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World hospice & palliative care day

Universal Health Coverage and Palliative Care - Don't leave those suffering behind



World Hospice and Palliative Care Day Toolkit 2017





Acknowledgements



Image: African Palliative Care Association, rights granted by the Diana, Princess of Wales Memorial Fund.

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Foreword - Dr Stephen R Connor

The theme for World Hospice and Palliative Care Day this year is: Universal Health Coverage and Palliative Care: Don't leave those suffering behind!

In September 2015, world leaders agreed on the 17 Global Goals for Sustainable Development, an ambitious agenda aiming to end extreme poverty, inequality, and climate change by 2030. One of the key targets under goal three (Good Health and Well-being) is achieving Universal Health Coverage by 2030.

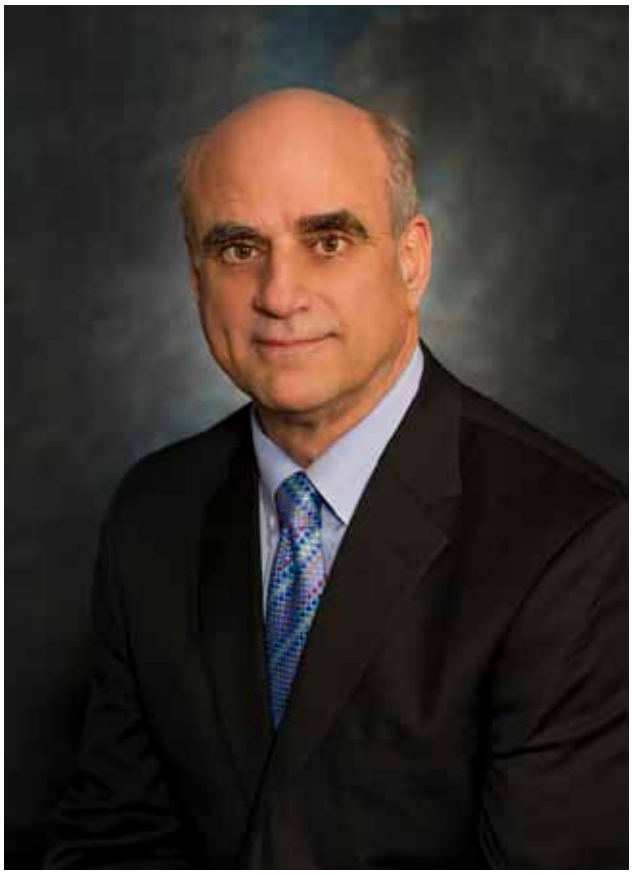
Palliative care is an essential and needed service under the Health Goal. Universal Health Coverage (UHC) means that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

UHC aims to ensure that countries develop a universally accessible health system for all citizens that meets population health needs and priorities. Palliative care is a population health need and a priority particularly given the global issues of an aging population and growing incidence of non-communicable diseases including dementia.

People who need palliative care have some of the highest healthcare needs and therefore often the highest healthcare costs. That is why it is critical that palliative care is included as a core part of Universal Health Coverage in every country so that people, at one of their greatest times of need, can access the care they need without their households being forced further into poverty.

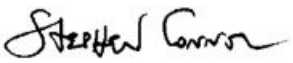
Absolutely central to Universal Health Coverage is a focus on equity, in that all populations, particularly the poorest and most marginalised, should be able to access the health care services that they require.

As an advocate for palliative care as part of Universal Health Coverage and with my



Dr Stephen R Connor

personal experience of palliative care in action, I am a firm believer that palliative care must be included in all Universal Health Coverage packages. This is a political movement, so civil society must act with other key stakeholders to make sure that it happens. We want to use World Hospice and Palliative Care Day this year as an opportunity to highlight the importance of achieving UHC that includes palliative care and hope this toolkit helps you to achieve progress in your own country.



Dr Stephen R Connor
Executive Driector, The Worldwide Hospice Palliative Care Alliance

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Using this toolkit



This toolkit provides key messages, ideas and resources for those who are planning activities to support World Hospice and Palliative Care Day on October 14, 2017.

The theme this year is: 'Universal Health Coverage and Palliative Care – Don't leave those suffering behind!'

It is divided into three sections, each based on an important dimension of palliative care as part of Universal Health Coverage. These are: CARE, COST, and COUNT.

For each of these sections, you will find a narrative explaining the concept, as well as key messages.

A section about social media includes advice for sharing your messages about palliative care and Universal Health Coverage, draft Tweets, and a list of associated hashtags.

Feel free to use the messages between now and World Hospice and Palliative Care Day on 14 October, along with the main World Hospice and Palliative Care Day hashtag #WHPCDay17 Remember to register your World Hospice and Palliative Care Day event online here: http://www.thewhpca.org/world-hospice-and-palliative-care-day/add-event

You can find out more about World Hospice and Palliative Care Day 2017, and access resources to support your celebration of the day here: http://www.thewhpca.org/world-hospice-and-palliative-care-day

If you have any questions, please contact Kate Jackson, WHPCA Communications Manager on k.jackson@ehospice.com

Introduction



Image: Hospice Palliative Care Association of South Africa

Universal Health Coverage (UHC) is arguably the most pressing issue in healthcare today. Although the United Nations recognise that everyone has the basic human right to 'the highest attainable standard of physical and mental health', very few countries have Universal Health Coverage for their citizens and none have universal access to palliative care.

Universal Health Coverage (UHC) means that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

Palliative care is a component of the essential and needed spectrum of health services within UHC, as defined by the World Health Organization.

Central to UHC is the concept of: 'reaching those who need it most' and therefore palliative care – caring for the sickest and most vulnerable people in the healthcare system – is critical to achieving this.

The theme for this year's World Hospice and Palliative Care Day is: 'Universal Health Coverage and Palliative Care – Don't leave those suffering behind', with the sub-themes: COUNT (Who needs palliative care and who is covered?), CARE (Which services are covered?) and COST (Who will pay for palliative care as part of UHC and how will they do this?).

To support hospice and palliative care advocates celebrating World Hospice and Palliative Care Day around the world, the Worldwide Hospice Palliative Care Alliance (WHPCA) has developed this toolkit containing key facts, messages and case studies to be used and adapted to different organisational, local or national contexts to raise awareness of palliative care as an essential and needed component of Universal Health Coverage.

What is palliative care?



Palliative care aims to improve the quality of life of adults and children living with and dying from serious and life limiting conditions. The hospice and palliative care approach focuses on meeting the needs of the whole person, not just treating their medical condition.

It addresses the physical, social, psychological, spiritual issues and other problems faced by those affected and their families[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.

People need to be able to access hospice and palliative care as soon as they are diagnosed with a life-limiting condition, and not just at the end of life. Ensuring that people are living with life-limiting conditions in comfort and without distress is as important as ensuring a good death.

Palliative care is applicable to many life-limiting conditions including non-communicable diseases such as cancer and heart disease and communicable conditions such as HIV and multi-drug resistant tuberculosis (TB). For children, the major disease categories which require palliative care are cancer, HIV and progressive non-malignant conditions, as well as congenitally acquired incurable, and perinatal, conditions.
Hospice and palliative care is provided wherever the person is, whether that is in the home, hospital, community clinic or hospice. It is generally provided by a team, depending on the setting and the resources available. This team may include family members, community carers, doctors, nurses, psychologists, pastoral

[1]World Health Organization. *WHO definition of palliative care.* [Online] Available from: www.who.int/cancer/palliative/definition/en

care workers, social workers and others.

Pain management is a key part of hospice and palliative care as pain is one of the most common and distressing symptoms that people with serious illness and at the end of life face. To treat a patient's pain, the simplest, least expensive and most effective method is the use of oral morphine. Unfortunately, it is rarely available in many countries. This is due to fears and myths surrounding addiction, over regulation and lack of training in pain management and understanding of the use of opioid medication[2].

Supporting family members and carers, including in the bereavement period, is a key aspect of palliative care. This is to improve their own quality of life and well-being and to help ensure the best quality of care for those that they are caring for.

[2]WHPCA (2016). *Living and Dying in Pain: It doesn't have to happen – World Hospice and Palliative Care Day 2016 Toolkit.* Available online at http://www.thewhpca.org/resources/item/world-hospice-and-palliative-care-day-toolkit

Universal Health Coverage and Palliative Care - Don’t leave those suffering behind!



Image: Hospice Palliative Care Association of South Africa

The theme for 2017 is: ‘Universal Health Coverage and Palliative Care – Don’t leave those suffering behind’.

As countries around the world commit to achieve Universal Health Coverage (UHC) by 2030, there is a strong focus on equity. Some of the most vulnerable in society are those who are living with and dying from incurable, life-limiting illnesses. It is critical that those people are not left behind. Palliative care must be included in all Universal Health Coverage Schemes aiming for universal access to essential palliative care services by 2030.
The sub-themes of this year’s World Hospice and Palliative Care Day are: COUNT, CARE & COST.

These speak to the three dimensions that will need to be addressed before countries can integrate palliative care as part of UHC.

These are:

- Political and population (COUNT) – Who needs palliative care and who is covered?
- Health services (CARE) – Which services are covered?
- Economics and financial protection (COST) – Who will pay for UHC and how will they do this?

Count



Image: African Palliative Care Association, rights granted by the Diana, Princess of Wales Memorial Fund.

In 42% of the world's countries there is ZERO availability of palliative care.

The WHO and WHPCA estimate the number of people needing palliative care at the end of life to be 20 million, 78% of these living in low and middle income countries, while reporting that only 14% of that need is met at the end of life, less than 10% overall.

This is an extremely conservative estimate, as it only calculates the need for palliative care at the end of life – rather than throughout the life course – and focusses on patients, leaving out family members and carers who could also benefit from palliative care. In only 20 countries is palliative care well integrated into the healthcare system.

Research by the International Children's Palliative Care Network (ICPCN) identified that less than 1% of children who need it are receiving palliative care. This is a prominent example of extreme inequality and injustice. It is vital that national governments and UN agencies include palliative care in the implementation strategy for the new Global Goals and create an environment that welcomes citizen advocacy.

91.5% of health systems globally do not yet have integrated palliative care. Low and Middle Income Countries (LMICs) have the greatest burden of disease, and also low availability of palliative care services, including inadequate access to medications for pain treatment or relief.

We need to measure palliative care coverage as part of UHC, and ensure that health services are accessible, of sufficient quality and affordable for all.

What gets measured gets done! If United Nations member states are not required to report on progress against a palliative care indicator, then this essential part of health care may be neglected in favour of those which are being measured.

We must hold our leaders, our health systems and ourselves to account to care for those living with life-limiting illness.

In May 2014, the WHO and the World Bank Group published their framework 'Monitoring

progress towards Universal Health Coverage at country and global levels: Frameworks, measures and targets'[3].

One of the guiding principles of the framework is that "Measures of coverage should comprise the full spectrum of essential health interventions – promotion, prevention, treatment, rehabilitation and palliation – and their associated costs." The framework however then goes on to clarify how it adopts 'tracer' indicators, with palliation and rehabilitation being included within treatment.

However, existing indicators for palliation are not sufficiently comparable or reliable measures of coverage.The indicator proposed by the WHPCA, and a number of other agencies, as a tracer indicator to monitor palliative care as a component of Universal Health Coverage was 'Access to palliative care assessed by morphine equivalent consumption of strong opioid analgesics (excluding methadone & pethidine) per capita".

According to WHO, this indicator did not reach the required standards in relation to the extent to which it measured coverage. While the indicator is evidently relevant, and is measured regularly, reliably and comparably, crucially there is currently no way of disaggregating data to measure the equitable coverage to ensure that palliative care, or the consumption of opioids for pain treatment, is reaching the poorest in society. The indicator measure is also affected by population demographic variability in age cohorts and disease incidence.

Without palliative care data collected in a routine manner at country level, it will continue to be difficult for palliative care indicators to get passed through the rigid assessment criteria.

National monitoring of palliative care

A report by the WHPCA assessed the extent to which national governments monitor palliative care coverage[4].

It found that irrespective of whether or not a country had a Universal Health Coverage policy, or had achieved it, of the 43 country respondents, 22 said that there was no national measurement of palliative care by governments in their countries, 12 said there was national measurement of palliative care coverage by governments. Nine did not know or did not respond.

This indicates that measurement of palliative care at the national level is very low globally. For those reporting that palliative care was measured, indicators were varied. This indicates that further comprehensive research is needed to investigate how palliative care coverage is measured and to test the strength and validity of these indicators. Data collection at country level must be standardised in order to measure UHC and compare data across countries.

Monitoring of palliative care as part of UHC is challenging. The issues include a lack of agreed, quality, comparable indicators, absence of routine data collection and inclusion within existing data collection tools as well as challenges with disaggregating data to show the equity of access and coverage.

Despite the challenges, the principle remains that measures of UHC should comprise the full spectrum of essential health services including palliation, and currently they do not. Tracer indicators are unlikely to cover the availability and accessibility of palliative care services for those who need them, including the poorest, and thereby do not provide an adequate measure of UHC.

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[3]WHO & World Bank (2014). *Monitoring progress towards Universal Health Coverage at country and global levels: Frameworks, measures and targets* Available online at http://apps.who.int/iris/bitstream/10665/112824/1/WHO_HIS_HIA_14.1_eng.pdf

[4]WHPCA (2014). *Universal Health Coverage and Palliative Care: Don't leave those suffering behind.* Available online at: http://www.thewhpca.org/resources/item/uhc-and-palliativecare

Questions to consider

- What national indicators are used to measure palliative care coverage in your country?
- Is a palliative care indicator currently used by your government to measure progress towards UHC?
- Are palliative care indicators used and accepted by official agencies e.g. WHO, government and UN bodies?
- Are national palliative care indicators fully defined, reliable, tested and used?
- Is data regularly and reliably collected?
- Is data disaggregated (i.e.: broken down according to age, income, etc.?)
- Do your palliative care indicators show the extent to which the poorest and most marginalized are being served by palliative care services?
- Do your palliative care indicators measure coverage?
- Do your palliative care indicators measure quality?
- Is a palliative care indicator currently used in how your government measures progress towards UHC?
- What indicator would you propose in your country to measure palliative care coverage as part of UHC?

Key messages - COUNT

- Measure what matters. Are health services accessible, of sufficient quality and affordable for all?
- What gets measured gets done! Measure palliative care coverage as part of UHC.
- We must hold our leaders, our health systems and ourselves to account to care for those living with life-limiting illness.
- Don't wait for political action: demand it. We must hold leaders accountable for leaving no one with life-limiting illness behind!
- In only 20 countries is palliative care well integrated into the health care system.
- 40 million people need palliative care annually including 20 million at the end of life.
- Only 14% of the need for palliative care is being met at the end of life, less than 10% overall.
- 78% of those needing palliative care live in low and middle income countries.
- Less than 1% of children who need it are receiving palliative care.

Care



It isn't Universal Health Coverage without universal access to palliative care.

Palliative care is an essential, defining part of Universal Health Coverage, and UHC, including palliative care, is critical to achieving the Sustainable Development Goals (SDGs). Every person deserves access to quality, affordable health services, including palliative care.

UHC is driven by equity and human rights. People who need palliative care have some of the greatest healthcare needs. They must be included in UHC and we must bring UHC and palliative care to those who need it most.

Governments need to introduce laws that acknowledge palliative care as part of the healthcare system under UHC, draft national standards of care including palliative care, as well as clinical guidelines and protocols and a national strategy on palliative care implementation.

People should not face poverty or financial hardship because they need to access essential healthcare services. Financial risk occurs through paying for costly treatment not covered by national health insurance, loss of income by the person who is ill or their carers, or costly travel when treatment and care services are situated far away from the family home.[5]

In many parts of the world, hospice and palliative care services initiated by civil society or voluntary organisations, provide free services to the people and families accessing care.[6] Some countries include these services in health insurance schemes, although most do not. It is not UHC if there isn't palliative care for everyone who needs it.

[5]Worldwide Hospice Palliative Care Alliance, (2014). *Universal Health Coverage and Palliative Care. Do not leave those suffering behind.* Available at: http://www.thewhpca.org/resources/item/uhc-and-palliativecare
[6]Worldwide Hospice Palliative Care Alliance, (2014). *Universal Health Coverage and Palliative Care. Do not leave those suffering behind.* Available at: http://www.thewhpca.org/resources/item/uhc-and-palliativecare

Questions to consider:

- Is there a palliative care plan as part of your country's plan to achieve UHC by 2030?
- Does your country have a national palliative care policy and is it implemented?
- Is your country measuring progress against the World Health Assembly palliative care resolution?
- Is palliative care integrated in the national health system?
- How many people get the palliative care that they need?
- How many do not get the palliative care that they need?
- Do people have access to the pain treatment they need?
- Is palliative care included in medical, nursing and social care undergraduate curricula?
- What impact does providing palliative care have on individuals, households and the health system?

Key messages - CARE

- Universal health coverage (UHC) means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need.
- Palliative care is an essential, defining part of Universal Health Coverage.
- Universal Health Coverage, including palliative care, is critical to achieving the Sustainable Development Goals.
- UHC means everyone must be able to access the health services they need, including palliative care, without being forced into financial hardship.
- Every person deserves access to quality, affordable health services, including palliative care.
- UHC is driven by equity and human rights. We must bring UHC including palliative care to those who need it most.
- People who need palliative care have some of the greatest healthcare needs. They must be included in UHC.

Cost



Palliative care can reduce the financial burden on households driven by serious chronic and life-limiting illness.

No one should face destitution and poverty when they get sick. Financial risk occurs through paying for costly treatment not covered by national health systems.

Households with people with life-limiting illness may face high costs and potential financial hardship for futile treatments. Loss of income by the person who is ill or their carers can lead to financial risk.

Costly travel when treatment and care services are situated far from home increases financial risk to people with serious illness and their families.

While there is some evidence on the cost and cost effectiveness of palliative care, more research needs to be done, especially in low and middle income countries.

Lack of evidence around the cost of palliative care, the differing costs of different service delivery methods and its overall cost-effectiveness may result in challenges to palliative care implementation as part of UHC. In many parts of the world, civil society and the voluntary sector have developed services which are free at the point of use and funded by the communities. In some settings, governments have palliative care, partly if not completely, included within their Universal Health Coverage schemes.

However, there are often poor protection systems in place to provide financial support for carers and households facing economic crisis due to the loss of household income because of life-threatening illness or caring responsibilities for family, including older parents and children, or community members.

Financing of UHC is a political issue. When healthcare is controlled by the private sector

and driven by the free market, poor people are priced out of quality healthcare. National governments must implement policies that allow well off, healthy people to subsidize the sick and the poor.

People with serious and life-limiting illnesses have a high need for healthcare services, but often have low access to the financial resources needed to pay for them.

Palliative care can deliver high quality services at a relatively low cost, and can reduce expensive unnecessary hospital admissions. As such, it should be a top priority for Universal Health Coverage and must be included in all UHC schemes.

Questions to consider

- How much does palliative care cost in your country?
- How much is spent on palliative care per person in your country?
- How much would it cost to provide palliative care to everyone who needed it by 2030?
- How much is spent on palliative care per person in your country?
- Does your government have a separate budget line on palliative care?
- What is the cost to the health care system of not providing palliative care?
- What is the cost to the household of not providing palliative care?

Key messages - COST

- No one should face destitution and poverty when they get sick.
- Financial risk occurs through paying for costly treatment not covered by national health systems.
- Households with people with life-limiting illness may face high costs and potential financial hardship for futile treatments.
- Loss of income by the person who is ill or their carers can lead to financial risk.
- Costly travel when treatment and care services are situated far from home increases financial risk to people with serious illness and their families.
- In most parts of the world, hospice and palliative care organisations provide free services to the people and families accessing care.
- Palliative care must be included in all UHC schemes.

Recommendations

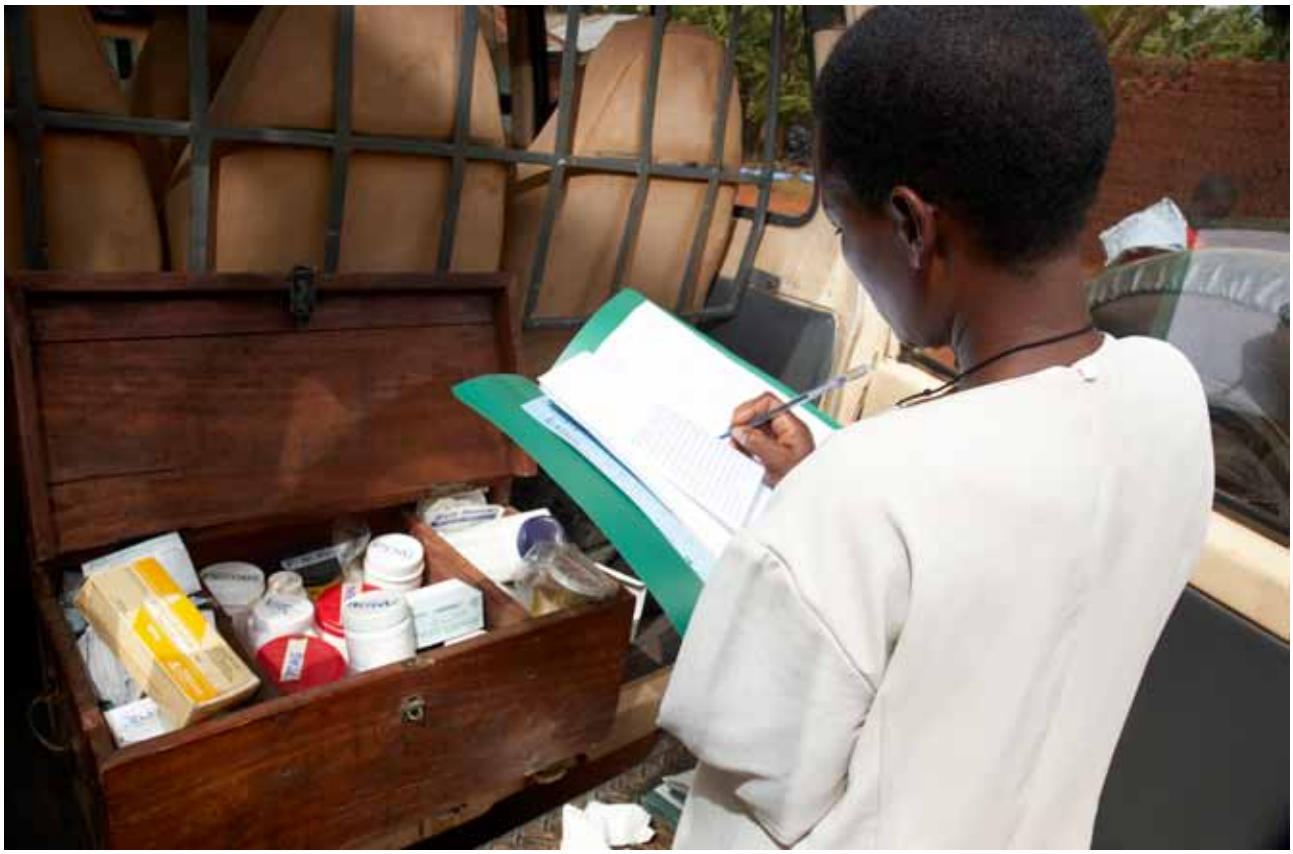


Image: African Palliative Care Association, rights granted by the Diana, Princess of Wales Memorial Fund.

Policy
Palliative care should be included within Universal Health Coverage global and national policies and strategies, along with allocated budget and appropriate resourcing for implementation to improve access and availability to meet the needs of the population.

Service delivery and implementation
Hospice and palliative care need to be fully integrated into mainstream health systems, including linkages with items such as Non-Communicable Diseases and HIV service delivery, to ensure effective coverage to meet the palliative care needs of the population.
Service delivery and implementation of UHC must ensure that no-one is left behind, including adults and children who are suffering throughout the life course, due to life-limiting conditions.

Education
Palliative care should be integrated in all preservice health worker training (e.g. doctors, nurses, clinical officers, social workers etc.) and as continuing professional development.

Financing
A thorough review should be undertaken of the inclusion of palliative care within health financing systems, including relevant health insurance and national healthcare schemes globally.

Palliative care interventions, including home based and inpatient hospice and palliative care and access to opioid analgesics, must be accessible to all and therefore included within national health financing systems such as health insurance and universal coverage schemes.
More rigorous and robust research needs to be done on the cost of hospice and palliative care and its cost-effectiveness.

More research is required on the financial burden that households face as a result of accessing, or not being able to access, hospice and palliative care services.

Monitoring and evaluation
An appropriate indicator must be added to the global monitoring framework on Universal

Health Coverage to ensure the measurement of palliative care.

Basic, standardised and routine data collection of palliative care needs to be included in existing tools such as health surveys and facility assessments. Palliative care indicators should be part of each country's Health Management Information Systems (HMIS).

Research has to be done to source relevant, quality and comparable indicators and data collection tools to improve the ability to monitor the equitable coverage of palliative care for all people, particularly the poorest.

Advocacy

Palliative care civil society providers and organisations need to advocate for the consistent and rigorous inclusion of palliative care within UHC strategies, policies, plans and monitoring frameworks at the global, regional and national level.

Civil society, including patient groups, need to be empowered and work with governments to raise peoples' awareness of their right to health, including palliative care, to thereby raise the demand for it.

Palliative care providers must work to develop clear targets, measure results, undertake focused activities and build critical relationships with other stakeholders working to achieve UHC by 2030.



Ideas on how to mark World Hospice and Palliative Care Day



Image: Rachel House via World Hospice & Palliative Care Day 2016

World Hospice and Palliative Care Day is celebrated around the world by hospices, palliative care organisations, palliative care departments within hospitals, government departments, academic institutions, patient and family groups and many more.

You can join this global community by organising an event and registering it on the interactive World Hospice and Palliative Care Day events map on the WHPCA website: http://www.thewhpca.org/world-hospice-and-palliative-care-day/add-event

The event can take any form, from an in-house seminar, to an art exhibition to a sporting event! Read on for some examples of last year's World Hospice and Palliative Care Day events to inspire you.

Canada – Special lecture

The National Initiative for the Care of the Elderly's (NICE) End-of-Life Issues Theme Team, in collaboration with Bruyère Continuing Care, the Champlain Hospice Palliative Care Program (CHPCP) and Pallium Canada, hosted the 2016 World Hospice and Palliative Care Day Special Lecture at the Auditorium of the Elisabeth Bruyère Hospital in Ottawa.

Korea – National Hospice and Palliative Care week

The National Cancer Center in association with the Ministry of Health and Welfare held a week-long national campaign and celebration for World Hospice and Palliative Care Day 2016, to increase the public's awareness of hospice and palliative care. The week included many different events, such as concerts, calligraphy

workshops, sand art displays and the creation of animated videos.

Palestine – Inauguration of first undergraduate palliative care course

The Islamic University of Gaza, in partnership with University of Edinburgh and Cairdeas IPCT timed the inauguration of the first palliative care course for medical undergraduates in Gaza to coincide with World Hospice and Palliative Care Day. The course is a step towards ensuring people in Gaza do not live and die in pain. Islamic University of Gaza is committed to integrating palliative care and to supporting the wider health system in partnership with the Ministry of Health and WHO.

Sierra Leone – Community home visits to talk about hospice and palliative care

The Shepherd's Hospice in Sierra Leone celebrated World Hospice and Palliative Care Day 2016 by conducting visits to the homes of community members in the Macdonald settlement to discuss the work of the hospice and palliative care service. MacDonald community consists of over 15 other villages, where the Shepherd's Hospice new in-patient facility is located.

South Africa – Pop-up vintage clothing store

The Hospice Palliative Care Association of South Africa organised a special event including a pop-up version of their vintage charity store: The Butterfly Box and a lunchtime 'braai' (barbecue).

Sudan – Opening of palliative care resource centre

Comboni College of Science and Technology in Khartoum, Sudan, held the inauguration ceremony of a Palliative Care Resource Centre. The programme included four 20-minute talks about: the history of palliative care, ethical issues, spiritual care and end of life care. Also taking place was: a folklore dance and the graduation of health professionals from Sudan and neighbouring countries who attended an intensive three-week course in palliative care. The resource center in palliative care (open 12 hours daily, 5 days a week) aims to help health professionals in Sudan increase their knowledge and conduct research in palliative care.

Ukraine – Round table discussion on the right to receive palliative care

The International Renaissance Foundation, in association with Chernihiv European, oraganised a round table discussion titled: palliative care and the right to receive it. During the discussion, the results of activities of the project: 'I'm alive – and I want to be heard' supported by the Public Health Initiative Group of The International Renaissance Foundation were presented. The results of a social study, advertising campaign and promotional materials, as well as an exhibition of unique photographs and others artwork will be presented.

Ukraine – Roundtable with regional government

Kharkiv Regional State Administration, in association with palliative care advocates, held a roundtable meeting to discuss hospice and palliative care in the region. Delegates included: Head of the Health Department of Kharkiv Regional State Administration, chief physicians, specialists, public, and the media.

Resources and further suggestions for World Hospice and Palliative Care Day events

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
- World Hospice and Palliative Care Day Flyer
- Key messages
- A model letter to government decision makers on the importance of UHC including palliative care that you can download and edit to suit your context.

Suggestions on how to mark World Hospice and Palliative Care Day

- Initiate or publish research that is critical for achieving universal access to palliative care as part of UHC
- Build links with civil society groups working on UHC in-country through an event or new partnerships
- Engage with the government department working on UHC to plan for the inclusion of palliative care
- Engage with the World Bank and WHO on their work on UHC in country and the extent to which palliative care is included
- Start a palliative care discussion group in person or online
- Download the template 'model letter to governments', adapt it to your local context and send it to the relevant decision makers
- Are you a member of a community philosophy group or evening class? Organise a themed discussion around World Hospice and Palliative Care Day
- Print out the World Hospice and Palliative Care Day Posters and flyers and display them around your place of work or study
- Put together a media campaign to raise awareness of World Hospice and Palliative Care Day
- Publish an article on your organisation's website
- Already have media contacts? Organise to speak on local radio stations or TV channels
- Organise a fundraising event (concert, theatre, exhibition, etc.)
- Run a social media campaign aligned to World Hospice and Palliative Care Day and the aims of your organisation
- Organise a sports or community event.

Remember to register your event on the World Hospice and Palliative Care Day webpage! http://www.thewhpca.org/world-hospice-and-palliative-care-day/add-event.

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.

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 to elaborate on the 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.

How to support World Hospice and Palliative care Day on Social Media



The use of social media, including Twitter and Facebook, is an effective way to reach a large audience with your messages.

Twitter

Twitter allows individuals or groups to communicate short messages (140 characters or less) to a wide global audience.

You can follow the @WorldHospiceDay Twitter account, and Tweet to show your support of the Day, either by using the official World Hospice and Palliative Care Day draft Tweets, or by Tweeting your own message and including the hashtag #WHPCDay17. Additional hashtags to use are listed below.

World Hospice and Palliative Care Day on Twitter

Twitter handle: @WorldHospiceDay

Main hashtag: #WHPCDay17

Social media hashtags

#UniversalHealthCoverage
#UHC #SDGs
#GlobalGoals
#PalliativeCare
#Hospice #HPC
#HPM #EndOfLife
#Health #Healthcare
#HealthForAll
#HumanRights
#HPMGlobal

Key social media accounts to @mention

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

Why does Facebook matter?

Facebook is about linking people to one another. In the non-profit sector, relationships are crucial.

Nongovernmental organisations (NGOs) depend on their relationships with members, donors and stakeholders for volunteering, financial support and advocacy muscle.

Facebook – and social media in general – offers development specialists and NGOs a chance to move away from one-way communications and move toward a type of communication in which they can interact with, listen to and engage citizens.

Facebook helps because it:

- helps people find you, connect to your message and differentiate you from other NGOs
- shows the human face of your organisation and encourages personal links in an often impersonal world.

#WHPCDay17 on Facebook

Worldwide Hospice Palliative Care Alliance
https://www.facebook.com/thewpca/?fref=ts

World Hospice and Palliative Care Day 2017
https://www.facebook.com/events/1079409718860031/

Best Practice for Social Media



Feeling stressed out when it comes to social media is a common emotion faced lately. Many small business owners, non-profits and even well-established corporates feel pressured to be on every social media channel, trying to keep up by regularly posting, and constantly 'thinking' that they are engaging.

As a result, post quality falls victim to quantity, and post-performance falls flat. To help you see engagement in the form of interaction on your social media posts by friends, fellow advocates, and followers, WHPCA have put together a list of 6 social media best practices that you should be using every day.

1. Keep Your Posts Precise and to the point
Shorter posts are more favourable to the way individuals use social media. Studies have indicated that shorter posts can increase engagement by up to 86%.[7]

But knowing what is the ideal length when you don't have a character limit can be difficult. So what is short and simple?

- Twitter: 71 – 100 characters
- Facebook: 40 – 119 characters

Sticking to these character counts has shown to be more conducive to more retweets, likes, comments and overall engagement.

2. Include a link or call to action
Always include a link with every social media post or a call to action – whether that links back to your website or to a crowdfunding initiative. Social media platforms are great tools for driving traffic to your digital channels. However, it is of great importance to make sure there is a link between the content and relevance of the link. Also, have an easy way for your viewer to then share that piece of content directly on the page by encouraging them to share it, like the page and keep up to date!

[7] Lee, K. 2014. The proven ideal length of every tweet, facebook post, and headline online Available: http://www.fastcompany.com/3028656/work-smart/the-proven-ideal-length-of-every-tweet-facebook-post-and-headline-online

3. Images get you a lot more clicks and higher engagement
It is always favourable to include an image with your social media posts. Posts with a stylish piece of original artwork or an appealing photo are much more likely to grab the attention of your followers.

Studies show engagement increases substantially when an image is included with a post. Social media posts with visuals deliver 180% higher engagement and images make up 93% of the most engaging posts on Facebook.[8]

A common problem faced is that not all organisations whether profit driven or non-profit driven have the internal resources to create beautiful graphics or photos that are of professional quality.

Luckily, there are companies such as Shutterstock and Visual.ly who offer a range of stock images and customised infographics, respectively. There are also a number of free resources out there that you can explore, one for example that we are very keen on using is Canva.

4. Become social with your networks
Engagement is a co-operative practice. You want your supporters and brand ambassadors to feel that you are very much engaged with them as they are with you. On Twitter, follow the ones that you engage with you most and make sure you respond to their mentions. By doing this you will build positive relationships with your fan base.

As mentioned before it's not just about transaction – it's also about building relationships. Observe hashtags on Facebook, Twitter, and Instagram and participate in relevant conversations. Even if you prefer not to express an opinion, acknowledge the conversation and ask your followers and fans what they think.

5. Monitor the time periods between when your post
Posts perish quickly on social media, and not all of your followers see all of your posts.

According to Facebook, each time a person engages with their News Feed, there are at least 1500 potential stories waited to be read and engaged with, however only about 57% of these posts are actually ever seen.[9]

All social media posts are short-lived, some more so than others. The average lifespan of a Facebook post is approximately 14 hours.[10] A tweet has a normal life span of just over 4 hours. And an Instagram photo's lifespan is approximately 21 hours.[11]

Social media is a great place to trial and test. Share similar articles or graphics more than once. Investigate and adjust several factors that will influence your engagement, such as different messaging, unique or common hashtags, and calls to action. Try also to post at different times of the day and on the different days in the week, noting how changing the timing of the post influences engagement.[12]

6. Keep your posts consistent and generate a strategy
It has been said that there are three important factors that have to be taken into consideration across your social media accounts in order to see favourable results and engagement.

The first is making sure that your content is

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[8]Jones, K. 2015. How to effectively use visual storytelling [infographicI]. Available: http://www.searchenginejournal.com/effectively-use-virtual-storytelling-infographic/136436
[9]AddThis Academy. (n.d). 6 Social media best practices you should know. Available: https://www.addthis.com/academy/6-social-media-best-practices-you-should-know/
[10]Camille. 2014. Social network studies: the 2014 number. Available: http://blog.overgraph.com/social-network-studies-the-2014-numbers/
[11]AddThis Academy. (n.d). 6 Social media best practices you should know. Available: https://www.addthis.com/academy/6-social-media-best-practices-you-should-know/
[12]AddThis Academy. (n.d). 6 Social media best practices you should know. Available: https://www.addthis.com/academy/6-social-media-best-practices-you-should-know/

relevant, engaging and that you use the correct social media channels for the content.[13]

The second is that you need to expand on the types of posts you're sharing – establish a balance between promotional, conversational and personal posts. It was recommended not to just have promotional posts about donations, appeals and so forth as it could end up as more likely to lose you followers than gain! Your followers need to know why they should donate to you so make sure content connects with emotions. Lastly, post on a regular basis, taking into consideration point 5 above and make sure that you post consistently.

Getting the right balance for overall engagement and establishing your brand in social media will take some time – it's not only tied to best practices, but also organisational resources and capacity. For example, you might only have the capacity to share one post a day, which is fine as its better than positing none! What's key is you experiment and note what works and what does not work.

By following the above 6 best practices we encourage you, if you have not already, to take action and start your journey with social media for your organisation's benefit.

Further resources on social media for NGOs

1. 8 Tips for establishing your non-profit on social media: http://bit.ly/2b44IvF
2. Winning non-profit social media strategies: https://maximizesocialbusiness.com/9-winning-nonprofit-social-media-strategies-25696/
3. Social media best practices for non-profits: http://www.crescentgroup.ca/2017/05/26/social-media-best-practices-non-profits/
4. 10 Social media strategies that increase engagement and inspire donors: http://www.nptechforgood.com/2016/11/08/10-social-media-strategies-that-increase-engagement-and-inspire-donors/
5. Five social media best practices for small NGOs in developing countries: http://www.nptechforgood.com/2013/09/23/five-social-media-best-practices-for-small-ngos-in-developing-countries/

[13]Jeyes, D. 2014. 5 proven ways to boost sharing on your site. Available: www.addthis.com/blog/2014/03/24/5-proven-ways-to-boost-sharing-on-your-site/#.Vd4mNORFjq

World Hospice and Palliative Care Day 2017 Draft Tweets



Use the draft tweets below to build momentum for your World Hospice and Palliative Care Day campaign or event, and tweet on the day (14 October) to join the global conversation.

#UHC & #PalliativeCare – Don't leave those suffering behind #UHC #SDGs @WHO @UN #WHPCDay17 @DrTedros

COUNT

In 42% of the world's countries there is ZERO availability of #palliativecare #WHPCDay17 #UHC @DrTedros

- Measure what matters. Are health services accessible, of sufficient quality and affordable for all? #UHC #SDGs @WHO @UN #WHPCDay17
- What gets measured gets done! Measure palliative care coverage as part of #UHC! #SDGs @ WHO @UN #WHPCDay17 @DrTedros
- We must hold leaders, health systems and ourselves 2 account 2 care 4 those living w life-limiting illness #WHPCDay17 #UHC #SDGs @WHO @UN
- Don't wait for political action: demand it. #WHPCDay17 #UHC #SDGs @WHO @UN
- We must hold leaders accountable for leaving no one with life-limiting illness behind! #WHPCDay17 #UHC #SDGs @WHO @UN

- In only 20 countries is #PalliativeCare well integrated into the health care system #WHPCDay17 #UHC #SDGs @WHO @UN @DrTedros

- 40 million people need palliative care annually including 20 million at the end of life #WHPCDay17 #UHC #SDGs @WHO @UN @DrTedros

- Only 14% of the need 4 #PalliativeCare is being met at the end of life, less than 10% overall #WHPCDay17 #UHC #SDGs @WHO @UN @DrTedros

- 78% of those needing #palliativecare live in LMICs #WHPCDay17 #UHC #SDGs @WHO @UN @DrTedros

CARE

It isn't Universal Health Coverage without universal access to palliative care #WHPCDay17 #UHC #SDGs @WHO @UN @DrTedros

- #UHC means that all people and communities can use all health services they need #WHPCDay17 #UHC #SDGs @WHO @UN

- #UHC includes promotion, prevention, cure, rehabilitation and #PalliativeCare #WHPCDay17 #SDGs @DrTedros

- Palliative care is an essential, defining part of #UHC #WHPCDay17#SDGs @WHO @UN @DrTedros

- Universal Health Coverage, including palliative care, is critical to achieving the #SDGs #WHPCDay17 #UHC @WHO @UN

- UHC means everyone must b able 2 access #healthcare incl #PalliativeCare, w/out being forced into poverty #WHPCDay17 #UHC #SDGs @WHO @UN

- Every person deserves access to quality, affordable health services, including palliative care #WHPCDay17 #UHC #SDGs @WHO @UN

- UHC is driven by equity & #HumanRights. We must bring #UHC incl #PalliativeCare 2 those who need it most #WHPCDay17 #UHC #SDGs @WHO @UN

- People who need #PalliativeCare have some of the greatest #healthcare needs. They must b included in #UHC! #WHPCDay17 #SDGs @DrTedros

COST

Palliative care can reduce financial burden on households driven by serious chronic & life-limiting illness #WHPCDay17 #UHC #SDGs @WHO @UN

- No one should face destitution and poverty when they get sick #WHPCDay17 #UHC #SDGs @WHO @UN @DrTedros

- Financial risk occurs through paying for costly treatment not covered by national health systems #WHPCDay17 #UHC #SDGs @WHO @UN

- Households w people w life-limiting illness may face high costs & potential financial hardship 4 futile Tx #WHPCDay17 #UHC #SDGs @WHO @UN

- Loss of income by the person who is ill or their carers can lead to financial risk #WHPCDay17 #UHC #SDGs @WHO @UN

- Costly travel when Txt & care services r far from home increases financial risk 2 ppl w serious illness & their families #WHPCDay17 #UHC

- In most countries hospice & #PalliativeCare orgs provide free services 2 people & families accessing #care #WHPCDay17 #UHC #SDGs @WHO @UN

- Palliative care must be included in all #UHC schemes #WHPCDay17 #SDGs @WHO @UN @DrTedros

Conclusion



Image: Hospice Palliative Care Association of South Africa

Universal Health Coverage is key to ensuring that all people, no matter how rich or poor, can access the health services they need, of sufficient quality to be effective and without being forced into financial hardship.

Palliative care is an essential, defining aspect of UHC. People with palliative care needs are among the sickest and most vulnerable in the healthcare system.

They must be included in and protected by UHC schemes.

This Toolkit offers a background on palliative care as part of UHC, as well as 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 interactive map on the World Hospice and Palliative Care webpage (http://www.thewhpca.org/world-hospice-and-palliative-care-day/add-event) and encourage your supporters to donate to the World Hospice and Palliative Care Day Just Giving campaign. (https://www.justgiving.com/campaigns/charity/wpca/whpcday17)

Together we can make sure that, by supporting Universal Health Coverage and Palliative Care, we don't leave those suffering behind!

Further resources



- WHO & WHPCA Global Atlas of Palliative Care at the End of Life http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care
- WHPCA report: UHC and Palliative Care: Do not leave those suffering behind! http://bit.ly/1QN8p5z
- WHPCA report: Palliative care and the global goal for health. http://bit.ly/2h6dB5O
- Rob Yates presentation: It is not #UHC without palliative care! http://bit.ly/2htxcgH
- Imagine: UHC and palliative care video: http://bit.ly/2vlKoiJ
- WHO webpage: Universal Health Coverage: http://bit.ly/1ILemMe
- Handbook: Building Integrated Palliative Care Programs and Services: http://bit.ly/2wJqfDv