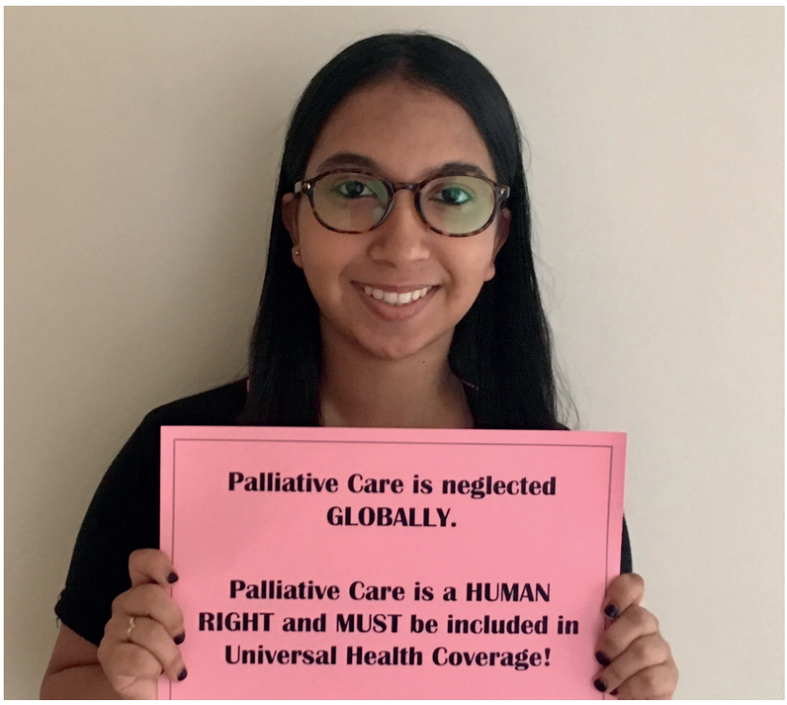
whpca
worldwide hospice palliative care alliance









Annual Report

April 2017 - March 2018

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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

The WHPCA has had a very busy year working to develop hospice and palliative care worldwide. We have grown as an organisation, bringing in new funding streams and starting exciting new projects. We have increased our focus on promoting palliative care as part of Universal Health Coverage. We have started to identify and support an empowered network of direct palliative care stakeholders, engaging and involving people affected by serious illness at all levels of our organisation. This report will share with you our activities, leadership, and finances for the past year. Please feel free to contact us with questions, suggestions and ideas.

Cover images: Huyaam Samuels, Lucy Watts, Petra Burger & Ferdousi Begum

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We impact people's lives on the ground

>>> The WHPCA works with partners to develop innovative, compassionate community-based programmes to improve the quality of life of people with serious illness. These programmes seek to show how quality, community led, cost-effective palliative care can be provided to people, including the poorest and most vulnerable, who need it as a component of Universal Health Coverage by 2030. They also seek to show how people can rise to understand and demand palliative care as part of their health systems. The initial three focus countries are: Bangladesh, Ethiopia and Jordan. We aim to develop our work in The Philippines, Ukraine and Panama in the coming years.



Compassionate Korail – Bangladesh

The WHPCA continues to work on our groundbreaking compassionate care project in the Korail slum in Bangladesh with the Centre for Palliative Care, a centre within Bangabandhu Sheikh Mujib Medical University (BSMMU). There are now 12 palliative care assistants from the community itself who are trained and mentored to reach older people who need palliative care. In addition, there is a growing cohort of volunteers. The project cared for more than 130 older people and enrolled more than 280 patients supported by volunteers. A hub has been developed in the Korail slum, with land offered by the Korail Slum leadership, showing increased ownership of the project. In addition, we are delighted that new projects have continued and begun in Korail led by our partner BSMMU working in collaboration with other NGOs and academics including a project focussed on children's palliative care and an ethnographic project to raise awareness of palliative care through theatre. This increases the sustainability of the project. In addition, the community continues to run their own palliative care awareness event for World Hospice and Palliative Care Day.

The compassionate community project includes care and support visits by healthcare professionals: doctors, nurses, Palliative Care Assistants (PCAs), physiotherapist, as well as a free eye clinic once a month. Social support activities include: free essential medicines and food packets provided, and winter blanket and warm clothing provision, supported by the local community.

Narayanganj Palliative Care

In 2017-2018 we developed a new programme building a compassionate community in palliative care in Narayanganj City Corporation based on the Korail model. We were delighted to be notified that we were successful in accessing funding for this project by UK Aid Direct. This 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 project will also particularly look at the gender and disability aspects of palliative care in low income settings.



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How many people have benefitted from Compassionate Korail?

The project has supported one hundred and thirty six (136) elderly patients with life limiting illness. Among them eighty one (81) are female, fifty four (54) are male and one (1) belongs to third gender. Their ages range from 20 years to 111 years and average age is 67 years.

1741 slum community patients having incurable and other various illnesses visited our satellite palliative care centre for physician consultation (including 779 people who attended seven free eye camps).

136 people
with life-limiting illness supported

1741 patients
consulted

12 PCAs
recruited & trained

95 volunteers

335 people
sensitized to palliative care

Palliative Care Assistants

11 young women, and one man, were recruited from the local community and trained as Palliative Care Assistants to provide basic palliative care and to refer patients to the project medical team.

Tutorials for continuing professional education of PCAs take place once per week.

Palliative Care Assistants join weekly project team meetings, with one PCA giving a PowerPoint presentation to the rest of the project team. Presentation skills are covered in the tutorials, and presenting to the larger group builds confidence and useful skills that can be transferred to other employment settings.

Community Involvement

95 volunteers have been recruited from the community to support the project.

335 people attended 17 sensitization meetings.

18 school teachers attended school awareness meetings.

Fundraising and sustainability

A pop-up charity shop runs four days per week with good support from the community, raising local funds for the project.

Two meetings have been held with local Community Based Organisation leaders to discuss the exit plan and sustainability beyond the end of the project period.

"The best thing is that she takes care of (my mother) and gives us a rest – we are exhausted."
Ferdousi,
daughter and carer



Supporting programmes and organisations

Resources for programme development

The WHPCA Palliative Care Toolkit continues to be a useful resource for those developing palliative care in resource limited settings.

In addition, we co-edited and published a new book: Building Integrated Palliative Care Programs and Services (2017). Our resources are freely available on our website.

National feasibility for Palliative Care in Greece

We have been working in Greece this year to assist the Ministry of Health and the palliative care community there, with the support of the Stavros Niarchos Foundation, to conduct a feasibility study. This study will provide recommendations to the government on how to scale up palliative care in the country.

Developing a national strategy for palliative care in Zimbabwe

We have also assisted Island Hospice and Healthcare in conducting an analysis of policies as part of a larger effort to develop a national strategy for palliative care throughout the country. At a crucial moment in the development of palliative care in Zimbabwe, we are delighted to be working with the Zimbabwe team to contribute towards palliative care as part of a stronger Zimbabwean health system and the move to Universal Health Coverage.

National Needs Assessment

We assisted the African Palliative Care Association to carry out national assessments of need for palliative care in three African countries.

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We influence policy at the highest levels

>>> The WHPCA represents its members at the highest levels to create an enabling environment for change locally. This year, we have worked hard with our members and many partners to keep palliative care on the global health agenda and to ensure its inclusion in policies, programmes and plans. As momentum towards Universal Health Coverage increases, 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.

Key successes



This year has seen an increased commitment and focus on palliative care as part of Universal Health Coverage at all levels but particularly by the World Health Organization.

Our Executive Director, Dr Stephen Connor, was a scientific advisor and co-author of the Lancet Commission on Palliative Care and Pain Relief, a ground-breaking study which has provided much needed, costed analysis of what an essential package of palliative care looks like. Many WHPCA Board members were also commissioners on this report.

In March 2018, we joined UHC2030 to be part of the collective movement to make 'Health for All' including access to palliative care a reality.

In March 2018, Dr Connor was appointed as a member of the Civil Society Working Group on the UN High Level Meeting on NCDS in September 2018.

In July 2017, we attended the High Level Political Forum to focus attention on the need for palliative care as part of the Sustainable Development Goals, and in particular the target towards Universal Health Coverage.

We, with our members and partners including the International Association for Hospice and Palliative Care successfully advocated for the inclusion of palliative care in WHO's General Programme of Work and its accompanying impact framework.

We, and our partners, successfully advocated for the inclusion of palliative care into the Montevideo declaration on Non-Communicable Diseases and were represented at the meeting to ensure the issue of palliative care was heard.

Dr Connor advocated for palliative care at the 70th World Health Assembly in May 2017. Key agenda items for the palliative care delegation this year included: promoting the health of refugees and migrants, preparation for the High Level Meeting on NCDs, discussion on the Global Action Plan on Dementia, the 'World Drug Problem' and access to essential medicines, cancer control, issues affecting women, children and adolescents, and progress in implementation of SDGs.

"My palliative care team helps me to combat the social isolation I feel due to my illness."

Nabanita Mandal



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"Palliative care brought much more meaning to me as an individual. It improved my life greatly as I was very poorly before I accessed palliative care. It has enabled me to live my life the way I can and see fit according to my health." Huyaam Samuels

In January 2018, we attended the World Health Organization Executive Board meeting where we shared the words of those directly affected by palliative care: Huyaam Samuels, Sharon Thompson and Lucy Watts. This led to a face to face meeting to discuss palliative care with Dr Tedros, the Director General of the World Health Organization, and increased commitment from WHO on palliative care as part of Universal Health Coverage.



"It was great to speak, Lucy. I look forward to meeting in person. Thanks for your commitment to advocating for others. #PalliativeCare transforms people's lives and must be a part of health systems that deliver universal health coverage. #HealthForAll"

Dr Tedros, Executive Director of the World Health Organization, 1 February 2018 tweeting about his meeting with palliative care direct stakeholder and WHPCA consultant Lucy Watts.

Well done Lucy!

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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, as well as an empowered network of direct stakeholders, and to 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.

The International edition of ehospice has supported WHPCA programmes and advocacy activity by reporting on: work on the Universal Health Coverage and global NCD agenda, palliative care as part of the WHO General Programme of Work, access to medications, rights of older persons, and advocacy at the World Health Organization Executive Board Meeting and the World Health Assembly.

ehospice international published 135 articles with stories from around the world this year.

The International edition of ehospice received 212,382 unique page views by 107,537 users over the reporting period, averaging 17,747 page views per month by 8,961 users.



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 67,000 times. Work has started on the 2nd edition of the Atlas in collaboration with WHO, the University of Glasgow, and other partners.

347 members
in 100 countries

Strengthening our global membership

Our global membership 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. Our membership has grown to 347 members as of November 2018, and we are committed to consulting with our membership on global advocacy and our work more broadly to become truly member led. Our diverse and active membership represent 100 countries.



Everyone, everywhere should get the care they need when facing serious illness.

Lucy Watts, MBE



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Building a global movement of people with lived experience (direct stakeholders) as advocates for palliative care

We were delighted to be supported by the Open Society Foundations in October 2017 to deliver an innovative project to build the voice of direct stakeholders in palliative care advocacy. This was developed in collaboration with Lucy Watts who is a direct stakeholder herself. While still ongoing, this project has seen a shift in how those with lived experience of palliative care are viewed and listened to on issues that directly affect them and we have a delivered a strong challenge on who speaks for who on palliative care issues. The project is based on the concept of 'Nothing about us, without us' with professionals/advocates acting as facilitators and supporters and giving up our platforms to those with lived experience. The growth of a direct stakeholder movement and their greater involvement in palliative care advocacy is crucial to increase demand for palliative care and win the hearts and minds of decision makers – particularly as we move towards Universal Health Coverage. As part of this project we:





- Recruited direct stakeholder consultants to support our work at all levels from planning to implementation. This will include a governance review of the WHPCA in how it engages direct stakeholders in all elements of its work.
- Worked with Lucy Watts, our direct stakeholder consultant, to set up the Palliative Care Voices network building an online global network of people with lived experience of palliative care
- Launched a $60,000 grants round for innovative projects supporting the voice of direct stakeholders in palliative care advocacy in low and middle-income countries
- Recruited a committee of direct stakeholders to support palliative care advocacy
- Undertook an open process to recruit direct stakeholders to be part of the WHPCA board strengthening the voice of those with lived experience on our governance structures
- Enabled the voices and words of direct stakeholders to be heard at the highest level including at the World Health Assembly executive board meeting and the World Health Assembly building the direct stakeholder voice from around the world and including people with various conditions including rare diseases and dementia. This led to a 1:1 meeting and a new friendship between Lucy Watts, a 25 year old palliative care direct stakeholder from the UK, and Dr Tedros, the Director General of the WHO. We also continue to encourage and support platforms being given to people with lived experience at palliative care events.
- Developed new materials which promote the voices of direct stakeholders through social media and other digital platforms – particularly in the move to Universal Health Coverage
- Enabled the voice of direct stakeholders to be heard in international media including Huyaam Samuels on the BBC World Service
- Consulted with direct stakeholders to plan and develop the theme and messaging for World Hospice and Palliative Care Day 2018.

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

In February 2018, we started the project: Patient Power – Increasing demand for palliative care as part of Universal Health Coverage in South Africa and Ethiopia. The project aims to increase the voice of direct stakeholders (people with lived experience of palliative care) in South Africa and Ethiopia and share learning throughout Anglophone Africa.

Previous research has identified a low demand for palliative care, and lack of political will as two main barriers to accessing palliative care. This project addresses these two issues and shares lessons learned for others to use worldwide.

We are engaging direct stakeholders in South Africa and Ethiopia to tell their story and speak out about the issues that matter most to them. The project is a model collaboration between international, regional, national and community-level groups, as well as individual patients and carers.

The project draws on the powerful stories of direct stakeholders to 1) raise demand for palliative care among people who would benefit from it and 2) to encourage national decision makers to include palliative care in Universal Health Coverage plans.

In the first two months of the project, strong partnerships are being built between direct stakeholders, local community hospices, national journalists, the national hospice organisations & government in each country. There are four organisational project partners across international, regional and national level. To date, two direct stakeholders have been recruited. Petra (South Africa) and Kalkidan (Ethiopia).

A key aspect of the project is to share learning across the African continent. We are sharing the stories, materials and lessons learned to specific target audiences using social media, as well as through regional and national news media, organisational communications channels, community meetings, and direct advocacy with national governments.

"Thanks to the palliative care team at Hospice Ethiopia, now I live pain free and I'm able to provide for my family. I'm now volunteering as a care giver and counsellor for Hospice Ethiopia, helping others with serious problems and illness like I once had." – Kalkidan



"Palliative care is not about death and dying, it's about quality of life." Petra Burger

Growing our digital presence

We have increased our engagement on social media channels, including Facebook and Twitter. We currently have 2,524 total page likes on Facebook and 4,045 followers on Twitter. We have been managing and updating our WHPCA website with regular news relating to hospice and palliative care worldwide. There were 40,520 sessions and 97,750 unique page views by 28,655 users on the WHPCA website during the reporting period.

4,045 followers

2,524 likes

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World Hospice and Palliative Care Day

We coordinated World Hospice and Palliative Care Day, the global day of action for palliative care on 14 October 2017. The theme was: Universal Health Coverage and Palliative Care – Don't Leave Those Suffering Behind!

Materials were produced and utilised around the world and 183 events were registered on the website from 49 different countries. The World Hospice and Palliative Care Day toolkit was accessed on the website 1,488 times.

For the first time this year, we created and shared videos as part of the World Day campaign. There was a very positive reaction to all four videos created.

Huyaam Samuels
Over 1,000 views, 35 like/love reactions, 16 comments, 44 shares

Lucy Watts
4,300 views, 61 like/love reactions, 8 comments, 62 shares

Rob Yates
120 views, 7 likes, 1 comment, 4 shares

Chris Pointon
75 views, 7 like/love reactions, 1 comment.

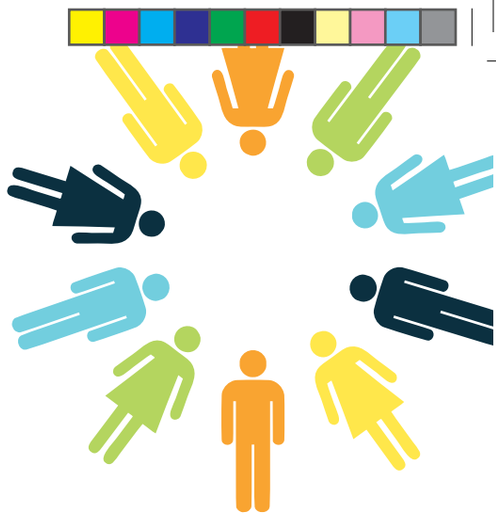
183
events

1488
toolkit downloads

49
countries



Thank you for the support



Improving collaborative working

The 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. We have initiated and curate the Global Palliative Care Advocates Google Group, which has over 150 members and is used routinely for real-time discussions on key global issues. We work to ensure a coordinated and collaborative voice on issues ranging from Universal Health Coverage to Non-Communicable Diseases. We have strengthened collaboration with non-specific palliative care allies and networks such as Action for Global Health, the NCD Alliance, the Union for International Cancer Control (UICC), the US National Cancer Institute's Center for Global Health, and the Global Alzheimer's and Dementia Action Alliance along with many other partners.

We curate the Global Palliative Care Advocates Google Group, which has over 150 members

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Governance representation



Ireland
Dr Julie Ling
Vice-chair
Chief Executive,
European Association
of Palliative Care
Appointed: January 2015

United Kingdom
Dr Julia Downing
Chief Executive,
International Children's
Palliative Care Network
Appointed: March 2017

United Kingdom
Dr Richard Harding
Cicely Saunders Institute,
King's College London
Appointed: August 2016

Canada
Ms Sharon Baxter
Chief Executive,
Canadian Hospice Palliative
Care Association
Re-appointed: June 2013
Resigned June 2017

United States
Ms Liliana De Lima
Executive Director,
International Association for
Hospice and Palliative Care
Appointed: August 2016
Resigned: August 2017

United States
Dr James Cleary
Head,
Pain and Policy Studies Group
University of Wisconsin
Appointed: December 2016

United States
Mr Edo Banach, JD
CEO and President,
National Hospice and Palliative
Care Organization
Appointed: October 2017

Argentina
Dr Jorge Eisenchlas
Advisory board
Argentina Association
of Medicine and Palliative Care
Re-appointed: May 2014 – May 2018

South Africa
Dr Elizabeth Gwyther
Chairperson
Chief Executive,
Hospice Palliative Care
Association of South Africa
Re-appointed: October 2013

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United Kingdom
Mr Craig Duncan
COO,
Hospice UK
Appointed: August 2016

Germany
Dr Tania Pastrana
President
Latin American Association
for Palliative Care
Appointed: August 2016

Hungary
Dr Ágnes Csikós
Pecs-Baranya Hospice Foundation,
Hungary
Appointed: March 2017

Jordan
Dr Mohammad Bushnaq
Chairman of Jordan
Palliative Care Society
Appointed: April 2015

India
Dr Priya Kulkarni
Secretary,
Indian Association of
Palliative Care
Appointed: October 2013
Resigned October 2017

India
Dr Abjihit Dam
Secretary
Indian Association
of Palliative Care
Appointed: October 2017

Malaysia
Dr Ednin Hamzah
Vice-chair
Asia Pacific Hospice
Palliative Care Network
Appointed: October 2013
Reappointed August 2017

Uganda
Dr Emmanuel Luyirika
Executive Director,
African Palliative Care Association
Reappointed Aug 2016

Kenya
Dr Zipporah Ali
Executive Directive,
Kenya Hospices and
Palliative Care Association
Reappointed Aug 2016

Australia
Dr Frank Brennan
Physician
Appointed: December 2016

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Challenges & opportunities

The need for palliative care still outstrips the capacity of providers 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 achieve Universal Health Coverage by 2030 and to meet the aims of the World Health Assembly (WHA) palliative care resolution much more work is needed. Targets include: to achieve inclusion of palliative care education for all health professionals, to ensure access to strong analgesics in every country for pain relief, to ensure all health professionals receive training, to guarantee inclusion of palliative care in all health policies, and to align resources for palliative care service implementation. Funding continues to be a challenge for palliative care organisations at all levels. Current efforts are aimed at ensuring that palliative care is included in all national plans for universal health coverage by 2030 so that people get the palliative care that they need when they need it without suffering financial hardship.

Future plans

The WHPCA will continue to work toward achieving its mission. We have identified six target low and middle-income countries (one in each WHO region) to focus our efforts on service development. We have developed fundable projects in three (Bangladesh, Ethiopia, & Jordan) and will work on the other three countries (Panama, Philippines, & Ukraine).

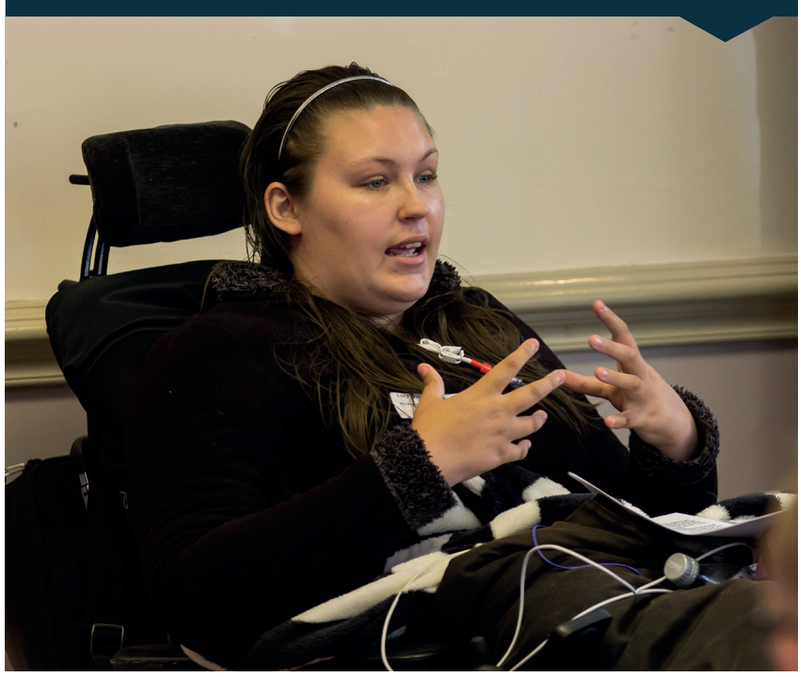
We will expand our direct stakeholder projects and work on inclusion of palliative care in universal health coverage in many more countries, in partnership with our members.

We will continue our critical advocacy work for hospice and palliative care at the upcoming UN General Assemblies, Non-communicable disease forums, World Health Organization meetings including the World Health Assemblies, and UN Sustainable Development events, with a focus on universal health coverage.

We will continue to grow ehospice internationally, will successfully manage the 2018 World Hospice Palliative Care Day, and will continue to advocate effectively to work toward meeting the unmet global need for palliative care.

"To me, palliative care means having the care and support I need to have the best quality of life possible and being able to enjoy whatever time I have left."

Lucy Watts, MBE



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Thank you

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

Anonymous Donor

Open Society Foundations

The Joffe Charitable Trust

True Colours Trust

Stavros Niarchos Foundation

US Cancer Pain Relief Committee

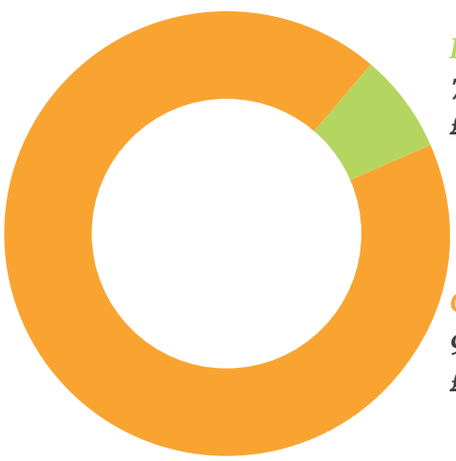
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Balance sheets

Balance sheet
As at the 31 March 2018

	Note	2018	2017
		£	£
Current assets			
Cash at bank and in hand		**176,187**	146,739
Debtors	**8**	**46,849**	119,242
		223,036	265,981
Liabilities			
Creditors: amounts due within 1 year	**9**	**4,798**	(6,667)
Net current assets		**218,238**	259,314
Net assets		**218,238**	259,314
Funds			
Restricted funds		**204,889**	259,342
Unrestricted funds		**13,349**	(28)
Total charity funds	**10**	**218,238**	259,314

Total Expenditures 2017/18



Raising Funds
7%
£18,397

Charitable Activities
93%
£254,881

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Statement of Financial Activites

(incorporating an income and expenditure account) For the year ended 31 March 2018

	Note	Unrestricted £	Restricted £	**2018 Total £**	2017 Total
Income					
Donations and legacies	**2a**	-	222,837	**222,837**	339,040
Income from charitable activities	**2b**	9,365	-	**9,365**	1,280
Total income		9,365	222,837	**232,202**	340,320
Expenditure					
Raising funds	**3**	-	18,397	**18,397**	39,123
Charitable activities	**3**	(4,012)	258,893	**254,881**	155,288
Total Expenditure		(4,012)	277,290	**273,278**	194,411
Net (expenditure) / income in the year		**(13,377)**	**(54,453)**	**41,076**	**145,909**
Reconciliation of funds					
Total funds brought forward		(28)	259,342	**259,314**	113,405
Total funds carried forward	**10**	13,349	204,889	**218,238**	259,314

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

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WHPCA publications

Book

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Book Chapters

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61.5 million people experience serious health related suffering worldwide.

Palliative care can relieve this suffering.



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