Living and Dying in Pain: It doesn’t have to happen

World Hospice and Palliative Care Day Toolkit 2016
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Cover photo 3: Island Hospice & Healthcare, Zimbabwe
The theme of World Hospice and Palliative Care Day (WHPCDay) 2016 is: “Living and Dying in Pain – It doesn’t have to happen.” Around the world, 75% of people cannot access the controlled medicines they need to treat moderate to severe pain. This may result in people living and dying in treatable, but uncontrolled pain.

This Toolkit has been produced by the Worldwide Hospice Palliative Care Alliance for hospice and palliative care advocates around the world.

Many of the barriers that exist to accessing pain management can be addressed with collaborative practical action. Once this happens, a significant amount of the pain that people are currently experiencing would be controlled.

Severe pain is debilitating and affects every aspect of the life of the person experiencing it, as well as the lives of family members and carers. In 2013, the United Nations Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or punishment, Juan E. Méndez, presented a report to the UN on torture in health care. He identified denial of pain relief as being tantamount to torture.

You can use this toolkit as 1) a reference for facts, figures and case studies use when approaching decision makers in your country to advocate for better access to controlled medications 2) a guide on how to celebrate and support the World Hospice and Palliative Care Day campaign.

This toolkit contains sections on:
1. Three main barriers to accessing controlled medicines for pain management: Regulatory, education and training, and economic.
2. Key resolutions, reports, position statements and other important global documents noting the commitment to improving access to controlled medications for pain management, while still preventing diversion and misuse.
3. Suggestions about how to mark World Hospice and Palliative Care Day, including examples of planned WHPC Day events, a social media guide, advice on working with the press, and web links to key resources to support your campaign.

We encourage you to join the global community celebrating World Hospice and Palliative Care Day 2016, and add your voice to say that living and dying in pain doesn’t have to happen.
Introduction

75% of the world’s population (5.5 billion people) has no, or inadequate, access to controlled medications for the relief of moderate to severe pain. As a result, millions of people, including around 18 million persons at the end of life, suffer from treatable pain that could be managed with proper access to the correct medications. Various barriers prevent people in need from accessing these essential medications.

This short report and toolkit, released prior to World Hospice and Palliative Care Day 2016, will examine three major barriers to access to essential palliative care medicines, provide case studies, advocacy resources, and examples of good practice, and suggestions for celebrating World Hospice and Palliative Care Day in your community.
Why is it important to advocate for palliative care and pain management?

Palliative care and pain control is a human right, and component of the right to the highest attainable standard of health, which is protected in article 12 of the International Covenant on Economic, Social and Cultural Rights\(^1\), and in article 24 of the Convention on the Rights of the Child\(^2\). Access to adequate pain relief is protected under Article 7 of the International Covenant on Civil and Political Rights\(^3\), which prohibits torture, inhuman or degrading treatment or punishment.

Palliative care is an essential and needed health care service within Universal Health Coverage (UHC) as defined by the World Health Organization. The two key elements of UHC are 1) accessibility and 2) affordability. This means that the full range of essential health services, including: promotion, prevention, treatment, rehabilitation and palliation must be available and accessible to all people, without risk of impoverishment or financial hardship. The WHPCA published a report: Universal Health Coverage and Palliative Care: Do not leave those suffering behind\(^4\), which provides more detail.

The new Sustainable Development Goals include palliative care as a component of Goal 3: ‘Good health and well-being: Ensure healthy lives and promote well-being for all at all ages’. The WHPCA report: ‘Palliative Care and the Global Goal for Health: Right. Smart. Overdue.’\(^5\) explains this further.

At the World Health Assembly in 2014, UN Member States unanimously passed the resolution: WHA 67.19: ‘Strengthening of palliative care as a component of comprehensive care throughout the lifecourse’\(^6\). This resolution calls on national governments, supported by the World Health Assembly, to ensure that palliative care and pain management is available and accessible to all people.
In countries where consumption of controlled palliative care medicines is low or inadequate, unduly restrictive national regulations often limit access for people and families in need. International law requires governments to develop balanced policies that ensure access to essential controlled medicines for pain management, while ensuring that they are not used for illicit purposes. Patients have a right to pain relief, which can be realised without significant risk of dependence through adequate training and education of healthcare workers and improved public awareness.

Access to pain treatment is a component of the right to access to health. In countries where national laws and regulations exceed the control measures required by the Single Convention on Narcotic Drugs, people in need of pain relief are unable to access the medications recommended by the World Health Organisation Model List of Essential Medicines. For example, some national laws and regulations limit the amount, dosage or units that can be prescribed by a physician, regardless of the condition or needs of the patient, guaranteeing that severe pain will not be effectively controlled. In some jurisdictions, physicians can be charged with a crime should they make documentation errors. Restrictive regulations, low national demand because of fear of addiction and criminal penalties, and expensive registration requirements, discourage pharmaceutical companies from producing morphine, doctors from prescribing it, and pharmacies from stocking it. Legally available morphine is difficult, if not impossible, to obtain in some countries. This forces some people in need of pain control, or their family members, to search for and purchase opioids through illicit channels. By definition, this puts them in danger of arrest and prosecution and fuels illicit drug trade.
Preparing oral morphine solution in Sudan
Photo credit: Dr Nahla Gafer
Case study: Sudan

“We saw a 38 year-old lady who was propped up in bed, because she could not lie down. She was in such severe pain, she could not even breathe.

Her sister was sitting observing her suffering with tears dropping from her eyes. The lady had a breast ulceration that extended all over her chest wall, both her legs were swollen and one arm was grossly lymphedematous; she could not raise it.

That was the most suffering I saw in my life; she could hardly take a breath to moan or cry and her teeth were clenched all the time. In fact one of our trainee physicians left the room crying as well.

My first impulse was to go to the pharmacy which was at the further end of the hospital – a 12 minute walk. A pharmacist from the trainees accompanied me.

We met the dispenser and told her we need 10 ampoules of morphine. The lady reacted: “Are you crazy! That is all I have for the night’s shift and it might be needed at the surgery or medicine department.”

We had a long discussion with her and telephone calls with the senior pharmacist ending in us securing four vials of 15mg morphine injection – enough for our patient for 24 hours.

We reconstituted the morphine with bottled water and agreed with her to prepare the solution until the hospital administration gets morphine solution or tablets.

How could it possibly be that making such important medications so difficult to access for our suffering patients results in less drug addiction, trafficking or crime? I frankly do not see where these two lines meet.

Our patient’s pains were silenced in a matter of 40 minutes; it was really nice to find her sleeping when we came back.”

- Dr Nahla Gafer, Radiation and Isotope Clinic, Khartoum
How are governments and organisations addressing the issue of unduly restrictive regulations?

In 2014, the upper house of the Indian Parliament approved amendments to the Narcotic Drugs and Psychotropic Substances Act, significantly reducing barriers to accessing essential pain relieving medications in that country. These amendments will pave the way for improved access to essential medicines for pain relief, although there is still much to be done.

Following the IAHPC Workshops in Latin America, some regulatory barriers have been successfully addressed. Elimination of barriers happened in Panama, Colombia, Bolivia, El Salvador, Peru and Chile.

In Georgia, regulators changed opioid prescription rules and regulations to allow prescription of medication containing controlled substances for seven days, an increase from three days. Also, two different controlled substances and their different forms can now be prescribed on one prescription. Primary healthcare staff, family doctors and village doctors are allowed to order and prescribe morphine independently.

Mexico has introduced a streamlined electronic prescription system for controlled medicines. Previously, doctors were required to travel in person to the capital of their state to pick up barcoded stickers to track each prescription. Each prescription transaction had to be recorded by a pharmacist in duplicate in multiple ledgers. Now, prescribing doctors can download the barcoded prescriptions from a secure website, and electronic record-keeping has been introduced in pharmacies.

ATOME

The Access To Opioid Medications in Europe (ATOME) project worked with stakeholders, including palliative care providers, academics and policy makers in 12 European Countries. The project aimed to 1) discover why opioid medications were not available to address...
Pain & Policy Studies Group

The Pain & Policy Studies Group (PPSG) is a global research programme and World Health Organization Collaborating Center at the University of Wisconsin Carbone Cancer Center within the School of Medicine and Public Health. The PPSG’s work is guided by a public health approach and aims to address governmental and regulatory environments governing professional healthcare practice relating to pain management, including barriers to legitimate access of prescription opioid analgesics that are essential for severe pain relief and palliative care.

Treat the Pain

Treat the Pain, an initiative of the American Cancer Society, works with partners in selected countries to address the problem of lack of access to opioids using a ‘mechanism of access’ approach.

The programmes focus on four main areas: 1) Strengthen government leadership by providing staff and technical assistance directly to health ministries, 2) Reduce cost and improve availability of medicines by negotiating with suppliers and providing technical assistance to buyers, 3) Improve clinical and regulatory policies and practice by advocating on international, national, and facility levels, and 4) Improve skills and motivation of individual clinicians by improving access to information and to other clinicians interested in pain treatment.

Together with partners, Treat the Pain identified an eight-step framework to group challenges and interventions, called the Morphine Framework. This acronym stands for: Mindset, Organize, Regulations, Procurement, Healthworker, Initiation, Nationalization, and Empowerment. You can read more about this approach on the Treat the Pain website: http://www.treatthepain.org/.

Key recommendations outlined in the project’s final report included: implementation of the WHO policy guidance on balance in national policies on controlled substances, identification and removal of legal and regulatory barriers, use of non-stigmatising language, establishment of communications networks and national databases to facilitate communication and information sharing around opioid medications, awareness-raising among healthcare professionals and the public around the use of opioid medications, and appropriate training of healthcare workers in the rational use of controlled medicines.

You can read more about the project on the European Association for Palliative Care website.
Opiophobia is the fear in the health professions of prescribing opioid medications. This contributes to their unavailability and leaves patients in untreated pain.

Doctors, nurses, and pharmacists are rarely educated about pain management and the use of morphine, or are taught that morphine and other opioids are dangerous and should be used as little as possible, or just at the end of life.

Since few health professionals are taught how to properly assess and manage pain, they fear that patients who are prescribed opioids will become dependent on them. Few countries have pathways for qualification as palliative care specialists, and do not include palliative care training in medical or nursing school curricula. Qualified health professionals receive little or no continuing education to counteract opiophobia.
How are educational institutions and countries addressing lack of training?

An increasing number of professional schools are now including palliative care education for pharmacy, medical, and nursing students. Education of health care workers is considered one of the crucial aspects suggested by the World Health Organization, in addition to adequate policies, adequate medicine availability and service implementation, in order to establish palliative care in a country.

The Hospice Africa Uganda morphine initiators’ course at the Institute of Hospice and Palliative Care in Africa trains healthcare workers from all over Africa to safely prescribe and administer morphine. The University of Cape Town runs a Master’s course and Postgraduate Diploma in Palliative Medicine, using distance learning so that busy professionals can expand access to palliative care and pain management, as well as the research base on this topic.

The goal of the IAHPC initiative, ‘Transforming the System’ is to facilitate and increase access to palliative care in the first level of care, through the integration of education on palliative care – including pain management – in undergraduate curricula in nursing and medical schools. The initiative was implemented in November 2014 in a workshop in Cali, Colombia, with participants of 18 universities, representing 16 medical and six nursing schools. The purpose of the workshop was to identify the palliative care competencies in undergraduate level for physicians and nurses in Colombia. The Pain and Policy Study Group at the University of Wisconsin has basic information about availability status in countries and regions, and the Opioid Price Watch Project collects data on affordability.
The conference ‘International Update on Pain Management and Palliative Care Advances 2016’, organised by the Shri Guru Ram Rai Institute of Medical and Health Sciences (SGRRIM&HS) and the Indian Medical Association (Dehradun), took place in India this year\textsuperscript{16}.

The event started on Saturday 25 June with an opioid workshop to emphasise upon the recent amendments pertaining to availability of essential controlled medications in India.

Mr Satya Narayana Dash, Undersecretary in the Ministry of Revenue, Government of India, was the chief guest at the event.

The aim of the workshop was to answer questions and concerns pertaining to opioid prescribing and availability from the attendees.

An opioid workshop booklet highlighting the current need and availability of essential narcotic drugs compiled by Dr Mayank Gupta was released and presented to all the delegates and faculty. The audience was reminded of poignant facts by palliative care physicians Dr Sushma Bhatnagar and Dr MR Rajagopal.

The conference was attended by more than 250 delegates from both India and abroad. The conference was multipronged in its approach in that it served as the continuing medical education for the palliative care physicians, sensitisation for the allied health care professionals, as well as an excellent educational opportunity for the undergraduate and postgraduate medical and nursing students.

Economic barriers
Morphine is inexpensive to produce yet expensive to bring to market in many places with unduly restrictive regulations, where demand is artificially low and few professionals are trained. As a result the pharmaceutical industry has no incentive to produce and market oral morphine for pain management, but prefers to register and market more expensive (less affordable) opioids such as fentanyl and oxycodone.

How are countries and organisations addressing these barriers?
In Colombia the Fondo Nacional de Estupefacientes (FNE) is responsible for the purchase and national distribution of opioid medications (morphine, hydromorphone, and methadone) in the country.

IAHPC has launched the second round of Opioid Price Watch (OPW), a project to monitor and report the dispensing price of opioids around the world. This project is as a component of the agreement of work as an NGO in formal relations with the World Health Organization (WHO) and is funded with grants from the US Cancer Pain Relief Committee and Atlantic Philanthropies.
Barriers specifically affecting children

Recent publications have highlighted the inequalities in access to controlled medicines around the world.

Even in countries where opioids are available for adults, additional barriers may still hinder access to pain management for children.

Impediments that prevent adults in pain from receiving adequate pain management and access to opioids, are applicable to children as well. Children experience additional impediments to access, including:

- impediments due to their age
- inability to describe their pain
- cultural factors that do not allow them to speak for themselves
- lack of healthcare professionals with the skills to assess pain in children, especially pre-verbal and non-verbal children
- lack of paediatric formulations of essential medications for pain management; and
- extra fears around prescribing opioids for children, such as fear of overdosing.
What is being done to address these barriers?

The International Children’s Palliative Care Network (ICPCN) works vigorously to address the barriers affecting children’s ability to access pain relief. Up-to-date resources on pain relief for children can be accessed and downloaded from the ICPCN website\(^{18}\) and include the 9th Edition Basic Symptom Control in Paediatric Palliative Care as well as the World Health Organization (WHO) Guidelines on persisting pain in children. In addition, the website provides links to national paediatric palliative care guidelines, for example those recently published online by the Starship Children’s Hospital in New Zealand\(^{19}\).

The network provides face to face training, to date in 24 countries, where medical professionals are given training on assessment and treating pain in children providing them with skills needed to assess and treat verbal, pre-verbal and non-verbal children. A one-day pre-conference seminar on pain was held at the 2nd ICPCN conference in Argentina in May 2016, led by experts in the field from around the world. The ICPCN e-learning module on pain relief for children, linked to the WHO Guidelines, is a free resource available in English, French, Spanish, Portuguese, Russian, Serbian and Dutch.

ICPCN has worked to address these barriers through advocacy up to the highest level, having held a side event at the 2015 World Health Assembly which focused on the importance of pain management and is part of an International Advocacy Group, working together with other organisations such as the International Association for Hospice and Palliative Care (IAHPC) and the Worldwide Hospice and Palliative Care Alliance (WHPCA) to address the barriers at the international level.

Whilst access to opioids is a key component of this advocacy work, wider issues around global access to quality palliative care services for children are also addressed. Within such international advocacy, ICPCN represents the voice of the children and also does this through working with organisations such as the WHO and the UN agencies. In an attempt to provide evidence for advocacy, the ICPCN also has a programme of research that links in with the advocacy, such as their recent research to identify the numbers of children worldwide that need palliative care.
Global advocacy work on access to controlled medications for pain management

Medicines used in pain management and palliative care are controlled, or “scheduled” under the Single Convention on Narcotic Drugs (1961. 1972), which “recognises that the medical use of narcotic drugs (sic) continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes.”

However, until very recently, the international drug control system, national legal systems, discourse and practices have been dominated by a law-enforcement/criminalization – rather than public health – approach to the availability of controlled medicines.

Coordinated civil society advocacy has influenced the production of a number of key official UN and regional reports and resolutions that direct UN member states to improve access to controlled medications for the relief of pain and suffering, while preventing their misuse and diversion.

The following resolutions and statements can be used to inform the development of rational national policies governing the importation, distribution, prescription and use of controlled medications.

Resolutions and statements can be used to inform the development of rational national policies governing the importation, distribution, prescription and use of controlled medications.
UNODC World Drug Report

In 2016, the United Nations Office of Drugs and Crime (UNODC) released a report\textsuperscript{21} reminding states that the medical use of narcotic drugs is “indispensable for the relief of pain and suffering,” and asking national governments to take the necessary steps to ensure that these controlled substances are made available for medical purposes in their countries.

The Organization of American States (OAS) Convention on the Rights of Older Persons

Add the OAS Convention on the Rights of Older Persons which includes the right to palliative care. This is a binding legal document and the only international one with such force which has been adopted.

INCB Annual report 2015

In 2015 the International Narcotics Control Board (INCB) released a supplement to its annual report, titled: Availability of Internationally Controlled Drugs: Ensuring Adequate Access for Medical and Scientific Purposes Indispensable, adequately available and not unduly restricted\textsuperscript{22}.

Opioid analgesics like morphine are indispensable for the treatment of pain caused by cancer, HIV/AIDS, cardiovascular disease, chronic respiratory disease, diabetes, childbirth, surgery, injuries and other conditions or situations.

INCB estimates that 92 per cent of morphine is consumed in countries in which only 17 per cent of the world population lives (United States, Canada, countries in Western Europe, Australia and New Zealand). At the same time, 75 per cent of the world population, predominantly in lower-income countries, is left with limited or no access to proper pain relief.

In this report, INCB highlights several recommendations to ensure the availability of internationally controlled substances for medical and scientific purposes while preventing their abuse and illicit trafficking. These include the review of laws and regulations to improve access to internationally controlled substances, the improvement in the training and awareness of health professionals.
World leaders and representatives of civil society organisations from all over the world attended the United Nations General Assembly Special Session (UNGASS) on the World Drug Problem in April 2016. The aim of the meeting was to review the global drug control system and to agree on a way forward. Improving access to controlled medicines was a leading agenda item.

The preamble of UN General Assembly Resolution A/S-30/L.1 April 19, 2016 states:

“We note with concern that the availability of internationally controlled drugs for medical and scientific purposes, including for the relief of pain and suffering, remains low to non-existent in many countries of the world, and we highlight the need to enhance national efforts and international cooperation at all levels to address that situation by promoting measures to ensure their availability and accessibility for medical and scientific purposes, within the framework of national legal systems, while simultaneously preventing their diversion, abuse and trafficking, in order to fulfil the aims and objectives of the three international drug control conventions.”

Only when UN bodies and Member States work with civil society organisations and citizens in a purposeful, coordinated way, will people have universal access to essential controlled medications for the relief of pain and suffering.
In the WHA resolution 67.19: ‘Strengthening palliative care as a component of comprehensive care throughout the lifecourse’, four of the nine action points for member states deal with improving access to controlled medications for pain relief:

Action Point #2: to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives, including development and implementation of palliative care policies, education and training, and quality improvement initiatives, and supporting the availability and appropriate use of essential medicines, including controlled medicines for symptom management;

Action Point #5: to assess domestic palliative care needs, including pain management medication requirements, and promote collaborative action to ensure adequate supply of essential medicines in palliative care, avoiding shortages;

Action Point #6: to review and, where appropriate, revise national and local legislation and policies for controlled medicines, with reference to WHO policy guidance, on improving access to and rational use of pain management medicines, in line with the United Nations international drug control conventions;

Action Point #7 to update, as appropriate, national essential medicines lists in the light of the recent addition of sections on pain and palliative care medicines to the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children.

It is vital that UN member states use the recommendations set out in this resolution to improve access to controlled medications for pain management in their countries.
The Common African Position

The African Union (AU) countries decided to submit a Common African Position with regard to the UN General Assembly Special Session (UN-GASS) on the World Drug Problem in New York. The document starts with the recognition that the world drug problem requires an “integrated approach to drug supply, demand reduction and harm reduction strategies, as well as ensuring the availability of controlled substances for medical and scientific use.”

According to the African Common Position on controlled substances and access to pain management drug24, published in October 2012, African Union Member States need to:

- Ensure a functioning and effective supply system through regulation, data management, access and reporting. States should:
  - Determine whether national narcotics laws […] take into account the fact that the medical use of controlled substances continues to be indispensable for the relief of pain and suffering and the fact that adequate provision must be made to ensure the availability of narcotic drugs and psychotropic substances for such purposes and to ensure that administrative responsibility has been established and that personnel are available for the implementation of those laws;
  - Determine whether there are undue restrictions in national narcotics laws, regulations or administrative policies that impede the prescribing or dispensing of, or needed medical treatment of patients with, narcotic drugs or psychotropic substances, or their availability and distribution for such purposes, and, should this be the case, make the necessary adjustments.

Civil society initiatives

A morphine manifesto25 has been signed by 64 organizations calling for universal availability of immediate release morphine.

The Prague Charter is a civil society initiative urging governments to relieve suffering and ensure the right to palliative care. You can view and sign the Prague Charter on the website of the European Association for Palliative Care26.

How can these documents be used in advocacy?

Advocacy — from “ad-voca” — means “to speak for.” Advocates speak for people and families needing palliative care and pain management to opinion leaders and policy makers who can use their power and influence to make controlled medicines more available.

United Nations resolutions, reports and declarations are worth no more than the paper on which they are written unless advocates work together to hold governments accountable for the commitments they have made within the international community.

If you want to make your voices heard at the national, local, and regional levels, join your national and regional palliative care associations and the international networks such as the Worldwide Hospice Palliative Care Alliance (WHPCA), the International Association for Hospice and Palliative Care (IAHPC), and the International Children’s Palliative Care Network (ICPCN). There you can work with other
advocates on targeted initiatives to hold your country accountable for its obligations under international law.

You have taken the first step by reading this document! The next step is to become familiar with the availability, accessibility, and affordability of controlled medicines in your own healthcare facility, country, and region. Then you can speak with authority about what you have and what you need.

The essential palliative care formulations for adults and children are listed in the WHO Model List of Essential Medicines and the IAHPC List of Essential Medicines for Palliative Care.

You can use these resources, reports, resolutions, and statements to update your competent authorities and policymakers about changing global attitudes towards medicines containing “narcotic drugs.”

With the help of your national association, or through one of the regional or global associations, you can find out who your drug regulators are and make an appointment to get to know them.

The regulators are in charge of compiling annual estimates and approving import licenses for controlled medicines. Ministries of Health are required to cooperate with drug regulators and competent authorities to provide accurate assessments of need for opioid analgesics to INCB, and to train providers in their use. INCB provides regular trainings upon request.

Once you are familiar with these resources, organise a study day with your staff to raise awareness among colleagues and within your professional associations. Very few public officials and journalists who have been conditioned by generations of fear about ‘addiction’, are aware that controlled medicines such as morphine can, and must be, be used safely by appropriately trained professionals to improve the quality of life of patients suffering from moderate to severe pain.

Global networks such as WHPCA and IAHPC, regional networks such as the African Palliative Care Association (APCA), the Asia Pacific Hospice Palliative Care Network (APHC), the European Association for Palliative Care, the Latin American Association for Palliative Care (ALCP), and national hospice and palliative care organisations can provide advocacy materials, suggestions, and organise workshops to update policymakers and civil society advocates on effective strategies.

You will find contact details for these organisations at the end of this toolkit. You can sign up for newsletters and request further information by email.

Model Hospice Open Day

One way to raise local awareness is to identify a model hospice/palliative care facility in your area where you can hold an “open day” for providers and patients to tell their stories to opinion leaders, local business owners, and media contacts about the successful use of controlled medicines and how they suffer when supplies are interrupted.
Recommendations

To people and their families in need of pain relief
1. Know your rights to palliative care and pain management and demand these from your healthcare providers and governments.
2. Talk to your healthcare provider about the options for pain management for yourself or your family member.

To healthcare workers and volunteers
1. Educate yourselves on the facts around controlled medicines for pain management.
2. Lobby your hospital administration and government to ensure access to pain treatment for patients in need.
3. Give your patients and their families accurate information regarding management of their pain.

To national governments
1. Review legislation to remove barriers to accessing controlled medications for pain management in your country.
2. Ensure that palliative care and pain management is included in the syllabus of healthcare worker education.
3. Incentivize the production or distribution of oral morphine tablets in your country.
Ideas on how to mark World Hospice and Palliative Care Day

World Hospice and Palliative Care Day is a GLOBAL day of ACTION! Draw inspiration from the unique ways that others around the world have chosen to celebrate the day, and find more suggestions below.

Uganda: PCAU Soccer Gala 2016

To Commemorate the World Hospice and Palliative Care Day 2016, members of staff from Ugandan palliative care services and organisations and the Ministry of Health shall participate in football competitions in Uganda’s Capital Kampala.

The event is aimed at raising public awareness about palliative care services in Uganda and also to strengthen partnerships and networking among service providers for the advancement of the services. At Least 27 organisations have been invited to participate and a total of 500 people are expected to attend this important celebration on 15 October 2016 at Old Kampala Primary School.

Members of the UN and other international agencies have been invited and are expected to attend. Posters, placards, stickers and banners with strong palliative care messages shall be displayed to make a palliative care statement at the event which will commence with a mammoth march with a brass band in Kampala City. The Minister of Health in the Ugandan Government shall be the guest speaker at the event.
Bangladesh: Presentation of draft palliative care guidelines and national opioid policy

Palliative care organisations throughout Bangladesh will celebrate World Hospice and Palliative Care Day under the banner of Bangladesh Medical Association (BMA). The full-day programme will include a discussion and film show in the morning, after which draft national guidelines for palliative care and a draft national opioid policy for Bangladesh, will be handed over to representatives from the Ministry of Health.

BMA will address the ministry and will formally handover the documents to the minister on their behalf. Invitees to this high level event include the WHO Country Representative for Bangladesh, and national level policy makers, such as the Director General of Narcotics and Drug Administration.

Singapore: Living Well Matters Photo Exhibition

A photo exhibition themed – “Living Well Matters” will be held in Singapore to mark World Hospice and Palliative Care Day. To some people, “living well” means engaging in their favourite hobbies, travelling to exotic places, enjoying good food or having get-together with family and friends. This photo exhibition showcases photo entries from healthcare staff of Alexandra Health System and partners on what “living well” means to them.


This UR2.Global Music Tribute, set to take place in Tallahassee, United States, was created to ease and facilitate the spiritual and emotional needs of those with life limiting illnesses and in the transitioning process through song and a music video that offers lyrical expression of these souls most sacred concerns and expressions.

The music video features Dr K’s Music Therapy aka Amelia Kemp, Ph.D., LMHC – psychotherapist, singer/song-writer and minister who states that: “how a soul feels about themselves during the last days of their physical life affects esteem, just as it did throughout their lives.”

The Music Video Exhibit begins on World Hospice and Palliative Care Day – 8 October 2016 on www.UR2.Global. A free copy of the video will be downloadable to any hospice agency to assist their patients indefinitely as a humanitarian effort of The Sacretherapy Institute created to uplift the self-esteem of humanity.

China: World Hospice and Palliative Care Day – Arts Move

To increase the awareness of palliative care in China, Beijing Living Will Promotion Association will organise the World Hospice and Palliative Care Day (China 2016) – Arts Move.

This is our first celebration of World Hospice and Palliative Care Day in Beijing, China, and to officially register the event on the WHPCA website. The event, it will have three sections, including a palliative care talk, arts exhibition and banquet to celebrate World Hospice and Palliative Care Day. We are glad to have different parties from government, business, cultural and arts, medical and health sectors participating and joining together to support us.
Further suggestions for World Hospice and Palliative Care Day

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

- Professionally designed posters
- Key messages
- A model letter to government decision makers on improving access to controlled medications that you can download and edit to suit your context.

Please see below for some suggestions on how to mark World Hospice and Palliative Care Day.

- Start a palliative care discussion group in person or online
- Download the template ‘model letter to governments’ on improving access to controlled medications for pain relief and palliative care, adapt it to your local context and send it to the relevant decision makers
- Are you a member of a community philosophy group or evening class? Organise a themed discussion around World Hospice and Palliative Care Day
- Print out the World Hospice and Palliative Care Day Posters and display them around your place of work or study
- Put together a media campaign to raise awareness of World Hospice and Palliative Care Day
- Publish an article on your organisation’s website
- Already have media contacts? Organise to speak on local radio stations or TV channels
- Organise a fundraising event (concert, theatre, exhibition, etc.)
- Run a social media campaign aligned to World Hospice and Palliative Care Day and the aims of your organisation
- Organise a sports or community event.


You can also see the events that have already registered http://www.thewhpc.org/world-day-2016

Working with the press

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

You may already have built up relationships with your local media, or you can take this opportunity to start.

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

1. Remember that journalists are very busy. The easier you make it for them to pick up a story, the more likely they are to do so. Keep this in mind when writing your press release.

2. Make sure you have an eye-catching headline

3. Include the key information in the first paragraph. Remember the five ‘W’s: What is your news? Where will it happen? When will it happen? Who is involved? Why should people be interested?

4. Include numbers, facts and statistics to strengthen your claims. You can find the World Hospice and Palliative Care Day Key Messages online and in the appendix.

5. Make sure your news is relevant to a wider audience than just you and your colleagues. Link your World Hospice and Palliative Care Day event to larger issues, such as global ageing, NCDs, the Sustainable Development Goals, Universal Health Coverage, or other themes relevant to your context.

6. Use quotes from recognised experts to elaborate on the point

7. Keep it short. Press releases should be one page long.

8. Include photos. Even if you don’t have photos yet for this year’s World Hospice and Palliative Care Day event, include photos from previous years, or of your organisations’ recent work.
9. Remember to proof read your press release to make sure it is grammatically correct and contains no typos

10. Include your contact information

11. Include a link to the World Hospice and Palliative Care Day page on the WHPCA website http://www.thewhpca.org/world-hospice-and-palliative-care-day/about

12. Create a contacts list. Identify which publications are most likely to pick up your story. Have they covered palliative care or related issues in the past?

13. Make sure the press release is approved by your CEO, legal team or communications director before sending it out.

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

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

You can follow the @WorldHospiceDay Twitter account, and Tweet to show your support of the Day, either by using the official World Hospice and Palliative Care Day draft Tweets, or by Tweeting your own message and including the hashtag #WHPCDay16. Additional hashtags to use are listed below.

World Hospice and Palliative Care Day on Twitter
Twitter handle: @WorldHospiceDay
Main hashtag: #WorldHospiceDay
Social media hashtags
#Care #EndofLife #EssentialMedicines #GlobalHealth #Health #HPMGlobal #Hospice #HIV #HumanRights #NCDs #NCDmomentum #Palliative #PalliativeCare #QualityOfLife #SDGs #Stigma #SocialJustice #UHC

World Hospice and Palliative Care Day draft tweets
Living and dying in pain: It doesn’t have to happen #WHPCDay16

#WHPCDay16 theme ‘Living and dying in pain: It doesn’t have to happen’ will focus on access 2 #pain & #palliativecare medicines worldwide

Oral #morphine is the standard of #pain management in #palliativecare #WHPCDay16

Tweets about restrictive regulations
Unduly restrictive regulations limit access 2 #pain relief and #palliativecare 4 ppl & families in need #WHPCDay16
Pain management is the right of the person with #pain #WHPCDay16

Oral #morphine & other @WHO essential #palliativecare meds shd b legally available & accessible everywhere #WHPCDay16

Tweets about education
Opiophobia = fear in the health professions of prescribing opioid medications. Prevents people from receiving #pain relief #WHPCDay16

Drs & nurses often not educated about #pain management & prescribing morphine #WHPCDay16

Unreasonable fear of #opioid use leads to increased suffering worldwide #WHPCDay16

Tweets about economic incentive
#Morphine is cheap 2 make but expensive 2 bring 2 market in many places with unduly restrictive regulations #WHPCDay16

Profit margin 4 oral #morphine tablets is 2 low 2 be of interest 2 most pharma producers #WHPCDay16

All people with life threatening illness & their families need & deserve care & #pain management through #palliativecare services.
Why does Facebook matter?

Facebook is about linking people to one another. In the non-profit or charity sector, relationships have always been the crucial exchange.

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

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

Facebook helps because it:

• Helps people find you, connect to your message and recognise the unique service you have to offer.
• Shows the human face of your organisation and encourages personal links in the often impersonal world.

World Hospice and Palliative Care Day on Facebook

Follow the Worldwide Hospice Palliative Care Alliance on Facebook (https://www.facebook.com/thewpca/) and sign up to the World Hospice and Palliative Care Day 2016 event (www.facebook.com/events/148385515566360/) to share your events and to join the discussion.

Facebook makes sharing content easy for you to do by connecting with influencers, sharing engaging content and keeping up with the latest news especially around World Hospice and Palliative Care Day.

You can use Facebook to gather support for your World Hospice and Palliative Care Day event and even to harness donations and potential leads. Facebook makes it extremely simple to present important messages, along with engaging pictures.
Conclusion

Barriers to accessing controlled medications for palliative care and the relief of pain include: legal and regulatory barriers, poor education of healthcare workers and the public on opioids and their use, and economic barriers to the supply of generic medicines such as oral morphine. All people with life threatening illness and their families need and deserve comfort care and pain management through palliative care services. Oral morphine and other WHO essential palliative care medications should be legally available, affordable, and accessible in all countries without undue legal or regulatory restrictions.

Suggestions and inspiration on how you can get involved in World Hospice and Palliative Care Day 2016 include: ideas on how to mark the day, advice on working with the press, and promoting hospice and palliative care on social media. A list of further resources that you can draw on for your own campaign is available in the appendix to this toolkit.
Common African Position:

- The African Union (AU) countries decided to submit a Common African Position with regard to the UN General Assembly Special Session (UNGASS) on the World Drug Problem in New York.

- The document recognizes that the world drug problem requires an integrated approach to drug supply, demand reduction and harm reduction strategies, as well as ensuring the availability of controlled substances for medical and scientific use.


Human Rights Watch

- Human Rights Watch has released in-depth reports, examining access (or lack of access) to palliative care and pain medications in many countries.


- Care When There Is No Cure: Ensuring the Right to Palliative Care in Mexico (2014): http://features.hrw.org/features/HRW_2014_report/Mexico_Care_When_There_Is_No_Cure/index.html


International Narcotics Control Board report for 2015

- The INCB reported on access to medications, noting that 75% of the world’s population has no or inadequate access to controlled medications for pain management


Open Society Foundations report: The impact of international drug policy on access to controlled medicines

- The Open Society Foundations produced a report examining the impact of international conventions on access to medications, including recommendations to States for how to improve access in a responsible way.

**Open Society Foundations Public Health factsheet: Palliative Care as a Human Right**

• The Open Society Public Health Program aims to build societies committed to inclusion, human rights, and justice, in which health-related laws, policies, and practices reflect these values and are based on evidence.

• This factsheet provides facts and quotes to be used for palliative care and pain relief advocacy.


**Pain and Policy Studies Group**

• This website contains useful information on global opioid consumption, interactive graphs, and country profiles

• http://www.painpolicy.wisc.edu/

**Stop the Harm**

• Stop the Harm calls on countries to review their drug policies to ensure no one is deprived of needed medical treatment.

• https://stoptheharm.org/essential-medicines

**UNGASS Outcome document**

• During the United Nations General Assembly Special Session on the World Drug Problem, UN Member States adopted UN Resolution S-30/1: Our joint commitment to effectively addressing and countering the world drug problem. This document contains a section on access to controlled medications for pain management.


• The UNODC World Drug Report 2016, acknowledges that ensuring access to essential medicines is an important part of addressing the ‘world drug problem’.


• WHA resolution 67.19: Strengthening palliative care as a component of comprehensive care throughout the life course

• The WHA resolution on palliative care contains four action points for member states regarding improving access to controlled medications for pain relief.
WHO Model List of Essential Medicines

- The WHO Model List of Essential Medicines presents a list of minimum medicine needs for a basic healthcare system, listing the most efficacious, safe and cost-effective medicines for priority conditions.


- WHO policy guidelines Ensuring Balance in National Policies on Controlled Substances, Guidance for Availability and Accessibility for Controlled Medicines

- The WHO Policy Guidelines for Controlled Substances provide guidance on policies and legislation with regards to availability, accessibility, affordability and control of medicines made from substances regulated under the international drug control conventions.


- WHPCA model letter to governments on improving access to controlled medications for pain relief

- The WHPCA has drafted a model letter to be used as a template by palliative care advocates when writing to their governments on the importance of improving access to controlled medications for pain relief.


International hospice and palliative care organisations

The International Association for Hospice and Palliative Care (IAHPC)

- The IAHPC is an international organisations dedicated to the promotion and development of palliative care throughout the world.

- http://hospicecare.com/home/

The International Children’s Palliative Care Network (ICPCN)

- The International Children’s Palliative Care Network (ICPCN) is a worldwide network of individuals and agencies working with children and young people with life-limiting and life-threatening conditions.

- http://www.icpcn.org/about-icpcn/
The Worldwide Hospice Palliative Care Alliance (WHPCA)

- The Worldwide Hospice Palliative Care Alliance (WHPCA) is an international non-governmental organisation focusing exclusively on hospice and palliative care development worldwide.

  - http://www.thewhpc.org/

Regional hospice and palliative care organisations

Asociación Latinoamericana de Cuidados Paliativos (ALCP)

- The ALCP is an association working towards universal access to palliative care in Latin America.

  - http://cuidadospaliativos.org/home/

The African Palliative Care Association (APCA)

- APCA is a pan-African organisation ensuring that palliative care is widely understood, integrated into health systems at all levels and underpinned by evidence in order to reduce pain and suffering across Africa.

  - https://www.africanpalliativecare.org/

The Asia Pacific Hospice Palliative Care Network (APHN)

- The APHN is dedicated to promoting hospice and palliative care in Asia and the Pacific, with the purpose of empowering and supporting organisations and individuals committed to alleviating suffering from life-threatening illness.

  - http://aphn.org/

The European Association for Palliative Care (EAPC)

- The EAPC is a membership organisations aiming to develop and promote palliative care in Europe.

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