

END-OF-LIFE CARE

# DYING HEALED: TRANSFORMING END-OF-LIFE CARE THROUGH INNOVATION

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Professor The Lord Darzi



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Sir Thomas Hughes-Hallett

# FOREWORD

Responsible societies ensure that everyone is able to live well until they die. Like birth, death is a part of life – something that no one can avoid – and yet all too often death is a taboo subject. How we care for the dying is a litmus test of a good health system and a responsible society – to be judged by the dignity and respect given to all people of all ages in all settings at the end of their lives.

Yet the specialty of end-of-life care remains in its infancy – the new kid on the clinical block. Some governments have now introduced end-of-life care strategies, but still too few health systems have embraced the reality of an ever-expanding aging population who, thanks to medical advances, live longer but whose final years with multiple long-term conditions increasingly challenge health systems. This is compounded by the demise of the extended family in so many societies (ranging from the US to China) who have been the historic caregivers to the dying.

We all wish for a pain-free, dignified death. The tragic lack of available treatments, particularly opioids, in so much of the world means that a pain-free death is denied to the majority of the world's population; 90 percent of the world's morphine is used by 16 percent of the population. This is a shameful reflection on our society, revealing our historic emphasis on curative treatment while leaving the dying in pain, ignoring the inevitability of death.

Health systems have to change and embrace the need to develop innovative approaches and technologies for end-of-life care. All resources in society have a role to play – families, communities, health and care providers and technology. There is, however, a dearth of appropriately trained professionals. The clinical specialty of palliative care, which provides pain and symptom control, is all too rarely available.

This report highlights the core issues that need to be addressed, with examples of best practices from countries that have made measurable progress, not least by embracing innovation and increasing the extent and scale of coverage. We recommend practical steps that can be taken by policy-makers to effect positive change and produce better care and better economic value.

The WISH summit provides a wonderful opportunity to harness the knowledge being developed in Big Data, accountable care systems, and patient and family involvement, while learning from the obvious parallels between mental health and end-of-life care. Creating a whole system approach to end-of-life care is a 'must do' for all countries participating in the WISH summit.

**Professor The Lord Darzi, PC, KBE, FRS**

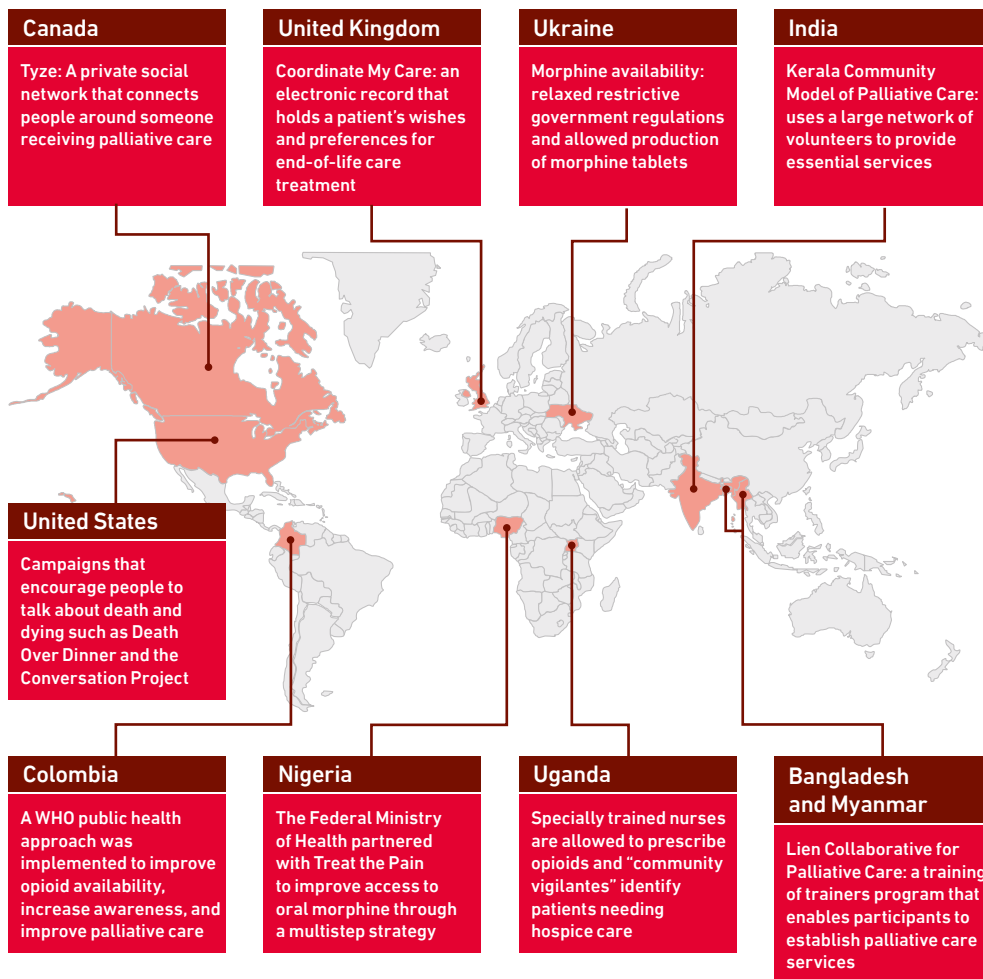
Executive Chair of WISH, Qatar Foundation

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# SELECTED END-OF-LIFE CARE INNOVATIONS



# EXECUTIVE SUMMARY

## WHAT IS THE CHALLENGE?

Advances in medicine, nutrition, and other factors have allowed people to live longer. Yet one aspect of life is constant. Human mortality remains 100 percent; we all eventually die. While where and when we die is regularly studied, how we die is often avoided or ignored. This has led to an unacceptable amount of unnecessary suffering worldwide during the last year of life. Each year, over 100 million people would benefit from palliative care, yet fewer than 8 percent of those in need access it.<sup>1</sup> This is a global tragedy, but it is one that can be effectively remedied.

We recognize that different countries are at different stages of establishing end-of-life care – for some the creation of 24/7 community services will be the key development. For others it will be providing access to pain and symptom-controlling essential medicines and staff trained to administer them.

We present a five-step strategy for improving quality of life at the end-of-life with specific examples of innovations that have proven effective at reducing unnecessary suffering and improving end-of-life care in different settings and cultures.

## KEY MESSAGES

**What:** To change attitudes toward death and dying and improve services and resources, allowing people to live well and die in their communities with access to effective pain and symptom management.

**Why:** Because caring for the dying is a fundamental responsibility of all societies and good stewardship of national resources requires an evidence-based approach to meet the ever-increasing and insupportable demands on hospital facilities.

**How:** By identifying the solutions needed to overcome barriers to quality end-of-life care; by setting out examples of best practice from around the world in improving end-of-life care; and by making specific recommendations on how individual countries can improve their approach to caring for the dying.

## UNDERSTANDING END-OF-LIFE CARE AND PALLIATIVE CARE

End-of-life care “helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support.”<sup>2</sup>

The “end-of-life” is generally understood as the last year of life.<sup>3,4</sup> Palliative care may start earlier and is advocated by the World Health Organization to begin alongside potentially curative care when an individual is diagnosed with a life-limiting condition.

As curative options decrease and the patient approaches the last year of life, end-of-life care becomes the main approach. For the purpose of this report, we focus on the needs of people of all ages, diagnoses and all cultures but do not seek to tailor individual recommendations for specific groups.

## **A ROADMAP FOR ACTION**

This report is a call to improve palliative and end-of-life care for all patients who need it. There is no time to waste, as ending unnecessary suffering is an achievable goal. We provide a series of recommendations in five steps as follows, backed up by innovations that can dramatically improve end-of-life care.

### **STEP 1: MAKE CARE OF THE DYING A PRIORITY FOR ALL**

Death and dying are taboo topics in many countries. Failing to discuss and plan for dying in advance often leads to unnecessary suffering and a difficult time for all involved. The first step to changing this attitude is to begin to normalize the inevitability of death and to advocate for the inherent right of all humanity to healthcare through their whole life and not just during their childhood or their economically productive years. Quality palliative and end-of-life care should be available to all, which requires appropriate policies, health services and trained staff.

### **STEP 2: REDUCE UNNECESSARY SUFFERING**

Lack of accessible, affordable palliative and end-of-life care results in uncontrollable pain, breathlessness, fatigue, and other disabling symptoms that drastically reduce quality of life. Essential medicines, including opioids, are often unavailable due to lack of resources, lack of skilled healthcare staff, and fear of illicit drug use, leading to overly restrictive regulations, dose limits, and other barriers to symptom relief. Through education and supportive regulation, restrictions on opioids should be relaxed. Governments should recognize the World Health Organization’s Model List of Essential Medicines and train staff to make appropriate medicines available to those in need.<sup>5</sup>



### **STEP 3: IMPROVE KNOWLEDGE AND USE DATA TO DRIVE INNOVATION**

Palliative and end-of-life care research is under-resourced and under-developed across the world, resulting in lack of knowledge and data about how people die. In many countries, less than 0.5 percent of cancer research spending is devoted to understanding end-of-life.<sup>6</sup> In order to improve access to and quality of palliative and end-of-life care, research must become a priority. Collaboration amongst leading researchers is key to establishing a best-practice evidence base that results in high-quality outcomes, and common research strategies that promote better care should be accepted and promoted.

### **STEP 4: MAXIMIZE RESOURCES**

All possible resources need to be maximized to improve palliative and end-of-life care quality and availability. Care strategies need to include support for not just the dying but also families and carers. Technologies such as telehealth and mobile health will play an important role in this, along with low-cost innovations that can be adopted regardless of income status.

### **STEP 5: IMPROVE SKILLS**

A key global challenge is the lack of doctors, nurses, pharmacists, clinical officers, community health workers, social workers and other health support workers and community volunteers with knowledge and training in palliative and end-of-life care. With early training on holistic care for the dying embedded into all health worker curricula, basic palliative care coverage can be increased. Additional skills, communication, bereavement support for family members and avoidance of overmedicalization will improve care and establish a more integrated and cost-effective care system.

# RECOMMENDATIONS

## STEP 1: MAKE CARE OF THE DYING A PRIORITY FOR ALL

- Produce a national strategy for end-of-life care.
- Include palliative and end-of-life care as part of healthcare for all diseases.
- Monitor the scale and need for end-of-life care locally.
- Sign the Prague Charter and recognize that access to palliative and end-of-life care is a human right.
- Set up a national initiative using online tools and innovative campaigns to encourage people to learn and communicate more about death and dying.
- Encourage the use of advance care directives, so that patients can make their own end-of-life wishes and expectations known beforehand, rather than under pressure at a time of crisis.

## STEP 2: REDUCE UNNECESSARY SUFFERING

- Adopt the WHO Model List of Essential Medicines and eliminate overly-restrictive regulations banning the use of opioids for palliative and end-of-life care.
- Ensure essential medicines are nationally available in central medical stores, licensed appropriately, and distributed effectively through existing distribution channels where possible.
- Ensure the appropriate use of opioids and other essential medicines.

## STEP 3: IMPROVE KNOWLEDGE AND USE DATA TO DRIVE INNOVATION

- Invest in research and development in palliative and end-of-life care.
- Form partnerships between national, regional, and international palliative care organizations to carry out research and publish high-quality reports.
- Capitalize on knowledge gained from research outcomes to lower costs and improve care.
- In places where Western medicine has not been fully adopted, engage with traditional healers to improve end-of-life care.

## STEP 4: MAXIMIZE RESOURCES

- Engage the local community in end-of-life care.
- Utilize telemedicine and technology-based innovations to improve access to end-of-life services, especially in rural and remote areas.
- Empower patients through better access to knowledge about end-of-life care choices and availability.

## STEP 5: IMPROVE SKILLS

- Include palliative and end-of-life care training in all professional healthcare undergraduate and postgraduate programs.
- Include bereavement support in palliative and end-of-life care training programs.
- Share global learning to enable all countries to build palliative and end-of-life care services.
- Access or develop e-learning training modules for staff and volunteers.

**END-OF-LIFE CARE FOR ALL**

# INTRODUCTION: UNDERSTANDING THE CHALLENGE

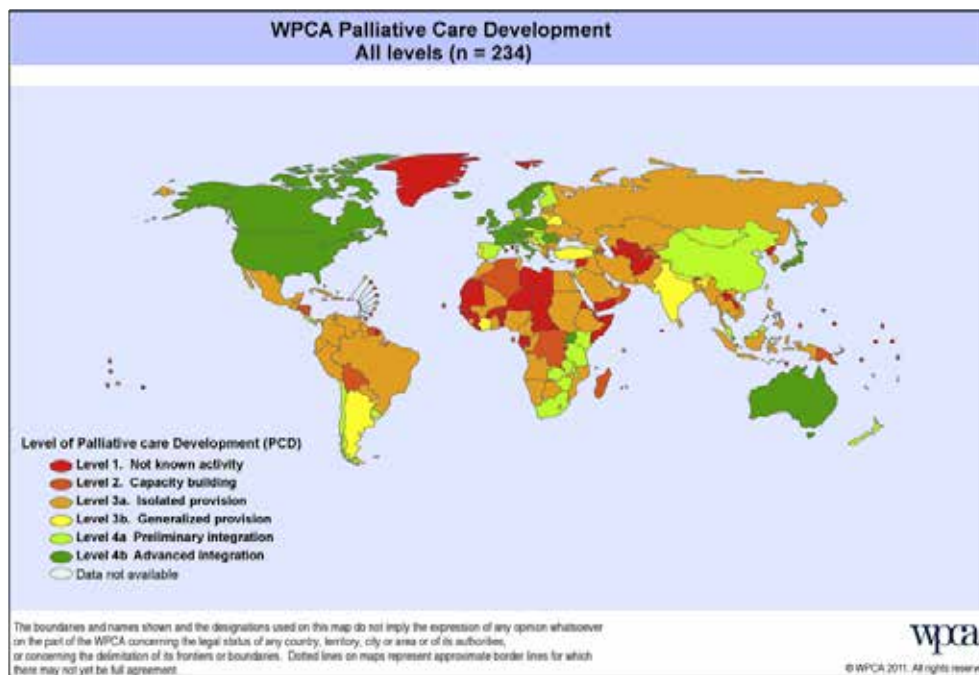
**“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”**

Dame Cicely Saunders, founder of the modern palliative care movement (1918-2005)

In 2013, more than 55 million people will die throughout the world.<sup>7</sup> The majority of these deaths, approximately 44 million, will occur in low- and middle-income countries (LMICs) where end-of-life care is rarely high-quality and is often completely unavailable. Apart from people who die suddenly – between 20 percent and 40 percent of all deaths, depending on the country<sup>7</sup> – all people, no matter who they are or where they die, would benefit from receiving some form of end-of-life care. Such care includes optimizing the quality of life remaining, and supporting the patient, carers, and family in ensuring that the patient’s death is as painless and dignified as possible. This report is a call to action: high-quality end-of-life care should be available to all who need it.<sup>8</sup>

End-of-life care is intrinsically linked to palliative care. Patients diagnosed with life-limiting conditions may need palliative care for many years before death, but palliative care does not signal the end of all curative treatments. Rather, within a continuum of holistic care, such care can work alongside active interventions to treat and alleviate symptoms. Where good palliative care is implemented, a reduction in ineffective, distressing and invasive curative treatments often occurs,<sup>9</sup> and as the last phase of life approaches and curative options reduce, end-of-life care enables patients to live as well as possible until they die. Currently, however, end-of-life care is provided mainly to those with advanced cancer,<sup>10-14</sup> often too late to be very effective.<sup>15-17</sup> For many people, regardless of income level, high-quality end-of-life care is simply not available.<sup>18-20</sup>

**Figure 1: Worldwide palliative care development.<sup>21</sup>**



Improving access to end-of-life care must begin by improving palliative care across the world. Few countries incorporate palliative care strategies into their overall healthcare policy. Lynch et al recently categorized palliative care development in 234 countries, ranging from those with no known hospice/palliative care activity to those with services with advanced integration into mainstream healthcare (Figure 1).<sup>21</sup> In 2011, 136 of the world's countries (58 percent) had one or more palliative care service, a 9 percent increase since 2006, with the most notable increases in service arriving in parts of Africa. However, only 20 (8.5 percent) countries have integrated their palliative care effectively into the wider health care system to enable greater access to all citizens. This clearly leaves much room for improvement in making palliative and end-of-life care accessible to all who need it.

**We believe that this is a global tragedy and that access to palliative and end-of-life care is a human right for every person and a benchmark for the development of a nation.**

## CRUCIAL FACTS ABOUT DEATH

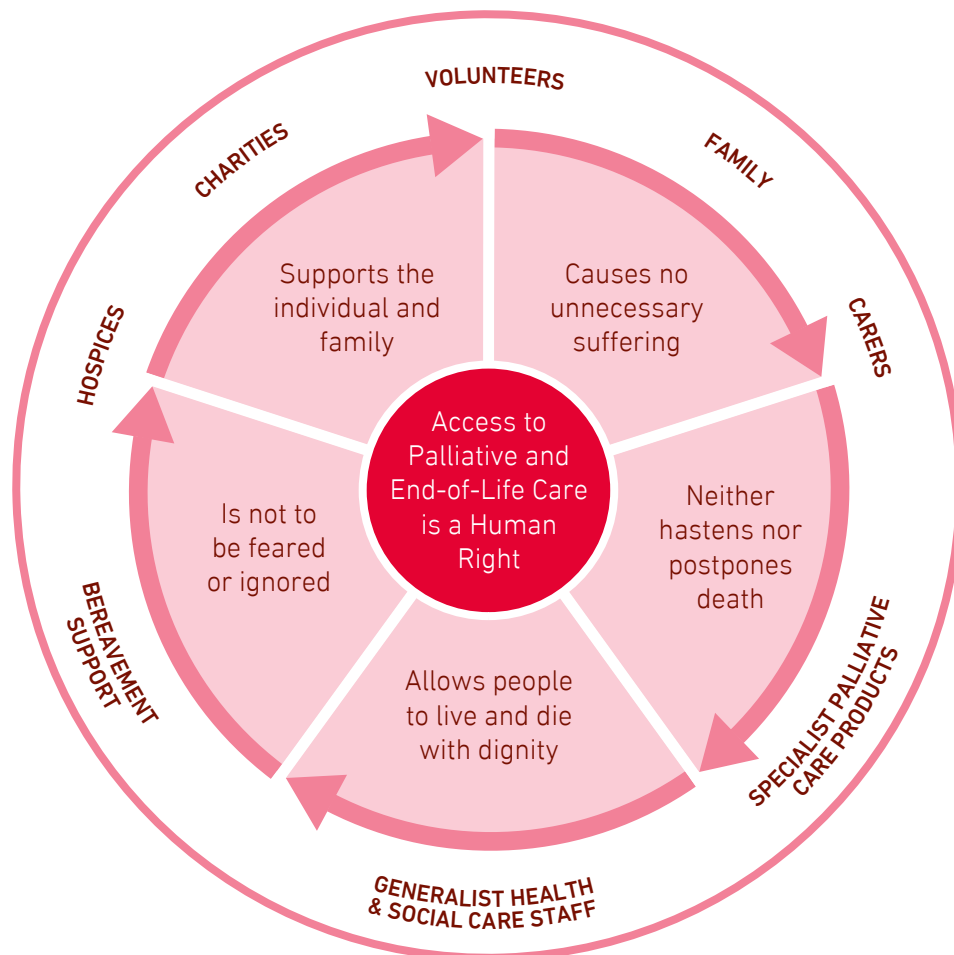
- Human mortality remains 100 percent; we all eventually die.  
HOW we die is up to us.
- 100 million people need palliative care each year – only 8 million people have access to it.
- 90 percent of the world's morphine is used by 16 percent of the population.

# STEP 1: MAKE CARE OF THE DYING A PRIORITY FOR ALL

“Unfortunately in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”

Professor Harvey Chochinov, University of Manitoba, Canada

**Figure 2: Access to palliative and end-of-life care is a human right that should be available to all individuals. This core declaration is supported by five fundamental principles of how to die well, surrounded by a continuum of people and support structures.**



## ACCEPT ACCESS TO PALLIATIVE AND END-OF-LIFE CARE IS A HUMAN RIGHT AND ADOPT POLICIES THAT PRIORITIZE END-OF-LIFE CARE, INCLUDING AN END-OF-LIFE CARE NATIONAL STRATEGY

While reducing untimely and preventable deaths is a well-established global health priority, improving the quality of life of those who are dying has been largely ignored. Palliative care is seldom recognized as a major health issue, and death, although inevitable, is often unmentioned. More than 100 million people would annually benefit


from palliative care (including family and carers who need help and assistance in caring). However, less than 8 percent of those who would benefit from palliative care are able to access it.<sup>1</sup>

Policy-makers and clinicians, struggling with limited resources, are engaged in developing strategies and actions that prioritize and tackle illnesses where they can save lives. Thus, even in many high-income countries, end-of-life care is left to the charitable and voluntary sector, who have to champion its importance and provide the majority of the required funding.<sup>22</sup> Dying is seen as a sign of the failure of the health system to successfully cure. Yet, dying is an inevitable outcome of living, thus supporting all policy-makers and clinicians to enable people to die well is an essential duty of a caring and civilized society.

The first step to achieving this aim is international recognition of palliative and end-of-life care as a human right (Figure 2). Despite growing international pressure in this direction, many countries still shy away from it, setting palliative and end-of-life care low on their list of priorities.<sup>8,23,24</sup> One of the primary tasks facing international palliative care organizations is to continue their advocacy for a change of attitude within national healthcare systems.

A leading advocate of good practice in this area is the European Association for Palliative Care (EAPC), which has published a series of white papers covering standards and norms in palliative care, outcome assessment, and palliative care for patients with dementia.<sup>25-28</sup> Along with other organizations, EAPC has been active in producing and promoting a range of other initiatives, most recently The Prague Charter (Table 1), a document that advocates the recognition of palliative care as a human right.

**Table 1: The Prague Charter**

	<p><b>The Prague Charter</b> urges governments to relieve suffering and ensure the right to palliative care. In recognizing and celebrating palliative care as a human right, the Prague Charter maintains that palliative care should be part of all governments' fundamental health policy and should be available to everyone. A copy of the Prague Charter can be found in Appendix 1.</p>
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Establishing palliative care as a human right will require some effort on the part of national governments. Countries need to formulate and publish their own national strategies for quality palliative and end-of-life care. In 2008, the UK published the document *End of Life Care Strategy: Promoting High-quality Care for all Adults at the End of Life*. Each year since, the Department of Health has published an annual report on progress achieved in implementing the strategy. The stated goal of the document was to set out a policy strategy for ensuring that everyone attains a “good death.” This “good death” was defined as: being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends. The document should act as an incentive to other countries to formulate and publish their own strategies, which would in turn raise the profile of end-of-life care in the eyes of the world.

### **RECOMMENDATIONS FOR POLICY-MAKERS:**

- Produce a national strategy for end-of-life care.
- Include palliative and end-of-life care as part of healthcare for all diseases.
- Monitor the scale and need for palliative and end-of-life care locally.
- Sign the Prague Charter and recognize that access to palliative and end-of-life care is a human right.

**Table 2: Integrating palliative and end-of-life care into public health**

### **CASE STUDY: COLOMBIA**

A Public Health Model developed by the WHO was implemented in Colombia to increase awareness about palliative and end-of-life care, include palliative and end-of-life care as a component of care in legislation, and improve opioid availability. In November 2007, a national workshop was organized and attended by pain and palliative care specialists from all over Colombia to identify barriers and possible solutions to opioid availability, inform regulators about the challenges physicians identify in the prescription process, and inform physicians about the limitations that regulators face. Following the workshop, the following recommendations were delivered to the Ministry of Health:

1. Modify a national policy to guarantee availability of opioid analgesics 24 hours a day/7 days a week in the capital cities of the 10 main states in Colombia.
2. Involve and engage the health maintenance organizations in order to inform them of the results of the workshop so that they can incorporate strategies in their quality improvement process to improve opioid accessibility.
3. Form an advisory group of pain and palliative care clinicians to help the National Drug Authority in the identification of essential medicines and in the development of estimates of controlled medications to submit to the International Narcotics Control Board.
4. Require Regional Hospitals to provide opioid medication for outpatients.

Following the workshop, aspects of palliative care improved in Colombia. A new regulation mandated all 32 states in Colombia have at least one place where opioids are guaranteed to be in stock. Consequently, from 2006 to 2009, the sale of morphine increased 42 percent and the sale of hydromorphone increased 195 percent nationwide. A course on Pain and Palliative Care was established at the Universidad de la Sabana and made mandatory for all undergraduate students in the school of medicine. These improvements in opioid availability and education are evidence that the WHO Public Health Model can be crucial in the development of palliative care, and Colombia should continue to prioritize palliative and end-of-life care to see further improvements.

### **START THE PUBLIC TALKING ABOUT DEATH AND DYING**

Changing government policy is only one step in making care of the dying a priority for all. Quality end-of-life care must also be built from the ground up. In some cultures, talking openly about death and dying is considered disrespectful and can lead to despair and even accelerate the process of dying. For many people, death is simply too distressing to contemplate and is therefore ignored or avoided.<sup>29-31</sup> Here anonymity can be an advantage, and in some countries, innovative online tools have become a welcome resource for information about end-of-life care (Table 3).



**Table 3: Online Tools That Promote Quality End-of-Life Care**

	
<b>Dying Matters, England, United Kingdom</b> <a href="http://www.dyingmatters.org">www.dyingmatters.org</a>	<b>Good Life, Good Death, Good Grief, Scotland, United Kingdom</b> <a href="http://www.goodlifedeathgrief.org.uk">www.goodlifedeathgrief.org.uk</a>

Grassroots groups have launched a number of campaigns aimed at encouraging people to initiate conversations about death with their family members and close friends. The objective is to lessen anxiety that typically accompanies such conversations. In particular, people are encouraged to talk about these topics before they are actually needed, and in familiar surroundings, such as at the dinner table, rather than somewhere that is felt to be threatening, such as a hospital intensive-care unit (Table 4).

**Table 4: Campaigns that Encourage People to Talk About Death and Dying**

	
<b>Death Over Dinner, United States</b> <a href="http://www.deathoverdinner.org">www.deathoverdinner.org</a>	<b>The Conversation Project, United States</b> <a href="http://www.theconversationproject.org">www.theconversationproject.org</a>

**RECOMMENDATION FOR POLICY-MAKERS:**

- Set up a national initiative using online tools and innovative campaigns to encourage people to learn and communicate more about death and dying.

## PLAN FOR THE FUTURE

The experience of dying can accentuate cultural, religious and social differences between carers, providers, and patients, and needs to be sensibly and sensitively approached in end-of-life care. Patients, even when they suspect they are dying, are often shielded from the knowledge that their condition has been diagnosed as terminal. Families, carers and health professionals are all likely to want to avoid raising the subject of death. This can lead to a failure to acknowledge the possibility of death and to discuss and plan for it in a way that respects the patient's and family's wishes.

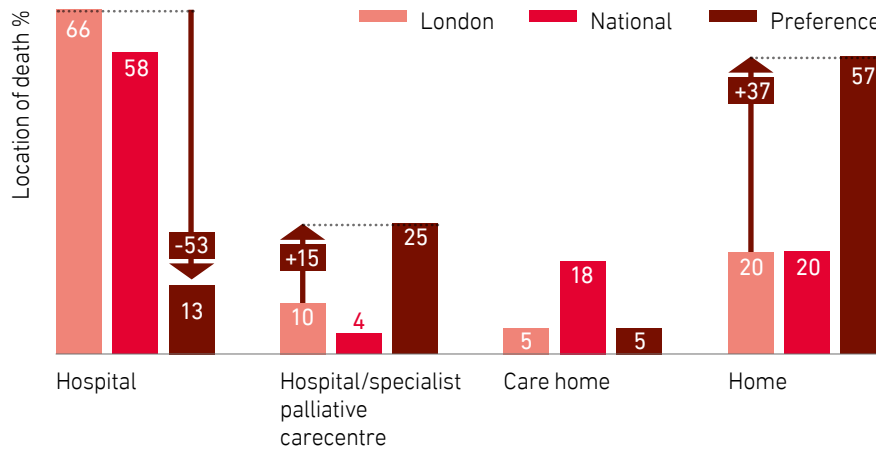
Research has shown that, when plans have been made beforehand, patients usually die where and in the way they would wish. When no such plans are in place, there is little opportunity to determine the patient's wishes and preferences: patients are rushed into hospital, and their last days are dominated by medical supervision, or worse still they are left to die unsupported and in pain.<sup>32</sup> Recently, various tools have been developed to better prepare patients and families for the process of dying. Advance healthcare directives are instructions given by patients beforehand, specifying how they want matters treated if they are no longer able to make independent decisions owing to illness or incapacity (Table 5). They allow patients to maintain a sense of control over daily life,<sup>33</sup> and it is clear that an advance care directive, if designed and implemented effectively, can contribute significantly to improving patient experiences at the end-of-life (Table 6).<sup>34</sup>

**Table 5: Advance Care Directives**

	<b>Five Wishes, United States</b> <a href="http://www.agingwithdignity.org/five-wishes.php">www.agingwithdignity.org/five-wishes.php</a>
	<b>MyDirectives, United States</b> <a href="http://www.mydirectives.com">www.mydirectives.com</a>
	<b>Coordinate My Care, London, United Kingdom</b> <a href="http://www.coordinatemycare.co.uk">www.coordinatemycare.co.uk</a>

**Table 6: Coordinate My Care helps Londoners die in their place of preference with the care they desire**

### CASE STUDY: WHERE WE DIE



Source: England, Wales and Scotland (2000); Telephone survey; Priorities and preferences for end-of-life care in England, Wales and Scotland (2003); Telephone Survey NCHPCS/Cicely Saunders Foundation; National statistics (2003), London Health Observatory (2005)

Despite a strong preference to die at home (57 percent), only 20 percent of Londoners actually die in the comfort of their own bed. Instead, 66 percent of people die in hospital. In order to reduce hospital deaths and allow people to die at their place of preference, the Government developed an End-of-Life Care Strategy that included setting up Electronic Palliative Care Coordination Systems (EPaCCs) for patients approaching the end-of-life, including Coordinate My Care.

Patients' wishes were documented through the Coordinate My Care program that, after a two-year pilot study, went live across London in the spring of 2013. Currently there are 8,030 CMC records, and 2,548 of these patients have died. Of the patients who have died with a Coordinate My Care plan in place, 79 percent have died in their place of preference, and 81 percent of patients have died outside of the hospital setting. In the summer of 2014, access to Coordinate My Care will be made easier through the introduction of a mobile app that patients can use to update their wishes.

### RECOMMENDATION FOR POLICY-MAKERS:

- Encourage the use of advance care directives, so that patients can make their own end-of-life wishes and expectations known beforehand, rather than under pressure at a time of crisis.

## STEP 2: REDUCE UNNECESSARY SUFFERING

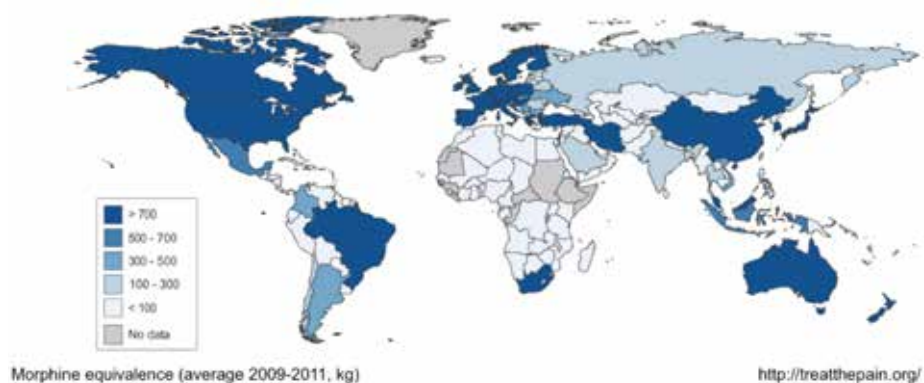
**“No one should die in the torture of pain when the drugs to stop that pain are available and so affordable... Living pain-free – especially but not only during our last period of life – is a right that can be met even in the poorest of settings.”**

Professor Felicia Knaul, Harvard University, USA

The most important practical issue facing end-of-life care providers is the availability of painkilling drugs or, more often, the lack of them. This remains a significant international challenge. For many people who are dying, access to pain relief is a basic requirement. In 2013, over seven million people will die of HIV or cancers in moderate to severe pain, and nearly three million of them will have no access to pain relief.<sup>7</sup> The lack of basic medication in many parts of the world causes huge suffering, not just for the dying themselves but also for their carers and families, who are left feeling helpless in the face of this suffering.

Pain and other symptom control is the basis of all palliative and end-of-life care, and the availability of opioids (morphine and its equivalents) is fundamental to quality palliative and end-of-life care. But across the world, an estimated five billion people lack access to opioids, largely because of concerns about illicit drug use and trafficking.<sup>7</sup> Despite long-standing efforts to ensure wider access to opioids for the control of pain at the end-of-life, major disparities exist among the countries of the world (Figure 3).

**Figure 3: Worldwide opioid consumption. The morphine equivalence metric is used to compare aggregate consumption of multiple opioids used to treat moderate to severe pain.**



## **MAKE ESSENTIAL MEDICINES AVAILABLE TO PATIENTS IN PAIN**

The importance of opioids in healthcare is reflected in the inclusion of morphine in the first WHO Model List of Essential Medicines in 1977. This list has been revised and republished every two years since then, with a separate List for Children published for the first time in 2007. Essential medicines are defined as those that “satisfy the healthcare needs of the majority of the population; they should therefore be available at all times in adequate amounts and in the appropriate dosage forms, at a price the community can afford.” However, medical needs for opioids were not being fully met at the time the first list was compiled – evidence of the low priority accorded to pain relief in even most high-income countries.

Many surveys since 1986 have identified multiple causes for this failure to increase supply to meet demand, including fear of addiction, poor estimates, lack of resources, poor professional education, multiple excessively restrictive laws and regulations and fear of legal consequences.<sup>35</sup> As a result, the availability of analgesics (including non-opioids) is inadequate within pharmacies, as essential medicines are often out-of-stock.<sup>36,37</sup>

The 18th general list and 4th list for children were published in April 2013, and included for the first time sections specific to pain and palliative care (Appendix 3). This change may be enough to influence the national drugs policies of many LMICs that currently place heavy restrictions on morphine and other opioids necessary for end-of-life care. However, policy-makers must first recognize the need for these medicines, and then enact policies to make them available to those who require them. Some countries, including Ukraine (Table 7) and Nigeria (Table 8), have already recognized the need to relax restrictions on morphine and other opioids that are essential for high-quality end-of-life care.

The HIV/AIDS epidemic that has affected much of the developing world has led to the development of drug supply chains and distribution centers for essential medicines. As a result, medicines such as anti-retroviral therapy drugs now reach millions of people every year. Similarly, there has been considerable success in initiatives to vaccinate millions of children worldwide against polio and other diseases. Systems are therefore in place, or at least feasible, for distributing essential medicines in LMICs, and these systems could prove invaluable in the distribution of opioids and other essential medicines for pain relief. While opioid distribution may have its own unique challenges – notably, the need for greater security – it is spared some of the challenges faced by HIV/AIDS and vaccine supply chains, such as requirements for cold storage.

### **RECOMMENDATIONS FOR POLICY-MAKERS:**

- Adopt the WHO Model List of Essential Medicines and eliminate overly restrictive regulations banning the use of opioids for palliative and end-of-life care.
- Ensure Essential Medicines are nationally available in central medical stores, licensed appropriately, and distributed effectively through existing health services where possible.

**Table 7: Improving morphine availability**

### **CASE STUDY: UKRAINE**

Promising recent developments could lead to dramatic improvement in the quality and availability of end-of-life care in Ukraine, a country with a population of around 46 million people. Approximately 500,000 people may need palliative care in any year, and of these almost 80,000 develop moderate to severe pain. Yet in 2011, Ukraine had only nine hospices with a total of 650 beds; the use and production of oral morphine was banned; and the country retained some of the most restrictive regulations in the world against the use and distribution of opioid medicines for pain relief.<sup>38</sup>

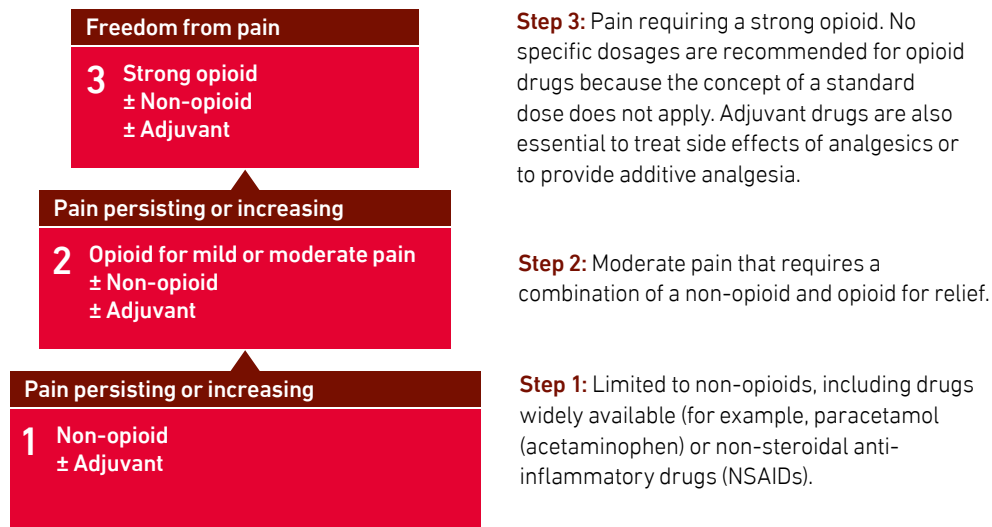
In February 2013, the Ukrainian government allowed a pharmaceutical company to begin production of 5 mg and 10 mg morphine tablets. In May 2013, the government relaxed its restrictions on prescribing and dispensing medical opioids. Prior to these changes, prescriptions for strong medicines required the signatures of four doctors, and injectable morphine legally be administered only by a nurse, and then often in doses too small to be effective for patients with severe pain. Since May 2013, patients have been allowed to keep a 15-day supply of strong pain medication at home.

The Ukrainian government has done well to recognize the need to improve opioid availability and should now reinforce and extend these reforms by ensuring that oral morphine tablets are widely available and that the new regulations are fully recognized and effective. Then it should continue its efforts to improve end-of-life care by ensuring that doctors have the proper training to prescribe oral morphine, and that public clinics have the necessary resources available to provide essential medicines to those in need.

### **USE ESSENTIAL MEDICINES APPROPRIATELY TO MANAGE PAIN AND REDUCE UNNECESSARY SUFFERING**

“The WHO three-step analgesic ladder” for cancer pain and its treatment was introduced in 1986 and included a strong opioid (morphine) (Figure 4). The steps in the ladder represent increasing pain severity and the drugs that should be used in each case.

**Figure 4: The WHO Three-Step Analgesic Ladder**

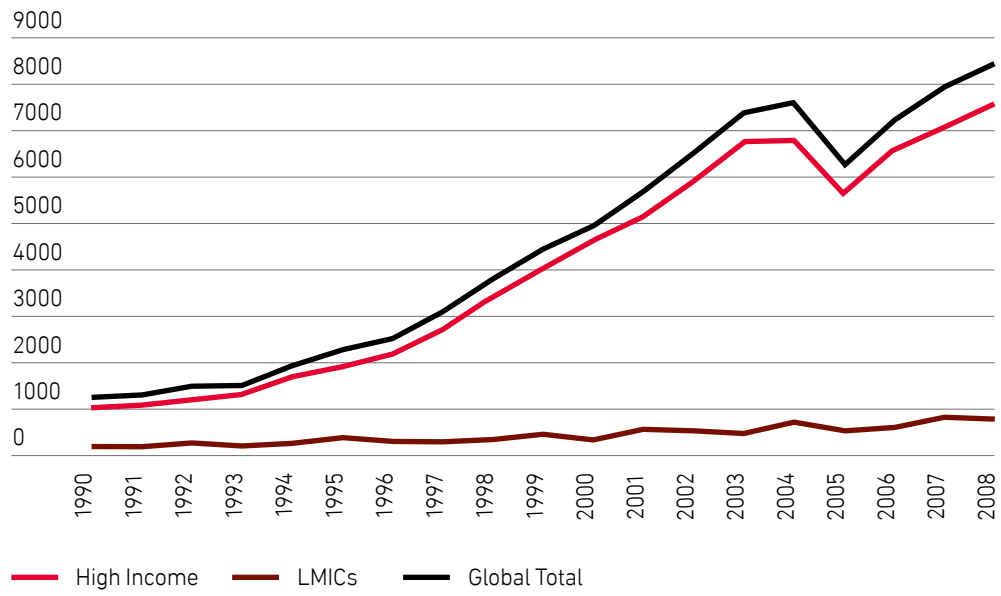


The original model of the WHO ladder suggested that clinicians start with step 1 and move up one rung at a time. A number of studies demonstrated that pain management administered according to the WHO guideline was 70-80 percent effective.<sup>39,40</sup> However, in many cases relief from pain was not immediate, and step 1 and 2 drugs were not effective; as a result, a significant number of patients spent considerable time without adequate pain relief. A similar study was carried out in eight German pediatric cancer centers, which came to the conclusion that opioid therapy should be the treatment of choice for inpatient pediatric patients with cancer.<sup>41</sup>

The WHO ladder has evolved, with the particular recommendation from the US Agency for Health Care Policy and *Research Cancer Pain Guidelines* in 1994<sup>42</sup> that the choice of analgesic agent should be based on a patient's pain severity rating. The AHCPR guidelines specified that mild pain should be treated with paracetamol and NSAIDs, moderate pain with "weak" opioids, and severe pain with "strong" opioids. The Cancer Pain Guidelines by the American Pain Society in 2009 recommend that all patients with cancer pain should have access to opioids, and support an approach based on the mechanism of pain.<sup>43</sup> The availability of strong opioids is particularly important for patients with advanced-stage disease and severe pain. However, in many LMICs, such opioids are unlikely to be available, even with prescriptions from health professionals.

Following the WHO Ladder and other guidelines, there was an increase in opioid consumption – but mainly in high-income countries (Figure 5). Currently, 15 percent of the world's population consumes 94 percent of the world's opioids.<sup>44</sup> As countries increase production and distribution of opioids, it is vital they also ensure these drugs are used appropriately to avoid addiction and illicit use.

**Figure 5: Total opioid consumption (morphine equivalence, kg) in high-income vs LMICs**



**RECOMMENDATION FOR POLICY-MAKERS:**

- Ensure the appropriate use of opioids and other essential medicines.



**Table 8: Improving opioid availability**

## **CASE STUDY: NIGERIA**

Nigeria is the most populous country in Africa with nearly 170 million people. Of the approximately 182,000 people who die in pain each year, it is estimated that more than 99 percent have no access to pain relief, as oral morphine had not been available since May 2010.<sup>45</sup> In February 2012, Treat the Pain, an international program within the American Cancer Society, partnered with the Federal Ministry of Health (FMOH) to improve access to oral morphine for the treatment of moderate to severe pain using a multistep strategy. Treat the Pain assisted the FMOH in the following ways:

1. Development of a strategic plan for improving access to pain relief.
2. Drug forecasting: developing a methodology and tools to do regular drug forecasts.
3. Stock monitoring: designing a system for monitoring stock in key facilities to ensure stock levels are maintained and central stocks are replenished before they are exhausted.
4. Supplier identification and negotiation.
5. Procurement of opioid analgesics.
6. Communication of availability of opioids.
7. Facilitation of approvals: streamlining the internal approvals required for a facility to procure opioids.
8. Stock tracking: creating a simple and inexpensive system to track stock levels of opioid analgesics.
9. HIV/Cancer guidelines: integrating effective pain control into national cancer and HIV clinical guidelines.
10. Medical training: integrating state-of-the-art training on pain relief into medical training programs.
11. Coordination with NGOs: providing clinical services to increase and improve access to pain relief.
12. Coordination with President's Emergency Plan for AIDS Relief (PEPVAR) and the Nigeria Agency for the Control of AIDS (NACA): ensuring that pain relief is integrated into all aspects of HIV service delivery.
13. Supporting infrastructure upgrades.

In December 2012, the FMOH procured nineteen kilograms of morphine sulphate powder, and Treat the Pain donated five kilograms of a preservative that increases the shelf life of the morphine powder from four weeks to six months. An SMS batch notification system was established that includes the phone numbers of healthcare providers who have been trained or are interested in pain treatment. By the end of 2013, the partnership is expected to:

- Complete renovation of a manufacturing lab and begin reconstituting morphine powder into oral morphine solution.
- Establish a second distribution point at the Federal Capital Territory Medical Stores in Abuja.
- Update the curricula in medical and nursing schools to include state-of-the-art pain treatment.
- Expand clinical training on pain treatment for physicians and nurses already in practice.

## STEP 3: IMPROVE KNOWLEDGE AND USE DATA TO DRIVE INNOVATION

“In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die.”

Professor Atul Gawande, Harvard University, USA

### **INVEST IN PALLIATIVE AND END-OF-LIFE CARE DEVELOPMENT AND RESEARCH ADVOCACY**

Palliative and end-of-life care research is under-resourced and under-developed across the world. As a result, there is a lack of reliable knowledge and data about how people die. In many countries, less than 0.5 percent of cancer research spending is devoted to palliative and end-of-life care.<sup>6</sup> To improve access to and quality of palliative and end-of-life care, research must be made a priority. Collaboration between palliative care researchers is key to high-quality outcomes, and research strategies must be adopted that identify and promote best practice.

Despite limited funding, palliative care has been the subject of important innovative reports and research by a number of international organizations, notably the aforementioned EAPC (Table 9).

**Table 9: The European Association for Palliative Care**

## EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

www.eapcnet.eu



**Mission:** "To bring together many voices to forge a vision of excellence in palliative care that meets the needs of patients and their families. It strives to develop and promote palliative care in Europe through information, education and research using multi-professional collaboration, while engaging with stakeholders at all levels."

### **Innovations:**

1. The Declaration of Venice (Appendix 2), published in 2006 in partnership with the International Association for Hospice & Palliative Care (IAHPC), proposes the development of a global palliative care research initiative.
2. The EAPC Atlas of Palliative Care in Europe was published during the Congress of Palliative Care in 2013. It is a detailed review and analysis of palliative care development in all 53 countries that make up the European Region of the WHO. It noted that the availability of palliative care was improving in Eastern Europe, particularly in Moldova, Romania, and Poland. In addition, palliative medicine is now a specialty or sub-specialty in 14 countries in Europe. From these results, it seems clear that palliative care advocacy is effecting positive changes in the quality of and access to palliative and end-of-life care in Europe, though there is still much room for improvement.
3. A Toolkit for the Development of Palliative Care in the Community, issued in 2013, lists five steps that can be taken to develop palliative care in your community. They are:
  - Step 1 Identify key individuals or organizations in your country interested in the development of palliative care in the community (eg GP organizations, palliative care specialists).
  - Step 2 Convene a meeting or working group to discuss locality specific challenges and solutions.
  - Step 3 Use the EAPC taskforce in Palliative Care in the Community database to contact experts who may be able to provide some specific guidance on relevant issues.
  - Step 4 Seek to establish improvements in each of the four domains of the public health model simultaneously in order to create a balanced system of provision. Review the resources and documents linked within this toolkit to scope potential approaches, which may be of benefit.
  - Step 5 Collate data supporting the need for and potential outcomes of palliative care in the community.

Research and analysis covering other parts of the world have been published by other international palliative care organizations. The Asociación Latinoamericana de Cuidados Paliativos (ALCP) promotes the development of palliative care in Latin America and the Caribbean (Table 10).

**Table 10: Asociación Latinoamericana de Cuidados Paliativos**

**ASOCIACIÓN LATINOAMERICANA DE CUIDADOS PALIATIVOS (ALCP)**  
www.cuidadospaliativos.org



**Mission:** "To promote the development of Palliative Care in Latin America and the Caribbean, through communication and integration of all those interested in improving the quality of life of patients with advanced life-threatening diseases, and their families."

**Innovations:**

1. The ALCP Atlas of Palliative Care in Latin America, published in 2012, provided an analysis of 19 countries within the region.
2. Palliative Care Indicators for Latin America, produced in collaboration with the IAHPHC, is a list of ten indicators that can be used for monitoring and evaluating palliative care across the region. The indicators cover health policy, education, infrastructure, and medication. Although the checklist was developed with special reference to Latin America, the ALCP encourages other countries and regions to make use of it to monitor palliative care development in their own areas.

These two regional palliative care associations have led the way in advocating improvements in palliative and end-of-life care, and in encouraging governments to formulate policies that will serve this end. Similar regional palliative care associations operate in Africa (the African Palliative Care Association – APCA), and Asia (the Asia Pacific Hospice Palliative Care Network – APHN) and act as advocates within their respective regions (Table 11).

**Table 11: Regional Palliative Care Organizations**

	<p><b>African Palliative Care Association (APCA)</b> <a href="http://www.africanpalliativecare.org">www.africanpalliativecare.org</a> <b>Mission:</b> To ensure 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.</p>
	<p><b>Asia Pacific Hospice Palliative Care Network (APHN)</b> <a href="http://www.aphn.org">www.aphn.org</a> <b>Mission:</b> To promote access to quality hospice and palliative care for all in the Asia Pacific region.</p>

### **RECOMMENDATIONS FOR POLICY-MAKERS:**

- Invest in research and development in palliative and end-of-life care.
- Form partnerships between national, regional, and international palliative care organizations to carry out research and publish high-quality reports.

### **QUANTIFY THE COST OF DYING AND DETERMINE WAYS TO LOWER COSTS WHILE IMPROVING CARE**

**“Our medical system is excellent at trying to stave off death with eight-thousand-dollar-a-month chemotherapy, three-thousand-dollar-a-day intensive care, five-thousand-dollar-an-hour surgery. But, ultimately, death comes, and no one is good at knowing when to stop.”**

Professor Atul Gawande, Harvard University, USA

Dying is expensive, but high costs do not necessarily produce a good death. The greatest burden of cost in providing end-of-life care in high-income countries is incurred in the last months of life as doctors, patients, and families use exhaustive measures to extend life by a few days.<sup>46,47</sup> In low-income countries, cost is also exceptionally and surprisingly high, often for similar reasons but with different results. There is a tendency for patients with terminal illnesses and their families to continue to search for cures, often because they are unaware of their diagnosis and prognosis; this ignorance can arise from a number of factors – an over-stretched workforce, for example, or the discomfort felt by health professionals in talking about death. The costs involved can have serious repercussions for the family as a whole; for instance, children might be taken out of school as their school fees are diverted to pay for futile medical treatments.<sup>48</sup>

One particular challenge is to obtain reliable figures for end-of-life costs (Table 12). Apart from medical costs, there are the costs met by the voluntary sector, patients and families, and data on these are lacking. Even in developed countries with detailed healthcare accounts, it is nearly impossible to extract such data from existing sources: end-of-life care is so complex, it is unclear at which point such care begins, and the care is delivered by both generalist and specialist staff. In the absence of definitive information, it is difficult to make a coherent argument to governments to set a higher priority on provision for end-of-life care.

**Table 12: The Cost of End-of-Life Care**

### **CASE STUDY: THE UNITED KINGDOM**

A report by the UK Government Auditor in 2008 highlighted the high cost of caring for people at the end of their lives. The total spend on cancer services alone was estimated at £1.8 billion, or around £14,000 per patient. However, the report also identified major differences between the costs involved with cancer patients and those with other life-limiting diseases: the cost of providing care in the last year of life to those with organ failure was found to be £19,000, owing to the generally longer non-curative treatment phase. Overall, the study concluded that there was real potential for palliative care services to reduce costs associated with hospitalization, as well as enabling patients to die at home or in a hospice if that was their wish.<sup>49</sup>

The Department of Health estimates that the cost of a hospital admission that ends in a palliative death is around £3,000 (based on a typical stay of 3 days). In 2010, an independent study modeled the costs of community staff care for patients in the last few days of life (typically 3-4 days): these costs were £1,200 for cancer, £1,400 for frailty and £1,800 for organ failure and other terminal conditions.

In 2011, an independent commission reviewed the whole issue of palliative care funding, with the aim of developing, for the first time, a per-patient funding mechanism for palliative care for adults and for children.<sup>22</sup> The commission recommended a funding system that appears cost neutral to the state; this system could, by 2021, potentially reduce deaths in hospital by up to 60,000 a year by optimizing palliative care services outside hospitals. Given the government estimate of £3,000 per hospital death, the new system would potentially reduce costs by £180m per year – a substantial proportion of the current £1.3 billion for adults and £18.2 million for children spent by the NHS on palliative care in hospitals.

The prevailing view is that the costs of end-of-life care would be much reduced if a greater proportion of care could be delivered in people's own homes, including care homes. The claim is that death in hospital – the default position in many countries – involves very high costs, owing to the length of stay and the expense of repeated medical intervention. The economics, however, are in fact much more complex. For example, some people at the end-of-life require round-the-clock care that may actually be cheaper in hospital than if provided one-to-one in the community. Also, the costs associated with non-cancer palliative care, particularly advanced dementia, are less predictable and can often be prolonged and exceed cancer-related care.

Economic research suggests that palliative and end-of-life care can be cheaper than traditional medical treatment for patients at the end of their lives.<sup>50</sup> Certainly, increasing the proportion of community and home care can reduce the costs associated with hospital stays and emergency admissions. In the US in particular, provision for death has become a major topic of debate, following the recent healthcare reforms and the attendant focus on ways of cutting healthcare costs.

A number of external factors influence the place and consequently the cost of death. These include: deprivation levels, population density, the age profile of the population, the proportion of deaths due to cancer, the proportion of people who are single and living alone with no family support,<sup>51</sup> and even ethnicity.<sup>52</sup> As people live longer and are more likely to spend several years with the conditions that will eventually kill them, the cost of end-of-life care as a percentage of overall healthcare spending is likely to rise sharply.

When it comes to financing end-of-life care, governments are rarely the main sources of funding. A range of funding models exists – church support, charitable and philanthropic funding (Table 13), international aid, patients' self-funding, and so on. In some cases, hybrid models exist, based on a variety of funding sources. Whatever the case now, the overall need for end-of-life care is certain to grow as the population ages, and that will necessitate more imaginative and innovative approaches to providing and financing the care.

#### **RECOMMENDATION FOR POLICY-MAKERS:**

- Capitalize on knowledge gained from research outcomes to lower costs and improve care.

**Table 13: Marie Curie Cancer Care**



Marie Curie Cancer Care supports patients, as well as their carers and families, delivering care to people in their own homes through its nursing service and in nine hospices across

the UK. It funds one of the largest palliative care research programs in the UK and campaigns to make practical improvements to the quality of life and care that terminally ill people and their loved ones and carers experience.

One such program is the Somerset Delivering Choice Project, which launched in 2008 and covered Somerset and North Somerset's population of 700,000 people. This project introduced new initiatives, such as coordination teams, an out-of-hours advice and response line, discharge nurses, support workers providing health, social and personal care, and an information website.

The University of Bristol published an independent evaluation of the Somerset Delivering Choice Project in October 2012. It found:

- In North Somerset, those receiving a Delivering Choice intervention were 67 percent less likely to die in hospital compared to those who did not receive care from Delivering Choice.
- Emergency admissions to hospital in the last month of life were 51 percent lower and A&E attendances 59 percent lower for Delivering Choice service users in North Somerset compared to people not in contact with the services.
- In Somerset, those receiving a Delivering Choice intervention were 80 percent less likely to die in hospital compared to those who did not receive care from Delivering Choice.
- Emergency admissions to hospital in the last month of life were 39 percent lower and A&E attendances were 34 percent lower for Delivering Choice service users in Somerset compared to people not in contact with the services.

## **IN PLACES WHERE ACCESS TO WESTERN MEDICINE IS LIMITED, ENGAGE WITH TRADITIONAL HEALERS TO IMPROVE END-OF-LIFE CARE**

The use of traditional healers, herbalists, shamans, or practitioners of alternative therapies is widespread in many non-Western communities, not least because of their accessibility and local availability. Such non-Western health interventions can have therapeutic value, but – as research is increasingly indicating – alternative care of this kind can still involve high monetary costs. Among these are: the ever-mounting charges made to people desperate to obtain cures, and the tendency of patients to delay seeking medical treatment while fulfilling rituals and rites prescribed by traditional therapists.<sup>53</sup> Since traditional communities are certain to continue their commitment to alternative healthcare, however, the best policy would seem to engage its practitioners cooperatively – whether in training, service development, or shared referrals – particularly in dealing with the final stages of end-of-life care.

### **RECOMMENDATION FOR POLICY-MAKERS:**

- In places where Western medicine has not been fully adopted, engage with traditional healers to improve end-of-life care.



## STEP 4: MAXIMIZE RESOURCES

“How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole, and it is a litmus test for health and social care services.”

End of Life Care Strategy, United Kingdom

### ENGAGE THE LOCAL COMMUNITY IN END-OF-LIFE CARE

In areas where palliative and end-of-life care is insufficient, the local community can fill in gaps in care and provide support to professional caregivers and families. Engaging this sector of the healthcare workforce requires a commitment by the local community to train volunteers to help with all aspects of care that do not require specialist training. An excellent example of where this has worked previously is the Community Model used in Kerala, India (Table 14).

### RECOMMENDATION FOR POLICY-MAKERS:

- Engage the local community in end-of-life care.

**Table 14: The Community Model**

#### CASE STUDY: KERALA, INDIA

Throughout most of India, a country of over a billion people, access to palliative and end-of-life care is poor. However, in the small southern state of Kerala a community model has emerged that has been described as a “beacon of hope.”<sup>54</sup> In 2005, Kerala provided two-thirds of the palliative care services in the whole of India, despite only having 3 percent of the total population.<sup>55</sup> In April 2008, Kerala was the first Indian state to develop a state health policy that includes palliative care as a major emphasis.

In 1985, the Narcotic Drugs and Psychotropic Substances Act made all opioids illegal in India. Yet, morphine is available for use by palliative care providers in Kerala, as Kerala is one of only a few Indian states that relaxed narcotics regulations specifically for this purpose.<sup>56</sup>

What makes Kerala unique is the community model used to provide care. In 2001, the Neighbourhood Network in Palliative Care (NNPC) was set up. It has grown into a large network, mostly of volunteers; they deliver services to patients who, for the most part, remain in their own homes. This type of community involvement focuses mostly on social, spiritual, and financial issues; the volunteers do not provide medical services, but they have proved highly efficient at identifying members of the community that are in need, and at providing essential services at low overall cost and with limited training.

Other communities, in India and across the world, can learn from this model. The Kerala Community Model appears to deal successfully with many of the issues relating to the lack of trained professionals, and so allows the few medically trained palliative care specialists to concentrate on areas where they can make the greatest impact.

## **HARNESS TELEMEDICINE AND TECHNOLOGY-BASED INNOVATIONS TO BRING END-OF-LIFE CARE TO RURAL COMMUNITIES**

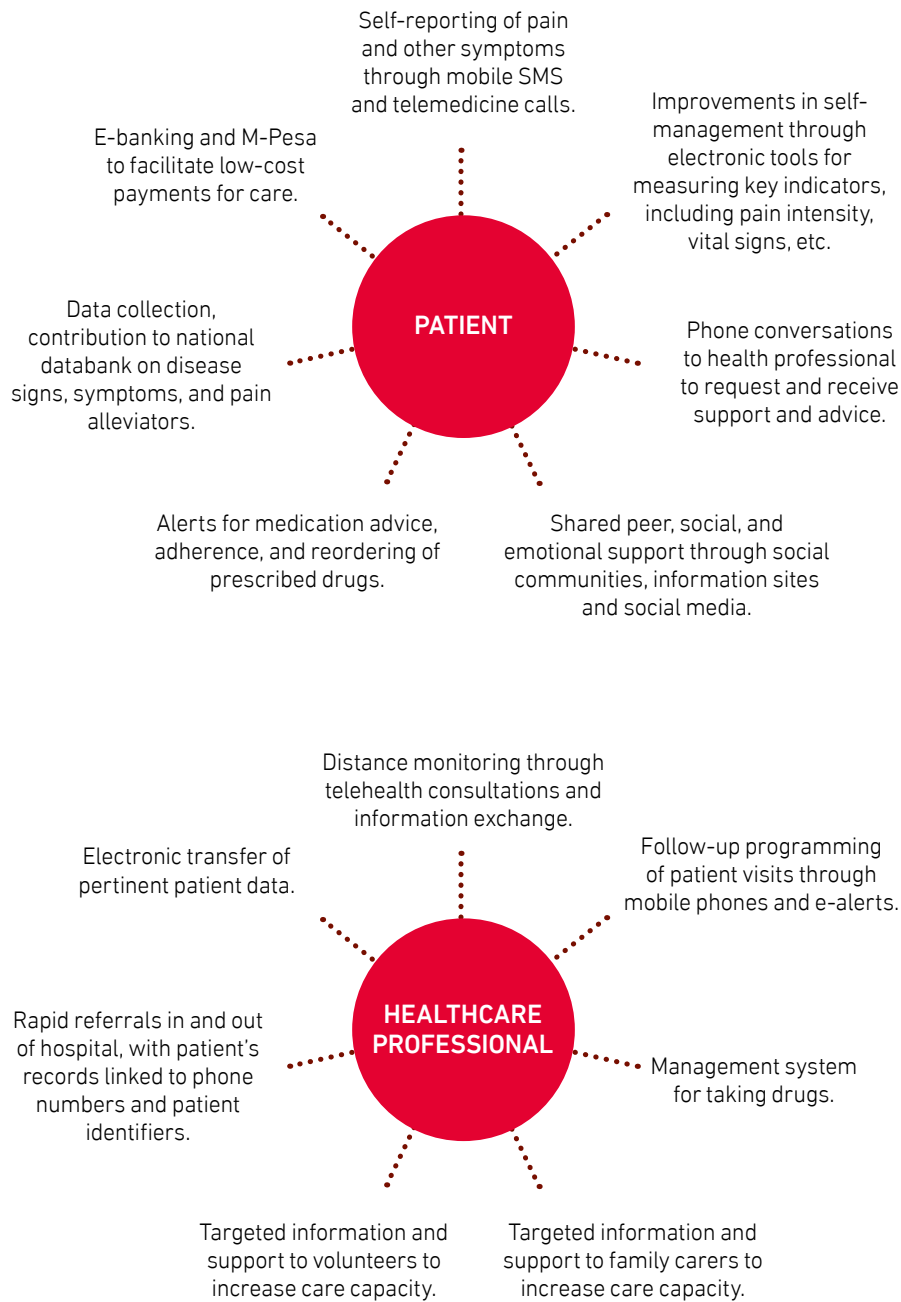
The greatest needs for those who are living with life-limiting illnesses, particularly as they approach death, are for sustained continuity of care, consistent and timely care planning, and coordination of care. Dealing with these challenges is especially difficult in rural or remote areas, and the provision of end-of-life care in these areas therefore presents particular problems.

For example, patients are forced to travel great distances to attend appointments and frequently receive poor quality of care and rarely any follow-up care, particularly in LMICs. The world rural population is expected to decline from 3.4 billion in 2010 to 2.9 billion in 2050, but the rural population of Africa is expected to increase over this period to nearly one billion.<sup>57</sup> Harnessing technological innovations using tools like telemedicine, e-health, m-health, social media and the internet could radically change global palliative and end-of-life care by enabling first responders and local volunteers to care for those in rural or remote areas who would otherwise have no access to care.

Telemedicine is defined as “the delivery of health care services, where distance is a critical factor, by all healthcare professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of diseases and injuries, research and evaluation, and for the continuing education of healthcare providers, all in the interests of advancing the health of individuals and their communities.”<sup>58</sup>

It includes a growing variety of applications and services using two-way video, email, mobile SMS and phones, tablets and smart phones, wireless tools and other forms of electronic and telecommunications technology that can benefit both patients and healthcare professionals (Figure 6).

**Figure 6: Telemedicine Tools Can Provide a Range of Applications of Benefit to End-of-Life Patients and Healthcare Professionals**



Technological innovations enable patients to seek treatment earlier and their families to receive advice on care. They also permit healthcare professionals to offer backup and reassurance to carers, and facilitate better adherence to prescribed treatments.

Thanks to cell phone networks, which now cover almost all parts of the world, health information can be delivered rapidly to patients and their families to improve end-of-life care. Large numbers of volunteers from community-based palliative care programs now use SMS to contact health professionals for advice when seeing patients; patients are alerted to follow-up management plans and can contact professionals to report changes in symptoms and needs for pain relief. GPS tracking can facilitate rapid home-based care – for example, among nomadic people.

Electronic pharmacy systems linked to electronic health records can be used to establish morphine management and governance systems. GPS can be used to track morphine movement and patient usage in combination with personalized reports from patients on current pain levels.

### **RECOMMENDATION FOR POLICY-MAKERS:**

- Utilize telemedicine and technology-based innovations to improve access to end-of-life care in rural areas.

**Table 15: Social Media Innovations for End-of-Life Care**

<p><b>TYZE, CANADA</b> <a href="http://www.tyze.com">www.tyze.com</a></p> <p>Tyze is a private social network that helps connect people around someone receiving palliative care. Tyze allows patients, families and carers to:</p> <ul style="list-style-type: none"><li>• Privately communicate with family, friends, and helpers about you or the person you care about.</li><li>• Schedule appointments and events on a shared calendar.</li><li>• Share files, photos, updates and more anywhere, anytime.</li></ul> <p>Mobile and tablet apps provide access to the network while on the go.</p>	
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## EMPOWER PATIENTS BY PROVIDING ACCESS TO CARE INFORMATION

A number of hospices, care programs, palliative agencies, and institutions have recently developed cell phone apps for use by end-of-life care patients. There are dedicated apps to teach patients more about their conditions, inform them about new developments in treatment and care, link them with their care providers, and enable them to access their medical records, report and manage their symptoms, and identify risk changes. US hospices – such as Hospice of Michigan, the Hospice by the Bay, and Hospice and Palliative CareCenter in North Carolina – have also introduced mobile apps to facilitate information transfer and publicize events they are organizing. The social media network Tyze connects people around someone receiving care (Table 15). The palliative care website ehospice provides end-of-life care news and views from around the world, as well as comments on international trends; it has had a mobile app since 2012 (Table 16).

**Table 16: ehospice**

**EHOSPICE**  
www.ehospice.com



ehospice is an international news and information resource committed to distributing news, commentary and analysis of relevance to hospice, palliative and end-of-life care. Aimed at anyone with a professional or personal interest in palliative care, ehospice offers a single point of access to information and good practice from around the world, with the aim of contributing to improvements in patient care internationally. It brings together the expertise and experience of the global hospice and palliative care community through multiple editions delivered by national and regional palliative care organizations.

### RECOMMENDATION FOR POLICY-MAKERS:

- Empower patients through better access to knowledge on end-of-life care choices and availability.

# STEP 5: IMPROVE SKILLS

“I hope we can... find ways of enabling those in the developing world to adopt the principles (of palliative care) and model services that meet their needs and cultures.”

Dr Derek Doyle, former medical director, St Columba's Hospice, Edinburgh, UK

## **PROVIDE HEALTHCARE PROFESSIONALS WITH PALLIATIVE CARE TRAINING, PARTICULARLY IN LOW AND MIDDLE-INCOME COUNTRIES WHERE CARE IS UNAVAILABLE**

All health professionals should be able to provide care for patients with palliative care needs as a part of their routine patient care. Yet in situations where a patient's recovery is unlikely, the task of minimizing suffering may fall to the local physician or nurse or, more often than not, the informal caregiver.

A key global challenge is to roll out education and support for generalists to learn palliative approaches. Just as important, countries must train an adequate number of palliative care specialists to support generalists and deal with more complex patients.<sup>59</sup>

For many professional healthcare pre-registration and in-service training programs, palliative care is still not a compulsory component. The WHO suggests that specialists should spend up to 50 percent of their time training and supporting generalists; if that were to happen, competence in palliative care would have far greater reach. But that 50 percent remains elusive. Many countries therefore fail to capitalize on the potential that general health workers, local communities, and volunteers have for supporting patients and families facing the end-of-life.

In palliative care training, healthcare workers should learn that it is not just the patient that is suffering. Families are often forgotten during the dying process. Improving palliative and end-of-life care also must also include an element of bereavement support.

To combat the shortage of specially trained professionals, a number of innovative leadership-training programs have recently been established. A good example is the International Palliative Care Leadership Development Initiative (LDI), run through The Institute for Palliative Medicine; it provides training for palliative care physicians throughout the world (Table 17).

**Table 17: International Palliative Care Leadership Development Initiative**



Currently, 22 physicians have participated in the LDI, representing regions of the world including Africa, Central Asia, Eastern Europe, Latin American, the Middle East, and Southeast Asia. The program aims to produce global leaders in the development of palliative care and uses regional mentors to guide these efforts. Participants also identified local mentors who could help them build skills and achieve their goals.

Another leadership-training program, the Lien Collaborative for Palliative Care, has recently been established and has started programs in Bangladesh and Myanmar (Table 18). Hospice Africa Uganda has taken a different but very innovative approach, which has trained “community vigilantes” to identify and refer potential patients to the hospice who would otherwise have no access to any form of palliative or end-of-life care (Table 19).

**Table 18: The Lien Collaborative for Palliative Care**



This program, funded by a Singapore-based family foundation, aims to build palliative care capacity in the mainstream health system through collaborations involving philanthropy, palliative care services and volunteer faculty from the Asia Pacific region, together with government health institutions and community organizations within the target countries. It works in resource-poor Asian countries with little or no palliative care services, with projects currently ongoing in Myanmar and Bangladesh.

The 3 main components of the program for each country include:

- 1) A Training of Trainers element where interdisciplinary teams of volunteer expert faculty from regional palliative care units spend one week twice a year for three years with the same group of trainees, with the aim of building up nationally based clinical training in the country. The parent institutions of the faculty participate in this collaboration by granting the faculty leave. Teaching content includes pain and symptom management; communication with patient, family and other parties; ways of setting up services, standards and audit.
- 2) Selected candidates who are regarded as having leadership potential are invited to spend three months at established palliative care units in the region for further training.
- 3) The program also conducts an opioid availability advocacy initiative.

Key to success is finding the right in-country partners to host the teaching and to help select the right candidates – those with the potential to become effective trainers and advocates for palliative care in their own countries. In identifying suitable candidates, the leadership teams consult leading government healthcare institutions, usually national referral centers and teaching hospitals, and solicit the support of the national Ministry of Health. The goal is to enable the trained participants to establish palliative care services in key institutions in their own countries, which can then act as training units in turn.



The drive to cure patients until they die is often a barrier to starting quality palliative care. The desire to cure at all costs and the inability of healthcare professionals to admit that the best course of action may be to stop trying to cure and focus on palliative efforts often leads to overmedicalization.<sup>60</sup> Accept that, in certain circumstances, “death can be our friend,” and you can sometimes reduce unnecessary suffering. By embracing the inevitable and making the best use of the time left, the patient often sees an improvement in quality of life.<sup>61</sup> Guidelines for creating national training programs in palliative are available from the EAPC, and some countries such as Scotland, Italy and Serbia have produced national guidelines, including learning objectives and resources to enable palliative care to be embedded in undergraduate and postgraduate training.

### **RECOMMENDATIONS FOR POLICY-MAKERS:**

- Include palliative and end-of-life care in all professional healthcare undergraduate and postgraduate programs.
- Include bereavement support in palliative and end-of-life care training programs.
- Share global learning to enable all countries to build palliative and end-of-life care services.

**Table 19: Palliative and End-of-Life Care in Uganda**

### **CASE STUDY: INNOVATION IN UGANDA**

Palliative care was established in Uganda 20 years ago with the opening of Hospice Africa Uganda (HAU). From its original premises in a two-bedroom house in Kampala, HAU has expanded and now operates from three sites – a head office in Kampala and local offices in the Mbarara and Hoima Districts. HAU receives most of its referrals from the National Referral Hospital in Kampala and from local hospitals in Mbarara and Hoima, but it also trains and utilizes a group of “community vigilantes” who identify and refer patients who would otherwise have no access to healthcare.

With assistance from HAU, Makerere University established a distance-learning Diploma in 2002 to train specialists in palliative care. In 2008, a Department of Palliative Medicine was established at Makerere University, and in 2010 the diploma was upgraded to a three-year Bachelor’s degree.

Currently, palliative care is available in 69 of Uganda’s 112 districts, and oral morphine is available on the national health system free of charge to all patients, thanks to a public-private partnership between the Ministry of Health’s National Medical Stores, HAU and the Joint Medical Stores. The use of oral morphine – in the hospice and for the purposes of palliative care – has increased, following changes in the law that now allow specially trained nurses and clinical officers, as well as registered doctors, to prescribe the medication. In a country with a serious shortage of doctors, and particularly doctors trained in palliative medicine, this upgrading of nurses and clinical officers is a bold and significant decision, which could have far-reaching consequences for palliative and end-of-life care.

While Uganda has successfully implemented several innovations to improve palliative and end-of-life care, the need for such care still vastly exceeds the supply. The next step must be a large-scale expansion of training in and access to end-of-life care. Distribution channels need to be improved in step, particularly in rural areas.

### **UTILIZE E-LEARNING STRATEGIES AND PROGRAMS TO TRAIN PALLIATIVE CARE PROFESSIONALS**

Useful specialist training can be conducted through e-learning programs. In the UK, the Department of Health and the National Health Service have developed a program called End of Life Care for All (e-ELCA) to train NHS workers: the intended outcome is an increase in well-informed and high-quality care, delivered by confident and competent staff and volunteers (Table 20).

**Table 20: End of Life Care for All**

**END OF LIFE CARE FOR ALL,  
UNITED KINGDOM**

[www.e-lfh.org.uk/projects/end-of-life-care](http://www.e-lfh.org.uk/projects/end-of-life-care)



End of Life Care for All (e-ELCA) is part of e-Learning for Healthcare (e-LfH), which provides free online training for the UK workforce. e-ELCA is delivered in partnership with the Association for Palliative Medicine of Great Britain and Ireland, and is designed to support the implementation of the national End of Life Care Strategy.

**RECOMMENDATION FOR POLICY-MAKERS:**

- Where possible, access or develop e-learning training modules for staff and volunteers.

# IMMEDIATE NEXT STEPS

## STEP 1: MAKE CARE OF THE DYING A PRIORITY FOR ALL

- Produce a national strategy for end-of-life care.
- Include palliative and end-of-life care as part of healthcare for all diseases.
- Monitor the scale and need for end-of-life care locally.
- Sign the Prague Charter and recognize that access to palliative and end-of-life care is a human right.
- Set up a national initiative using online tools and innovative campaigns to encourage people to learn and communicate more about death and dying.
- Encourage the use of advance care directives, so that patients can make their own end-of-life wishes and expectations known beforehand, rather than under pressure at a time of crisis.

## STEP 2: REDUCE UNNECESSARY SUFFERING

- Adopt the WHO Model List of Essential Medicines and eliminate overly-restrictive regulations banning the use of opioids for palliative and end-of-life care.
- Ensure essential medicines are nationally available in central medical stores, licensed appropriately, and distributed effectively through existing distribution channels where possible.
- Ensure the appropriate use of opioids and other essential medicines.

## STEP 3: IMPROVE KNOWLEDGE AND USE DATA TO DRIVE INNOVATION

- Invest in research and development in palliative and end-of-life care.
- Form partnerships between national, regional, and international palliative care organizations to carry out research and publish high-quality reports.
- Capitalize on knowledge gained from research outcomes to lower costs and improve care.
- In places where Western medicine has not been fully adopted, engage with traditional healers to improve end-of-life care.

## STEP 4: MAXIMIZE RESOURCES

- Engage the local community in end-of-life care.
- Utilize telemedicine and technology-based innovations to improve access to end-of-life services, especially in rural and remote areas.
- Empower patients through better access to knowledge about end-of-life care choices and availability.

## STEP 5: IMPROVE SKILLS

- Include palliative and end-of-life care training in all professional healthcare undergraduate and postgraduate programs.
- Include bereavement support in palliative and end-of-life care training programs.
- Share global learning to enable all countries to build palliative and end-of-life care services.
- Access or develop e-learning training modules for staff and volunteers.

**END-OF-LIFE CARE FOR ALL**

# APPENDIX

## APPENDIX 1: THE PRAGUE CHARTER

The Prague Charter was published in 2013 at the Congress of Palliative Care by the EAPC, in collaboration with the International Association for Hospice & Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA) and Human Rights Watch (HRW).

### **Palliative Care: a human right**

1. Governments should develop health policies that address the needs of patients with life-limiting or terminal illnesses.
  - Governments should develop comprehensive health care policies that provide for integrated palliative care, along with other forms of health services.
  - Governments should ensure that the laws include support to the relatives of patients during the time of care and after the time of death.
2. Governments should ensure access to essential medicines, including controlled medications, to all who need them.
  - Governments should identify and eliminate unduly restrictive barriers which impede access to controlled medications for legitimate medical use.
  - Governments should ensure that they develop an appropriate system for estimating their need for such medications so as to ensure that availability is guaranteed without interruption.
  - Governments should ensure that they establish safe and secure distribution and dispensation systems so that patients can access the opioid medications regardless of their prognosis, place of treatment or geographic location.
3. Governments should ensure that healthcare workers receive adequate training on palliative care and pain management at undergraduate and subsequent levels.
  - Governments should adopt the necessary changes in the training curricula for healthcare providers (medical, nursing, pharmacy, psychology, etc.) at undergraduate levels to ensure that all healthcare workers obtain basic knowledge about palliative care and are able to provide it to patients regardless of where in the healthcare system they work.
  - Governments should support the development and implementation of postgraduate and specialty palliative care programs so that patients with complex cases can receive appropriate care,
  - Governments should ensure that adequate continuing education courses in palliative care are available to current healthcare workers.
4. Governments should ensure the integration of palliative care into healthcare systems at all levels.
  - Governments should design and develop plans to create and implement palliative care units, groups and programs according to morbidity and mortality indicators, and population dispersion data.

## **APPENDIX 2: THE DECLARATION OF VENICE (2006)**

### **Work and collaborate together to:**

1. Identify, develop and implement effective strategies to improve palliative care research in developing countries.
2. Identify palliative care research priorities in developing countries according to the needs of specific patient populations, and take into consideration the regional, socio economic and cultural contexts.
3. Identify funders and help mobilize resources to support palliative care research in the developing world.

### **Recommendations:**

1. The development of palliative care services that include a focus on research and education.
2. A concentration on palliative care research that considers the needs and preferences of individual patients and their families, which takes into account physical, psychological, social, and spiritual dimensions of suffering and which makes use of multi-disciplinary approaches.
3. The production by each organization representing a country and/or region of a research agenda for palliative care that contributes to the development of a global research strategy. Those which have done so already should collaborate with regional, national or local groups to further promote such development.
4. A focus within national research agendas on the predominant problems and needs of patients and families and on those areas where sustainable palliative care effects are possible.
5. An acknowledgement within local research strategies of different priorities among the diseases requiring palliative care and an awareness of the differing implications for how palliative care should be developed.
6. The development within resource poor countries of cost effectiveness and economic evaluations to provide a basis for evidence based policy-making and clinical practice.
7. The inclusion within the global research agenda of specific technical and ethical problems relating to research methodology and promotion of the value and relevance of both qualitative and quantitative methods, used in combination where appropriate.
8. The generation within countries with limited resources of tools for the evaluation and implementation of evidence based research that will produce relevant and applicable information regarding the effectiveness of palliative care treatment interventions in these settings.
9. The adoption by governments, policy-makers and legislators in developing countries of measures needed to implement and support research in palliative care.

10. The commitment by individuals, institutions and organizations with a research mandate in developed countries to assist developing countries identify and establish adequate quality control and standards for research programs, protocols and initiatives.
11. A commitment by universities and academic hospitals that have traditionally trained and supported the vast majority of researchers in the world to establish the academic structures for hosting and promoting palliative care research.
12. A commitment by granting agencies to ensure that a fair proportion of funds given to palliative care services in developing countries is allocated to support research in the field and to ensure its long term sustainability.

### APPENDIX 3: WHO MODEL LIST OF ESSENTIAL MEDICINES FOR PAIN AND PALLIATIVE CARE

Category		
<b>1</b> Non-Opioids and Non-Steroidal Anti-Inflammatory Medicines (NSAIDs)	<b>2</b> Opioid Analgesics	<b>3</b> Medicines for other common symptoms of palliative care
Medicines		
acetylsalicylic acid, ibuprofen, paracetamol	codeine, morphine	amitriptyline, dexamethasone, diazepam, docusate sodium, fluoxetine, haloperidol, hyoscine butylbromide, hyoscine hydrobromide, lactulose, loperamide, metoclopramide, midazolam, ondansetron, senna

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# NOTES

# NOTES

# WISH ACADEMIC PARTNERS



