


# Advocacy Guide

# Palliative Care and Universal Health Coverage

2023

Plain text version

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# Abbreviations

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|---|---|
| **LMIC** | Low- and middle-income country |
| **NCD** | Non-communicable disease |
| **PC** | Palliative care |
| **PPC** | Paediatric Palliative Care |
| **PHC** | Primary healthcare |
| **SDG** | Sustainable Development Goal |
| **UHC** | Universal Health Coverage |
| **WHO** | World Health Organisation |
| **WHPCA** | Worldwide Hospice Palliative Care Alliance |

# Acknowledgement

This advocacy guide evolved from—and in some cases quotes directly—materials developed by the International Federation of Psoriasis Associations (i.e. *Advocacy Toolkit for Universal Health Coverage: A guide to using Universal Health Coverage to campaign for psoriasis and psoriatic arthritis* plus the associated Factsheet). The International Federation of Psoriasis Associations granted WHPCA permission to make this adaptation with a focus on palliative care; WHPCA is sincerely grateful for their generosity. In places, this guide also replicates text that was first published in WHPCA (2014) *Universal Health Coverage and Palliative Care: do not leave those suffering behind* and WHPCA, ICPCN and PallCHASE (2020) *Palliative Care, COVID-19 and Universal Health Coverage.*

# A note on this edition

This version of the guide has been created in MS Word with minimal formatting. This is done in case users wish to print all or parts of it, and also to encourage and facilitate users to add to it, i.e. insert their own context-specific information, notes, contacts etc.

A professionally designed PDF version of the guide is also available from the WHPCA website.

# Executive summary

"Advocacy for health policy is defined as 'the processes by which the actions of individuals or groups attempt to bring about social and/or organization change on behalf of a particular health goal, program, interest, or population. Health advocacy includes educating policymakers and the public about evidence-based policy.' Palliative care advocacy is strongest when it includes the *voices* of direct stakeholders, those who deliver and receive essential services, and can *testify, witness* to the vast unmet need for palliative care"

Source: Pettus and de Lima[1]

This guide provides a framework to support advocacy to facilitate policymakers at national, regional, or local level making a robust and meaningful commitment to palliative care (PC) as part of their commitment to UHC and sets out evidence that can be used for this advocacy process. It is designed to be adaptable to your own context and to provide guidance on supporting documents that you may want to access to further your cause.

Palliative care is defined by the World Health Organisation (WHO) as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" [2].

Whilst similarities exist there are differences between palliative care for children and adults. WHO defines children's palliative care as "the active, total care of the child's body, mind and spirit, and also involves giving care to the family. It begins when the illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres, and in children's homes"[3].

Palliative care is a basic human right—and should provide care early in the trajectory of an illness that is accompanied by serious health-related suffering, not just at the end of life. Furthermore, palliative care may be delivered alongside active treatment of a disease or diseases including treatment aimed at cure. Palliative care provision should not include continuing potentially futile treatment. Each year an estimated 56.8 million people need palliative care, most of whom live in low- and middle-income countries (LMIC). For children, 98 per cent of those needing palliative care live in LMIC, with almost half of them living in Africa. It is estimated that 86 per cent of people who need palliative care do not receive it and 78 per cent of the people who need palliative care are in LMIC.

[1] *Palliative Care Advocacy: Why Does it Matter?* Pettus & de Lima. Journal of Palliative Medicine. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7404818/#:~:text=Why%20This%20Is%20Important%3F,the%20development%20of%20public%20policy

[2] WHO Fact sheet on Palliative Care (https://www.who.int/news-room/fact-sheets/detail/palliative-care)

[3] National cancer control programmes : policies and managerial guidelines, 2nd ed. WHO 2002. p. 85. https://apps.who.int/iris/handle/10665/42494

The *Lancet Commission on Palliative Care and Pain Relief*[4] has devised an essential package of palliative care medicines, basic equipment, and human resources that could alleviate much avoidable suffering in LMICs. The WHO *Model List of Essential Medicines*[5] and the *Model List of Essential Medicines for Children*[6] also include a section on palliative care and pain relief which can inform palliative care implementation. Unequal access to morphine is of particular concern and ensuring affordable, accessible opiates in appropriate formulations, for pain relief and respiratory distress must be a priority for any palliative care programme.

Palliative care need not be expensive and indeed there is emerging evidence that PC may be cost-effective in some circumstances as it potentially permits carers and/or patients to return to work and thus avoids the household being forced into poverty by out-of-pocket health-related spending.

Measuring the quality and effectiveness of PC in a consistent, comparable way is now possible using the WHO set of actionable indicators. PC development should be guided by the WHO house model[7] (see adjacent image), designed to "assist policymakers and programme managers consider how to strengthen and integrate palliative care throughout their health system, including social and long-term care".




The first *High-Level Meeting on Universal Health Coverage* (UHC) took place in September 2019 and resulted in an international commitment to achieve UHC set out in the *Political Declaration* [8] adopted by member states on 23rd September 2019.

According to WHO, UHC means that "all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course"[9].

The Political Declaration aims to accelerate progress towards achieving UHC and reinforce the commitments taken in 2015 by UN member states towards attaining the health-related sustainable development goals (SDGs). This measure, SDG Target 3.8 aiming to achieve UHC, by 2030, includes the implementation of PC.

[4] https://www.thelancet.com/commissions/palliative-care
[5] https://www.who.int/groups/expert-committee-on-selection-and-use-of-essential-medicines/essential-medicines-lists
[6] https://www.who.int/publications/i/item/WHO-MHP-HPS-EML-2021.03
[7] *Assessing the development of palliative care worldwide: a set of actionable indicators*. WHO. *https://www.who.int/publications/i/item/9789240033351*
[8] *Political Declaration of the High-level Meeting on Universal Health Coverage "Universal Health Coverage: moving together to build a healthier world"*. The Political declaration. United Nations. https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf
[9] *Universal Health Coverage*. WHO. https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)

Currently, especially in LMICs where it can least be afforded, much of healthcare is funded by out-of-pocket health-related spending pushing families into poverty or indeed catastrophic expenditure (more than 10 per cent of household income). If UHC is to be achieved, it is essential that PC is integral to the UHC package. As well as being affordable, healthcare should be of high quality and delivered in the most appropriate setting for the individual concerned.

Primary healthcare (PHC) is a whole of society approach which includes primary care, secondary care, and tertiary care. As a policy, it aims to achieve healthcare for communities and individuals as early as possible in the continuum from health promotion and prevention to treatment, rehabilitation, and palliative care. It also seeks to provide care as close to the patient's environment as possible.

PHC is integral to effective delivery of UHC. However, there is currently a great shortage of healthcare workers, both voluntary and employed, to deliver PC. Financial investment, education, and training of all healthcare workers are essential if UHC including PC is to become universally available.

Palliative care is often delivered in the community in or close to the patient's home increasing its affordability as it is delivered as part of primary care. This is usually cheaper than secondary or tertiary care. Levels of training vary from basic to intermediate to specialist depending on the extent to which the healthcare worker was involved in the delivery of palliative care. However, it would be expected that all healthcare workers would receive at least basic training in palliative care.

The need for both UHC and PHC has been exacerbated by the epidemic of non-communicable diseases (NCDs), of which the five most prevalent, impacting both adults and children, are cardiovascular disease, respiratory disease, diabetes, cancer, and problems with mental health with a recognition that many NCDs have their origins in childhood[10]. Provision of high-quality palliative care is essential for optimal management of NCDs.

Advocating for palliative care involves utilising the need for progress towards UHC and the integral part primary healthcare plays in this as leverage. The 2019 High-Level Meeting Political Declaration can be used to add weight to arguments put forward concerning the importance of UHC.

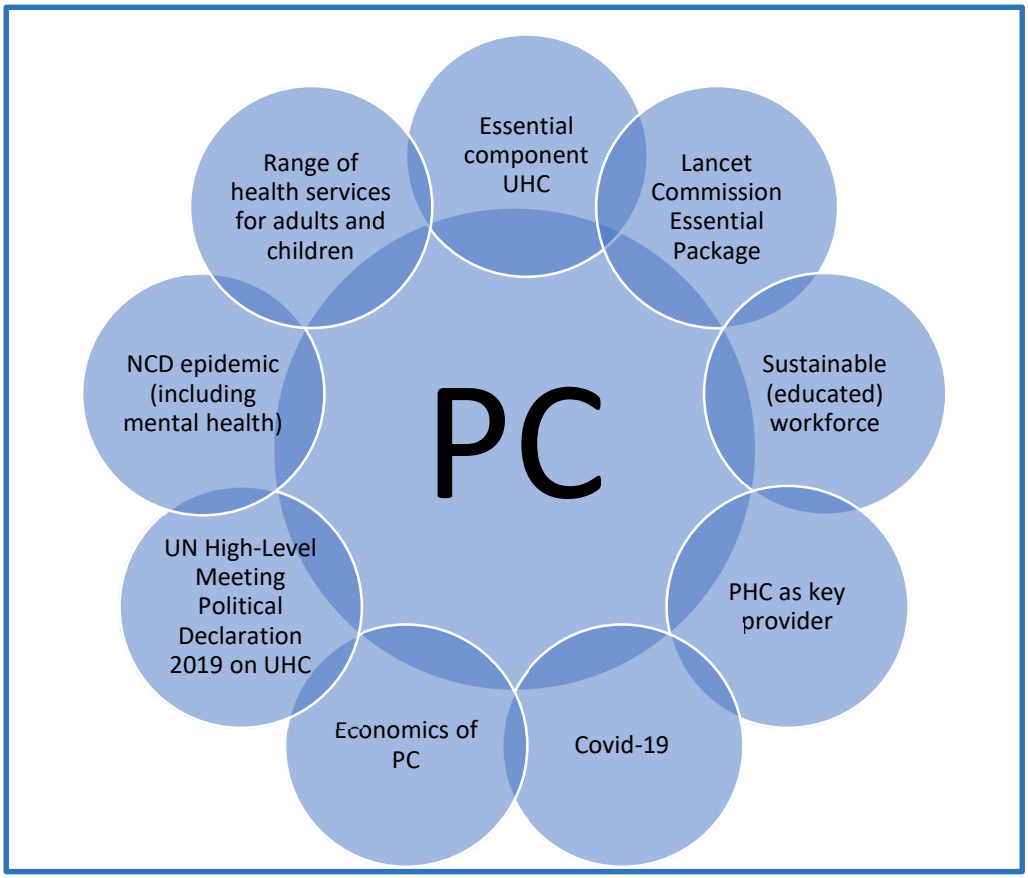
When preparing an *advocacy ask* to present to policymakers, it is helpful to understand the general principles of primary healthcare NCDs, Universal Health Coverage, sustainable workforce and palliative care along with the principles of adult and paediatric service provision. It is also useful to possess situational knowledge of these in specific contexts.

Existing progress towards achieving UHC in a given context can be gained from the WHO publication *Tracking Universal Health Coverage 2021 Global Monitoring Report*[11]. A range of country specific data relating to the achievement of UHC is available from the *data portal of UHC2030*[12]. The current state of palliative care provision can be obtained from the WHPCA and WHO publication *Global Atlas of Palliative Care 2nd. Edition 2020*[13].

Effective advocacy involves not only an understanding of the current position of PC and UHC provision, but also who is the most appropriate person or organisation to address when

[10] *https://www.who.int/teams/maternal-newborn-child-adolescent-health-and-ageing/child-health/prevention-of-noncommunicable-diseases*
[11] *Tracking Universal Health Coverage: 2021 Global monitoring report*. WHO. https://www.who.int/publications/i/item/9789240040618
[12] *UHC Data Portal.* UHC 2030. https://www.uhc2030.org/what-we-do/knowledge-and-networks/uhc-data-portal/
[13] *Global Atlas of Palliative Care. 2nd Ed*. WHPCA. http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care

delivering your justification for the inclusion of PC in UHC. A summary of areas to be considered when preparing such an advocacy argument is provided in the figure below.




These considerations are all expanded on in the guide, enabling you to put together a document using Universal Health Coverage to advocate effectively for palliative care provision in a specific context.

It is essential that as many of us as possible advocate for the provision of palliative care for all those who need it whatever their age, gender, social status, financial situation, or disease, and that they receive the highest possible level of palliative care without financial hardship.

# 1. Introduction

"We cannot achieve Universal Health Coverage without palliative care"

Dr Tedros Adhanom Ghebreyesus,
Director General, World Health Organisation (WHO)

This guide is designed to help you advocate for palliative care (PC) to be included in Universal Health Coverage (UHC) as a priority for your country or district working towards achieving UHC. It provides a brief summary of key issues relating to palliative care in **Section 2** and then an introduction to Universal Health Coverage in **Section 3**.

**Section 4** focuses on advocacy for palliative care and how specific paragraphs of the Political Declaration on UHC and the general stated principles of UHC can support your advocacy for inclusion, or the improvement of palliative care as part of UHC. **Section 5** briefly highlights the important role of palliative care in the response to COVID-19. **Section 6** is a summary *call to action* and there is a brief **Conclusion**. **Annexe 1** provides reference paragraphs taken from the Political Declaration, and **Annexe 2** contains the two-page WHPCA *Advocacy Factsheet for Palliative Care and Universal Health Coverage*[14]. Finally, we list our sources.

The guide contains a range of ideas and supporting evidence to help prepare advocacy for the inclusion of palliative care into UHC. However, it will be important for you to develop your plans considering the specifics of your unique situation, i.e., the nature of the existing palliative care provision as well as other aspects including the healthcare funding model in your context, who delivers palliative care, access to essential medicines (particularly opioids), and where palliative care is delivered.

Please feel free to use and/or adapt any part of this guide. Acknowledgement of WHPCA is welcome but not essential. And if you have any feedback on how we can improve the guide or questions about the content please contact us at info@thewhpca.org.

[14] http://thewhpca.org/resources/joomla-template/get-support/universal-health-coverage/item/whpca-uhc-toolkit-factsheet

# 2. Palliative care

## 2.1 Palliative care

Palliative care is a central component of integrated, person-centred healthcare. It aims to improve quality of life and relieve symptoms in people with serious health-related suffering. This is the case regardless of whether the suffering is physical, psychological, spiritual, or social in nature.

Palliative care is a global human right and should be available to all who need it. This is in keeping with *The International Covenant on Economic, Social and Cultural Rights*, which "recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" and includes "the creation of conditions which would assure to all medical service and medical attention in the event of sickness"[15].

The current epidemic of non-communicable diseases (NCDs) increases the need for palliative care, which historically has largely been reserved for individuals with (end-stage) cancer. Long-term survival with HIV and multi-drug resistant TB creates an additional need for PC and many of these individuals will have NCDs as well as their underlying communicable disease. Furthermore increased survival in children with complex needs creates an additional PC need.

Palliative care is not just about end-of-life care but about the relief of suffering throughout the whole course of an illness. Given this, PC is often provided alongside curative or life-prolonging treatments. However, PC should not include futile attempts to prolong life.

Each year an estimated 56.8 million people need palliative care, most of whom live in low- and middle-income countries. For children, 98 per cent of those needing palliative care live in low- and middle-income countries (LMIC) with almost half of them living in Africa. We estimated that 86 per cent of people who need PC do not receive it and 78 per cent of the people who need PC are in LMIC.

**INFO: Palliative care**

"an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual".

"Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death"

"Palliative care is explicitly recognized under the human right to health. It should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals"

Source: WHO Fact sheet[16]

[15] *International Covenant on Economic, Social and Cultural Rights*. United Nations. https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights

[16] WHO Fact sheet on Palliative Care (https://www.who.int/news-room/fact-sheets/detail/palliative-care)

**INFO: Palliative care for children**

"Palliative care for children is the active, total care of the child's body, mind and spirit, and also involves giving care to the family. It begins when the illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres, and in children's homes"

Source: WHO 2002[17]

## 2.2 Essential package for palliative care

The *Lancet Commission on Palliative Care and Pain Relief*[18] has devised an essential package of palliative care medicines, basic equipment, and human resources that could alleviate much of the avoidable suffering in LMICs (see box over the page). This essential package must be part of Universal Health Coverage platforms and the drive to achieve the Sustainable Development Goals (SDG 3, particularly 3.4 and 3.8) by 2030. The cost of this essential package in LMICs is about USD 3 per capita. An essential package focused on children's palliative care is under development.

Morphine is the mainstay of pain relief and the most critical medicine but access to morphine is very unequal: LMICs account for only 0.1 metric tonnes of morphine equivalent opioids of the estimated annual 298.5 metric tonnes distributed globally. The Lancet Commission on Palliative Care and Pain Relief also notes that at best international prices, the medical need for opioid analgesia for children in low-income countries is estimated at just over $1 million dollars.

**INFO: Access to morphine varies**

In Haiti, only 5mg of morphine equivalent opioids are available per capita per year. The result is that 99 per cent of palliative care needs for morphine equivalent opioids goes unmet. In stark contrast, the equivalent figure in the USA is 55,000mg and in Canada 68,000mg.

Source: Lancet Commission on Palliative Care and Pain Relief

Low- and middle-income countries have an opportunity to address serious health-related suffering at relatively low cost through the essential palliative care package.

Providing for the entirety of the essential package may not be feasible in an initial stage. In such circumstances, deciding what to provide will require policymakers to strike a balance of necessity, accessibility, ease of use and cost. For example, in terms of equipment, it may be necessary to prioritise opioid lockboxes and adult diapers (or their equivalent). In terms of medicines, opioid provision (with necessary training for prescribing and administering them) should be the top priority

[17] National cancer control programmes : policies and managerial guidelines, 2nd ed. WHO 2002. p. 85. https://apps.who.int/iris/handle/10665/42494
[18] https://www.thelancet.com/commissions/palliative-care

## The Lancet Commission

## Essential Package Of Palliative Care And Pain Relief Health Services

The Essential Package contains the inputs for safe and effective provision of essential palliative care and pain relief interventions to alleviate physical and psychological symptoms, including the medicines and equipment that can be safely prescribed or administered in a primary care setting. The list of essential medicines in the Essential Package is based on WHO's list of essential medicines, and considers the medicines, doses, and administration routes for palliative care for both adults and children.

The Essential Package is designed to be lowest cost by including only off-patent formulations, frugal innovation for needed equipment, and a staffing model based on competencies rather than professions. Tasks often undertaken by specialised medical personnel in high-income countries can be performed by other specialised and general practitioners and nurses or by community health workers empowered with the necessary training and medical supervision to participate effectively in the delivery of palliative care and pain treatment at all levels of care, from the hospital to the home.

With the key exception of morphine, the medicines in the Essential Package are available in most countries even if supply is limited. For morphine, an essential palliative care medicine, assuring safety and accessibility is complex. Ensuring a balance between appropriate medical access to controlled medicines and the prevention of their diversion and non-medical use is crucial, and the Commission not only designed appropriate human resource models but also the strategies to provide the complementary policy and stewardship to expand access to an Essential Package that includes morphine.

The health services of the Essential Package must be complemented by interventions for the relief of social and spiritual suffering to preserve the dignity of patients, facilitate access to health interventions, and prevent financial hardship and impoverishment. Yet, these social supports are neither part of the remit of health ministries nor should they be financed from a health budget.

Antipoverty and social development policies, publicly funded safety nets, programmes, and ministries must give special attention to ensure that families do not sacrifice their basic needs in desperate attempts to care for loved ones. These persons with life-limiting or life-threatening health conditions and their families should be mainstreamed into existing social support and social welfare programmes, yet they are often ignored, excluded, or marginalised, preventing them from being effectively integrated into these programmes.

**Medicines**

- Amitriptyline
- Bisacodyl (Senna)
- Dexamethasone
- Diazepam
- Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate)

*Lancet Commission Essential Package continued …*

- Fluconazole
- Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline and citalopram)
- Furosemide
- Hyoscine butylbromide
- Haloperidol
- Ibuprofen (naproxen, diclofenac, or meloxicam)
- Lactulose (sorbitol or polyethylene glycol)
- Loperamide
- Metoclopramide
- Metronidazole
- Morphine (oral immediate-release and injectable)
- Naloxone parenteral
- Omeprazole
- Ondansetron
- Paracetamol
- Petroleum jelly

**Medical equipment**

- Pressure-reducing mattress
- Nasogastric drainage or feeding tube
- Urinary catheters
- Opioid lock box
- Flashlight with rechargeable battery (if no access to electricity)
- Adult diapers (or cotton and plastic, if in extreme poverty)
- Oxygen

**Human resources (varies by referral, provincial or district hospital, community health center, or home**

- Doctors (specialty and general, depending on level of care)
- Nurses (specialty and general)
- Social workers and counsellors
- Psychiatrist, psychologist, or counsellor (depending on level of care)
- Physical therapist
- Pharmacist
- Community health workers
- Clinical support staff (diagnostic imaging, laboratory technician, nutritionist)
- Non-clinical support staff (administration, cleaning)

Source: Lancet Commission on Palliative Care and Pain Relief [19]

[19] https://www.thelancet.com/commissions/palliative-care

## 2.3 The economics of palliative care

The perceived or actual availability or lack of funding plays a significant role in shaping the decisions of government policymakers. Given this, it is important to have some understanding of the health economics of palliative care or the cost-related arguments that can be made in favour of PC provision. The WHO is working on a technical document on palliative care and costs, scheduled for publication in 2023[20]. This should help health policymakers to make informed and frugal decisions in favour of integrating palliative care into Universal Health Coverage.

**INFO: WHO on PC and poverty**

It is estimated that 930 million people are at risk of falling into poverty often due to palliative care-related out-of-pocket expenditure (of more than 10 per cent of their household budget) and about 90 million people (1.2 percent of the world population) are still being pushed into "extreme poverty" (living on USD 1.90 or less a day) because they paid for healthcare out-of-pocket.

Source: WHO on Financial Protection[21]

Funding for palliative care comes from different sources. Even in high-income countries such as the UK, most hospices are at least partly funded by charitable funding. Across the world, individuals and families also share the financial burden as they incur out-of-pocket expenses or loss of earnings due to illness or care responsibilities. In developing your UHC-related advocacy, it is important to understand the specific ways in which palliative care is financed in your country context (government, health insurance, donors, individuals, and families etc.).

More research is needed, but there are indications that not only is palliative care a medical and moral imperative, but it turns out to be cost-effective for both health insurers and patients (adults and children) and families:

- Early introduction of palliative care improves survival, (despite less aggressive treatment than a group who did not receive palliative care), quality of life, and wellbeing. It is thus cost-effective, since carers and sometimes also patients may be able to return to work[22].
- Palliative care can reduce the use of costly and mostly non-beneficial interventions, such as unnecessary emergency services, hospitalizations, testing and treatments, thus decreasing the costs of care.
- Early integration of a low-cost palliative care intervention in patients with newly diagnosed cancer reduced both out-of-pocket expenditure and loss of wages of informal caregivers[23].
- Palliative care in advanced cancer in Malawi reduced catastrophic costs to households[24].

[20] Once published this will be available as a resource on the WHPCA website
[21] *Financial protection.* WHO. https://www.who.int/health-topics/financial-protection#tab=tab_1
[22] *Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer.* Temel et. al. https://www.nejm.org/doi/full/10.1056/nejmoa1000678
[23] *Early integrated palliative care in patients newly diagnosed with cancer in Ethiopia: a randomised controlled trial and cost–consequence analysis*. Reid et. al. The Lancet Global Health. https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(22)00142-5/fulltext
[24] *Palliative care and catastrophic costs in Malawi after a diagnosis of advanced cancer: a prospective cohort study.* Bates et al 2021. https://www.sciencedirect.com/science/article/pii/S2214109X21004083

- Palliative Care does reduce hospitalisations including repeat admissions and facilitates fewer high-cost, low-value treatments[25].
- Health care during the last year of life represents a large proportion of an individual's healthcare costs so reducing costs at this point is particularly cost-effective.

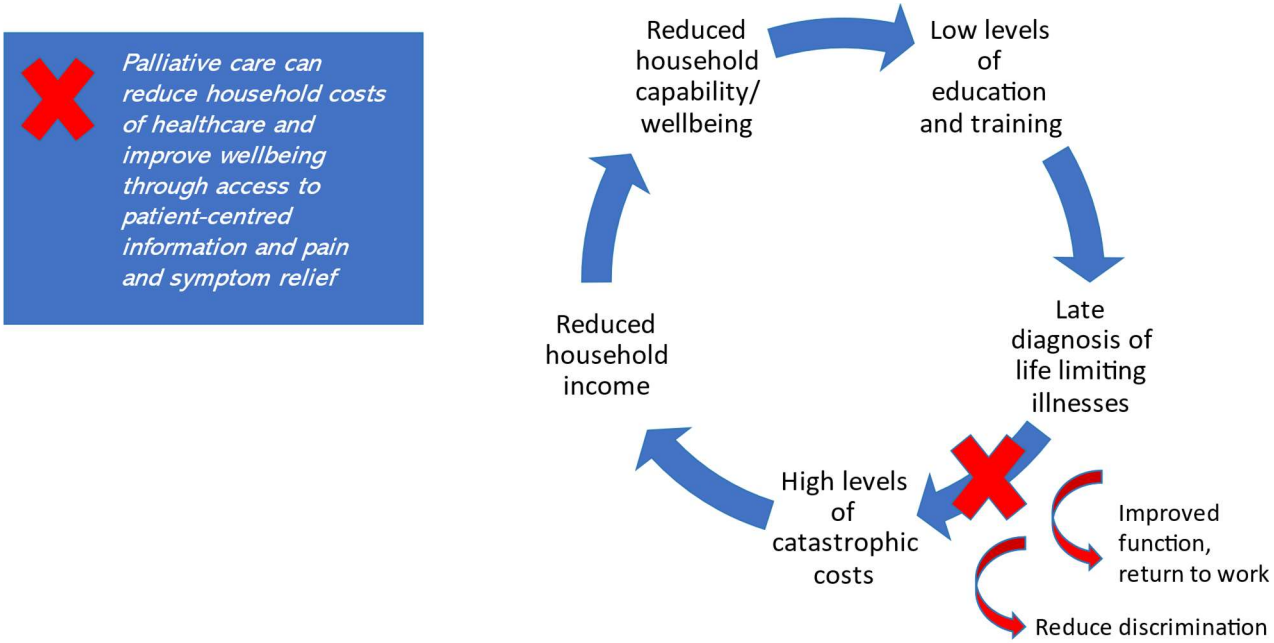



**Figure1: The economics of palliative care**

*Source: with permission Dr Maya Jane Bates*

## 2.4 Developing palliative care: WHO model and actionable indicators

In 2014 the World Health Assembly (the governing body of the WHO) passed a resolution calling for the expansion of palliative care throughout the continuum of healthcare systems[26]. National level palliative care development should be guided by the *house* model developed by the WHO and assessed using the set of WHO actionable indicators—see the figure overleaf. The house model is designed to "assist policymakers and programme managers consider how to strengthen and integrate palliative care throughout their health system, including social and long-term care"[27].

[25] *Cost Savings Associated With US Hospital Palliative Care Consultation Programs.* Morrison et. al. JAMA Internal medicine. https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/414449

[26] *Strengthening of palliative care as a component of comprehensive care throughout the life course*. Resolution WHA67.19. World Health Assembly. https://apps.who.int/iris/handle/10665/162863

[27] *Assessing the development of palliative care worldwide: a set of actionable indicators*. WHO. *https://www.who.int/publications/i/item/9789240033351*




Source: WHO *Assessing the development of palliative care worldwide: a set of actionable indicators,* pp. 17, 19

| INDICATOR | CORE | STRATEGIC |
|---|---|---|
| **Integrated palliative care services** | | |
| • Number of specialized palliative care programmes in the country per population | ✓ | ✓ |
| • Number of specialized palliative care programmes for paediatric population in the country | ✓ | |
| **Health policies** | | |
| • Existence of a current national palliative care plan, programme, policy or strategy with defined implementation framework | ✓ | ✓ |
| • Inclusion of palliative care in the list of health services provided at the primary care level in the national health system | | ✓ |
| • Existence of national coordinating authority for palliative care (labelled as unit, branch, department) in the Ministry of Health (or equivalent) responsible for palliative care | | ✓ |
| **Use of essential medicines** | | |
| • Reported annual opioid consumption – excluding methadone – in oral morphine equivalence (OME) per capita | ✓ | ✓ |
| • Availability of essential medicines for pain and palliative care at all levels of care | | ✓ |
| • General availability of immediate-release oral morphine (liquid or tablet) at the primary care level | | ✓ |
| **Education and training** | | |
| • Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula | ✓ | ✓ |
| • Specialization in palliative medicine for physicians | ✓ | |
| **Empowerment of peoples and communities** | | |
| • Existence of groups dedicated to promote the rights of patients in need of palliative care, their families, their caregivers and disease survivors | ✓ | ✓ |
| • Existence of national policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care | ✓ | |
| **Research** | | |
| • Existence of congresses or scientific meetings at the national level specifically related to palliative care | ✓ | |
| • Palliative care research on the country estimated by peer reviewed articles | ✓ | |

**Figure 2: WHO *house* model for development of palliative care worldwide and actionable indicators**

The WHO house model is a useful reference point when advocating for the integration of palliative care in UHC. It illustrates that the provision of palliative care for both adults and children requires a multi-dimensional and integrated approach achieved through the scale-up and alignment of health policies, research, education and training, and essential medicines. It emphasises the need to empower people and communities and, critically, to meaningfully involve people living with palliative care needs.

The WHO indicators are also a useful addition to your advocacy toolkit, providing an authoritative, standardised way of monitoring and evaluating your country's progress.

The palliative care indicators were developed to be used in all countries. Ten are considered *core* indicators "for the comparative and in-country evaluation of palliative care development". Nine *strategic* indicators are "more relevant and feasible for countries at initial stages of palliative care development". A quick scan may be sufficient to assess your country's progress against these indicators—the core list or the strategic list—for onward discussion with and advocacy to, policymakers.

# 3. Universal Health Coverage

## 3.1 Political Declaration on UHC

The international commitment to achieve Universal Health Coverage comes from the *Political Declaration*[28] adopted by UN Member States on 23 September 2019. The occasion was the first High-Level Meeting on Universal Health Coverage.

The declaration is meant to accelerate progress towards achieving UHC and reinforce the commitments taken by UN Member States in 2015 when the *Sustainable Development Goals* (SDGs) were approved.

**INFO: Sustainable Development Goals**

"The Sustainable Development Goals are the blueprint to achieve a better and more sustainable future for all. They address the global challenges we face, including poverty, inequality, climate change, environmental degradation, peace and justice"

The most important SDG for palliative care is:

**SDG 3: Ensure healthy lives and promote well-being for all at all ages**

**Target 3.8:** Achieve Universal Health Coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all

**Indicators:**
3.8.1: Coverage of essential health services
3.8.2: Proportion of population with large household expenditures on health as a share of total household expenditure or income

Source: Sustainable Development Goals[29]

The *Political Declaration on UHC* opens with a strong affirmation that everyone has a right to the highest attainable standard of physical and mental health. This is a commitment that strengthens the right to health as presented in the U*N Universal Declaration on Human Rights* of 1948. The fundamental principle of UHC—no one should be left behind—is reiterated throughout the whole text of the declaration.

The declaration recognizes that UHC should include a broad range of health services, including Promotion, Prevention, Treatment, Rehabilitation and Palliative Care, not only treatment of diseases. Interventions on NCDs and mental health disorders are reiterated throughout the declaration as urgent measures to be implemented.

Ample room is given to financing health systems and the importance of finding resources to finance health services. This is essential so that people in need of healthcare are not excluded by financial barriers and/or do not incur excessive costs as a result of receiving health services.

[28] *Political Declaration of the High-level Meeting on Universal Health Coverage "Universal Health Coverage: moving together to build a healthier world"*. The Political declaration. United Nations. https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf
[29] *Sustainable Development Goals*. United Nations. https://www.un.org/sustainabledevelopment/sustainable-development-goals/

The declaration urges governments to find solutions to the lack of a health workforce in general and its uneven distribution across the country. These health workforce problems particularly affect rural areas and LMICs.

The need for disaggregated data to inform policy is highlighted throughout the Political Declaration.

Weaknesses of the Political Declaration include the lack of financial and time-bound commitments from signatories and the lack of an overall accountability framework. There is also no strong language emphasizing the importance of public healthcare versus private healthcare.

It is up to advocates at the national level to push for the full realization of the commitments taken at the High-Level Meeting on Universal Health Coverage and to hold their government accountable.

## 3.2 What is UHC?

"UHC means that all individuals and communities receive the health services they need without suffering financial hardship. It includes the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course"

Source: WHO[30]

In many settings, poor and marginalized people are the ones with reduced access to health services. UHC is intended to make sure that all these individuals have access to healthcare and receive the services and support they need so that no one is left behind.

UHC implies that the health services provided to people in need are high quality. That means, for example, that prevention strategies should include accurate and up-to-date information, that diagnosis of a disease is prompt and correct, and that necessary healthcare and support are received by the person in need.

UHC does not mean that all health services should be provided for free; this is not feasible or sustainable for many health systems. However, necessary health services should be affordable. This means that people in need of healthcare should be able to afford the costs of care besides their other living costs, such as food and other living necessities. Those in need of health services should not be pushed into poverty because of health expenditure, and those who are already below the poverty threshold should not be pushed further into poverty because of their healthcare needs. Currently, a high proportion of healthcare costs in LMICs is funded by out-of-pocket expenditure pushing families and caregivers into poverty or catastrophic expenditure. UHC implementation aims to prevent this. The WHO suggests the key to financial protection is pre-payment and pooling of resources rather than relying on individuals paying through out-of-pocket spending at the time of healthcare delivery.

An important feature of UHC is progressive universalism, meaning that countries start by implementing a core set of essential interventions and expand coverage over time when more resources become available. Similarly, UHC is not a finite process, as coverage for health services should be expanded once more resources become available. Additionally, the nature of health services will change over time.

[30] *Sustainable Development Goals*. United Nations. https://www.un.org/sustainabledevelopment/sustainable-development-goals/

"All countries can take actions to move more rapidly towards UHC despite the setbacks of the COVID-19 pandemic, or to maintain the gains they have already made"

Source: WHO[31]

## 3.3 Primary healthcare and primary care

"Primary health care (PHC) is a whole-of-society approach to health that aims at ensuring the highest possible level of health and well-being and their equitable distribution by focusing on people's needs (and) as early as possible along the continuum from health promotion and disease prevention to treatment, rehabilitation and palliative care, and as close as feasible to people's everyday environment"

Source: WHO and UNICEF[32]

"Investments in quality primary health care will be the cornerstone for achieving UHC around the world"

Source: WHO[33]

The World Health Assembly stated that palliative care is "an ethical responsibility of health systems". However, inequality of access to palliative care for both adults and children, is one of the greatest disparities in global healthcare. Recognising this, there is a moral imperative to provide palliative care as part of primary healthcare. This is because the whole of society approach in primary healthcare will facilitate increased equity of provision for all services including palliative care.

As highlighted by the WHO[34], most people receiving palliative care prefer to be treated at home. Given this, community provision of palliative care through primary care (a component of primary healthcare) is preferable.

For advocacy work on palliative care in UHC, it is therefore important to understand and distinguish between *primary healthcare* (PHC) and *primary care*—they are not the same thing, and the two terms should not be used interchangeably (see the info box over the page).

Successful implementation of palliative care as part of UHC depends on the whole-of-society approach of primary healthcare.

Despite widespread recognition of the need to integrate palliative care into primary healthcare to achieve UHC, significant barriers exist. Not least, many countries do not have palliative care policies, strategic plans, or clinical guidelines at national, programme or service level, and there is a lack of trained healthcare professionals to deliver palliative care. Addressing these generic issues and accelerating progress towards SDG 3.8 should form part of the work advocating for palliative care to be an essential component of PHC.

[31] *Sustainable Development Goals*. United Nations. https://www.un.org/sustainabledevelopment/sustainable-development-goals/
[32] *A vision for primary health care in the 21st century: Towards UHC and the SDGs. WHO and UNICEF. https://apps.who.int/iris/handle/10665/328065*
[33] *Sustainable Development Goals*. United Nations. https://www.un.org/sustainabledevelopment/sustainable-development-goals/
[34] *Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. WHO. https://apps.who.int/iris/handle/10665/274559*

| Primary Health Care | Primary Care |
|---|---|
| Three critical synergistic components:<br>• Primary care and public health as part of comprehensive integrated health services at the centre of PHC<br>• Multisectoral approaches and policies that address the wider determinants of health<br>• Engaging and empowering individuals, families, and communities to promote self-care and self-determination of health.<br><br>WHO has recommended every country allocate or reallocate an additional 1 per cent of GDP to PHC from government and external funding sources.<br><br>The whole-of-society approach of primary health care facilitates greater equity of provision of all services including palliative care. | Refers to health care that is delivered by generalists close to the patient, is usually based in the community, and refers onwards to specialists in secondary and tertiary care as necessary. Typically, primary care (or community healthcare) is the first point of contact with a healthcare provider and is also the main provider of healthcare for the majority of the population.<br><br>Investing in primary care as part of UHC is potentially a cost-effective strategy in that it usually provides care more cheaply than specialist care. In addition, it is more likely that the poorest, most disadvantaged, and marginalized populations will have better access to primary care than to other more specialist services. |

## 3.4 Sustainable health workforce

An adequate, sustainable workforce is critical to effective primary healthcare and therefore is essential for achievement of UHC and integration of palliative care into UHC.

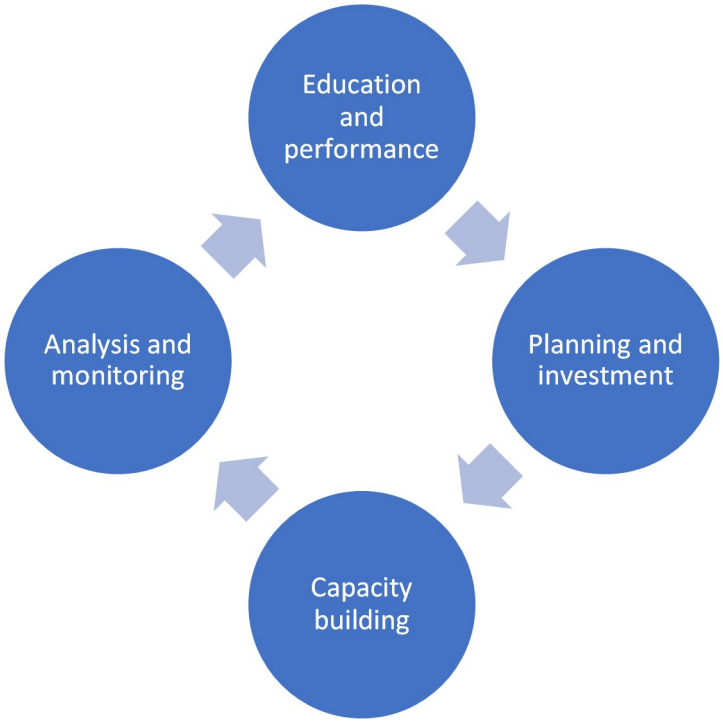
According to recent calculations, it is anticipated that globally there will be a shortage of 18 million health workers by 2030. The WHO *Global Strategy on Human Resources for Health: Workforce 2030* [35] sets out recommendations and responsibilities for member states necessary to achieve an adequate healthcare workforce by 2030.

Inadequate provision of healthcare workers tends to disproportionately affect LMICs and the poorest, most disadvantaged populations within these countries. Effective provision of PHC is dependent on addressing this anticipated shortage to ensure there is an adequate sustainable workforce which includes coverage of the poorest, most marginalised, and disadvantaged populations. This requires both capital and recurrent financial investment to ensure that increases in the workforce are sustainable.

The WHO *Toolkit for a sustainable health workforce in the WHO European Region*[36] proposes a policy matrix to inform implementation of a sustainable workforce – see figure 3 below.

[35] *Global Strategy on Human Resources for Health: Workforce 2030*. WHO. https://apps.who.int/iris/bitstream/handle/10665/250368/9789241511131-eng.pdf
[36] *The toolkit for a sustainable health workforce in the WHO European Region*. WHO. https://www.euro.who.int/__data/assets/pdf_file/0004/375547/WH11_TK_text_AW-2.pdf

**Figure3: A policy matrix**




Education and training should include palliative care as part of UHC and be part of pre-entry training and continuing professional development for all healthcare professionals, not only those who are palliative care specialists. Basic training for everyone could consist of the equivalent of one week training, for healthcare professionals likely to give PC (but not specialists in PC) intermediate training of two months equivalent, and for specialist PC providers one to two years equivalent. It is important to address this shortage of healthcare workers together with the challenges of the uneven distribution of healthcare providers. But it is also important that the health workforce at all levels and in all countries be well-trained in palliative care and ready to respond to the health necessities of the population they serve.

## 3.5 UHC and non-communicable diseases

Non-communicable diseases are a growing challenge worldwide across the life course[37] from neonates, through children into adulthood and the elderly.

NCDs kill 41 million people each year, equivalent to 74 per cent of all deaths globally. NCDs are chronic in nature, many people living with NCDs have 2 or more co-morbidities and NCDs potentially have a lifelong course. Exposure to risk factors such as tobacco and alcohol can begin as early as in utero and consumption of unhealthy products begin in childhood or adolescence.

The four main NCDs are cardiovascular disease, respiratory disease, cancer and diabetes and mental health is an important consideration for all individuals living with NCDs. In children anaemia, injuries and accidents are also common[38]. UHC aims to ensure that no one suffers financial hardship because of the costs of healthcare. This is particularly important for NCDs

[37] See for example the UK Working Group on NCDs definition of the life course approach: *https://globalncdsuk.org/2023/02/03/a-life-course-approach-to-ncds-new-report/*

[38] https://www.who.int/teams/maternal-newborn-child-adolescent-health-and-ageing/child-health/prevention-of-noncommunicable-diseases

whose management is characterized by a generally high share of out-of-pocket expenditure. UHC makes sure that the management of NCDs is appropriate, from prevention and control of NCDs to treatment and palliative care.

UHC facilitates timely diagnosis and better management of NCDs, permitting individuals living with NCDs to minimize time taken off from work or school because of their disease(s). Progressive expansion of services included in healthcare packages, following the concept of *progressive universalism* should mean that increasing numbers of people will benefit from quality health services and, in turn, will be able to be part of the productive population contributing to the well-being of their countries.

- **LMIC NCD burden.** NCDs are widespread in developed countries as well as in LMICs but the burden is much greater for LMICs than for their high-income counterparts. Each year, 17 million people die from an NCD before the age of 70, but 86 per cent of these premature deaths occur in LMICs and of all NCD deaths, 77 per cent are in LMICs.
- **Global economic impact.** As well as their impact on health there is a significant economic consideration—NCDs are predicted to be responsible for economic losses of USD 7 trillion over the two decades from 2010 to 2030.
- **Individual economic impact.** The burden of NCDs at the individual level is increased by their financial impact; the majority of funding for healthcare for NCDs especially in LMICs comes from out-of-pocket expenditure which can lead to catastrophic health expenditure with families being pushed below the poverty line.
- **Treatment focus.** Most health systems are not designed to cope with the current epidemic of NCDs. Typically, their major focus is on treatment rather than prevention; they are mainly disease-centred. In contrast, NCDs are often multi-morbid.
- **Access to therapies.** Access to health promotion and prevention services, screening routines, cutting-edge therapies (both pharmacological and surgical), recurrent monitoring of disease development, rehabilitation and palliative care are privileges largely reserved for high-income countries and are only provided for a proportion of this population.
- **PHC model for NCDs.** A PHC whole society model for UHC ensures that management of NCDs includes health prevention, promotion, and rehabilitation as well as treatment and palliative care.
- **A life course approach**. Whilst the WHO advocate that policies and programmes take a life course approach this is often not seen in practice, and more attention paid during childhood can help shape future health even decades later[39].
- **Access to palliative care.** Access to palliative care is critical to the effective management of NCDs and associated serious health-related suffering. It should be introduced early in the trajectory of an illness or illnesses and not reserved for end-of-life care.
- **SDG 3.4.** Failure to address NCDs is compromising progress towards Sustainable Development Goal 3.4: "By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being".
- **Importance of UHC.** Effective UHC can help address many of the challenges faced by people living with NCDs. As NCDs can affect anyone regardless of social and economic

[39] N. *Jones et al., 'Life course approaches to the causes of health disparities' (2019) Am J Public Health 109(Suppl 1): S48–S55 https://doi.org/10.2105/AJPH.2018.304738.* B. Mikkelsen et al., 'Life course approach to prevention and control of non-communicable diseases' (2019) *BMJ* 364 https://doi.org/10.1136/bmj.l257; https://www.who.int/publications/i/item/9789240025271

status, a health system that leaves no one behind increases the level of equity within society.

Tackling NCDs is included in the set of essential interventions suggested by the Lancet Commission (see above). The WHO *NCD Global Action Plan 2013-2020* [40] outlines six objectives and nine voluntary targets to help achieve their vision of "a world free from avoidable non communicable diseases" which include "to strengthen and orient health systems to address the prevention and control of non-communicable diseases and the underlying social determinants through people-centred primary healthcare and Universal Health Coverage" (Objective 4), as well as listing UHC as one of its overarching principles. Clearly, integration of cost-effective management of NCDs is critical to achieving effective UHC.

[40] *Global Action Plan for the prevention and control of NCDs 2013-2020*. WHO. https://www.who.int/publications/i/item/9789241506236

# 4. Advocacy for palliative care

## 4.1 Advocacy

"We're all advocates! You don't need to have had 'advocacy' in your job title to have had experience of advocacy. In our daily lives, most of us are constantly trying to influence others to take a certain course of action. Remember to draw on these experiences when advocating for the changes you seek"

Source: INTRAC[41]

"Advocacy for health policy is defined as 'the processes by which the actions of individuals or groups attempt to bring about social and/or organization change on behalf of a particular health goal, program, interest, or population. Health advocacy includes educating policymakers and the public about evidence-based policy.' Palliative care advocacy is strongest when it includes the *voices* of direct stakeholders, those who deliver and receive essential services, and can *testify, witness* to the vast unmet need for palliative care"

Source: Pettus and de Lima[42]

Advocacy is a way we can highlight the importance of palliative care as an essential part of UHC, mobilise support for more and better palliative care services, and hold governments accountable to their international commitments. This may be at the national/policy level (e.g., focusing on policy and resource allocation issues), the local level (e.g., focusing on allocation of staff or supply of medicines) or at the service delivery level (e.g., focusing on patient care, community involvement, and essential medicines and products).

Advocating for palliative care requires a multipronged approach drawing on all the different information and ideas in this guide, your experiences and context and much more. It will also involve those mainly focusing on adults and those who mainly focus on children to work together in their advocacy. Spotlighting and amplifying lived experience of palliative care are powerful and persuasive strategies that complement the data being used as hard evidence. Indeed, it is critical that people living with palliative care needs are included in the preparation of arguments and documentation presented to policymakers, local government, and at service delivery level as this adds authenticity to an argument. Figure 4 over the page outlines components to be considered when preparing an advocacy document arguing for inclusion of palliative care in a meaningful way into UHC.

When advocating for palliative care who are your main *targets*? For example, in your country, who in the Ministry of Health is responsible for Universal Health Coverage? In official UHC meetings at the global level (often in Geneva, Switzerland), which officials will be in the delegation representing your country? It is also useful to find out whether there are other key power players, or *gate-keepers*, such as someone in the Office of the President or the Prime Minister her/himself.

A good place to start is making contact with your allies. Make sure you are working in concert with the other palliative care leaders and advocates in your country so there is a unified effort.

[41] *Section 01 Introducing advocacy*. INTRAC. *https://intrac-1.gitbook.io/advocacy/section-01-introducing-advocacy*
[42] *Palliative Care Advocacy: Why Does it Matter?* Pettus & de Lima. Journal of Palliative Medicine. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7404818/#:~:text=Why%20This%20Is%20Important%3F,the%20development%20of%20public%20policy.

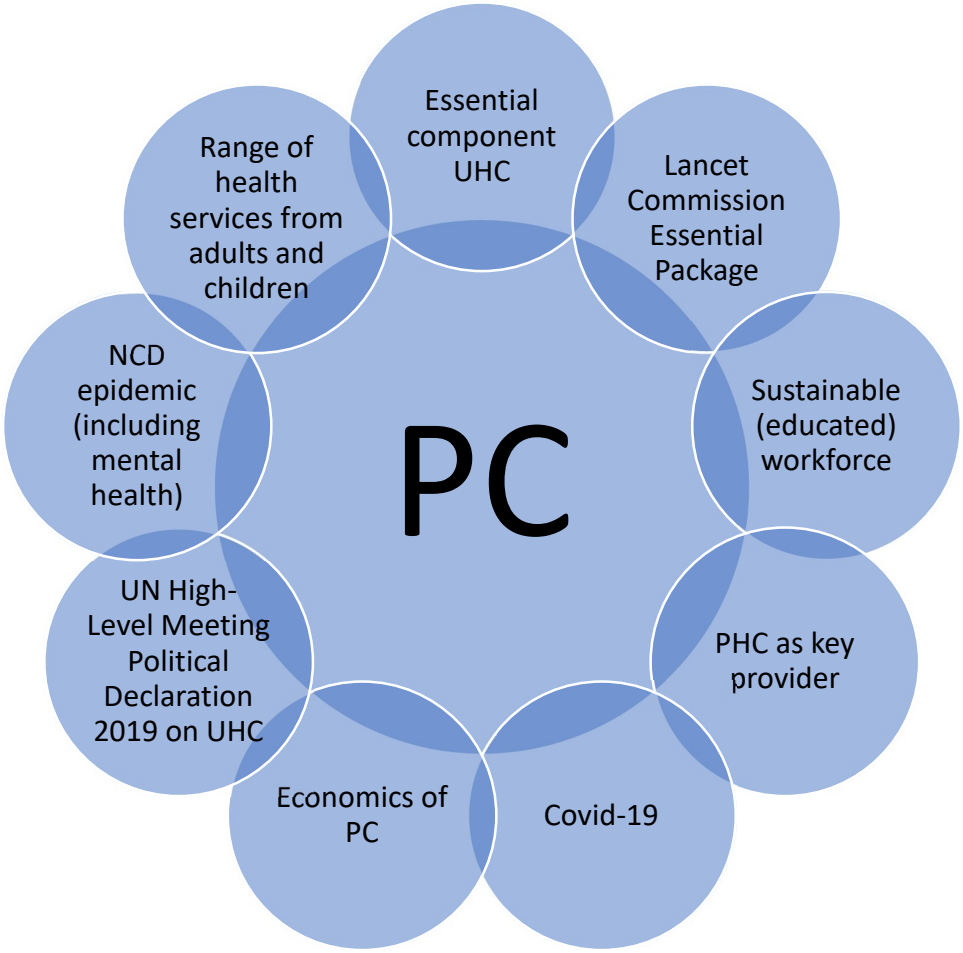



**Figure 4: Components of an advocacy document arguing for inclusion of palliative care into UHC**

*Source: WHPCA*

## 4.2 Progress on UHC?

Where do people go to get a sense of how their country is doing on UHC generally, and palliative care as part of UHC more specifically? What are the key domestic and global resources?

**INFO: UHC2030 data portal**

"UHC2030 has developed this Data Portal to provide access to the evidence used to track the state of commitment to Universal Health Coverage (UHC). The State of UHC Commitment brings a unique multi-stakeholder view to a simple question: Are countries acting on their commitments to UHC?"

Source: UHC2030 Data Portal[43]

The WHO has published a guide to monitoring UHC progress, *Tracking Universal Health Coverage 2021 Global Monitoring Report*[44]. This highlights the fact that prior to the COVID-19

[43] *UHC Data Portal.* UHC 2030. https://www.uhc2030.org/what-we-do/knowledge-and-networks/uhc-data-portal/
[44] *Tracking Universal Health Coverage: 2021 Global monitoring report*. WHO. https://www.who.int/publications/i/item/9789240040618

pandemic gains in service coverage were significant, although largely focused on communicable diseases, particularly HIV, TB, and malaria. Out-of-pocket expenditure on healthcare pushing families into poverty has decreased in recent years but is still unacceptably high. Furthermore, there are large discrepancies between and within countries exacerbating these trends.

The WHPCA *Global Atlas of Palliative Care 2nd. Edition*[45] provides specific data on how individual countries are receiving and managing palliative care provision. Specific mapping of palliative care development at country level began in 2006, was updated in 2011 and most recently in 2017. Data from 198 countries categorises their palliative care development into 1 of 6 levels:

**1** No known PC activity

**2** Capacity building PC activity

**3a** Isolated PC provision

**3b** Generalised PC provision

**4a** PC at preliminary stage of integration

**4b** PC at advanced stage of integration

According to the WHPCA *Global Atlas* (Chapter 4), only 30 countries achieve level 4b of which only 2, Malawi and Swaziland, are outside Europe, America, and the Western Pacific. By contrast, 47 countries are at level 1 with no PC provision. The largest group was level 3a with 65 countries having isolated PC provision. *The Global Atlas* is an invaluable resource for detailed information on PC provision at individual country level as well as general information about PC. Other resources are available that focus specifically on children's palliative care such as the ICPCN website and maps, as well as the global atlases for specific regions. Used in conjunction with the WHO guide on tracking UHC progress (see above), it will help provide specific information about your individual context to enable preparation of a draft advocacy document. This can then be further developed as your own research on the status of PC development and integration in your location takes place.

## 4.3 Using the Political Declaration in advocacy for palliative care in UHC

"Governments have the primary responsibility to ensure people's health, but governments alone cannot achieve UHC. Whole-of-society engagement in government processes and through social participation mechanisms ensures accountability and legitimacy.

Governments need to involve civil society and communities in decision-making about their health. Inclusive involvement ensures that polices respond to all people's needs and it creates the basis for trust in policies"

Source: UHC 2030 Universal Health Coverage Message Sheet for 2023[46]

[45] *Global Atlas of Palliative Care. 2nd Ed.* WHPCA. http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care
[46] *Universal Health Coverage (UHC) Message Sheet for 2023.* UHC 2030. https://www.uhc2030.org/fileadmin/uploads/uhc2030/UHC_MESSAGE_SHEET_FOR_2023.pdf

If your government is a signatory (and most are), you can use the Political Declaration on UHC to advocate for more and better palliative care. The Declaration is useful in many ways.

Some of the key avenues of pursuit relate to the right to health, NCDs, people living with palliative care needs, access to medicines, health workforce preparedness and presence, financial costs of living with palliative care needs, disabilities, and mental health.

Below, each of these diverse issues is highlighted and the relevant paragraphs of the Declaration are flagged. The text of these relevant paragraphs is then provided in **Annexe 1** for you to use as reference material.

## The Right to Health

The declaration opens by reaffirming the right to health for every human being. Paragraph 1 not only mentions the right to health but also the *highest attainable standard* of both physical and mental health and may be leveraged in multiple settings.

*[The Right to Health—see the Political Declaration …Paragraph 1]*

## NCDs and Mental Health

The declaration urges action against NCDs in multiple paragraphs. Palliative care is integral to the effective management of NCDs and mental health and, as emphasised earlier, this is critical to the effective implementation of UHC.

Mental health has earned a place under the spotlight at the World Health Organization and at the United Nations in recent years. The importance of good mental health is also present in the political declaration on UHC in paragraphs 1 and 12(c) (see above) as well as in a dedicated paragraph requesting governments to act to combat the epidemic of poor mental health that has just started to reveal itself.

As the text acknowledges, mental health conditions are increasing the burden of NCDs and many NCDs are associated with poor mental health as well as poor mental health being an NCD per se. Optimal management of NCDs depends on optimal integration into UHC and for many NCDs that optimal management will include palliative care implemented at an early stage in the illness trajectory. This reflects the "comprehensive and integrated services for prevention and treatment of mental health disorders" that the declaration calls for.

*[NCDs and Mental Health—see the Political Declaration …Paragraph 4 Paragraph 12(c) Paragraph 33 Paragraph 36]*

## Health Services

UHC is about providing quality health services to the people (adults and children) in need so it is important to note that a broad range of health services should be included under the phrase *quality health services*. Particularly in LMICs, the emphasis will be on healthcare provided by primary and community care with referral upward to secondary and tertiary hospital-based services only as needed. Because palliative care reduces the need for costly interventions it potentially reduces the need to utilise secondary and tertiary services while still providing quality health services. Palliative care is of course provided in the context of secondary and tertiary care by palliative care specialists but basic palliative care can also be provided in the community by volunteer community workers at the opposite end of the healthcare spectrum.

*[Health Services—see the Political Declaration …Paragraph 9 Paragraph 25}*

## Disabilities

People living with serious health-related suffering face multiple barriers in their daily lives and most experience increasing disability as their illness progresses.

The 2014 Declaration acknowledges the existence of "physical, attitudinal, social, structural and financial barriers" faced by people with disabilities and urges governments to work to remove them. Without this one of the most marginalized groups cannot gain meaningful full access to Universal Health Coverage.

The language around disabilities used in the Political Declaration is a useful tool to advocate for palliative care. Paragraph 37 recognizes that persons with disabilities still face unmet health needs and barriers in many aspects of life, and paragraph 50 emphasizes the need to improve the availability and affordability of assistive products.

Discrimination in the workplace, limited access to buildings and public spaces, high cost of rehabilitation and of assistive products for people with specific needs can all be addressed by using the Political Declaration on UHC, as it is clearly stated that all the barriers faced by people with disabilities in their daily lives should be tackled and removed.

Rehabilitation is another key area that can be addressed by using the Political Declaration on UHC.

> "Palliative care requires a broad multidisciplinary approach that includes rehabilitation, defined as 'a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment'. Suffering in life-threatening illness often relates to a decline in function and the related loss of usual roles and routines, independence, choice and sense of dignity. Rehabilitation is recognized as an essential health service, and when integrated into palliative care, it can slow decline and may reverse previous decline in physical and cognitive functioning. Integrated palliative and rehabilitative services represent a good investment, since by improving a person's function rehabilitation can cut ongoing care costs and may prevent avoidable hospital admissions, length of stay and complication risk"
>
> Source: WHO[47]

*[Disabilities—see the Political Declaration …Paragraph 37 Paragraph 50]*

## Access to Medicines

Together with improved access to assistive products, paragraph 50 of the declaration includes the commitment to improve availability and affordability of a wide range of medical products. Access to medicines has always been debated in the global health policy arena not only because of its implications on population health but also its repercussions on countries' economy and health expenditures. Other than paragraph 50, access to medicines is included in paragraphs 49 and 51.

[47] *Quality Health services and palliative care. Practical approaches and resources to support policy, strategy and practice*. WHO. *https://www.who.int/publications/i/item/9789240035164*

The essential package for palliative care designed by the Lancet Commission (see Section 2.2) lists the essential medicines for provision of quality, affordable palliative care as well as the equipment required such as an opioid lockbox and adult diapers.

However, access to these medicines is currently extremely unevenly distributed with most essential medicines being difficult or impossible to access in many LMICs and disproportionately available in high-income countries including paediatric formulations. This is despite opioids being relatively inexpensive.

The Lancet Commission cited that as little as USD 145 million would close the global gap in the need for morphine in palliative care.

The WHO *Model List of Essential Medicines*[48] also provides guidance on essential medicines; it includes twenty four medicines and six therapeutic equivalents in the section on palliative care and pain relief.

While recognising that it is currently aspirational for all countries to be able to provide access to the complete list of essential medicines we should be aiming to have this essential list of medicines available, affordable and easily accessible by those in need of them.

As previously highlighted, UHC embodies the concept of *progressive universalism*, meaning that the coverage of health services should progressively expand once more resources become available. Although the essential package list of medicines is low cost it may be that access to opioids as the most important aspect of pain relief is prioritised and additional essential medicines added to the package as more resources become available within UHC for a given context.

*[Access to Medicines—see the Political Declaration …Paragraph 49 Paragraph 50 Paragraph 51]*

## Financial Hardship

Actions must be taken to avoid people being pushed into poverty due to their life-limiting illness or the illness of their family. Avoiding financial hardship is a key aspect of UHC (treated as important as access to quality health services) and is covered in the Political Declaration in paragraph 9 (reported above) and paragraphs 12, 24, and 39. As stated by the WHO[49], "Palliative care is not a luxury, it is essential. It should be available and affordable to each and every person who needs it".

*[Financial Hardship—see the Political Declaration …Paragraph 12(a) Paragraph 12(e) Paragraph 24(b) Paragraph 39]*

## Primary Healthcare

Primary healthcare is the cornerstone of UHC and is of utmost importance if we want to achieve the people-centred model of care that the World Health Organization advocates. The importance of primary healthcare in UHC is reported in paragraphs 13, 39, and 46 of the political declaration.

[48] *WHO Model Lists of Essential Medicines. 2. Medicines for pain and palliative care*. WHO. *https://list.essentialmeds.org/?section=323&indication=&year=&age=&sex=*

[49] *Palliative Care: The essential facts*. Powerpoint presentation. WHO. https://cdn.who.int/media/docs/default-source/integrated-health-services-(ihs)/palliative-care/palliative-care-essential-facts.pdf?sfvrsn=c5fed6dc_1

The Astana Declaration[50] as part of its commitment to building sustainable PHC (Section V) includes an explicit commitment to prioritising health across the life course from preventative through to palliative care, further endorsing the importance of primary healthcare in integrating palliative care into Universal Health Coverage.

*[Primary Healthcare—see the Political Declaration …Paragraph 13 Paragraph 39 Paragraph 46]*

## Health Workforce

Delivery of quality palliative care requires a health workforce that is sufficient in numbers, appropriately distributed, and operating with a clear understanding of palliative care. Many countries face significant challenges relating to the health workforce and fall short of satisfying these criteria for the achievement of UHC. The challenges of human resources for health include inadequate numbers by cadre in the health systems where they are required, inadequate country budgets to hire even where they exist, lack of relevant expertise and skills where they are employed, and disparate distribution between rural and urban centres. All these challenges are particularly acute in relation to palliative care. Paragraphs 60-2 of the Political Declaration push governments to address these issues by training more healthcare professionals and community workers and creating incentives for them to work in underserved areas.

Around the world, the absence or insufficient coverage of palliative care in training curricula for health professionals also needs to be addressed. All healthcare professionals, especially those working in primary care, should learn about palliative care as part of their training.

*[Health Workforce—see the Political Declaration …Paragraph 60 Paragraph 61 Paragraph 62]*

[50] *Declaration of Astana. Global Conference on Primary Health Care.* https://www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf

# 5. Palliative care and COVID-19

The global COVID 19 pandemic has created a massive additional need for palliative care. This additional need is both acute and chronic:

- **Acute need—**numbers of people with COVID disease experiencing serious health-related suffering.
- **Chronic need—**prevalence and impact of long COVID on individuals and their families/carers.
- **Grief and bereavement need—**families of those that die of COVID need close assessment and support and are at risk for prolonged grief disorder.

At the UN level, the importance of palliative care in the response to COVID-19 and as a crucial part of the spectrum of essential health services within Universal Health Coverage is well recognised—see WHPCA, ICPCN and PallCHASE *Palliative Care, COVID-19 and Universal Health Coverage*[51]. In many cases, however, national responses have not yet adequately met the acute and chronic needs associated with COVID-19. The main recommendations in the report to governments, which can be used in national level advocacy, are reproduced below.

**INFO Recommendations for government**

"In order to ensure that people with serious illness and those with severe COVID-19 have the best quality of lives and their family members and carers are supported, it is crucial that palliative care is integrated in immediate COVID-19 responses as well as longer term integration into health systems and Universal Health Coverage reforms. Our recommendations to government are:

- Integrate palliative care into the COVID-19 response—in line with the WHA Resolution on the COVID-19 Response, ensure that palliative care is included in COVID-19 response plans and is adequately financed.
- Ensure that the most vulnerable with palliative care needs, including older people, refugees and children, are not left behind.
- Train healthcare workers in palliative care—ensure health care workers are trained in palliative care and palliative care is integrated into health care workers curricula at all levels as well as COVID-19 specific training.
- Engage with civil society providing palliative care to address sustainability issues—options may include undertaking a risk assessment on the impact on people's lives and health systems of civil society palliative care organisations collapsing due to financial insecurity.
- Ensure palliative care inclusion in Universal Health Coverage including public financing and indicators to track progress—assess and address gaps in palliative care as part of UHC reforms and systems"

Source: WHPCA, ICPCN and PallCHASE[52]

[51] *Palliative care, COVID-19 and Universal Health Coverage*. WHPCA, ICPCN and PallCHASE. http://www.thewhpca.org/resources/whpca-publications-and-reports/item/palliative-care-covid-19-and-universal-health-coverage-report
[52] *Palliative care, COVID-19 and Universal Health Coverage*. WHPCA, ICPCn and PallCHASE. http://www.thewhpca.org/resources/whpca-publications-and-reports/item/palliative-care-covid-19-and-universal-health-coverage-report

# 6. Call to action

## 6.1 Ready for action?

If you are ready to take the next step, or already active and want some ideas, this section summarises what you might want to find out and what you might want to focus on in your *advocacy asks*. **Sub-section 6.2** focuses on the information on palliative care and UHC that will provide a strong foundation for your advocacy work. **Sub-section 6.3** highlights the six *advocacy asks* of the UHC movement. These asks, provided by UHC2030, focus on Universal Health Coverage *in general*. **Sub-section 6.4** reproduces the WHO key messages specifically relating to quality palliative care, which should be core to your UHC-related advocacy. Finally, **sub-section 6.5** focuses on advocacy asks specific to palliative care as an essential component of UHC. In practise, you should feel free to dip into any of these and other relevant sources to develop your strategy—the specific, planned actions and requests best suited to your situation.

## 6.2 Information you will want to gather

- **The state of play—**how is PC provided (adults and children)? How much does it cost? Who is/is not able to access PC? How is PC provision funded? Using the WHO indicators (core or strategic set), what stage has your country reached in the development of palliative care?
- **Understanding of palliative care—**do policymakers understand that PC is an essential component of UHC? Have they taken relevant steps (financial and policy-related) to ensure development of PC? Is there a PC policy in place?
- **Availability of the essential package—**is the Lancet Commission Essential Package available? What is missing and why? Is government, local or central, committed to providing the essential package? If not, why not? Does government ensure funding to deliver the essential package?
- **Involving people with palliative care needs—**are people with palliative care needs or their caregivers such as parents of children with palliative care needs, actively and meaningfully engaged in policy discussions about palliative care development?
- **Workforce requirements—**are there healthcare workers trained in palliative care available at primary/community, secondary and tertiary level care. Is there (basic, intermediate, advanced) palliative care training in place for all healthcare workers?
- **Government commitments re: the Political Declaration—**is your country a signatory to the Political Declaration? If so, what steps are being taken to meet the specific commitments of the Declaration that directly relate to palliative care.
- **Progress towards UHC—**what progress has been made in your country towards securing UHC? What are the main gaps or obstacles to achieving UHC?

## 6.3 Advocacy asks on UHC—general

What are the key asks relating to the achievement of Universal Health Coverage *in general*? The table over the page is reproduced from the UHC 2030 resource *Moving Together to Build a Healthier World: Key Asks from the UHC Movement*[53]. The six asks "are core requests for governments and political leaders to take action on Universal Health Coverage and were created collectively by a range of health and other stakeholders from around the world".

[53] *Moving Together to Build a Healthier World. Key Asks from the UHC Movement.* UN High-Level Meeting on Universal Health Coverage 2019. UHC 2030. https://www.uhc2030.org/fileadmin/uploads/uhc2030/Documents/UN_HLM_2019/UHC_Key_Asks_final.pdf . p.2.

| | | |
|---|---|---|
| **ASK 1** | **Ensure Political Leadership Beyond Health –**<br>Commit to achieve UHC for healthy lives and wellbeing for all at all stages, as a social contract.<br>Health is the foundation for people, communities and economies to reach their full potential. Universal health coverage (UHC) is primarily the responsibility of governments, which ensure people's health as a social contract. Achieving UHC is essential for inclusive development, prosperity and fairness, and requires political decisions that go beyond the health sector | **MILESTONE**<br>By 2023, governments incorporate aspirational health-related SDG targets into national planning processes, policies and strategies to ensure everyone can access quality health services without financial hardship. |
| **ASK 2** | **Leave no-one behind –**<br>Pursue equity in access to quality health services with financial protection.<br>Health is enshrined as one of the fundamental rights of every human being. UHC is key to reducing poverty and promoting equity and social cohesion. Governments should invest in everyone's health. Extension of geographical coverage and reaching the most marginalised and hard-to-reach populations are essential to achieving positive health outcomes. A strong system for monitoring and evaluation is needed to ensure accountability and participation. | **MILESTONE**<br>By 2023, governments report disaggregated data to SDG official statistics to capture the full spectrum of the equity dimensions of UHC monitoring progress (SDG 3.8.1 and 3.8.2). |
| **ASK 3** | **Regulate and legislate –**<br>Create a strong, enabling regulatory and legal environment responsive to people's needs.<br>UHC requires a sound legal and regulatory framework and institutional capacity to ensure the rights of people and meet their needs. Governments are the primary duty bearer under the International Covenant on Economic, Social and Cultural Rights, even in cases when they rely on private providers. | **MILESTONE**<br>By 2023, governments introduce legal and regulatory measures that accelerate progress toward UHC. |
| **ASK 4** | **Uphold quality of care –**<br>Build high-quality health systems that people and communities' trust.<br>Quality primary health care (PHC) is the backbone of UHC and creates trust in public institutions. Expansion of health coverage must be accompanied by investments in the quality of health services. People should be able to access a full spectrum of safe, quality services and products in their community, delivered by well-trained, well-paid, culturally and gender-sensitive health workers. | **MILESTONE**<br>By 2023, the coverage of quality essential health services has been delivered to one billion additional people (SDG 3.8.1). |
| **ASK 5** | **Invest more, invest better –**<br>Sustain public financing and harmonise health investments.<br>Current funding levels are insufficient to achieve UHC by 2030. Governments need to increase domestic investment and allocate more public financing for health through equitable and mandatory resources. Governments must improve efficiency and equity in the use of existing resources and reduce reliance on impoverishing out-of-pocket payments. Development assistance to health should reduce fragmentation and strengthen national health financing capacities. | **MILESTONE**<br>By 2023, governments adopt ambitious investment goals for UHC, make progress in mobilising domestic pooled funding and reduce catastrophic health expenditure (SDG 3.8.2). |
| **ASK 6** | **Move together –**<br>Establish multi-stakeholder mechanisms for engaging the whole of society for a healthier world.<br>All countries must take active steps to meaningfully engage non-governmental actors - particularly from unserved, underserved or poorly-served populations - in shaping the UHC agenda. Solutions for each country must be tailored to context and population needs. The international community and global health partners should unite to support countries to build a healthier world. | **MILESTONE**<br>By 2023, all UN Member States join the UHC movement and establish multistakeholder platforms to ensure the involvement of civil society, communities and the private sector, in regular policy dialogue and review of progress with all government actors. |

## 6.4 Advocacy asks on quality palliative care

"Delivery of quality palliative care is a moral imperative and a human right. Quality health services and palliative care are inextricably linked and both vital for achievement of Universal Health Coverage. What do we mean by quality? Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with evidence-based professional knowledge. Quality health services should be effective, safe, people-centred, timely, equitable, integrated and efficient"

Source: WHO[54]

These key messages about quality palliative care should be at the heart of our advocacy.

**INFO Key actions for quality palliative care**

**National level**

- Incorporate quality considerations into all levels of palliative care planning for adults and children, including policy, strategy and service delivery plans with attention to resources, implementation and monitoring.
- Align national palliative care planning with a clearly articulated national strategic direction on quality.
- Integrate palliative care across the health system, embedding it in a primary health care (PHC) approach throughout the lifespan, across relevant health programmes and all levels of the health system.
- Develop robust measurement systems, aligned across the health system, to drive improvement in the quality of palliative care; use this measurement to drive further action, including advocacy, resource mobilization and service planning.
- Utilize existing quality assurance mechanisms such as licensing, registration and quality standards to assure quality palliative care services. Account for special considerations in palliative care such as multiple providers, opioids and task shifting.

**District level**

- Commit to quality palliative care at the district level, acting as a strong linkage point between national plans and operational activity at the point of care.
- Use data at the district level to improve the quality of palliative care with a particular focus on understanding and addressing health inequalities at the district level.
- Engage communities to improve the quality of palliative care, creating models of service delivery that are truly people-centred and addressing misconceptions about palliative care

**Point of care level**

- Maintain and improve quality palliative care throughout the lifespan, including care provided at home, through adaption and implementation of evidence-based quality interventions at the point of care.
- Collect and use data at the point of care to drive improvement efforts.
- Integrate quality improvement methods into usual practice at the point of care, focusing on provision of compassionate care to those facing serious health-related suffering.

Source: WHO[55]

[54] *Quality Health services and palliative care. Practical approaches and resources to support policy, strategy and practice*. WHO. *https://www.who.int/publications/i/item/9789240035164*
[55] *Quality Health services and palliative care. Practical approaches and resources to support policy, strategy and practice*. WHO. *https://www.who.int/publications/i/item/9789240035164*

## 6.5 Advocacy asks on palliative care in UHC

These are some of the key points to assert or demand in your advocacy work. Each is linked specifically to palliative care as an essential component of UHC and particular paragraphs of the political declaration (as shown in sub-section 4.3 above):

**The state of play:**

- Everyone has a human right to palliative care.
- The needs of poor and marginalised people with PC needs must be met. No-one should be left behind.
- People experiencing serious health-related suffering must not be priced out of PC by out of pocket health spending.
- PC development should be assessed and monitored using the WHO indicators. Lack of progress in PC development for both adults and children, should be challenged.

**Understanding of palliative care**

- Palliative care is an essential component of UHC service delivery (Promotion, Prevention, Treatment, Rehabilitation, Palliative Care). No UHC without PC.
- Sufficient funding, human resources, infrastructure, services, and products must be secured to deliver palliative care as part of UHC.

**Availability of the essential package**

- All people with PC needs must have access to the essential package of palliative care and pain relief. This is an essential component of UHC.
- Government budgets cover the essential package of palliative care and pain relief as part of UHC. Do governments recognise the potential economic benefits of PC as well as the impact on quality of life?
- As a minimum, is oral or parenteral morphine available for relief of pain and/or respiratory distress? What other essential medicines are available? Is an opioid lockbox on the essential products availability list? Are paediatric formulations available?

**Involving people with palliative care needs**

- Any assessment of PC provision must ensure full and meaningful engagement of people with palliative care needs.
- People with PC needs and/or their carers must be at the centre of palliative care development.

**Workforce requirements**

- Funded training programmes should be developed or in development for all levels of PC provision.
- People with PC needs should be involved in the development and delivery of training as appropriate.

**Government commitments**

- Commitments listed in the Political Declaration must be delivered.
- Palliative care is a core component of UHC.
- SDGs 1,3,4,5,8,10, UHC focus especially 3.4.

**Progress towards UHC**

- (Where relevant) challenge lack of progress towards UHC.
- Design, funding, and delivery of the health system must promote progressive achievement of UHC with the goal of achieving UHC by 2030 (SDG.3.8).

# 7. Conclusion

Palliative care is an essential healthcare service and a human right for adults and children living with, and dying from, life-limiting conditions. It should be a central component of any healthcare system and included within Universal Health Coverage schemes. The implementation of comprehensive Universal Health Coverage schemes could significantly increase access to quality hospice and palliative care for all those in need.

UHC is an ambitious commitment to achieve health and well-being for all. It encompasses all the aspects of health along the life course, including all aspects relating to palliative care. It also seeks to tackle the financial hardship often faced by people with palliative care needs because of the costs associated with their illness. The Political Declaration on UHC is a new tool at our disposal and can be used together with the World Health Assembly resolution WHA67.19 calling on all governments to strengthen palliative care throughout the life course and to advocate for improving the lives of people living with palliative care needs worldwide.

# Annexe 1: Key paragraphs of the Political Declaration

**The right to health**

**Paragraph 1.** Reaffirming the right of every human being, without distinction of any kind, to the enjoyment of the highest attainable standard of physical and mental health

**NCDs and Mental Health**

**Paragraph 4.** Reaffirm the strong commitments made thought the political declaration adopted at the high-level meetings […] on the prevention and control of non-communicable diseases

**Paragraph 12(c).** Despite major health gains over the past decades, […] challenges remain with regard to emerging and re-emerging diseases, non-communicable diseases, mental disorders and other mental health conditions […]

**Paragraph 33.** Further strengthen efforts to address non-communicable diseases, including cardiovascular diseases, cancer, chronic respiratory diseases and diabetes, as part of Universal Health Coverage

**Paragraph 36.** Implement measures to promote and improve mental health and well-being as an essential component of Universal Health Coverage, including by scaling up comprehensive and integrated services for the prevention, including suicide prevention, as well as treatment for people with mental disorders and other mental health conditions as well as neurological disorders, providing psychosocial support, promoting well-being, strengthening the prevention and treatment of substance abuse, addressing social determinants and other health needs, and fully respecting their human rights, noting that mental disorders and other mental health conditions as well as neurological disorders are an important cause of morbidity and contribute to the non-communicable diseases burden worldwide

**Health Services**

**Paragraph 9.** Recognize that Universal Health Coverage implies that all people have access, without discrimination, to nationally determined sets of the needed promotive, preventive, curative, rehabilitative and palliative essential health services, and essential, safe, affordable, effective and quality medicines and vaccines, while ensuring that the use of these services does not expose the users to financial hardship, with a special emphasis on the poor, vulnerable and marginalized segments of the population

**Paragraph 25.** Implement the most effective, high-impact, quality-assured, people-centred, gender- and disability-responsive and evidence-based interventions to meet the health needs of all throughout the life course, and in particular those who are vulnerable or in vulnerable situations, ensuring universal access to nationally determined sets of integrated quality health services at all levels of care for prevention, diagnosis, treatment and care in a timely manner

**Disabilities**

**Paragraph 37.** Increase access to health services for all persons with disabilities, remove physical, attitudinal, social, structural and financial barriers, provide quality standard of care and scale up efforts for their empowerment and inclusion, noting that persons with disabilities, who represent 15 per cent of the global population, continue to experience unmet health need

**Paragraph 50.** Improve availability, affordability and efficiency of health products by increasing transparency of prices of medicines, vaccines, medical devices, diagnostics, assistive products, cell- and gene-based therapies and other health technologies […]

**Access to Medicines**

**Paragraph 49.** Promote equitable distribution of and increased access to quality, safe, effective, affordable and essential medicines, including generics, vaccines, diagnostics and health technologies, to ensure affordable quality health services and their timely delivery

**Paragraph 50.** Improve availability, affordability and efficiency of health products by increasing transparency of prices of medicines, vaccines, medical devices, diagnostics, assistive products, cell- and gene-based therapies and other health technologies […]

**Paragraph 51.** Promote increased access to affordable, safe, effective and quality medicines, including generics, vaccines, diagnostics and health technologies, reaffirming the World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement) as amended, and also reaffirming the 2001 World Trade Organization Doha Declaration on the TRIPS Agreement and Public Health, which recognizes that intellectual property rights should be interpreted and implemented in a manner supportive of the right of Member States to protect public health and, in particular, to promote access to medicines for all, and notes the need for appropriate incentives in the development of new health products

**Financial hardship**

**Paragraph 12(a)** At least half of the world's population lacks access to essential health services, more than 800 million people bear the burden of catastrophic spending of at least 10 per cent of their household income on healthcare, and out-of-pocket expenses drive almost 100 million people into poverty each year;

**Paragraph 12(e)** The high prices of some health products, and inequitable access to such products within and among countries, as well as financial hardships associated with high prices of health products, continue to impede progress towards achieving Universal Health Coverage;

**Paragraph 24(b)** To stop the rise and reverse the trend of catastrophic out-of-pocket health expenditure by providing measures to ensure financial risk protection and eliminate impoverishment due to health-related expenses by 2030, with special emphasis on the poor as well as those who are vulnerable or in vulnerable situations;

**Paragraph 39.** Pursue efficient health financing policies, including through close collaboration among relevant authorities, including finance and health authorities, to respond to unmet needs and to eliminate financial barriers to access to quality, safe, effective, affordable and essential health services, medicines, vaccines, diagnostics and health technologies, reduce out-of-pocket expenditures leading to financial hardship and ensure financial risk protection for all throughout the life course, especially for the poor and those who are vulnerable or in vulnerable situations, through better allocation and use of resources, with adequate financing for primary healthcare, in accordance with national contexts and priorities

**Primary Healthcare**

**Paragraph 13.** Recognize that primary healthcare brings people into first contact with the health system and is the most inclusive, effective and efficient approach to enhance people's physical and mental health, as well as social well-being, and that primary healthcare is the cornerstone of a sustainable health system for Universal Health Coverage and health- related Sustainable

Development Goals, as was declared in the Declaration of Alma-Ata and reaffirmed in the Declaration of Astana;

**Paragraph 39.** Pursue efficient health financing policies, including through close collaboration among relevant authorities, including finance and health authorities, to respond to unmet needs and to eliminate financial barriers to access to quality, safe, effective, affordable and essential health services, medicines, vaccines, diagnostics and health technologies, reduce out-of-pocket expenditures leading to financial hardship and ensure financial risk protection for all throughout the life course, especially for the poor and those who are vulnerable or in vulnerable situations, through better allocation and use of resources, with adequate financing for primary healthcare, in accordance with national contexts and priorities;

**Paragraph 46.** Expand the delivery of and prioritize primary healthcare as a cornerstone of a sustainable people-centred, community-based and integrated health system and the foundation for achieving Universal Health Coverage, while strengthening effective referral systems between primary and other levels of care, recognizing that community- based services constitute a strong platform for primary healthcare

**Health Workforce**

**Paragraph 60.** Take immediate steps towards addressing the global shortfall of 18 million health workers in accordance with the Global Strategy on Human Resources for Health: Workforce 2030, and addressing the growing demand for health and social sectors, which calls for the creation of 40 million health worker jobs by 2030, taking into account local and community health needs;

**Paragraph 61.** Develop, improve and make available evidence-based training that is sensitive to different cultures and the specific needs of women, children and persons with disabilities, skills enhancement and education of health workers, including midwives and community health workers, as well as promote a continued education and lifelong learning agenda and expand community-based health education and training in order to provide quality care for people throughout the life course;

**Paragraph 62.** Scale up efforts to promote the recruitment and retention of competent, skilled and motivated health workers, including community health workers and mental health professionals, and encourage incentives to secure the equitable distribution of qualified health workers, especially in rural, hard-to-reach and underserved areas and in fields with high demands for services, including by providing decent and safe working conditions and appropriate remuneration for health workers working in these areas, consistent with the World Health Organization Global Code of Practice on International Recruitment of Health Personnel,7 noting with concern that highly trained and skilled health personnel continue to emigrate, which weakens health systems in the countries of origin

# Annexe 2: WHPCA UHC advocacy factsheet

whpca
worldwide hospice palliative care alliance

## Advocacy Factsheet for Palliative Care and Universal Health Coverage

**Palliative care is a fundamental human right and an integral component of Universal Health Coverage (UHC). UHC is essential to achieving the Sustainable Development Goals (SDGs), particularly SDG 3 relating to health.**

### The High-Level Meeting on UHC and the Political Declaration

In September 2019, participants at the UN High-Level Meeting on UHC unanimously approved the political declaration on UHC. The right to have the highest standard of physical and mental health is highlighted in the first paragraph of the political declaration. It is specified that UHC should include a broad range of health services, including prevention, promotion rehabilitation and palliative care, not only treatment of diseases. The political declaration urges action to tackle non-communicable diseases and mental health disorders. The importance of achievement of UHC to achieve the SDGs 2030 is emphasized. Finding resources to finance health services, to avoid catastrophic expenditures and the high share of out-of-pocket expenses, with a special emphasis on the vulnerable and the marginalised is highlighted. The declaration urges governments to find solutions to the lack of health workforce and its uneven distribution. The need to promote gender equality is stressed.

### Universal Health Coverage

UHC means that everyone, irrespective of their age, sex, gender, financial situation, or living standards, can access the health services they need, without experiencing financial hardship. Health services should cover the entire life span of individuals, be of high quality and be affordable. A core set of essential interventions can be implemented according to the national context and priorities, but coverage should be expanded over time as more resources become available.

Primary healthcare is the core of UHC because it covers all the aspects of care, from prevention and health promotion to treatment, rehabilitation and palliative care, and is more likely to be within geographical reach than secondary / tertiary care. Primary care workers can serve as the focal point of the multidisciplinary team necessary to ensure holistic care and can provide comprehensive care including palliative care in those settings where access to specialist care is limited.

ACKNOWLEDGEMENT
This fact sheet evolved from – and in some cases quotes directly - materials developed by the International Federation of Psoriasis Associations (IFPA). IFPA granted WHPCA permission to make this adaptation with a focus on palliative care. WHPCA is sincerely grateful to IFPA for their generosity.

### Palliative care – a human right

Palliative care is an approach that aims to improve the quality of life of patients (adults and children) and their families / carers who are experiencing serious health-related suffering associated with life-limiting disease. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Palliative care is not just about end-of-life care but covers the whole trajectory of illness including when potentially curative treatment is being undertaken.

The International Covenant on Economic, Social and Cultural Rights "recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". This includes "the creation of conditions which would assure to all medical service and medical attention in the event of sickness". Access to health services such as hospice and palliative care, including access to opioids and other essential medications, must be available to all. Currently, 88% of those in need of palliative care do not receive it. 78% of those people in need of palliative care live in low- and middle-income countries.

### Palliative care development

In 2014 the World Health Assembly passed a resolution calling for the expansion of palliative care throughout the continuum of healthcare systems. Palliative care development should be guided by the conceptual model developed by the World Health Organisation (the 'house model') and assessed using the set of WHO actionable indicators. The house model is designed to 'assist policy-makers and programme managers consider how to strengthen and integrate palliative care throughout their health system, including social and long-term care'.




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# How can you use UHC to support Palliative Care Advocacy?

## Non-communicable diseases

The declaration encourages governments to take action against non-communicable diseases (NCDs). WHO states that 'Palliative care is an essential component of a comprehensive response to NCDs. It is ideal that palliative care is included within NCD action plans in all countries'. Effective management of NCDs is an essential component of UHC and key to the achievement of SDGs 2030.

## Financial hardship

Families affected by life-limiting illnesses often experience considerable financial hardship. Income may be reduced and out-of-pocket expenses may be increased. The financial implications of being a person living with palliative care needs, or a person supporting someone with palliative care needs should be addressed, and actions must be taken to avoid people being pushed into poverty.

## People with palliative care needs

Meaningful engagement of people living with palliative care needs is critical to the effective integration of palliative care in Universal Health Coverage in practice. People living with palliative care needs must be involved at every stage of advocacy for palliative care in the context of UHC.

## Palliative care indicators

Progress in implementing palliative care in keeping with the 'house' model should be measured against the WHO actionable Indicators for assessing the development of palliative care worldwide. This enables robust evaluation of progress.

## Access to medicines

Pain is one of the most common and distressing symptoms that people with serious illnesses and those at the end of life face. Pain management is a core component of palliative care. The simplest, least expensive and most effective method to treat pain is the use of oral morphine. Unfortunately, access to opioids may be limited; oral morphine is reported to be generally available in only 32% of countries. Multiple factors contribute to this including fears of addiction, overregulation, lack of training in pain management, and lack of understanding of the use of opioids. Increased access to affordable, safe, effective and quality medicines should be promoted to ensure health for all. Medicines for pain and palliative care – as a minimum those included in the WHO Model List of Essential Medicines (sect. 2) - should be provided by public and private facilities. Access to opioids must increase.

## Mental health

Mental health is an important issue for palliative care since 'Mental health conditions contribute to poor health outcomes, premature death, (and) human rights violations' (WHO, 2019) and also because the experience of being diagnosed with or living with, a life-limiting illness can itself negatively impact on mental health. The declaration reaffirms 'the right of every human being, without distinction of any kind, to the enjoyment of the highest attainable standard of physical and mental health'.

## Health workforce

Human resources for health are vital to achieve UHC and address the range of people's health needs including promotion, prevention, treatment, rehabilitation and palliation. Many countries lack staff trained in palliative care and/or display an uneven distribution of staff trained in palliative care. The political declaration pushes governments to address these issues by training more healthcare professionals and community workers and creating incentives for them to work in underserved areas. All healthcare professionals, especially those working in primary healthcare, should learn about palliative care as part of their training.

## Disabilities

People living with life-limiting illness face multiple barriers in their daily lives. The 2014 declaration acknowledges the existence of 'physical, attitudinal, social, structural and financial barriers' faced by people with disabilities and urges governments to work to remove them. Without this one of the most marginalized groups cannot gain meaningful full access to Universal Health Coverage.

## Primary healthcare

Primary healthcare practitioners can be coordinators of the multidisciplinary care team necessary to ensure palliative care needs are met. Moreover, primary healthcare practitioners can provide comprehensive care in those settings where access to hospices and palliative care specialists is limited. To appreciate the numerous benefits that primary healthcare can offer to the management of palliative care, primary healthcare should be strengthened and adequately financed in keeping with the attainment of SDG 3.

'We cannot achieve Universal Health Coverage without palliative care'

*Dr Tedros Adhanom Ghebreyesus, Director General, WHO*

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