Imagine two brothers living with high levels of pain and psychological distress in a community where there is little access to essential health services. Then imagine your relief as a mother when you are told there is help at hand. That help is Compassionate Narayanganj, a unique community-based partnership palliative care service in Bangladesh.
COMPASSIONATE NARAYANGANJ has been running for 3 years and has been funded by UK Aid Direct but now funding for the project has come to an end, and your help is needed to continue this extraordinarily important work in Bangladesh. In Bangladesh, each year 602,890 people have palliative care needs and most do not have access to the essential health services, including palliative care that is so needed to improve quality of life, provide pain relief, and alleviate unnecessary suffering.

In Narayanganj City Corporation, a city near Dhaka where this family lives, there were no palliative care services at all before the project was introduced, meaning that people with serious and life limiting conditions lived with high levels of physical pain and psychological distress. Also, it is important to remember that 70% of people with palliative care needs helped by the UK Aid project also have some level of disability. Both palliative and disability care needs are inextricably linked.

The brothers, Rajon and Shahjahan (age 25 and 30), living with muscular dystrophy suffered from multiple symptoms including anorexia, extreme weakness, and depression from social isolation. Their mother, who worked as a cleaner and maid, did not make enough money to pay the rent let alone essential medication for the two young men.

Community members, trained by the project, recognised the family’s situation and then this led to regular visits from the Compassionate Narayanganj palliative care team to the family’s small tin home. Their mother received training and support to know how to care for their medical needs and the family was provided with food packs, medicines, and sanitation items for daily use. Gradually, the brothers’ weakness and tremors subsided, and they increasingly began to gain some mobility.

The visiting Palliative Care Assistant (PCA), Nusrat Jahan Munia, is like a sister and family member,” they said. The PCA added, “Sometimes drops of tears of the mother come down as a sign of gratitude and words of blessings are expressed like, ‘May you live years as much as hair I have in my head!’”

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What is Compassionate Narayanganj?

It is a partnership between the Department of Palliative Medicine of Bangabandhu Sheikh Mujib Medical University Hospital- BSMMU (Dhaka), the Worldwide Hospice Palliative Care Alliance- WHPCA (UK) with support from the Narayanganj City Corporation.

The first three years of the project, supported by UK Aid, led to the formation of the Narayanganj Palliative Care Society, a group made up of volunteers from Narayanganj who wish to see palliative care services expanded and made available to all those who need them.

How it works

By mobilising the community, raising awareness on palliative care health and associated rights

By improving knowledge and skills amongst health workers in public health facilities

By establishing community home-based palliative care services, we are creating a locally owned, cost-effective, and innovative care model for replication throughout Bangladesh and South Asia

Help us build on an existing successful model of care

To date, over **120 doctors**, nurses and allied health professionals from the hospitals and clinics in Narayanganj have been trained in basic palliative care so they can better support patients with palliative care needs.

Local youth have been trained as **Palliative Care Assistants (PCAs)** and visit allocated households at least once a week. They provide basic care to the people with palliative care needs (wound dressing, measuring levels of pain, listening to patient concerns and needs, providing basic psychological and spiritual support, running small errands or chores) and support their carers by encouraging them, listening to their concerns and teaching them basics of care.

**Palliative care doctors, nurses and a physiotherapist** have also set up an accessible outpatient clinic in the local community - the first of its kind. **Community awareness events** have raised the profile of palliative care in Narayanganj and led to a group of volunteers forming the Narayanganj Palliative Care Society to roll out palliative care in Narayanganj.

**Patients and carers, especially women**, have been trained on their legal rights such as inheritance and property issues.

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WITH YOUR HELP, MORE PEOPLE LIKE RAJON AND SHAHJAHAN CAN LIVE FULLER LIVES, WITH PAIN CONTROLLED AND HOPE FOR THE FUTURE.

£1.17/DAY will provide a patient like Rajon and Shahjahn with home care including regular visits by palliative care assistants, nurses, doctors, physiotherapists, medicine, and a monthly food pack.

£937 would cover a full year’s salary for one Palliative Care Assistant to provide home based care.

£428/YEAR will provide a patient and their carers with a full year of comprehensive support to address the physical, psychological, legal, economic and spiritual needs.

£64,300 would enable us to provide continued comprehensive support to 150 patients and their carers for a full year.

DURING COVID-19
This project has continued throughout the pandemic and in fact, we saw volunteer engagement increase. People wanted to make a difference to their local community. This highlights ownership and sustainability of the project.

The project has:
• Reached over 12,000 people with factual information about the virus.
• Trained the home based care team and the volunteers to care for patients safely using PPE.
• Distributed soap and hand sanitizer to nearly 2,000 people.
• Provided 455 families affected by COVID-19 with emergency food support.
• Set up a system of telephone consultations instead of face to face visits.

“In Bangladesh, each year 256,000 people die from life-limiting illness and most do not have access to the essential health services”

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What has been the impact?

100% of patients would recommend the services to their family or friends and 97% rated the service as good or excellent meaning there was an extremely high rate of approval from the community for quality, accessible palliative care services.

Patients particularly appreciated the home care and visits and care from the PCAs. They also appreciated the food packs and medicines as well as reported feeling less lonely because of the services.

Out of pocket expenditure on health was markedly reduced for the families.

Vulnerable women supported by the project were able to resolve long standing legal issues related to property and inheritance as a result of legal rights workshop.

A year after training, 85% of health professionals reported they had applied what they learnt. They used the knowledge to care for patients, to improve communication with patients and to provide better basic psychological support to the patients on issues of pain and suffering.

Carers found comfort from sharing their experiences and grief with other people in a similar situation who were also grieving.

How much do we need?

**Narayanganj basic costs 1 year**

- Palliative Care Community Hub running costs (outpatient and office) plus training, helpline and food and medicine support of patients: £13,700
- Funding to support community Palliative Care Assistants: £13,000
- Other medical, nursing, psychosocial and physiotherapy specialists: £13,300
- Project staff, admin, and support: £24,300
- **TOTAL: £64,000**

For more information about how you can help please contact

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"Listening is an important part of palliative care"