whpca
worldwide hospice palliative care alliance

Palliative Care #BecauseIMatter









Toolkit 2018

World hospice & palliative care day

Acknowledgements

Contributors: Petra Burger; Dr Helena Davies; Nabanita Mandal; Huyaam Samuels; Dr Stephen Watiti; Lucy Watts, MBE.

Editor: Kate Francklin, The WHPCA

Design: HeylinSmith Ltd



Foreword

Helena Davies, WHPCA Direct Stakeholder Trustee



Palliative care – #BecauseIMatter!

The theme for this year's World Hospice and Palliative Care Day is: Palliative care – #BecauseIMatter! This has great relevance to me at a personal level and also as an advocate for palliative care for all those in need of it globally.

Palliative care is a basic human right that should be an integral part of all Universal Health Coverage (UHC) programmes. Central to palliative care is the goal of optimising quality of life for individuals with serious or life-limiting illnesses. Treatment of pain to allow a life to be well lived is key, but so also is holistic care with attention to physical, psychological, social and spiritual needs.

Until my mid 30s I was the stereotypical picture of health and fitness; very sporty, cycled everywhere, worked as a consultant paediatrician, travelled frequently and enjoyed the delights of raising two small boys. In 1997 aged 36 I was diagnosed with an inflammatory disease needing steroids and a range of other medications to control it. I had six months off work in early '98 and again in 2000 but over the 10 years from '97 to 2007 despite needing medication and having ups and downs I lived a full and busy life.

However, a major flare with muscle and nerve inflammation in 2008 resulted in my losing a huge amount of mobility and being discharged from hospital dependent on an electric wheelchair, unable to work and on a range of medication.

Over the last decade I have had multiple hospital admissions and acquired many new diagnoses, including breast cancer. I have had to come to terms with a very different life in my 40s and 50s than I had imagined, lived in the context of serious life-limiting illness. However, input from palliative care has enabled me to have a good quality of life, albeit framed within this new context.

I have been also been fortunate that excellent palliative care has been provided free within the UK's National Health Service (NHS), and perhaps most importantly, I have felt that I mattered. I have been listened to, so that my healthcare providers understood what mattered most to me and were able to make treatment decisions and options available to me based on this knowledge. Palliative care has allowed me to function as well as possible within the context of my physical disabilities, to engage in life despite my limitations and to retain as much of my dignity as possible.

However, issues clearly still exist around the globe. As an example, in India until as recently as 2014, unnecessarily restrictive regulations meant that it was almost impossible to access oral morphine for the treatment of severe pain. In this context, I wouldn't have been able to access this basic pain relief for five of the nine years I have received palliative care.

Palliative care is deemed a basic human right, that should be available to all regardless of their social, political or economic background. In countries where universal health coverage does exist, palliative care should be an integral part of the system and not an afterthought as

people stand on death's door. Importantly, patients, who are the direct stakeholders affected by serious/life-limiting illness, should have input into all aspects of palliative care from influencing government policy to being at the centre of their own care.

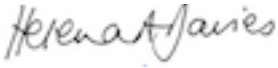
World Hospice and Palliative Care Day is an opportunity for anyone and everyone to make a difference. To advocate for ourselves or on behalf of those affected by serious or life-limiting illness, particularly those in need in low and middle-income countries (LMICs). The Lancet Commission on Palliative Care and Pain Relief emphasised both the disproportionate number of individuals with serious life-limiting illness in LMICs and the poor access to palliative care, even simple pain relief, for many of these individuals. An essential palliative care package for these countries described by the Lancet Commission would cost only $3 per person.

I have been lucky. The context within which palliative care is provided inevitably varies enormously. Countries have different methods of healthcare delivery and many do not have palliative care as an integral component of healthcare. Despite this we must highlight the need for palliative care and the involvement of direct stakeholders at all levels.

We need voices at International and National policy levels, at local hospice, village or town levels, in the development of teaching and research materials and in the development of palliative care packages. This will help to ensure the needs of the patient are met and palliative care packages and policies don't simply reflect the world view of the individuals who are in power where they are developed.

People affected by serious and life limiting illness have been involved in the development of the messaging and materials for World Hospice and Palliative Care Day from the beginning. People from around the globe have generously shared their stories and what is really important to them. The key statements encapsulate this.

We are asking you to listen to individuals affected by life-limiting illness, to support them in demanding essential palliative care and to demand palliative care for everyone who needs it, everywhere but especially in LMICs. This toolkit provides you with resources that can be modified for your setting to help you share the key messages and sub-themes. Thank you for your help! #BecauseIMatter.



Helena Davies,
The Worldwide Hospice Palliative Care Alliance
Direct Stakeholder Trustee

Contents

Foreword – Helena Davies, WHPCA Direct Stakeholder Trustee 3
Using this toolkit 6
Introduction 6
What is hospice and palliative care? 7
This year's campaign 8
World Hospice and Palliative Care Day 2018 Report 8
Palliative Care Champions Awards 8
Palliative Care – Because I Matter! 8
Campaign key messages 9
Because I Matter 10
What Matters to Me 11
Why Does Palliative Care Matter to Me? 12
Recommendations 13
Governments 13
Healthcare providers 13
Hospice and Palliative Care Organisations 13
Public 13
How to mark World Hospice and Palliative Care Day 14
Resources 14
Supporting World Hospice and Palliative Care Day on social media 15
Facebook 15
Twitter 15
Other key hashtags 15
Accounts to @ mention 15
World Hospice and Palliative Care Day 2018 Draft Tweets 15
Working with the press 16
Conclusion 17

Using this toolkit

This toolkit provides individuals and organisations with ideas and guidance on how to mark World Hospice and Palliative Care Day 2018.

It contains key messages, ideas and resources to support the day and spread the key messages of the campaign.

The theme this year is: '**Palliative Care – Because I Matter**'. This speaks to the individual experience of people directly affected by serious illness. It highlights the importance of listening to people directly affected when planning healthcare policies, individual care and any advocacy or communications work in hospice and palliative care worldwide.

Together – as palliative care workers and supporters and people directly affected by serious illness – we can demand quality palliative care for all as part of Universal Health Coverage.



Introduction

People directly affected by serious illness should be at the centre of palliative care, but how often are they involved in communications, advocacy and governance in palliative care organisations? Despite being the strongest advocates for their own health and care, they are often overlooked, sidelined or assumed to be too ill to speak.

This year, we invite everyone working in hospice and palliative care to challenge your assumptions about who you are working for and do more to involve them in the work that you do. For people who are directly affected by serious illness – or affected as family members or carers – take this opportunity to speak out and let the world know what matters to you!

People directly affected by serious illness have been involved in this year's World Hospice and Palliative Care Day from the beginning, from the consultation on the theme, to the drafting and approval of key messages to creating and sharing stories, images and videos for social media.

This should be the norm for every World Hospice and Palliative Care Day. We encourage you to reach out to the patients and families involved with your hospice or palliative care organisation to see how together you can raise your voices to demand quality palliative care for all as part of Universal Health Coverage.



What is hospice and palliative care?

The central element of hospice and palliative care is the relief of suffering. The goal is to improve quality of life for people and family members affected by life-threatening and life-limiting illness.

WHO Definition of palliative care for adults and children.

The WHPCA supports the WHO definition:

"Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1]

Palliative care must be integrated into health systems at primary healthcare level, and basic, intermediate and specialist education must be implemented for health professionals globally. It is a fundamental part of healthcare and it is the responsibility of national governments to ensure a healthcare system that treats suffering right up until the end of life and into bereavement for loved ones.

1 WHO definition of palliative care: http://www.who.int/cancer/palliative/definition/en/

This year's campaign

During the campaign we will ask people to take specific actions that will improve the public understanding of palliative care, and encourage governments to dedicate time and money to palliative care as part of Universal Health Coverage to improve the quality of life of people living with serious illness and their families.

A key aspect of this year's World Hospice and Palliative Care Day campaign will be to call on governments to listen to people who need or access palliative care and support the inclusion of the essential package of palliative care in all national UHC schemes.

But just listening is not enough! People directly affected by serious illness must also be included in palliative care services and advocacy. They are a vital part of the solution and should be engaged and involved in making positive change to improve access to quality palliative care services worldwide.

World Hospice and Palliative Care Day 2018 Report

The WHPCA will produce a report, to be released on World Day 13 October, publishing letters written by direct palliative care stakeholders to government and UN representatives around the world.

Palliative Care Champions Awards

The Palliative Care Champions Award will be announced on World Hospice and Palliative Care Day. There will 10 awards in total, recognising the extraordinary contributions made by individuals to palliative care in low and middle-income countries.

Palliative Care – Because I Matter!

The theme for 2018 is: 'Palliative Care – Because I Matter!'

The sub-themes of this year's World Hospice and Palliative Care Day are: Because I Matter, What Matters to Me, and Why does Palliative Care Matter to Me?

Campaign key messages

Engage with and involve people directly affected by serious illness in all aspects of palliative care.

Support people with serious illness to demand quality palliative care for all as part of Universal Health Coverage

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

Because I Matter

Getting appropriate care is a basic human right and should be part of all UHC programmes. Building on the principle of 'leaving no one behind', palliative care is a holistic approach essential to achieving sustainable development for all.

Governments should treat their citizens equitably, providing them with the care they need. They must equitably distribute health services including palliative care for all people, including older people and children, and persons with disability. Governments must fund palliative care to make it available to all.

All healthcare providers, social workers and allied health professionals should be trained in palliative care. Healthcare workers must learn about palliative care, practice palliative care and uphold palliative care values and principles in their work.

Hospices and palliative care providers should have financial assistance to provide palliative care to all who need it.



"I matter! Listen to me when discussing my care and planning policies that will impact my life."



"I rely on palliative care to achieve and maintain an optimum quality of life, so why is there limited access?"

Key messages – Because I Matter

- Listen to people with direct experience of serious illness when discussing individual care and planning healthcare policies.
- People directly affected by serious illness must also be included in palliative care services and advocacy.
- People with direct experience of serious illness are a vital part of the solution and should be engaged and involved in making positive change to improve access to quality palliative care services worldwide.
- People experiencing serious illness are as important as those without any health problems.
- Getting appropriate palliative care is a basic human right and should be part of all UHC programmes.
- Governments must equitably distribute health services including palliative care for all people, regardless of age and diagnosis.
- Building on the principle of 'leaving no one behind', palliative care takes a holistic approach essential to achieving sustainable development for all.
- Palliative care is essential to achieving and maintaining optimum quality of life
- Everyone deserves the best possible quality of life.
- Everyone deserves excellent pain and symptom management.
- All healthcare providers and allied health professionals should be trained in palliative care.
- All people with disability should be able to access palliative care should they need it.
- Every person with disability should have access to palliative care.
- Hospices and palliative care providers should have financial assistance to provide palliative care to all who need it.
- Palliative care is everyone's business.

What Matters to Me

People with serious illness must be able to live a life where they are treated with equal respect to those who do not need palliative care. They must be enabled to life a life where they are able to be respected and function equally in society.

Pain and symptom control is essential to enable people directly affected by serious illness to engage as fully as possible in life. It is also vital to make sure that people's psychological and spiritual needs are supported, alongside physical needs, to enable them to function in a dignified and thoughtful way.

It is important that stigma associated with HIV and chronic diseases like cancer is eradicated, so that all people can live a dignified and full life.

We must all support people directly affected by serious illness to demand that governments make palliative care available to all as part of UHC.

Key messages – What Matters to Me

- People with serious illness must be able to live a life where they are treated with equal respect to those who do not need palliative care.
- People experiencing serious illness should be respected and enabled to function equally in society
- People experiencing serious illness should be provided with care such as pain relief, and enabled to engage as fully as possible in life
- People experiencing serious illness should have their psychological and spiritual needs supported – as well as their physical needs – to function in a dignified and thoughtful way
- We must eradicate stigma associated with HIV and chronic diseases like cancer, so that all people can live a dignified and full life regardless of their health status.
- Governments must make palliative care available to all as part of UHC.



Demand with me that my government make palliative care available to all as part of UHC!

Why Does Palliative Care Matter to Me?

Palliative care improves the quality of life for people directly affected by serious illness and their families. It helps people to have the quality of life they aspire to in the context of health difficulties.

It assists people facing serious illness to function as fully as possible and contribute to society in the way that they wish to, and helps to ensure that people are as free of pain as possible, essential to optimising everyday functioning.

Some diseases and the medications used to address them will need long term management. Palliative care will help to deal not only with the effects of the disease, but also the side effects of medications.

Palliative care is a human right. People should be able to access hospice and palliative care as soon as they are diagnosed with a life-threatening or life-limiting condition, and not just at the end of life.

Hospice and palliative care is most effective when started early in the course of an illness. This care can take place together with treatment such as anti-cancer therapy or anti-retroviral therapy.

Supporting family members and carers is a key aspect of hospice and palliative care. This is to improve their quality of life and well being, an often neglected area of care.

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

Key messages – Why does palliative care matter to me?

- With palliative care, people are supported to live a good quality of life in the context of health difficulties.
- Palliative care allows people with serious illness to function as fully as possible.
- Palliative care aims to manage pain and optimize everyday functioning
- Palliative care addresses not only the effects of the disease, but also side effects of medications.
- Palliative care helps to combat social isolation and stigma.
- Palliative care is about living, not dying!
- It is estimated that 61.5 million people experience serious health related suffering worldwide.
- Serious health related suffering can be addressed by palliative care.

Recommendations

We can all take specific actions to ensure that people with direct experience of serious illness are listened to and enabled to participate in healthcare decision making, and to advance palliative care for all as part of UHC.

Governments

1. Consult people with direct experience of serious illness when drafting healthcare policies.
2. Ensure that palliative care is included in national Universal Health Coverage plans.
3. Set aside funding for hospice and palliative care in national budgets.
4. Support the inclusion of palliative care in UN planning documents.

Healthcare providers

1. Listen to people with serious illness when planning their care.
2. Ask people what they want.
3. Introduce yourself.

Hospice and Palliative Care Organisations

1. Employ people with direct experience of serious illness in your organisation.
2. Invite people with direct experience of serious illness to join your Board of Trustees.
3. Involve people with direct experience of serious illness in hospice and palliative care advocacy.
4. Involve people with direct experience in communications planning and drafting of materials. Don't just use them as 'case studies'.

Public

1. Show solidarity with people directly affected by serious illness to demand palliative care for all as part of UHC.
2. Oppose stigma against people living with serious illnesses such as HIV or cancer.

How to mark World Hospice and Palliative Care Day

World Hospice and Palliative Care Day is celebrated around the world by individuals and organisations with a passion for palliative care!

You can join this global community by organising an event and registering it on the World Hospice and Palliative Care Day Global Map of Impact: **http://www.thewhpca.org/world-hospice-and-palliative-care-day/add-event**

Resources

The WHPCA have developed resources that you can use to support your World Hospice and Palliative Care Day campaign. These include:

- **World Hospice and Palliative Care Day Posters –** Use the standard World Day posters, or customize them with your own photo or translated text.
- **Event advertising poster –** Download the World Day poster and modify it either on your computer or by hand to include details of your World Day event
- **Key messages –** It is vital that we speak in one voice to amplify our messages for World Day 2018. Download the Key Messages to use in your communications around the event!
- **Model letter to government decision makers –** Download this model letter on the importance of listening to people directly affected by serious illness and edit it to suit your context
- **Draft press release –** Use the draft press release as a base for your own press release. Add your own country statistics and quotes from local direct stakeholders.

Supporting World Hospice and Palliative Care Day on social media

Show your support for World Hospice and Palliative Care Day on social media by updating your Facebook and Twitter profile picture with the World Day 'Twibbon'.

Are you directly affected by serious illness? Share what matters most to you in a short message, using the official campaign hashtag #BecauseIMatter.

Record a short video, telling your government, your healthcare providers or just about anyone what matters most to you as someone directly affected by serious illness.

Facebook

Follow the Worldwide Hospice Palliative Care Alliance on Facebook for updates about World Hospice and Palliative Care Day: https://www.facebook.com/thewpca/

Twitter

Follow the @WorldHospiceDay Twitter account, and Tweet to show your support of the day. Use the World Hospice and Palliative Care Day draft Tweets, or tweet your own message. Remember to include the hashtags #BecauseIMatter and #WHPCDay18.

If appropriate, @mention relevant accounts, such as government representatives responsible for healthcare and financing.

World Hospice and Palliative Care Day on Twitter
Twitter handle: @WorldHospiceDay
Main hashtags: #BecauseIMatter #WHPCDay18

Other key hashtags
#UHC #UniversalHealthCoverage #PalliativeCare #Hospice #Health #Healthcare #HealthForAll #HumanRights #HPMGlobal

Accounts to @ mention
@WHO @UN @DrTedros @IAHPC @WHPCA @ICPCN @ UHC_Day @UHC2030 @ _ALCP @APHPCN @EAPCOnlus @APCAssociation

World Hospice and Palliative Care Day 2018 Draft Tweets

Use draft tweets to build momentum for your World Hospice and Palliative Care Day campaign or event, and tweet on the day (13 October) to join the global conversation. You can find some general Tweets right, or download the full list of draft Tweets from the WHPCA website.

World Hospice and Palliative Care Day on Twitter

Twitter handle:
@WorldHospiceDay

Main hashtags:
#BecauseIMatter
#WHPCDay18

Other key hashtags
#UHC
#UniversalHealthCoverage
#PalliativeCare
#Hospice
#Health
#Healthcare
#HealthForAll
#HumanRights
#HPMGlobal

Accounts to @ mention
@WHO
@UN
@DrTedros
@IAHPC
@WHPCA
@ICPCN
@UHC_Day
@UHC2030
@ _ALCP
@APHPCN
@EAPCOnlus
@APCAssociation

General tweets

Today is World Hospice and Palliative Care Day! Help to spread the word. #WHPCDay18 #BecauseIMatter

13 October is World Hospice and Palliative Care Day! Help to spread the word. #WHPCDay18 #BecauseIMatter

Today is World Hospice and Palliative Care Day. Show your support and demand quality #palliativecare for all as part of #UHC. #WHPCDay18 #BecauseIMatter

Working with the press

Once you have planned your World Hospice and Palliative Care Day event, it is important to tell people about it. The press and local media can help you to do this.

You may already have built up relationships with your local media, or you can take this opportunity to start. Reach out to people in your networks who have experienced serious illness and work with them to reach out to the media.

Here are some tips to writing a good press release and maximising the chances that the media will pick it up:

1. Remember that journalists are very busy. The easier you make it for them to pick up a story, the more likely they are to do so. Keep this in mind when writing your press release.
2. Make sure you have an eye-catching headline
3. Include the key information in the first paragraph. Remember the five 'W's: What is your news? Where will it happen? When will it happen? Who is involved? Why should people be interested?
4. Include numbers, facts and statistics to strengthen your claims. You can find the World Hospice and Palliative Care Day Key Messages online and in this toolkit.
5. Make sure your news is relevant to a wider audience than just you and your colleagues. Link your World Hospice and Palliative Care Day event to larger issues, such as global ageing, NCDs, the Sustainable Development Goals, Universal Health Coverage, or other themes relevant to your context.
6. Use quotes from recognised experts and people with direct experience to illustrate your point
7. Keep it short. Press releases should be one page long.
8. Include photos. Even if you don't have photos yet for this year's World Hospice and Palliative Care Day event, include photos from previous years, or of your organisations' recent work.
9. Remember to proof read your press release to make sure it is grammatically correct and contains no typos
10. Include your contact information
11. Include a link to the World Hospice and Palliative Care Day page on the WHPCA website http://www.thewhpca.org/world-hospice-and-palliative-care-day/about
12. Create a contacts list. Identify which publications are most likely to pick up your story. Have they covered palliative care or related issues in the past?
13. Make sure the press release is approved by your CEO, legal team or communications director before sending it out.



Conclusion



People with direct experience of serious illness can be the most powerful advocates for hospice and palliative care. This World Hospice and Palliative Care Day is about standing with people directly affected to demand quality palliative care for all as part of Universal Health Coverage.

This Toolkit offers key messages, advice and resources that you can use to spread the word in your country, your place of work or online.

Remember to **add your event to the Global Map of Impact** on the World Hospice and Palliative Care webpage.

Together we can make sure that the voices of people directly affected by serious illness are heard loud and clear to demand quality palliative care for all as part of Universal Health Coverage.