whpca

worldwide hospice palliative care alliance

ANNUAL REPORT



2018-2019

We impact people's lives on the ground

We influence policy at the highest levels

We are building a diverse and strong movement demanding care for all.

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We are building a diverse and strong movement

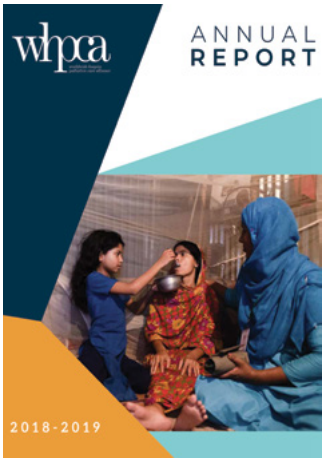
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About the cover



The report's cover image depicts the reality of financial hardship that many families around the world face when in need of palliative care services. Palliative care cannot change the reality of this child assisting her mother in a vulnerable state, but it can ensure that she is not doing so alone. Captured, with a hand on the mother's shoulder, is a palliative care provider who is present, attentive and providing necessary home-based support to increase this family's quality of life.

Executive summary

Welcome to our 2018/19 annual report. The WHPCA's focus this year has been on supporting patients to have a clear pathway to access palliative care services through Universal Health Coverage.

With this in mind, we have worked to capture global data that would guide policymakers in their decision-making to strengthen palliative care programming worldwide. We have also supported innovative programmes that pilot new advocacy and community-based models to support patients to advocate for their own right to care.

As we look to the future of a Universal Health Coverage package inclusive of palliative care services, we acknowledge that collaboration is of essence to achieve this collective aim.

We thank each of our partners, donors and members for your support in helping to make global access to palliative care a reality to the patients we all serve.

As you review this report, we welcome your questions, suggestions and ideas.

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We impact people's lives on the ground

The WHPCA has been working to develop innovative, compassionate community-based programmes to improve the quality of life of people experiencing serious health-related suffering. We do this by strengthening an evidence base to show how all people, including those most vulnerable living in extreme poverty, benefit from quality, community-led, cost effective palliative care as a component of Universal Health Coverage (UHC).

Through strategic partnerships, we have worked to show how people can rise to understand and demand palliative care as part of their own health systems.

This year, our programmatic focus has been on strengthening palliative care services through two pilot projects in Bangladesh. These have demonstrated how palliative care can be delivered as a cost effective model to support vulnerable and marginalised populations.

Developing a "compassionate care" community model

Korail, Bangladesh

In the Korail slum of Bangladesh, we have been working to build a compassionate community model for older people with life-limiting conditions.

With this aim, an innovative approach has been used to train community-based palliative care assistants (PCAs) in service delivery. This year, 575 community members received palliative care services locally from 12 PCAs.

PCAs have hosted 31 courtyard meetings, which as the name suggests, are held in the courtyard of a community member with their adjacent neighbors invited to attend. This means that women who are often unable to leave their house for a long period of time, are able to hear about palliative care services within their own neighborhood. A total of 983 people were reached through these courtyard meetings.

The PCAs have continued to receive mentorship at monthly meetings in Dhaka at the Bangabandhu Sheikh Mujib Medical University (BSMMU) medical centre, our local partner, and have grown in confidence as they share their experiences with the wider palliative care team at the university. They have also contributed to training newly recruited PCAs who started a new palliative care programme in Narayanganj, modelled on this successful project.

As a result of the impact of the community home-based palliative care model, and as a result of the people in Korail raising their voices and making their need for primary care known, the BSMMU has agreed to expand its services and will start sending advanced medical students to hold regular community-based clinics. This will increase access to basic care that they otherwise cannot receive, highlighting the value of palliative care as an integrative community service.

A total of 983 people were reached through these courtyard meetings.

Through strategic partnerships, we have worked to show how people can rise to understand and demand palliative care as part of their own health systems.



A neighbor looks on during one of the courtyard meetings in Korail slum where women in the community learned how to access palliative care services for themselves and their family members.

A recent external evaluation of the Korail project found that it "is addressing an important local need from the angle of health and human rights perspectives." It demonstrates local action as a national and global priority in view of the ageing population in low-and-middle income countries.



This year,

575

community members received palliative care services locally from

12

PCAs.

Narayanganj, Bangladesh

Building upon the Korail model, this year we commenced a community home-based palliative care service in Narayanganj, a city of 2.9 million. Prior to the start of the project, there was not a single palliative care service in the city. As a first introduction to palliative care services, this project is providing an essential element of care and awareness to patients, with an emphasis on sustainability.

A key priority has been placed on increasing knowledge among local health professionals around palliative care and its importance as an integral part of UHC.

By the end of the first year, a fully trained palliative care team consisting of PCAs, nurses, doctors, and volunteers has provided palliative care services to 129 patients (80 females; 49 males) and 480 family members. A further 17 doctors and 26 nurses from health facilities in the city were trained in basic palliative care. Further, through the establishment of a referral system, we are seeing patients who need more specialised care now being able to access these services.

We have also raised awareness and sensitised diverse sectors of the community (schools, community-based organisations, and community leaders) about how palliative care can benefit the community. Through this initiative we have reached over 627 strategic community members (323 females; 304 males).

Moving towards Sustainability

The project's reach has been extended to have policy implications. Our partner, the Centre for Palliative Care at BSMMU, was involved in writing the Bangladesh policy and clinical guidelines for palliative care, an important step towards making palliative care available in the country. A further positive development is that the National Cervical Cancer Programme has recommended the formation of a National Palliative Care Committee and has allocated 1.5% of its budget for this purpose.

Both the Korail and Narayanganj projects have successfully engaged with the wider community in the capital, Dhaka, and have raised local funds for a number of project activities - an important step towards sustainability. The Narayanganj project has also received the full support of the mayor, who has provided a rent-free space for the project to operate.

The WHPCA looks forward to the continued delivery and expansion of its community home-based palliative care project in Bangladesh, in partnership with the Department for Palliative Medicine of BSMMU, as the primary postgraduate medical institution in the country.

The Narayanganj project will run for three years, providing a model for how cost-effective palliative care can be implemented on the path to Universal Health Coverage.



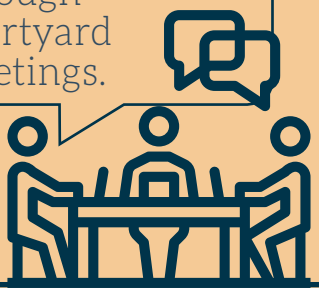
The Narayanganj project particularly focuses on the gender and disability aspects of palliative care in low income settings as over 95% of the project's participants have a reported disability.

BY THE NUMBERS

HOW MANY PEOPLE HAVE BENEFITTED FROM COMPASSIONATE KORAIL*

12,170
HOME VISITS THIS YEAR FROM 12 FULLY TRAINED PALLIATIVE CARE ASSISTANTS AND VOLUNTEERS.

983
Community members reached through courtyard meetings.



583
PEOPLE CARED FOR BY THE PALLIATIVE CARE ASSISTANTS, OF WHOM **400** ARE WOMEN.



95 COMMUNITY VOLUNTEERS TRAINED
in palliative care to help identify and support community members with palliative care needs.



37 BROADCAST AND PRINT MEDIA REPORTS
HIGHLIGHTING PALLIATIVE CARE FOR THE ELDERLY AND THE 'COMPASSIONATE KORAIL' PROJECT.

23
Visits to the project by medical staff, teachers and students from universities, and other international and community-based nonprofits for shared learning.

36 COMMUNITY VOLUNTEERS WHO ARE ELDERLY
AND ARE REACHING OUT TO THEIR PEERS.

31
COURTYARD INFORMATIONAL MEETINGS HELD TO LEARN ABOUT PALLIATIVE CARE SERVICES.

HOW MANY PEOPLE HAVE BENEFITTED FROM THE NARAYANGANJ PROJECT?*

627
COMMUNITY MEMBERS REACHED THROUGH INFORMATIONAL SESSIONS THAT HIGHLIGHTED LOCAL ACCESSIBILITY TO PALLIATIVE CARE SERVICES.

102
Patients and carers who had their experiences captured through an 'experience of care' survey.

98%
of surveyed patients and carers would recommend palliative care services through the Narayanganj project to someone else.

95%
of palliative care patients in the project have a reported disability.

93
COMMUNITY VOLUNTEERS HAVE BEEN TRAINED IN PALLIATIVE CARE TO HELP IDENTIFY AND SUPPORT COMMUNITY MEMBERS WITH PALLIATIVE CARE NEEDS.

88%
OF FEMALE PCA'S HAVE BEEN TRAINED IN PALLIATIVE CARE.

32 CARERS TRAINED
IN HOW TO SUPPORT AND CARE FOR THEIR FAMILY MEMBERS.

26
NURSES WHO COMPLETED BASIC PALLIATIVE CARE TRAINING.

17 DOCTORS HAVE BEEN TRAINED IN PALLIATIVE CARE.

28
Patients referred from community volunteers, partnering hospitals and institutions for patients to receive palliative care.

9
PALLIATIVE CARE ASSISTANTS COMPLETED A TWO-MONTH TRAINING IN PALLIATIVE CARE.

**Figures reflect cumulative activity outcomes over the full course of the project.*

Restoring hope and mobility:

A tale of two brothers



When Palliative Care Assistants visited a small tin home in Narayanganj, they were surprised to meet two brothers, aged 25 and 30, who were completely isolated while living with a disability from (Erb) muscular dystrophy.

The brothers suffered from multiple symptoms from the disease, including anorexia, extreme weakness, tremors and constipation. Their mother, who worked as a cleaner and maid in other people's homes, did not make a sufficient income to make their rent payments.

Further, access to funds for their essential medications did not seem feasible as the family was dependent on the kindness and good will of their neighbors through donations to meet their basic daily needs.

The brothers, who enjoy social interaction immensely, felt socially isolated and depressed. Without treatment in sight, they said they had lost hope, felt spiritually demoralised, and accepted their dire situation as their fate in life. They were so lonely and depressed that they even shared very little conversation amongst themselves.

After recognising the family's situation, with support from community members trained by the project who helped to identify the family, the palliative care team regularly met with the brothers.

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 become mobile. Their demeanor shifted as a result of this unexpected service. They even described themselves as 'cheerful'.

"The visiting Palliative Care Assistant 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 Allah bless you' and 'May you live years as much as hair I have in my head!'"



"The visiting Palliative Care Assistant is like a sister and family member," they said.

Support for global palliative care development

Determining national feasibility for a palliative care policy in Greece

The WHPCA collaborated with the Greece Ministry of Health (MoH) and the Stavros Niarchos Foundation (SNF) to complete a feasibility study on the operational structures and programmes needed to provide palliative care services to meet the country's health needs.

The study assessed the capacity to deliver palliative care in the country, and put forward recommendations for overcoming barriers to palliative care development, which culminated in a press conference in Athens where findings were shared with national media.

The final report addressed all the policy makers in Greece, including the prime minister's office, the parliament, the ministries of health, labor, education, finance and interior; academics; scientists; public health officials; NGOs and civil society organisations.

A summary of the study is available at: https://ehospice.com/international_posts/greecefeasibilitystudy/

The complete study can be downloaded at: http://www.thewhpca.org/resources/item/greek-palliative-care-feasibility-study



Dr Stephen Connor, principal investigator of the Palliative Care Feasibility Study in Greece addressing the media to discuss report findings in Athens.

Assessing the capacity to provide palliative care services through UHC in India

The WHPCA has been supporting partners in India, in cooperation with the Government of India, to determine current capacity to deliver palliative care services according to recognised standards and to build the country's capacity to meet palliative care needs. We are providing technical assistance to source funding for the Indian Association of Palliative Care (IAPC) to map the capacity for palliative care delivery for adults and children in each state in the country. Our collaborating partners in this study include the All India Institute for Medical Sciences in collaboration with the Indian Association of Palliative Care (IAPC).



Co-chairing one of six thematic areas for the World Cancer Congress

2020 World Cancer Congress

World Cancer Congress Muscat, Oman 20–22 October 2020 | The way forward المضي قدما

WHPCA's executive director has been invited to co-chair one of six thematic areas at the Union for International Cancer Control (UICC) World Cancer Congress to be held in Muscat, Oman from 20-22 October, 2020. The conference will include eight sessions that focus on challenges to palliative care globally as well as barriers to improving patient outcomes to cancer care and palliative care.

The WHPCA continues to focus on the support of hospice and palliative care development around the world. Here is a snapshot of this year's initiatives.

Partnering to support the Federal Palliative Care Centre launch in Moscow

The WHPCA engaged with partners to support the lead up to the launch of the Federal Palliative Care Centre in Moscow. The launch of the centre was the result of many years of work by Russian state and public organisations, and is significant as palliative care is identified as one of the Russian Federation's strategic areas of engagement within its health industry.

The Russian government has also dedicated the equivalent of over USD $60 million annually to palliative care development across the Federation. An informal partnership to promote palliative care in Russia and former Soviet republics has been formed to include the WHPCA, the American Eurasian Cancer Alliance, Harvard Medical School, Johns Hopkins Medicine, Indiana University, St Christopher's Hospice, the Hospice Care Professionals Association in Russia, and PACED in the United Kingdom.



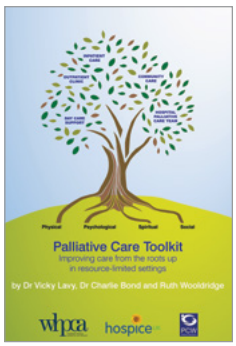
Dr Stephen Connor speaking at the opening of Russian palliative care centre in Moscow.

Technical support for palliative care as a component of programme development

We supported Hospice Ethiopia to obtain a grant from EthiopiAID to improve access to compassionate community home-based palliative care. The project aimed to show how a cost-effective and sustainable palliative care service can be provided to cover the population of an urban setting in Ethiopia, including those experiencing extreme poverty, through community Iddirs which are traditional burial and community support societies. Iddir leaders play active roles in advocating for more support from the government and other organisations as well as empowering beneficiaries on their health, legal and economic rights in the country.

Read more about this project at: https://ehospice.com/africa_posts/palliative-care-patient-advocate-educates-community-leaders-in-ethiopia/

Resources for programme development



The WHPCA *Palliative Care Toolkit* and training manual continues to be a useful resource for partners developing palliative care programmes in limited resource settings and has been downloaded over 35,600 times.

This updated resource is available at: http://www.thewhpca.org/resources/item/palliative-care-toolkit-2016



We co-edited and published a new book, *Building Integrated Palliative Care Programs and Services* (2017). This resource has been downloaded over 2,000 times.

This resource is freely available at: http://www.thewhpca.org/resources/building-integrated-palliative-care-programs-and-services

We influence policy at the highest levels

This year, we have continued to focus on ensuring the voices of people with palliative care needs are heard and included in policy formation for change to occur at the grassroots level -- where communities truly experience the impact of palliative care services.

Elevating the platform of persons receiving palliative care services

We continue to ensure that the voices of people with palliative care needs is central to driving our advocacy work. We have done this by supporting an increased engagement of direct stakeholders in global and national palliative care advocacy events. This year, we recruited two trustees who are direct stakeholders whom have personally benefitted from palliative care services.

We also supported a bereaved parent (Sharon Thompson) to speak out at the January 2019 WHO Executive Board and to have direct contact with the WHO Director General, Dr Tedros Adhanom Ghebreyesus.

On World Hospice and Palliative Care Day, we published a report with letters from women directly affected by palliative care which was shared with key decision makers globally.

With support from the Open Society Foundations, we ran a grants programme to elevate the voices of people with palliative care needs in direct advocacy in low-and-middle income countries. The aim of the project was to address the power dynamics involved in palliative care patients having external advocates speaking out on their behalf. Four grants were given to direct stakeholder programmes in India, Romania, Rwanda and Zimbabwe.

Read more about the project at: http://www.thewhpca.org/about-us-3/direct-stakeholders-project

Increasing demand for palliative care as part of Universal Health Coverage in South Africa and Ethiopia

Through the Patient Power project, the WHPCA and its partners are providing a platform for direct stakeholders (people with lived experience of palliative care) to highlight their experiences to policymakers, the media and the general public. In both South Africa and Ethiopia, mainstream media reports covered the experiences of direct stakeholders receiving palliative care services.

As part of media palliative care trainings in South Africa and Ethiopia, we produced a media fact sheet on palliative care and Universal Health Coverage, drawing upon the experience of the African Palliative Care Association in media outreach across Africa.



The media factsheet is available at the following link: http://www.thewhpca.org/resources/item/palliative-care-fact-sheet-for-media-in-south-africa



In South Africa, we supported the Hospice Palliative Care Association of South Africa (HPCA) to recruit three direct stakeholders who shared their experiences on social media and through media interviews with the South African Broadcasting Corporation (SABC), the Centre for Health Journalism, and the Daily Maverick, among other media outlets. Here is a select list of media reports:

- ***Dying of the light: How Soweto lost its only hospice.*** An article by Joan Van Dyk, Bhekisisa, Centre for Health Journalism.
- ***Managing pain, not death – how hospice helps.*** Hospices are associated with dying, but many simply help people to cope with the pain they are experiencing. An article by Amy Green, Daily Maverick.
- ***What people don't realise is how expensive it is to die***. An article by Katherine Child which was featured in TimesLIVE.
- ***HPCA Calls for Quality Care for all South Africans***. An article by Terri Chowles which was published on the website eHealthNews.

Additional outreach strategies leveraged through the project included meetings with Iddir leaders in Ethiopia who are influential at the community level, particularly around emergency situations and funerals. Outreach to these leaders included the dissemination of flyers and posters to support their efforts to raise awareness of palliative care in their community. The flyer focused on the meaning and benefit of palliative care, information on who would benefit from this service, and included contact details of Hospice Ethiopia. A total of 257 flyers and 80 posters were distributed in Amharic.

Meet the palliative care patient champions who are speaking to power



Huyaam is a 20 year-old student from Cape Town, living with a rare condition called Pseudoachondroplasia and Hypermobility Syndrome. She is a vocal advocate for hospice and palliative care, based on her positive experience of palliative care, with organisations in Cape Town supporting her throughout her illness.



Petra Burger has been employed by the HPCA as their Disability Mainstreaming Coordinator. She was thrilled when approached to be a direct stakeholder in the project. She is a passionate woman who proudly advocates for palliative care, drawing on her own experience. Petra was a keynote speaker at the two journalist training sessions. After the session she was interviewed by SABC news (a prominent national radio station in South Africa) and was featured in TimesLive & the Daily Maverick (prominent national newspapers in South Africa).



Kalkidan is a 24-year-old mother of twins who has shared her experience in accessing palliative care services for breast cancer. She has presented her story to the media repeatedly and has been influential in highlighting the importance of palliative care in Ethiopia. Her presentations have addressed the Ethiopian Federal Ministry of Health's support of palliative care – addressing the importance of a national palliative care policy and guidelines, the issue of opioid availability in the country, and palliative care as part of Universal Health Coverage.

A total of 257 flyers and 80 posters were distributed in Amharic.

Building partnerships around UHC and NCDs

Much of our work this year was centred upon preparations for the UN High Level Meeting on Universal Health Coverage in September. In the leadup, we supported national partners with key messages, technical assistance and materials for their national advocacy on the inclusion of palliative care within UHC.

The United Kingdom has played a unique role in hospice and palliative care development globally. This year, we have focussed on relationship building with UK-based civil society and academia to increase UK government support for palliative care as part of their global health and UHC work.

At the World Health Assembly in January, we advocated for the inclusion of palliative care in the WHO General Programme of Work as part of UHC deliberations. In 2018, we supported our partners to advocate and mobilise national advocates to include palliative care in the Astana Declaration on Primary Health Care.

The WHPCA, with its allies, is also working to ensure that governments translate their promises into tangible progress in addressing the integration of palliative care services into NCD policies. WHPCA's Executive Director Dr Stephen Connor continues as a member of WHO's Civil Society Working Group on Non Communicable Diseases (NCDs). The remit of the Civil Society Working Group has been extended to 2021 to allow for civil society input into UHC deliberations from the UN High Level Meeting, and beyond.

Throughout the deliberation process in the lead up to the UN political declaration on Non-Communicable Diseases, the WHPCA advocated for the inclusion of palliative care in the final declaration, as it was not included in the zero draft. As a result of our work and the collaboration of partners, we are pleased to report that two references to palliative care were included in the final declaration.



"Promotive, preventative, rehabilitative services and palliative care must be accessible to all. We must save millions of people from poverty, particularly extreme poverty, caused by disproportionate out-of-pocket spending on health" – Astana Declaration, 2018

Our goal is to open the minds of policymakers to the idea that palliative care is an essential and cost effective service under Universal Health Coverage. We influence policy by:

1 Mobilising our membership and many partners to engage in global, regional and local legislative developments that underpin palliative care services under Universal Health Coverage.

2 Contributing to technical plans and the palliative care research landscape.

3 Influencing policy through the voices of patients who carry influence in expressing their first hand experience of palliative care services.

As momentum increases towards the attainment of Universal Health Coverage by 2030, we continued to advocate in collaboration with our members and partners for the inclusion of an essential package of care as part of Universal Health Coverage. Those who are suffering must not be left behind.

Developing advocacy materials

In preparation for the UN High Level Meeting on UHC, we developed a two-page factsheet on palliative care and UHC in collaboration with our partners - the ICPCN and the IAHPC.

The factsheet is available at: http://thewhpca.org/resources/item/palliative-care-and-universal-health-coverage-fact-sheet-june-2018



We also developed a short film of Lucy Watts, a palliative care direct stakeholder, calling on the UK government to increase its support of palliative care globally.

The video is available at the following link: https://www.youtube.com/watch?v=NgUPnGhGuos

"I'm asking you, the UK Government, to use your power well to provide funding and technical assistance to lower middle income countries to institute Universal Health Coverage, inclusive of palliative care..."

Lucy Watts, MBE



We are building a diverse and strong movement demanding care for all

We are working to engage and build our membership to be an empowered advocacy network for universal coverage of palliative care. Through our stewardship of World Hospice and Palliative Care Day, and through the dissemination of palliative care news through the International edition of ehospice, we are bringing the global palliative care community together to strengthen our collective impact.

Strengthening our global membership

Our global membership includes institutions at the forefront of improving people's lives through essential health services. To see policy level success translate to action on the ground, we aim to listen and to consistently support our membership.

Our diverse and active membership has grown to 356 members, representing over 100 countries and we are committed to consulting and engaging with our members on global advocacy for our work to become truly member-led.

ehospice

The WHPCA manages the International edition of ehospice, the world's leading news website for hospice and palliative care. This year, ehospice updated its interface to be more economic and efficient in platform management.

This year, ehospice International published 66 articles with stories from around the world, drawing 206,656 unique page views by 138,842 users, averaging over 17,000 page views per month by 1,570 readers.

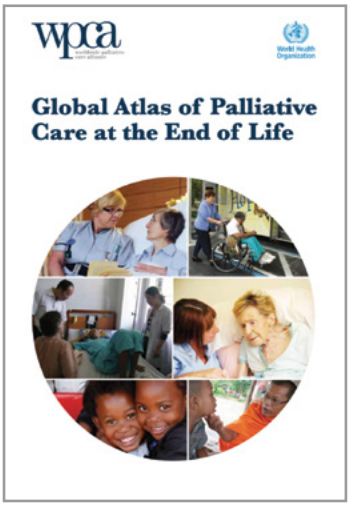


Growing our digital presence

We have increased our engagement on social media channels, including Facebook and Twitter. This year, we grew our following to 3,269 total page likes on Facebook and 4,921 followers on Twitter. We have been managing and updating our WHPCA website with news updates relating to hospice and palliative care worldwide. This year, there were 46,279 sessions and 110,113 unique page views by 34,120 users on the WHPCA website.

The WHPCA has further been strengthening communication with its partners and members through its monthly newsletter which is circulated to over 1,500 recipients in 115 countries.

17,000 ehospice page views per month by 1,570 readers.



WHO/WHPCA Global Atlas of Palliative Care at the End of Life

Our WHO/WHPCA *Global Atlas of Palliative Care at the End of Life* (2014) has now been downloaded over 86,000 times. We are working on gathering data for the 2nd edition of the Atlas, in collaboration with the WHO, the University of Miami, the University of Glasgow, and other partners.

The Atlas is available at the following link: http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care

The 2nd edition, to be released in 2020, will include new sections addressing the relationship between curative and palliative care, health workforce need, a minimum package of palliative care services and palliative care for new diagnostic conditions, among other new sections.

86,000 downloads of the Global Atlas of Palliative Care at the End of Life

World Hospice and Palliative Care Day

The 2018 theme for World Hospice and Palliative Care Day, 'I am Because I Matter' resonated globally with 142 events registered on the WHPCA website from 51 countries.

In alignment with the theme, a report of open letters from six extraordinary women who have directly experienced palliative care was published. These letters addressed decision-makers who can influence access to palliative care in Australia, Bangladesh, India, South Africa and the UK, among other global policymakers.



We are pleased to report that these open letters were viewed 537 times on the WHPCA website.

BY THE NUMBERS

#BECAUSEIMATTER

1500

The number of times the hashtags #BecauseIMatter and #PorqueYoImporto were tweeted

1.8 million

the number of accounts reached through the hashtag

6.4 MILLION

the number of hashtag impressions.



The top contributor to the conversation was @MinSaludCol (Colombia Ministry of Health), contributing 3.5 million impressions to the campaign's reach

We would like to thank our partners for their annual support in mobilising communities worldwide to celebrate World Hospice and Palliative Care Day.

Strengthening collaboration with partner institutions

The WHPCA has been strengthening its partnerships with regional and international institutions working on issues relating to palliative care.

We have initiated and curate the Global Palliative Care Advocates Google Group, which has **168 members** and is used routinely for real-time discussions on key global issues.

Every quarter, we coordinate a teleconference for sharing experiences, opportunities and collaborative planning with our international allies such as the International Children's Palliative Care Network (ICPCN), the International Association for Hospice and Palliative Care (IAHPC), the Union for International Cancer Control (UICC), and Human Rights Watch.

A partnership with the ICPCN and the IAHPC is in process of being more formalised with a statement of collaboration, recently accepted for publication in the *Journal of Palliative Medicine*.

We have also strengthened collaboration with non-specific palliative care allies and networks such as the Action for Global Health, the NCD Alliance, the UICC, the Center for Global Health within the National Cancer Institute (NCI), and the Global Alzheimer's and Dementia Action Alliance, along with many other partners. We are working to ensure a coordinated and collaborative voice on issues ranging from Universal Health Coverage to NCDs.

WHPCA publications

Book

Connor, S. (2018). *Hospice and Palliative Care: The Essential Guide*, 3rd Edition. New York: Routledge.

Book chapters

Connor S. (2018). *Global Aspects of Palliative Care*. In R. McLeod & L. Block (eds.), Textbook of Palliative Care. https://doi.org/10.1007/978-3-319-31738-0_4-1

Journal articles

Baur, N., Centeno, C., Garralda, E., Connor, S., & Clark, D. (2019). Recalibrating the 'world map' of palliative care development. *Wellcome open research*, 4, 77. doi:10.12688/wellcomeopenres.15109.2

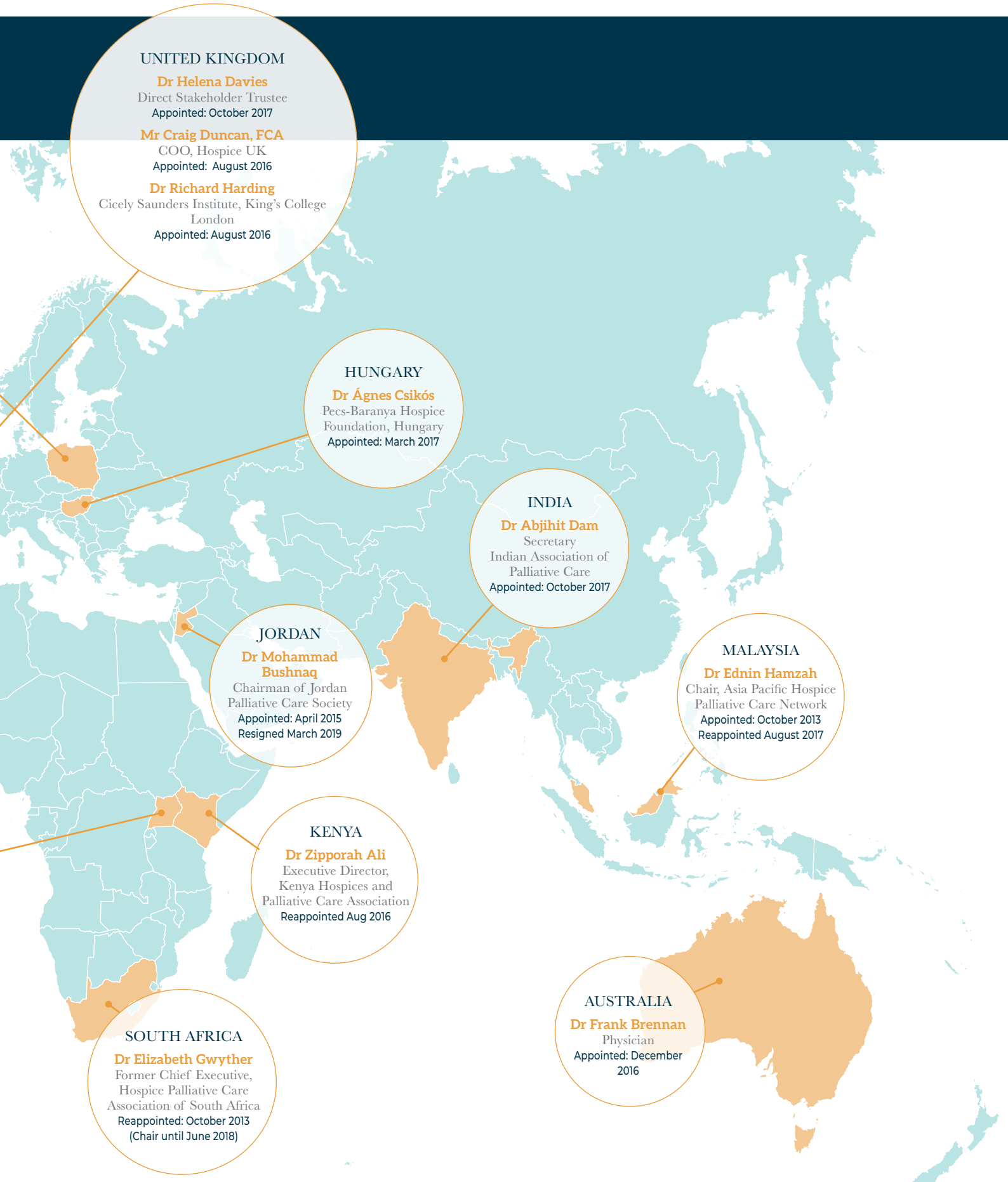
Connor S, De Lima L, Downing J, Ling J, Quillam P, Radbruch L. (2019). The Berlin Declaration – a Collaborative Roadmap to Advance Global Hospice and Palliative Care. *J Pall Med*

Muir JC., Davis M.,Connor S., Kuhl E., Fine P. (2018). A Systematic Assessment and Monitoring Intervention to Improve Pain Management and Quality Reporting Among Home Hospice Patients. *Journal of Pain and Symptom Management*. 56. 10.1016/j.jpainsymman.2018.08.014.

Pettus K., De Lima L., Maurer M., Husain S., Connor S., Torode J., Ling J., Downing J., Rajagopal M., Radbruch L., Pastrana T., Luyirika E., Goh C., Marston J., Cleary J. (2018). Ensuring and Restoring Balance on Access to Controlled Substances for Medical and Scientific Purposes: Joint Statement from Palliative Care Organizations. *Journal of Pain & Palliative Care Pharmacotherapy*. 32. 1-5. 10.1080/15360288.2018.1488792.

Governance representation




UNITED KINGDOM
Dr Helena Davies
Direct Stakeholder Trustee
Appointed: October 2017
Mr Craig Duncan, FCA
COO, Hospice UK
Appointed: August 2016
Dr Richard Harding
Cicely Saunders Institute, King's College London
Appointed: August 2016
HUNGARY
Dr Ágnes Csikós
Pecs-Baranya Hospice Foundation, Hungary
Appointed: March 2017
INDIA
Dr Abjihit Dam
Secretary
Indian Association of Palliative Care
Appointed: October 2017
JORDAN
Dr Mohammad Bushnaq
Chairman of Jordan Palliative Care Society
Appointed: April 2015
Resigned March 2019
MALAYSIA
Dr Ednin Hamzah
Chair, Asia Pacific Hospice Palliative Care Network
Appointed: October 2013
Reappointed August 2017
KENYA
Dr Zipporah Ali
Executive Director, Kenya Hospices and Palliative Care Association
Reappointed Aug 2016
AUSTRALIA
Dr Frank Brennan
Physician
Appointed: December 2016
SOUTH AFRICA
Dr Elizabeth Gwyther
Former Chief Executive, Hospice Palliative Care Association of South Africa
Reappointed: October 2013
(Chair until June 2018)

Challenges and Opportunities

This year has carried significant momentum towards mainstreaming palliative care into national health systems through UHC. However, with this growth, the need to cultivate new avenues for funding has increased while palliative care funding streams have diminished.

Our current efforts are aimed at ensuring palliative care is included in all national plans for UHC by 2030 so that people can get the palliative care they need, when they need it, without suffering financial hardship.

The demand for palliative care research remains imperative to this aim, in order to guide policymakers in their fiscal allocations for palliative care services. We are seeking new funders to support an expansion of research and advocacy initiatives to meet the global demand for palliative care services.

Future plans

The WHPCA will continue to expand its efforts to formalise partnerships with two international institutions that share a similar vision to advance palliative care globally. As noted, further information on this initiative is pending publication in the *Journal of Palliative Medicine*.

We are seeking new funders to support an expansion of research and advocacy initiatives to meet the global demand for palliative care services.

We are also examining opportunities to advance palliative care by continuing to explore innovative and effective implementation models for palliative care in low and middle income countries, such as Kenya and Bangladesh, for broader applications to other contexts.

Throughout the year, we will continue to advocate for palliative care through research and its intersection with public policy. We will do this through a third wave of mapping for palliative care development in partnership with the University of Glasgow, and through the forthcoming publication of the Second Edition of the *Global Atlas for Palliative Care at the End of Life*. We also anticipate learning and new partnership development at the 2020 UICC Congress themed 'The Way Forward' in Oman, where we are co-chairing a thematic section.

In our advocacy, we will continue to bring national advocates together and we are developing a series of webinars with this aim. Through the International edition of ehospice, we will also continue to build the global palliative care movement by sharing news and analysis of palliative care developments. Through our stewardship of World Hospice and Palliative Care Day, we anticipate strengthened partnerships and hope to find new avenues for growth and collaboration.



Thank you

We would like to thank our donors for this year without whom our work would not be possible.

WE EXTEND OUR APPRECIATION TO:

1. Anonymous Donor
2. UK aid from the British people
3. Open Society Foundations
4. Stavros Niarchos Foundation
5. The Joffe Charitable Trust
6. United States Cancer Pain Relief Committee.

Financial Report

Statement of financial activities
(Incorporating an income and expenditure account)

				2019	2018
		Unrestricted	Restricted	**TOTAL**	TOTAL
	NOTE	£	£	**£**	£
Income					
Donations and legacies	*2a*	1,136	366,520	**367,656**	226,849
Income from charitable activities	*2b*	6,155	-	**6,155**	9,365
TOTAL INCOME		**7,291**	**366,520**	**373,811**	**236,214**
Expenditure					
Raising funds	*3*	18	-	**18**	18,397
Charitable activities	*3*	(1,992)	361,955	**359,963**	258,893
TOTAL EXPENDITURE		**(1,974)**	**361,955**	**359,981**	**277,290**
Net income / (expenditure) in the year		9,265	4,565	**13,830**	(41,076)
Reconciliation of funds					
Total funds brought forward		13,349	204,889	**218,238**	259,314
TOTAL FUNDS CARRIED FORWARD	*11*	**22,614**	**209,454**	**232,068**	**218,238**

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above.

For the year ended 31 March 2019

Balance Sheet

	Note	2019 £	2018 £
Tangible Fixed Assets		879	0
Current assets			
Cash at bank and in hand		151,393	176,187
Debtors	*9*	80,678	46,849
		232,071	223,036
Liabilities			
Creditors: amounts due within 1 year	*10*	(882)	(4,798)
Net current assents		231,189	218,238
Net assets		232,068	218,238
Funds			
Restricted funds		209,454	204,889
Unrestricted funds		22,614	13,349
TOTAL CHARITY FUNDS	*11*	232,068	218,238

© November 2019 Worldwide Hospice Palliative Care Alliance

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