine worries. We surmounted these and have grown into a very cohesive outfit with staff and trustees working together." Our Trustees have valued opportunities to visit our programmes, as Siân explains: "Most memorable will be my trips to India and Nepal to better understand the work with partner organisations and carers on the ground. The way carers have taken up the challenge to fight for their own rights is one of the most enduring impacts of Carers Worldwide. Hearing the individual experiences of carers struggling with the gruelling effects of poverty, isolation and stigma showed me just how vital this work is."

"After a pretty long run as Founder-Chair it is the right time to move on. It has been a thoroughly enjoyable experience and I wish our partners, the carers in Nepal, Bangladesh and India along with the whole team at Carers Worldwide in India and the UK great good fortune in the months and years to come." Chris Underhill

"Being founding Trustee has been an enormous privilege. To have been able to help build the organisation, its approach, its team and its networks has been both a rewarding experience and a privilege." Siân Edwards

The legacy left by Chris, Siân and Sue will endure as we move on to the next phase of the Carers Worldwide journey. As we embark on our ambitious 10 year vision we are expanding our Board, welcoming five new Trustees, including a new Chair and bringing in a rich mix of skills and diversity which will assist us in placing carers even more firmly on the agendas of governments, NGOs and corporates across the Global South. Our existing Trustees bring personal and professional experiences of caring to the Board and this lived experience is continued in the new Board. The skills needed to strengthen all areas of the organisation, including our new training and consultancy offer will continue to be very present.

In the words of Siân, "Through the past year living with Covid-19, there has been a shift towards much greater recognition of the contribution family carers make. My hope is that this greater level of awareness will result in new sources of funding plus new avenues of influence. I have faith that the team, including a newly invigorated Board of Trustees, are up for the challenge."

"It has been an honour and a privilege to work with Chris, Siân and Sue from the very start of the Carers Worldwide journey. They have been central to the organisation's growth and impact, acting as mentors and critical friends. Their skills, expertise and imagination have challenged us, laying solid foundations for our continued growth as we enter the next phase of our ambitious plans to achieve equality for all carers." Anil Patil

Huge thanks are due to all our Trustees for their dedication and passion for Carers Worldwide and for carers.

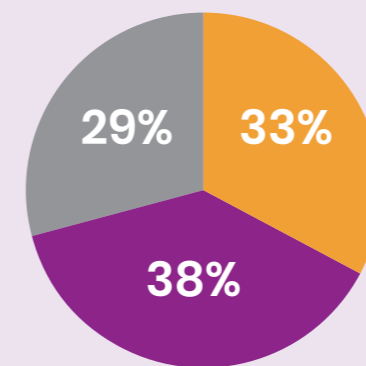


OUR FUNDING

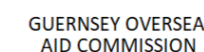
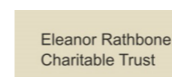
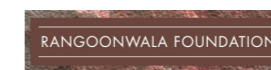
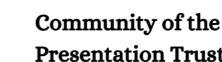
The last twelve months have been a challenging time for small international development charities like Carers Worldwide. Many funders have turned their focus to funding causes within the UK and reductions in UK Aid from the UK government have hit the sector hard. Public events and sponsored challenges have had to be cancelled. So at the same time as concentrating on how to adapt our programmes to deal with the impacts of COVID-19 in our countries of operation, we have needed to be ever more creative in how we raise funds to continue our vital work.

We have been positively overwhelmed by the response to our COVID-19 appeals, the virtual events we have held and the direct approaches we have made to Trusts and Foundations, companies, supporters and individuals. We have been delighted to receive funding from a number of new donors as well as repeat funding from those who already know us. The pandemic has shone a light on the vital role played by carers and we thank everyone who has listened to our stories and engaged with our work.

Income £349,180 Expenditure £249,792
(for the period 1st January – 31st December 2020)



Country spend
India 33%
Nepal 38%
Bangladesh 29%





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Thank you to our partner staff for providing the photos used in this report