

carers
worldwide

**CARERS
WORLDWIDE
IMPACT REPORT**

ABOUT US

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

We were registered as a UK charity in 2012 and have established operations in India, Nepal and Bangladesh with plans to expand into Sri Lanka in 2019. We draw attention to the poverty, vulnerability, marginalisation and exclusion faced by carers - lobbying local organisations, NGOs, and governments for positive change. We then work together to develop carer inclusive initiatives that meet their needs at all levels **emotionally, physically, socially** and **economically**.

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.

THANK YOU FROM OUR CHAIRMAN



I am honoured to be the Chairman of the Board of Trustees at Carers Worldwide and to see the significant contribution being made to the lives of carers in developing countries. With no other organisation focused solely on tackling this growing global issue, we know just how important our work is. In the five short years since our establishment, I have been amazed by what has been achieved and humbled by the energy and passion of the staff, donors and communities that I have met.

To date, we have helped over 35,000 carers and their families dealing with illness, disability and mental health challenges in India, Nepal and Bangladesh. Our research shows that this is a small fraction of those who need help, but it is the beginning of a journey that will see us reach more than 100,000 people by 2019.

I would like to extend my personal thanks to our donors, supporters and investors. Your belief that change for carers is possible has enabled us to shape and grow our organisation. Without you, the impressive community impact that you will read about in the pages of this report would never have been possible.

I look forward to sharing the next phase of our development with you.

CHRIS UNDERHILL, MBE
Chairman

A MESSAGE FROM OUR FOUNDER



I am delighted to bring you this report showcasing the work and impact of Carers Worldwide since its inception in 2012. Back then, if anyone had asked me where I thought we would be today, I could never have imagined the incredible journey we have taken and the number of lives we have touched and indeed, transformed. With collaboration and inclusion at the core of our Carers Worldwide model, we are ensuring no-one is left behind.

From the humble beginnings of a pilot project with just 250 carers in collaboration with our three longstanding partners SACRED, SAMUHA and NBJK, we now have nine partners across India, Nepal, and Bangladesh. Our work has impacted

over 35,000 individuals. Highlights of this impact include facilitating the independent functioning of five Carers Associations, paving the way for a sustainable carers movement across South Asia and achieving economic inclusion for 93% of carers involved in our projects. This would not have been possible without the enthusiasm and dedication of the carers, family members, partner organisations and supporters with whom we have had the honour of working. To them, our Trustees and our many donors, I extend heartfelt thanks.

Caring is a global issue. It impacts us all, and its scale is growing at a fast pace. Our catalytic approach – raising awareness, strengthening local capacity, building evidence and linking networks – is well placed to tackle the issue. Joining hands with carers and raising their voices from the margins, whilst at the same time influencing the strategy of policymakers is effecting lasting change. I know that as you read the articles and case studies included in this report, you will understand for yourself the impact of that change and join with us to achieve still more in the coming years.

DR ANIL PATIL
Founder and Executive Director

STRATEGIC OBJECTIVES 2017-2019

1. To work in partnership with 12 key delivery organisations in 4 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

“

Our approach is like adding ink to a bucket full of water – you only need a drop, not a whole bottle, to change the colour.

Anil Patil – Founder and Executive Director

”

OUR MODEL

The Carers Worldwide Model comprises five core elements:



CARERS' SUPPORT GROUPS

Reducing loneliness and isolation, creating social networks and supporting emotional wellbeing



ADVOCACY

Strengthening the collective voice of carers at community, regional and national level to achieve changes in policy and practice



HEALTH SERVICES

Creating access to physical and mental health services including locally available counselling services



RESPIRE AND SHORT BREAKS

Offering a break from caring responsibilities and developing alternative, high quality care options



EMPLOYMENT, TRAINING AND EDUCATION

Facilitating access to employment, training or education opportunities tailored to exist alongside caring responsibilities

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 nine 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. We are now poised to replicate and scale up our work across more partners in more countries and to reach our goal of changing the lives of 100,000 carers and their family members by the end of 2019.

BUILDING THE CAPACITY OF CARERS

Mallikarjun's story – Andhra Pradesh, India

Mallikarjun cares for his wife who lost her sight in adulthood. Their sons are grown up and recently left home, leaving Mallikarjun to provide the 24 hour assistance his wife needs. Missing his sons and unable to work, he often felt isolated and worried about the future.

Hearing about a new carers' group in his village gave Mallikarjun fresh hope.

After joining the Yerragudi carers' group, Mallikarjun drew renewed strength from talking to other carers about some of the challenges he faced in caring for his wife. He learned about government schemes that could provide financial support and explored the emotional and financial strain that he was feeling. As his confidence grew, so did his belief that he could help other carers in similar situations.

With a renewed focus and greater knowledge about his rights, Mallikarjun realised that he wanted to be part of the growing movement that would not only help his situation but potentially hundreds if not thousands of others. In June 2017, the Thrinethra Carers Association was registered as an independent organisation in Andhra Pradesh

and Mallikarjun became one of its carer representatives. The Association brings together representatives from carers' groups across the area and is dedicated to providing them with a voice. Carers receive training to build their capacity as community leaders and ensure the sustainability of the organisation. Together they seek solutions to challenges and work collectively to promote health, livelihoods, respite and poverty alleviation initiatives.

Recently, Mallikarjun and the Association President Thufanraju spoke at a Carers Worldwide event in Bangalore, bringing the issue of carers to policymakers, practitioners and academics for the first time in India. We are proud to support Mallikarjun and all the Carers Association members as they continue to take ground-breaking steps towards creating systemic change for all carers across India.

Our Impact

- 342 Carers Groups
- 10 Community Caring Centres
- 2 Carers Co-operatives Registered
- 5 Carers Associations Registered
- 10,000+ carers attended 12 Carers Day celebrations

“

Before the carers' movement began, we had no hope. Now we are making progress and finding solutions to our problems.

Mallikarjun – Thrinethra Carers Association

”



WHERE WE WORK

INDIA

In 2012, we started working with 250 carers of relatives living with a disability or mental illness and by the end of 2017, our work in India had expanded to over 5,500 carers and 22,000 family members. Working with six NGOs across four states, we remain focused on the carers of those living with a disability or mental illness but also see our work expanding to other sectors – the elderly, chronically ill and those living with HIV/AIDS. The successful establishment of four district level Carers Associations - a platform for carers to come together and selfadvocate for their rights - has paved the way for the development of regional forums and ultimately a National Carers Alliance, which will change the landscape for carers and their families into the future.

OUR INDIA PARTNERS

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

NEPAL

Since 2014, we have transformed the lives of over 2,200 carers of people living with mental illness and epilepsy, cerebral palsy and other neurological conditions. We currently work with two highly experienced local NGOs, who act as our delivery partners across urban and rural Nepalese communities. Our operations to date have been diverse and varied, especially in 2015 when our community centred approach proved invaluable after two major earthquakes hit the country. The situation facing carers and their families was devastating, with many losing their homes and livelihoods. We were able to work with some of those worst affected, ensuring that their otherwise silent voice was heard during the subsequent relief and rehabilitation efforts. As a result, co-operative systems for livelihoods diversification and disaster-preparedness are now key features of our programmes.

OUR NEPAL PARTNERS

Kathmandu Valley - Cerebral Palsy Nepal (SGCP)
Baglung and Myagdi – LEADS Nepal

BANGLADESH

Our work in Bangladesh will begin in earnest in 2018. Initial consultations with carers, families and local professionals in Dhaka has echoed the inequalities experienced by carers the world over and our holistic approach of support and advocacy will add significant value. We will also be developing and co-delivering a training programme for NGOs working in the disability sector to ensure awareness of carers' needs is raised and their vital role is recognised. By building the capacity of grassroots NGOs in this way, our 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)



A BRIGHTER FUTURE FOR CARERS

Community Caring Centres, a pathway to independence

Community Caring Centres open the door of opportunity for carers who are disconnected, isolated and alone to re-engage within their communities and access appropriate care options.

Our research shows that more often than not, mothers take on the main role of carer when a child is born with a disability. As the child grows, these mothers become increasingly isolated, impacted further by gender inequality which further disadvantages women in developing countries. Unable to access therapy or educational support for their children,

mothers become responsible for all aspects of their development and care.

Tied to the house, they begin to lose their sense of self. As the years progress, they become less employable, less connected and struggle with the systemic lack of social support and the reality of what the future holds for them and their family. For these women, the reality of their situation can be devastating. We are committed to establishing a network of Community Caring Centres, so that all carers are able to explore a different future for

themselves and their families. Once their children are receiving appropriate care, mothers can explore pathways into employment opportunities and over time renew their sense of emotional wellbeing by connecting with other people who understand their situation.

Economic security – Our Impact

- 93% of carers in our programmes are now earning a living
- £330,000+ in new government support accessed by carers
- £14,500 in group saving schemes



“

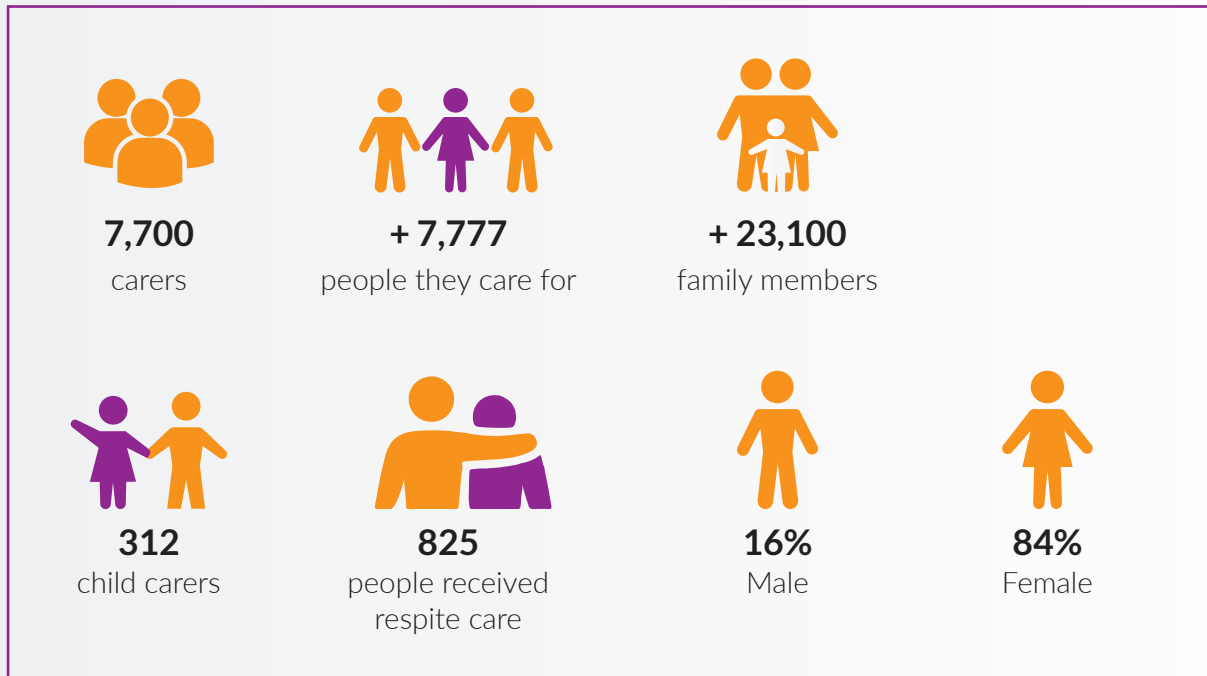
I can now go to work as my child is looked after. My neighbours and local people are also kinder towards us.

*Female carer -
Kathmandu, Nepal*

”

OUR IMPACT SINCE 2012

Our work has touched the lives of 38,577 people in India, Nepal and Bangladesh



3 countries reached (India, Nepal and Bangladesh)



9 NGO partnerships established

2017 INDIA EVALUATION REPORT - CARER FAST FACTS

	Before	After
Families living below the poverty line	97%	22%
Engaged in employment	30%	84%
Have no reliable income	62%	7%
Experiencing anxiety or depression	61%	9%
Have significant health worries	55%	16%

CARING FOR OTHER CARERS

Roshan's story, Koppal District - India

Roshan lives in Agalakari Village with her family. She is 20 years old. Her younger brother was born with an intellectual disability. Now he's a teenager, his needs are becoming more complex which is a strain on the family, so the caring is shared between Roshan and her parents. She also makes and sells jewellery and clothes to help subsidize the family income.

Although entirely committed to helping her parents to care for her brother, Roshan sometimes finds it hard to be so isolated from other young women her age, so she joined the local carers' group set up

by SAMUHA, our partner in Karnataka.

Last year, Roshan trained in embroidery and tailoring in Bangalore. She then returned to her village to work unpaid, further developing her skills by learning from other village women. Now fully trained, Roshan has set up a training programme for other carers in the group, so that they can earn a living by working from home. Her workshops cater for 15 people at a time, teaching the basics of machine and hand stitching, needlework and other tailoring skills.

Her mother Haseena is also a member of the carers' group and provides advice to carers on how to set up a small business and manage the responsibilities of caring and home-based employment. Together, they assist other carers to secure loans through the carers' group to buy sewing machines and other materials to start working and become more financially stable.

Further support of carers like Roshan and Haseena through our livelihoods programmes is critical in helping to build the capacity of local communities to help themselves.



“

Knowing my brother is safe, healthy and well cared for is important to me.

Roshan - Karnataka state, India

”

SAFEGUARDING THE HEALTH AND WELLBEING OF CARERS

Bindira Shrestha's Story – Kathmandu Valley, Nepal

Bindira's son Shrijan Jonsey was born with cerebral palsy. As the years pass, the physical and emotional demands of caring are becoming increasingly challenging for her.

In 2015, Bindira's family home was completely destroyed by the massive earthquake that devastated many communities in Nepal. Along with her husband and their extended family, Bindira was forced to leave her home in ruins and move to Kathmandu. Without employment or a sense of community and living in overcrowded rental accommodation, the uncertainty of their situation took its toll

on Bindira's health. She began to experience constant lower abdominal pain, which restricted her ability to care for Shrijan.

One of the greatest worries facing carers is that one day, their ability to look after their loved one will decline. Facing this reality, Bindira became increasingly distressed and had no idea what the future would hold. After hearing about a carers' group established through the work of Carers Worldwide in her village, Bindira made the decision to attend a meeting.

Over time, she built her confidence and trust with the rest of the group and accepted

an invitation to attend a health camp. Here she talked to specially trained health workers, the first time she had told anyone about her health worries.

Bindira confessed that lifting her son to feed him and helping him on to the toilet caused her excruciating pain, but that she had hidden her worsening health condition because she thought nothing could be done to help her. Since attending the health camp, Bindira has received medical help, her quality of life has greatly improved, and she no longer feels worried about the future.



“

I did not have money or the courage to visit the doctor. I feared that I would never get better and Shrijan would suffer. That worry has been lifted from me now.

Bindira Shrestha – Kathmandu Valley, Nepal

”

HELPING YOUNG CARERS REGAIN THEIR CHILDHOOD

Many of the carers that need our support are children or young people. These youngsters should be going to school, playing with friends and having time to grow up. Instead, many of them are confined to the house, doing everything that a parent would usually do like help dress, feed or bathe their loved one, often their parent. They also take care of household tasks including cooking and cleaning or looking after younger siblings.

Like Ramanjinamma who cares for both her parents, the lives of young carers are dedicated to caring and they miss out on the educational and social experiences many children take for granted. Unable to complete their schooling and with limited opportunities to build relationships, the choices available to young carers later in life can be extremely limited.

Carers Worldwide helps young carers regain their childhood. By raising awareness of their situation and the funds to help, our aim is to ensure young carers can have a childhood, go back to school and socialise with other young people. Having time out from their caring role helps them build the skills they will need for the future. We are committed to identifying more hidden young carers and enabling them to regain as much of their childhood as possible.

WE NEED YOUR HELP

As little as £50 donated to our child carer programme will:

- enable one child to attend private tuition that works around their caring duties
- pay for all the books and stationary they need for their studies
- provide opportunities for them to meet up with other young carers.

For more information on how to give a single or regular gift to help young carers like Ramanjinamma, please contact us at info@carersworldwide.org



Although she still has caring responsibilities, Ramanjinamma now has hope for the future and people she can talk to who understand her situation.

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.



*The Wyn and Ken Lo
Memorial Foundation*



CONTACT US

Carers Worldwide
30 Lodgefield
Welwyn Garden City
Hertfordshire
AL7 1SD
w: carersworldwide.org
e: info@carersworldwide.org
ph: +44 (0) 7745 608438
Charity no. 1150214
Company no. 08083816

