



IMPACT REPORT 2019

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*Transforming the lives of carers*

## ABOUT US

**Carers Worldwide is the only organisation working exclusively and strategically with unpaid family carers in developing countries.**

Established in 2012, we implement a range of grassroots projects across India, Nepal and Bangladesh and engage in advocacy at national, regional and global level. We draw attention to the poverty, vulnerability, marginalisation and exclusion faced by carers through lobbying local organisations, NGOs, governments and international agencies for positive change. We then work to develop carer-inclusive initiatives that meet the emotional, physical, social and economic needs of 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 developing world, ensuring balance and equal value is given to the needs of the carer and the person receiving care.**



## A MESSAGE FROM OUR CHAIRMAN

In his introductory piece to our second Impact Report, our Founder and Executive Director rightly emphasises the transformational effect our work is having on the lives of carers in our partner managed programmes. It is this change for the better in the lives of resource poor carers that the trustees maintain as our guiding light. It is our duty as a board to keep the main vision in mind whilst constantly being vigilant about our financial, legal, programmatic and safeguarding responsibilities. In Anil our founder and his wife Ruth we have two highly committed individuals who, carers themselves, understand the challenges that carers face. They bring their passion to our work matched by a very high degree of professionalism. As Chair I am very lucky in the board that I have to work with. Deeply committed to our cause they have worked carefully and thoughtfully alongside the leadership team to ensure consistency in our programming, our growth and our impact.

We have begun the work of crafting a new strategic plan for 2020 and

beyond and in this endeavour we see the combining of Anil's vision with the strategic insight of the board. Without doubt we are keen on deepening our programmatic approach as well as creating a long-lasting bond with our sister organisation Carers Worldwide India. In addition we will continue to develop our skills in the social enterprise field and, overall, seek careful and managed growth both in territory covered and people served but also, most important, in the quality of our impact.

I commend this Impact Report for your attention and thank our staff both in the UK and in our programme countries for their service. Equally warm thanks to our partners both programmatic and financial and, finally, to our individual contributors whose belief in us keeps us all going!

**CHRIS UNDERHILL, MBE**  
Chairman

## A MESSAGE FROM OUR FOUNDER

I am delighted to bring you our second Impact Report and give you a flavour of the work carried out by Carers Worldwide and our 10 partner organisations this year, bringing changes to the lives of almost 60,000 unpaid family carers and their family members in India, Nepal and Bangladesh. Carers are the invisible army among us that we often do not see.

Renukamma, a carer from rural India, summarises this beautifully: "If you don't see us, you don't count us, but we are still there." It is time for us all to recognise and appreciate the work that carers do.

If I had to select one word to describe the past year it would be 'transformational'. We have taken great steps in bringing about systemic change, within our countries of operation as well as globally, towards the recognition of carers as a vulnerable group and an understanding of the vital role they play.

Whilst there have been many achievements over the previous year, three key highlights stand out. We have registered Carers Worldwide India, our first

independent in-country entity which will allow us to mobilise local resources and expand our work with a range of stakeholders. Our pilot project in Bangladesh has started, alongside our new partner the Centre for Disability in Development (CDD). This will bring the voice of carers into the mainstream development agenda for the first time in Bangladesh. Finally, we have taken our first steps into social enterprise, with an exploration of the feasibility of establishing paid-for care services in urban settings.

Our 2017 - 2019 strategic plan is coming to an end and I would like to draw attention to the significant inroads we have made in raising awareness of the issues of carers at a local and global level; building the capacity of our local partner organisations and Carers Association representatives; and promoting practical, life changing services for carers and their families. There is much still to do but I am more confident than ever that in collaboration with our partners - existing and new - we will continue to progress towards our vision of a carers movement for all.



As we move ahead, we value your continued support and look forward to building the lasting relationships we need to enable us to improve the lives of the millions of unpaid family carers and their families across the developing world.

**DR ANIL PATIL**  
Founder and Executive Director

### STRATEGIC OBJECTIVES 2017-2019

1. **To work in partnership with 12 key delivery organisations in four countries**
2. **To provide training and consultancy support to 5 influential stakeholders**
3. **To initiate development of sustainable social enterprises to provide services for carers**
4. **To build evidence of the needs of carers and measure the impact of our strategic interventions**
5. **To advocate in order to achieve recognition of carers and ultimately promote a carers' movement**

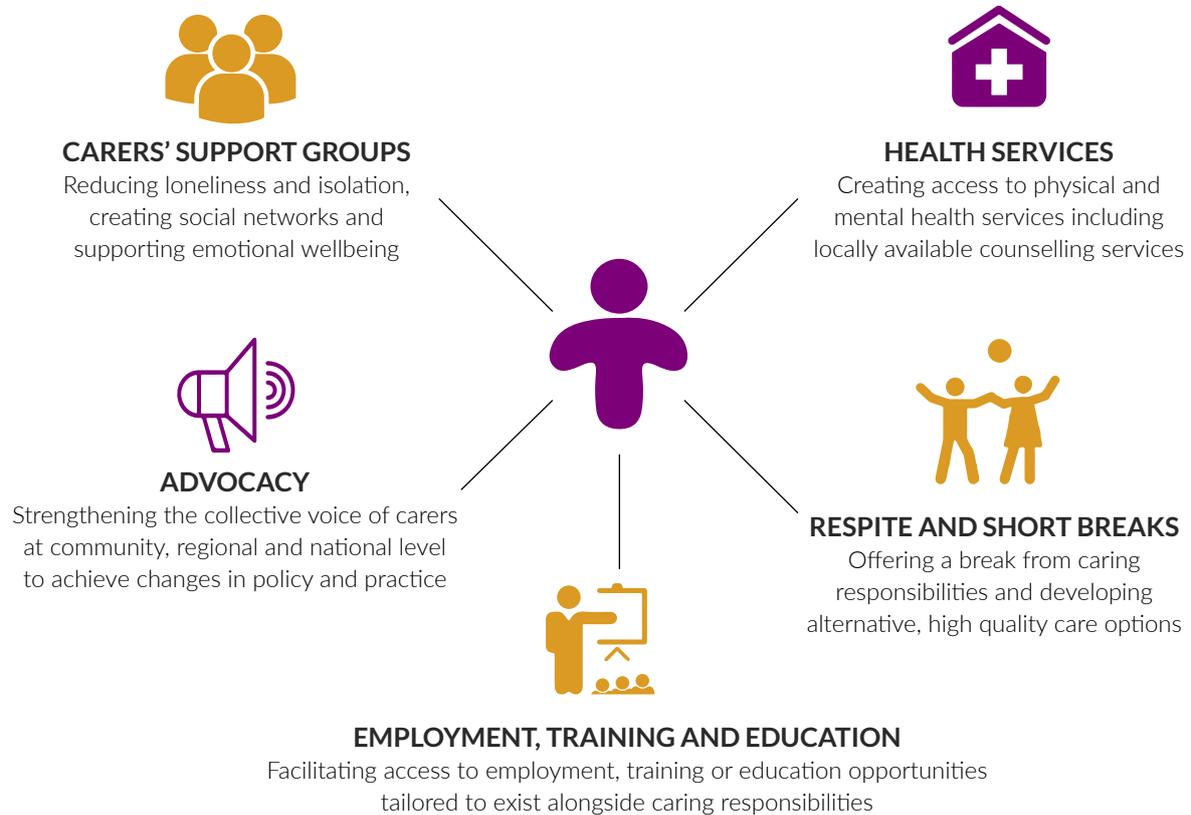
“ Carers are the invisible army of people keeping everything going. They are among us but we don't have eyes to see them.

Anil Patil – Founder and Executive Director

”

## OUR MODEL

The Carers Worldwide Model comprises five core elements:



### PARTNERSHIP APPROACH

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.

### STRATEGY AND THE FUTURE

Our community-based empowerment model is now well established with ten partner NGOs. Careful monitoring, evaluation and analysis of our programmes has placed us in a strong position to advocate with policy makers within the governmental, non-governmental

and private sectors. This area of our work is being strengthened further by forging alliances with academic institutes in the UK and India. We are working closely with policy makers in India and with the support of the Commonwealth Foundation are now poised to establish state level Carers Federations and an Indian National Alliance of Carers. This will be a model of engagement which can then be replicated across south Asia.

## CARERS INSPIRING CARERS

### Jyoti Carers Group - Nepal

Jyoti Carers Group of Manamaiju is a powerful group of carers based in the Kathmandu Valley, Nepal. The nine members came up with the name "Jyoti" as it means "Enlightenment", highly appropriate as their purpose is to meet together to discuss the challenges carers face and to come up with solutions.

Since the group started two years ago, the carers have not only found emotional support, but have also been busy with a range of other activities:

- **Savings:** The carers save NPR 500 (£3.50) per month which is held in a joint account. This growing pot of money is available to group members to provide emergency loans to meet unexpected medical or household costs.
- **Livelihoods:** Eight of the carers have taken part in basic training

on how to make shoes. They have begun making shoes to sell to neighbours and relatives and are generating a steady income. They plan to undergo more advanced training soon and start selling to a wider market.

- **Health Assessment Camps:** The group agreed that they were all neglecting their own health as they were focused on looking after the needs of their disabled children. To address this, they organised a health assessment camp at the local Chhetrapati Community Hospital and invited other carers to attend. All the carers had a free health check and access to specialists.
- **Respite:** The group are lobbying local government officials and school authorities for a space which they can use to set up a community caring centre. This will

enable them to take it in turns to care for each other's children and provide opportunities for respite.

Speaking of the group, Mr. Ramakrishna Surdeo who works closely with Carers Worldwide to strengthen our carers groups and grow the grassroots carers movement said:

"This group is very strong. The members regularly attend meetings and are dedicated to improving the lives and wellbeing of all carers. It is inspiring to see their continued efforts in advocating for a community caring centre and I wish them every success in achieving their goal."

We also join in wishing the members of Jyoti Carers Group every success in their future plans.

#### Our Impact

- 487 Carers Groups
- 6 Carers Associations Registered
- 2 Carers Co-operatives Registered
- 17 Community Caring Centres
- 2,825 Receiving Respite Care

“

The members show a high level of dedication towards improving the lives and wellbeing of carers

Mr. Ramakrishna Surdeo –  
Development Trainer

”



## WHERE WE WORK

### INDIA

From a pilot project with just 250 carers in 2012, our work has now touched the lives of over 6,900 carers and 34,800 family members. Working with seven NGOs across four states, we are transforming the lives of carers of those living with a disability or mental illness, with financial support for our projects increasingly being generated from within India. The next year will see us partner with four new local and state level NGOs. We have made significant progress at policy level, working closely with state authorities to ensure recognition for carers in legislation related to disability and mental health and advising on ways to identify carers for the first time in local censuses. These gains, along with our latest initiatives to establish state and national level advisory bodies, have the potential to change the landscape forever for carers and their families across India.

#### OUR INDIA PARTNERS

Nav Bharat Jagriti Kendra (NBJK) - Jharkhand  
 SACRED - Andhra Pradesh  
 SAMUHA - Karnataka  
 EKTA - Odisha  
 Society for Promoting Rural Education and Development (SPREAD) - Odisha  
 Women's Organisation for Rural Development (WORD) - Odisha  
 Margadarshi - Karnataka

### NEPAL

Since 2014, we have transformed the lives of 2,300 carers of people living with mental illness and epilepsy, cerebral palsy and other neurological conditions in both rural and urban settings in Nepal. We have achieved this through our multi-year partnerships with two highly experienced local NGOs and with support from UK Aid Direct and the National Lottery Community Fund. As we consolidate and strengthen our carer-led Associations and Co-operatives in the Western region and focus on community care in the Kathmandu Valley, we are also working hard to expand our new partnerships and consultancy services to organisations working across Nepal.

#### OUR NEPAL PARTNERS

Self-help Group for Cerebral Palsy, Nepal (SGCP) - Kathmandu Valley  
 LEADS Nepal - Baglung and Myagdi districts, Western region

### BANGLADESH

This year has seen us launch our first project in Bangladesh, in partnership with the Centre for Disability in Development (CDD). The 18-month project is operating in Savar sub-district on the outskirts of Dhaka, and will pilot the use of our community empowerment approach to address the social and economic wellbeing of 500 carers, of whom 90% are women. CDD is a national training agency on disability. Together, we will use the results of the project to inform our future strategy in Bangladesh and to include the issue of carers into CDD's training programmes for grassroots NGOs across Bangladesh. In this way, the Carers Worldwide approach will reach many thousands more carers, transforming their lives and those for whom they care now and into the future.

#### OUR BANGLADESH PARTNERS

Centre for Disability and Development (CDD) - Dhaka



## A SISTER'S LOVE

Kalkoly - Bangladesh

Kalkoly is 12 years old and cares for her elder brother Milon, who has an intellectual disability and communication difficulties. They live in a small village on the outskirts of Dhaka, Bangladesh with their parents who both work long hours every day as garment workers. Kalkoly used to attend school regularly and had lots of friends there but has had to drop out to ensure the wellbeing of her brother. Although Kalkoly is proud to care for her brother, her caring role has had a big impact on her life. Her social life has suffered and Kalkoly now feels lonely and isolated from her peers. She is also very worried about missing out on her education and wonders what her future will be.

Kalkoly's mother heard about the carers group that was being set up close to their home and encouraged the group to welcome Kalkoly as a child carer. The group were happy to accept Kalkoly as part of their network and she is a regular attendee at monthly meetings. Kalkoly is delighted to have a platform where she can share her feelings and opinions about her role as a carer. Her presence has also raised awareness of the role of child carers, who are invisible to their local communities.



“

I am pleased to be part of a carers group so I can share my feelings and opinions about my role as a carer.

Kalkoly - Carer

”

The Centre for Disability in Development (CDD), our partner organization in Bangladesh, has listened to Kalkoly's concerns and are finding the best way to support her. Plans are in place to get Kalkoly back in to education through the use of a home based tutor. She is also being helped to access schemes on behalf of her brother that will improve his welfare.

As our newest project, and our first in Bangladesh, we are impressed by the impact that the work of CDD has already had on Kalkoly's life. We look forward to hearing more updates as this project progresses.

### HOW WE HELP CHILD CARERS

**There are lots of ways that Carers Worldwide and its partners support child carers and their families:**

- **Arranging alternative care arrangements, so that children can re-enter school and have a break from caring**
- **Providing uniform, books and extra tuition to enable children to re-integrate and catch up on their missed education**
- **Upskilling and training local NGOs and community-based services to offer specialist support to child carers**
- **Promoting opportunities for children to meet other child carers for mutual support**
- **Lobbying school authorities to train teachers and provide practical support for child carers**

## OUR IMPACT SINCE 2012

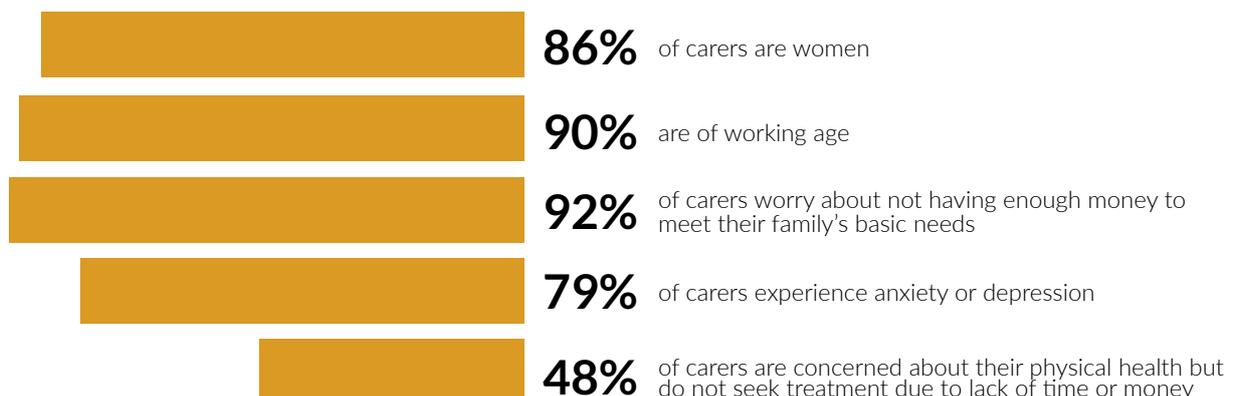
Our work has touched the lives of 58,731 people in India, Nepal and Bangladesh



## FACTS ON CARING

In the last year, we have completed surveys in Odisha, eastern India and in Dhaka, Bangladesh with a total of 1,789 carers. The evidence that we gather is critical to our wider work of informing and influencing policy makers and practitioners on the challenges faced by carers. The data, which is gathered before our interventions start, also provides us with a robust tool with which to measure our impact once a project has been implemented.

Increasingly we find that the issues facing carers across south Asia are the same, and that the Carers Worldwide model is a highly effective way to address those challenges with carers and their communities.



## TWO LIVES TRANSFORMED

### Kalabati - India

When we first met Kalabati Benya, she was living in an old, thatched house in a tribal village in Odisha, western India. Kalabati cares fulltime for her grandson, Rabi, who has multiple disabilities and is dependent on her for everything. Her caring role took up so much of her time that Kalabati was left with no time to work, socialise or look after her own physical and mental wellbeing. She received limited financial support from the government, but was facing severe economic hardship and could not afford to take Rabi to hospital for treatment that he needed.

Our local partner EKTA encouraged Kalabati to join her local carers group. In the meetings, the many challenges she was living with were

discussed with the group and plans were made to improve her situation. Kalabati learned about available services, facilities and provisions for children like Rabi. She began to realise that she was not alone in the challenges she faced as a carer. She felt motivated by being surrounded by other carers who understood her situation.

A year on, with the help of the project and her carers group, Kalabati and Rabi are now living in a new house, have accessed the financial support available for Rabi so that he can attend hospital regularly to receive medical treatment and are benefiting from the regular income Kalabati is earning from the grocery store she has set up at her home thanks to funding from the project.



With support from the carers group and EKTA staff, we are positive that Kalabati will continue to grow in strength and Rabi will thrive.

“

I have more quality time to spend with Rabi now. Our lives have been transformed, thanks to my carers group.

Kalabati - Carer

”



Two of our Trustees, Siân Edwards and Alastair Page, were delighted to see first-hand our work with carers like Kalabati when they visited Odisha as representatives of the Andrews Charitable Trust.

## EMPOWERING FEMALE CARERS THROUGH LIVELIHOOD ACTIVITIES

Our research shows that women account for carers in 84% of cases. Unpaid care work means women have less time to engage in paid labour and often become economically vulnerable as a result. Working across India, Nepal and Bangladesh we seek to empower female carers by providing them with opportunities to establish their own income-earning ventures which improves their welfare.

Our projects are unique programmes that enable women to continue to perform their caring duties, which they proudly do, whilst also offering them a chance to be financially independent.



“The income that has been generated from the goats and buffalo has saved my family from debt.”

Goma - Carer

One female carer who has benefited from our work is Goma from the village of Kudule in Nepal. At the age of 16 she married and immediately became the carer of her mother-in-law who lived with a mental illness. Unable to work due to her caring responsibilities, Goma’s family struggled to survive on the small earnings her husband made.

medicine for her mother-in-law and that they could all eat nutritious food.

Now, Goma has purchased a buffalo which provides additional income for her family. There has been a significant improvement in Goma’s wellbeing now that her financial problems have been addressed.

Through one of our projects, Goma was given a goat and earned an income from selling the kids that the goat produced.

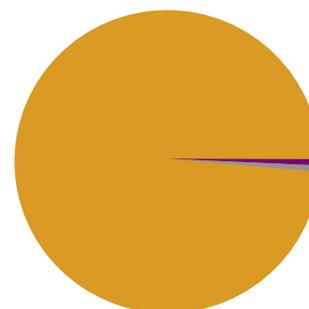
Going forward, we will continue to extend our reach and ensure that more female carers are not disproportionately burdened as a result of caring.

The profits ensured that Goma’s family could afford

## OUR FUNDING

We are delighted that our income in 2018 increased to £222,454, our highest ever annual income. In a time when raising funds is increasingly challenging, we believe this clearly demonstrates the value of our work and it is evident that donors have a strong belief in the impact we can deliver.

Our expenditure in 2018 was £176,127 with an additional £33,076 earmarked for projects continuing into 2019. We are committed to ensuring that as much as possible of the funds that we raise reach those most in need - the carers and their families.



Charitable Activities 98.5% Fundraising 0.8% Governance 0.7%

## CORPORATE FUNDRAISING

In 2018, we entered into our first funding partnerships with the corporate sector.

As part of our membership of the International Alliance of Carer Organisations, we were delighted to be included in the Embracing Carers initiative, a global advocacy campaign promoted by Merck Pharmaceuticals that seeks to increase awareness and promote action on the needs of carers. As part of the campaign, we contributed to the first ever Global State of Care report. The Embracing Carers initiative is



also supporting our state and national level multi-stakeholder activities in India.

Through our association with the Andrews Charitable Trust, we were excited to secure our first Charity of the Year partnership with the Andrews Property Group. Their branch and head office staff threw themselves into a range of fundraising activities from cake sales to colouring competitions to a sponsored cycle ride dressed as a Valentine's heart. In addition, individual employees took part in the London Marathon, the Royal Parks Half Marathon and Ride London. Their incredible efforts raised a colossal £18,592, all of which will go directly to improving the lives of carers in low-and middle-income countries.



Thank you to everyone at Andrews Property Group!

We are also grateful for the support we have received from Boehringer Ingelheim through our association with the Making More Health initiative promoted by Boehringer Ingelheim and Ashoka.

# WITH THANKS TO ALL OF OUR DONORS

Our work is not possible without the individuals and organisations that support us and enable us to achieve real change for carers.



# WITH THANKS TO ALL OF OUR PARTNERS

Our work is not possible without the commitment of our dedicated partners.



## CONTACT US

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