

# Annual Report

*April 2016 to March 2017*

whpca

worldwide hospice palliative care alliance

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We impact on 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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## Executive summary

WHPCA has had a terrific year growing and developing palliative care worldwide. We are working hard to realise the promise of the World Health Assembly resolution on palliative care calling on all countries to prioritise and promote palliative care development as part of Universal Health Coverage. This report will share with you our impact, activities, leadership, and finances for the past year. Please feel free to contact us with questions, suggestions and ideas on info@thewhpca.org

Cover image: Community meeting, Korail slum, Bangladesh




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# We impact people's lives on the ground

The WHPCA is focusing its programming work on 6 target countries to develop innovative, compassionate community based programmes to improve the quality of life of people with serious illness. These 6 countries are: Bangladesh, Ethiopia, Jordan, The Philippines, Ukraine and Panama.

We have initially focused on programme development with our partners in Bangladesh, Jordan, and Ethiopia. These programmes will seek to show how cost-effective palliative care can be provided to people who need it as a component of Universal Health Coverage by 2030.



Palliative Care Assistants help an elderly man trim his nails in Korail slum Bangladesh

***"Girls (PCAs) take care of me as their mother. They check my blood pressure, massage my body, spend their time with us, have a chat and inquire about our health status."***

Project beneficiary

## Compassionate Korail – Bangladesh

The WHPCA is working with local partner, the Centre for Palliative Care at Bangabandhu Sheikh Mujib Medical University (BSMMU), to build a sustainable compassionate community for older people with serious illness in the largest slum of Dhaka (Korail).

We completed a one year pilot project and worked with the University of Glasgow to oversee the evaluation. In February 2016, we secured funding to undertake an additional two years to make the project fully sustainable within the community itself and to share learning internationally.

A total of **106 patients** and their families benefited through this project since its inception in 2015.

Eight young women were **recruited from the slum,** trained as Palliative Care Assistants (PCAs) and supported by a team of doctors and nurses.

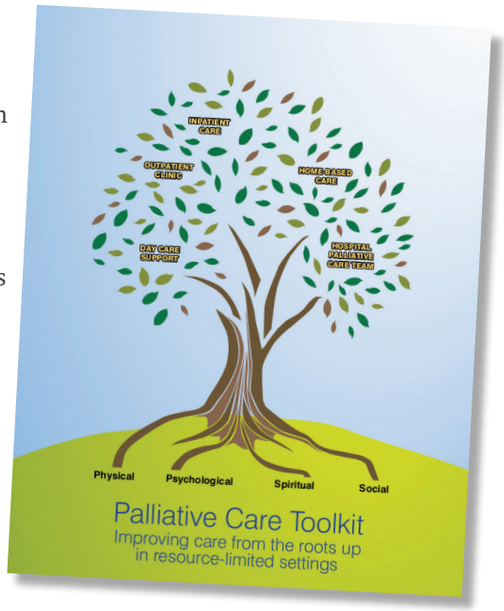
The project found that beneficiaries were **highly satisfied** with the care and support they received.



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## Palliative Care Toolkit

This year, we worked with Palliative Care Works to develop and publish a revised edition of the '*Palliative Care Toolkit: improving care in resource-limited settings*' based on an evaluation in 2015. This is a critical resource for supporting those in low and middle income countries to provide, and train others to provide, palliative care. It is now translated into nine languages.




***"We tried implementing palliative care at the district hospital but it was difficult due to competing priorities and focus on other disease burden. Around that time, we had some visitors from Europe and one of them gave me a copy of the toolkit. I was surprised, if not shocked, because it was like discovering a new field of medicine. I had not been exposed to other palliative care resources other than the slides from the initial training I received and would occasionally reference. The toolkit was marvelous as it put all the components in one, in a very clear, easy to follow and practical way. We pioneered the dissemination of palliative care thereafter and facilitated the development of a national curricula based on the toolkit. Palliative care has been integrated in our public health sector and since 2012 all districts have been trained using the national curricula."***

Informer for the Palliative Care Toolkit evaluation, 2015



Hospice Ethiopia

Hospice Ethiopia beneficiary.

## Improving compassionate community palliative care – Ethiopia

We worked with Hospice Ethiopia and other partners in Ethiopia to co-develop a programme to improve access to quality palliative care services (contributing to UN SDG 3, target 3.8) in Ethiopia. We are working to access funding for this project which will help over 4300 people and provide a model for sustainable community based action on palliative care in Ethiopia.

In addition, we worked with Ethiopia Aid to secure financial support for Hospice Ethiopia to build their crucial work caring for people with serious illness in Addis Ababa.

***"Working with the WHPCA to develop a new project plan around a community based palliative care programme with the Iddir groups has been a great learning experience for Hospice Ethiopia. To get this funded would make a huge difference to so many people's lives."***

Ephrem Abathun, Executive Director, Hospice Ethiopia



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# We influence policy at the highest levels

The WHPCA represents our global membership at the highest level. We ensure that the voices of those working on palliative care on the ground and those who are accessing, or need, palliative care are heard and their experiences are acted upon. We work in partnership and collaborate with all those who share our goals and vision. The commitment of the World Health Organization and other UN bodies, multilateral agencies and national governments to improve access to palliative care is crucial to achieve our goal of universal coverage of palliative care for all.



United Nations General Assembly



## United Nations General Assembly Special Session on the World Drug Problem

Following great advocacy by our partners at the International Association for Hospice and Palliative Care and others, WHPCA Trustee, Dr Zipporah Ali, addressed world leaders at the plenary session of the United Nations General Assembly Special Session (UNGASS) on the World Drug Problem. The aim of the meeting was to review the global drug control system and to agree on a way forward. Dr Ali's plenary brought the need for balance in drug control policies to the attention of delegates.

## Universal Health Coverage

Universal Health Coverage is the most crucial health movement of our generation and a key target within the United Nations Sustainable Development Goals. People around the world, under the leadership of the World Health Organization, are demanding health for all as a human right.

UHC means that everyone has access to the essential health services that need from promotion, prevention, treatment, rehabilitation and palliative care without being forced into financial hardship. At every opportunity, at all levels, we are clearly articulating that Universal Health Coverage cannot be achieved without palliative care.

The WHPCA collaborated with Hospice UK and Island Hospice and Healthcare, Zimbabwe, to host an event in London in November 2016. The event provided an opportunity for crucial dialogue on how quality community based care programmes, specifically palliative care programmes, fit into this discussion and the implementation of UHC and was attended by a diverse range of stakeholders from the Department for International Development, the diaspora, funders, academia and International Non-Governmental Organisations.

***"It is not Universal Health Coverage if there isn't palliative care for everyone who needs it!"*** Robert Yates, Director of the UHC Policy Forum, Chatham House



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## World Health Assembly

Our Executive Director, Dr Stephen Connor, advocated for palliative care at the 69th World Health Assembly in May 2016.

WHO reported back on the resolution adopted two years previously at the 67th WHA: 'Strengthening of palliative care as a component of comprehensive care throughout the life course (resolution WHA67.19)'. Dr Connor presented the Civil Society report on progress towards the resolution, calling on WHO and member states to prioritise the development of palliative care, and that they dedicate resources to accelerate this process.





### Global Action Plan on the Public Health Response to Dementia

WHPCA and our global, regional, and national allies advocated successfully to include palliative care in the Global Action Plan on the Public Health Response to Dementia.

In September 2016 the WHO Secretariat published a Zero Draft Global Action Plan on the Public Health Response to Dementia that did not reference palliative care and advocated with our partners for strong language on access to palliative and end of life care to be included.

PCAs and palliative care pharmacist visit a beneficiary in Dhaka, Bangladesh



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

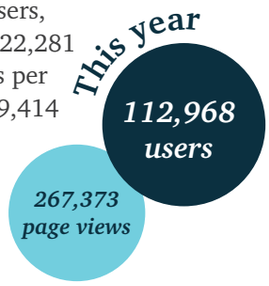
We know that universal coverage of palliative care for all those who need it will only be achieved through a strong movement at all levels. For this reason, we are working hard to engage and build our membership, be transparent and open with learning and information and provide opportunities for people at all levels to act, engage and demand increased access to care.




## ehospice

The WHPCA manages the International edition of ehospice, the world's leading news website for hospice and palliative care.

This year, ehospice international received 267,373 page views by 112,968 users, averaging 22,281 page views per month by 9,414 users.




## Strengthening our global membership

Our global membership of 250 organizations in 90 countries are those doing the work on the ground to improve people's lives. To see policy level success translate to action on the ground we know we must listen and support our membership more to build the global voice. We are doing this by increasing interactive conversations through social media and WhatsApp enabling us all to share opportunities and learning relating to advocacy, fundraising and communications and provide critical opportunities for equal dialogue to increase impact. We have also been working to develop country-based programme development and fundraising capacity in target countries to access funding for country level palliative care development. The increased capacity of the WHPCA membership is critical to achieving universal coverage by 2030.




## World Hospice and Palliative Care Day

We coordinated World Hospice and Palliative Care Day, the global day of action for palliative care on 8 October 2016. The theme was: Living and Dying in Pain - It doesn't have to happen. This highlighted the "global crisis" in access to pain relief, whereby 75% of the world's population live in countries with no – or inadequate – access to controlled medications to manage their pain.

116 events were registered from 41 countries but we know that events took place in many more countries that were not registered. The World Hospice and Palliative Care Day toolkit was viewed on the website 3377 times.



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'Imagine' – YouTube video created for Universal Health Coverage Day.

## Creating new resources: 'Imagine' - UHC and Palliative Care

We created a short animation explaining UHC and palliative care and shared this via social media on UHC Day (12 December). The animation reached 639 people, and received 13 likes and six shares on Facebook, and 607 impressions and 72 engagements on Twitter. It was viewed 1025 times on our website.




Dr Amandua Jacinto, palliative care advocate and beneficiary, addresses the plenary session at the 5th International African Palliative Care Conference.

## 5th International African Palliative Care Conference

In August 2016, along with the African Palliative Care Association, we co-hosted the 5th International African Palliative Care Conference in Munyonyo, Uganda. Delegates attended from around Africa and beyond. The 2nd African Ministers of Health session took place ahead of the conference, with Ministers discussing and adopting the Kampala Declaration, a consensus statement for strengthening palliative care as a component of comprehensive care throughout the life course in Africa.




World Hospice and Palliative Care Day 2016 celebrations in Korail slum, Bangladesh.

## Improving collaborative working

WHPCA has strong partnerships with others working internationally and regionally on issues relating to palliative care. Every quarter we coordinate a teleconference for sharing experiences and opportunities and harmonising actions with our international allies such as the International Children's Palliative Care Network (ICPCN), the International Association for Hospice and Palliative Care (IAHPC), Union for International Cancer Control (UICC) and Human Rights Watch. Critically, we are building collaboration with non-specific palliative care allies and networks such as Action for Global Health, the NCD Alliance and the Global Alzheimer's and Dementia Action Alliance to build a big tent of those who want palliative care to be available to everyone who needs it.



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# Membership

We have a diverse and active membership of 250 hospice and palliative care organisations based in over 90 countries.

**250**
hospice and palliative care organisations

**90** countries



# Governance representation

## WHPCA Board of Directors (During Fiscal Year)

Dr Elizabeth Gwyther - Chairperson
Hospice Palliative Care Association of S. Africa

Prof. Julia Downing
International Children's Palliative Care Network

Dr. J. Donald Schumacher
National Hospice & Palliative Care Organization (USA)

Ms Joan Marston
International Children's Palliative Care Network

Dr. Eduardo Yanneo
Latin American Palliative Care Association

Dr Priyadarshini Kulkarni
Indian Association of Palliative Care

Ms. Sharon Baxter
Canadian Hospice Palliative Care Association

Dr. Julie Ling
European Association of Palliative Care

Dr. Jorge Eisenchlas
Argentine Association of Medicine and Palliative Care

Dr. Zipporah Ali
Kenya Hospice and Palliative Care Association

Dr. Emmanuel Luyirika
African Palliative Care Association

Dr. Ednin Hamzah
Asia Pacific Hospice Palliative Care Network

Dr. Tania Pastrana
Latin American Association for Palliative Care

Dr Mohammad Bushnaq
Jordan Palliative Care Society

Mr. Craig Duncan
Hospice UK

Dr Ágnes Csikós
Pees-Baranya Hospice Foundation, Hungary

Dr. Richard Harding
Kings College London, Cicely Saunders Institute

Ms. Liliana De Lima
International Association for Hospice and Palliative Care

Dr Frank Brennan
Australian New Zealand Society of Medicine

Dr James Cleary
Pain and Policy Studies Group, University of Wisconsin



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Hospice Palliative Care Association of South Africa

# Challenges & opportunities

The need for palliative care still outstrips our capacity to deliver. Last measurement showed less than 10% of the overall global need being met. In 2018 a third iteration of the World Map of palliative care development will be conducted so we can see what progress has been made since 2011. To meet the aims of the World Health Assembly (WHA) palliative care resolution much more work is needed to achieve inclusion of palliative care education for all health professionals, to ensure access to strong analgesics in every country for pain relief, to guarantee inclusion of palliative care in all health policies, and to align resources for palliative care service implementation.

# Future plans

WHPCA is growing and gaining strength as an international NGO. We will be developing a new strategic plan in 2018 for the coming years and expect to expand our development work to realise the promise of the universal coverage of palliative care including the implementation of WHA resolution on palliative care. We will be working increasingly closely with our members and partners to develop palliative care advocacy from the grassroots, building palliative care programmes which will increase global awareness of palliative care's benefits and value to people with serious illness and families in need. Critically, we want to grow a social health movement on palliative care with diverse voices, including those directly affected, to ensure universal coverage of palliative care by 2030.





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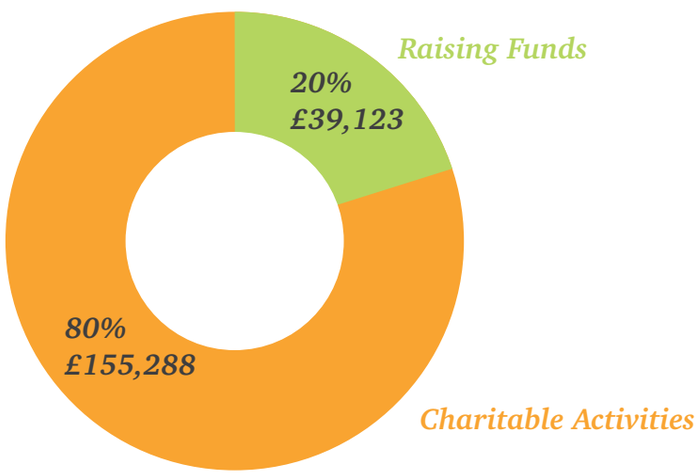
# Financial statements

## Balance sheet

As at the 31 March 2017

| | | 2017 | 2016 |
|---|---|---|---|
| | | £ | £ |
| | Note | | |
| **Current assets** | | | |
| Cash at bank and in hand | | **146,739** | 131,327 |
| Debtors | **8** | **119,242** | 470 |
| | | **265,981** | 131,797 |
| **Liabilities** | | | |
| Creditors: amounts due within 1 year | **9** | **(6,667)** | (18,392) |
| **Net current assets** | | **259,314** | 113,405 |
| **Net assets** | | **259,314** | 113,405 |
| **Funds** | | | |
| Restricted funds | | **259,342** | 91,462 |
| Unrestricted funds | | **(28)** | 21,943 |
| **Total charity funds** | **10** | **259,314** | **113,405** |

## Total Expenditures 2016/17






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# Statement of Financial Activites

(incorporating an income and expenditure account) For the year ended 31 March 2017

| | Note | Unrestricted £ | Restricted £ | **2017 Total £** | 2016 Total |
|---|---|---|---|---|---|
| **Income** | | | | | |
| Donations and legacies | **2a** | - | 339,040 | **339,040** | 174,016 |
| Income from charitable activities | **2b** | 1,280 | - | **1,280** | - |
| **Total income** | | 1,280 | 339,040 | **340,320** | 174,016 |
| **Expenditure** | | | | | |
| Raising funds | **3** | 2,921 | 36,202 | **39,123** | 51,183 |
| Charitable activities | **3** | 20,330 | 134,958 | **155,288** | 179,434 |
| **Total Expenditure** | | 23,251 | 171,160 | **194,411** | 230,617 |
| **Net (expenditure) / income in the year** | | **(21,971)** | **167,880** | **145,909** | **(56,601)** |
| **Reconciliation of funds** | | | | | |
| Total funds brought forward | | 21,943 | 91,462 | **113,405** | 170,006 |
| Total funds carried forward | **10** | (28) | 259,342 | **259,314** | 113,405 |

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

# Thank you

We would like to thank our donors for this year without whom our work would not be possible. Thank you to:
Open Society Foundations
True Colours Trust
US Cancer Pain Relief Committee.



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# Less than 10% of the overall palliative care global need being met

# www.thewhpca.org

**Email** info@thewhpca.org

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