

FIND OUT WHAT LIFE ASKED DEATH IN THE FILM DEBUT ON WORLD HOSPICE & PALLIATIVE CARE DAY

Documentary reveals the challenges and triumphs of bringing palliative care¹ to parts of Asia & how pain relief eludes the dying

SINGAPORE, 8 OCT, 2016 – Today, 8 October 2016, is World Hospice and Palliative Care Day. The theme this year is **LIVING AND DYING IN PAIN: IT DOESN'T HAVE TO HAPPEN**.

This is the message of the 26-minute documentary "LIFE ASKED DEATH" which will premiere online and in Myanmar, Bangladesh and Sri Lanka today. For people living with a life-threatening illness, access to palliative care and essential pain medications will relieve much of this unnecessary suffering.

This film is timely as an estimated 40 million people globally require palliative care each year, of whom half will require care at the end of life. In Asia alone, annual estimates indicate that 24 million people need palliative care and nearly 11 million will die, many in pain and distress because they cannot access pain medicines.

The documentary is part of the **Lien Collaborative for Palliative Care**, which is a joint initiative of the **Lien Foundation**² and the **Asia Pacific Hospice Palliative Care Network**³ (APHN). The Collaborative's objective is to build capabilities in palliative care in parts of Asia where such services are sparse or unavailable.

Developing palliative care in Asia

Produced by **Moonshine Movies**, LIFE ASKED DEATH highlights the scale of pain and suffering that needs to be urgently addressed in Asia, and offers insights into the positive outcomes that can be

¹ Palliative Care is an approach, a way of delivering services, that cares for the patient as a whole person, addressing the physical, emotional and spiritual needs and practical concerns, of both the patient and the family. It aims to improve the quality of life of a patient facing a life-threatening illness and that of his family.

² The Lien Foundation is a philanthropic house in Singapore which works in the areas of water and sanitation, early childhood education as well as ageing and palliative care.

³ The APHN is a charitable non-governmental organisation registered in Singapore in 2001 which supports the development of palliative care in the Asia Pacific region. The charity's mission is to promote access to quality hospice palliative care for all in the Asia Pacific region. APHN members include some 230 organisations that support or provide palliative care and over 1,300 individuals working in the field in the Asia Pacific region.

achieved even in resource-limited countries. The documentary brings viewers to **Bangladesh**, **Myanmar and Sri Lanka** to witness how Lien Collaborative's specialist volunteers bring palliative care and training to these countries. When international experts and local stakeholders work together to develop palliative care capacity in the government-run health systems, the barriers to pain relief and humane care can be removed.

The short film reveals how palliative care helps to improve the quality of life of patients and uplift their families who are struggling to cope with the suffering and the practical and financial implications of a life-threatening illness. It also uncovers how essential pain medications such as oral morphine can bring relief to patients who are in agony, because of lack of access, awareness and availability of palliative care and pain relief medications. What is urgently needed are policy changes which will allow the integration of palliative care into health systems to provide patients with better care and greater access to pain relief medications.

Make palliative care an essential service

"Relief of suffering is an ethical imperative. We cannot walk away from suffering when we know we can do something about it," said Associate Professor Cynthia Goh, project leader of the Lien Collaborative and palliative care specialist from the National Cancer Centre Singapore. "For this to happen, there must be support, understanding and action all round, from policy makers, healthcare professionals, the local community and concerned global citizens. Palliative care needs to be an essential service that governments provide for all their citizens, and oral morphine to alleviate pain should be made available, accessible and affordable to patients wherever they are."

"LIFE ASKED DEATH" also hopes to inspire healthcare professionals from the Asia Pacific region and beyond to join the Lien Collaborative to improve care for patients by sharing their expertise and knowledge through training others.

Vision of "Training of trainers" to expand palliative care outreach in Asia

The Lien Collaborative draws on philanthropic and tertiary institutions, palliative care providers and individuals to collaborate on a 'Training of Trainers' in palliative care programme targeted at resource-limited countries in Asia. Started in Bangladesh and Myanmar in 2013 and Sri Lanka in 2014, it recently initiated a project in India.

The initiative has involved over 40 international experts, comprising of doctors, nurses and social workers who volunteer their time to train some 140 health professionals so far. These in turn are expected to start palliative care services in the key government-run hospitals they work in, and share their knowledge and skills with colleagues in other parts of the countries. The international

experts also work with local stakeholders and government policy makers to make essential medications s like oral morphine available to the patients.

Collective action needed to remove the barriers to pain relief

The Lien Collaborative believes that by working collectively with the local community, the government, healthcare professionals, patients and their caregivers, unnecessary suffering can be avoided by breaking down the barriers to pain relief.

Such barriers include:

- + Unfounded fears about morphine in patients and family members
- + Fear and ignorance of doctors in prescribing morphine
- + Over-restrictive rules governing the prescribing and dispensing of morphine
- + Over-regulation and unfounded fears resulting in most hospitals and pharmacies not stocking morphine.

According to the Global Atlas of Palliative Care, published jointly by the World Health Organisation (WHO) and the Worldwide Hospice Palliative Care Alliance (WHPCA), Bangladesh, Myanmar and Sri Lanka are countries with inadequate access and availability of hospice and palliative care.

Availability of morphine is severely limited, despite the WHO's recommendation that oral morphine is the gold standard, essential medication for pain relief that should be available to suffering patients. (Chart: Morphine Consumption)

Film premiere events in Bangladesh, Myanmar & Sri Lanka

Debuting online on World Hospice and Palliative Day, the film will also be premiered at special events in Bangladesh, Myanmar and Sri Lanka involving invited guests from the country's healthcare community, government representatives and palliative care advocates. Complementing the film screening in each country is a photo exhibition underscoring the urgency for countries to integrate palliative care into their existing healthcare systems and remove barriers to pain relief medications. The exhibition can be viewed online at www.lifeaskeddeath.com

Touching lives, Relieving Pain, Empowering the patient and family

In 'LIFE ASKED DEATH', viewers are taken on a journey to Bangladesh, Myanmar and Sri Lanka to discover how palliative care relieves the pain affecting millions of sufferers worldwide.

In **Bangladesh**, they get a glimpse of how 60-year old **Mrs Sophia Khatun** had her pain brought under control with oral morphine, and how good assessment and communication

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helped avoid the pursuit of futile treatment, empowering Mrs Khatun and her family to make an informed decision on how she could spend quality time with her family in the remaining time she has left.

Over in **Myanmar**, the physical pain and financial stress commonly experienced by patients and families are seen in **Mr Sein Hla Aung's** story. He suffers from mouth cancer and has no access to pain relief medicines where he lives. He has to travel long distances every three weeks to seek treatment in the Yangon hospital. His wife risks losing her job as she has to take time off to care for him. In addition to better management of his pain and symptoms, the Lien Collaborative trainees include social workers who can help his family obtain other forms of support.

In **Sri Lanka**, good communication by the palliative care team alleviates mental stress and empowers **38-year old lung cancer patient**, **Mrs Perera (not her real name)**, who has a young son, to plan for the future. With the facts of her condition explained to her, she is able to understand the seriousness of her illness and this knowledge gives her new strength, removing the mental anguish of the unknown.

Apart from pain relief medications, better knowledge of their condition and support from healthcare professionals trained in palliative care help patients at the end of life resolve their mental and emotional distress, find closure in relationships, plan for the future and avert financial disasters that take place when families get into debt in the pursuit of false cures and futile treatment.

Curtain of hope

The Lien Collaborative has drawn open a curtain of hope on what palliative care can do in these countries. With training and access to pain relief medications, needless suffering is prevented. The film "LIFE ASKED DEATH" concludes: "For millions around the world, death is indeed a painful truth, but there is an alternative which delivers quality of life until our dying breath. This is not a beautiful lie. It is already here for the asking."

Chart – Morphine Consumption, A Comparison

Annex A - Progress in Palliative Care: Bangladesh

Annex B - Progress in Palliative Care: Myanmar

Annex C - Progress in Palliative Care: Sri Lanka

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About the Lien Collaborative

The Lien Collaborative for Palliative Care project is co-developed by the Asia Pacific Hospice Palliative Care Network (APHN) and the Lien Foundation.

This initiative seeks to match the supply of expert resource and knowledge to the demand from developing countries for such skills and know-how so as to build Palliative Care capabilities in a systematic, impactful and sustainable way. It draws on philanthropy, tertiary educational institutions, palliative care service providers and individuals to collaborate on a project designed to strengthen Palliative Care capacity and leadership.

The project aims to help build Palliative Care capacity in the Asia Pacific region and to integrate palliative care services into the mainstream government health system. Its focus is on countries with few or no services.

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BANGLADESH



Swallowing is not easy – patient supported by her sister after taking a morphine tablet to manage her pain

MYANMAR



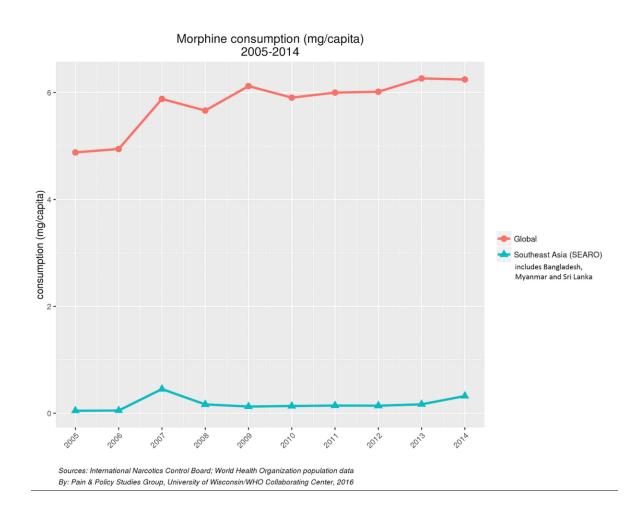
It hurts – patient and caregiver in Yangon General Hospital, Myanmar

SRI LANKA



Faculty and participants visiting the wards as part of the teaching program conducted at the National Cancer Institute Maharagama, Sri Lanka

CHART - MORPHINE CONSUMPTION, A COMPARISON



Annex A: Palliative Care in BANGLADESH

Global standing			
Ranking in the world – Quality of Death Index ⁴	79 th out of 80 countries Did best in Affordability of Care category		
Global Atlas of Palliative Care at the End of Life ⁵	Isolated service provision: Access & availability of hospice and palliative care needs to be improved		
	Palliative care activities need to be less donor dependent in order to be sustainable		
Morphine usage <based (2005-2014)<sup="" 10="" data="" on="" year="">6></based>	Generally very low, annual average consumption of less than 5 mg/capita, well below world average		
	Availability of morphine is severely limited ²		
Key Challenges			
Getting funds for palliative care	Lack of professional training & trained specialists		
	Largely charitably funded community services		
	Mainly unofficial palliative care services at key government run hospitals & cancer centres		
Weak health infrastructure	Finding psycho-social support, bereavement care, volunteer support		
	Limited access to painkillers		
Recent Milestones in Palliative Care De	Recent Milestones in Palliative Care Development		
Policy	Government has incorporated palliative care into its National Cancer Strategy & Plan of Action.		
	National Institute of Population Research and Training commissioned a nationwide assessment of palliative care, conducted and reported on by the Centre for Palliative Care, Bangabandhu Sheikh Mujib Medical University in 2014		
	Government approved the production of immediate release morphine syrup in 2014		
	Affordable oral preparations of morphine are now produced and distributed in Bangladesh		

⁴ The 2015 Quality of Death Index, Economist Intelligence Unit

⁵ Global Atlas of Palliative Care at the End of Life published jointly by the WHO and the Worldwide Hospice Palliative Care Alliance (WHPCA), January 2014

⁶ International Narcotics Control Board, World Health Organisation by Pain & Policy Group, University of Wisconsin, WHO Collaborating Centre, 2016

Services	New outpatient service started at Dhaka Medical College and Hospital in February 2016
	New outpatient service started at National Institute of Cancer Research and Hospital in July 2016
Education	Palliative Medicine is recognised as a specialty with the first Professor appointed in 2015
	First intake of three doctors into specialist programme in March 2016
About the Lien Collaborative in BANGLA	ADESH - started in 2013
Number of Lien Collaborative faculty members	13 doctors and nurses from Australia, Canada, India and Singapore
Number of Participants	35 from 9 institutions
	- 23 doctors, 10 nurses, 2 pharmacists
	Centralised training at BSMMU, DMCH & NICRH
Training of Trainers in Palliative Care program	4 in-country training sessions – total 20 training days
Overseas Clinical Attachment program	Two doctor participants attended a one-month attachment program at the All India Institute of Medical Sciences

Annex B: Palliative Care in MYANMAR

Global standing	
Ranking in the world – Quality of Death Index ⁷	76 th out of 80 countries Did best in Affordability of Care category
Global Atlas of Palliative Care at the End of Life ⁸	Isolated service provision: Very limited hospice and palliative care services
	Palliative care activities need to be less donor dependent in order to be sustainable
Morphine usage <based (2005-2014)<sup="" 10="" data="" on="" year="">9></based>	Very low, annual average consumption of 5 mg/capita, well below world average
	Oral morphine is being made available by the government
Key Challenges	
Getting funds for palliative care	Lack of professional training & trained specialists
	Largely charitably funded community services
No government-led strategy	Government subsidies absent
	Limited access to painkillers
Recent Milestones in Palliative Care Development	
Policy	Two trainees of the Lien Collaborative program are participating in a project on palliative care establishment as part of the National Cancer Control Program
Services	New outpatient and inpatient services started at Yangon General Hospital in 2015
	New inpatient services started at Mandalay General Hospital in 2016
Education	Plans to introduce palliative medicine in the medical undergraduate and post-graduate curriculum

 $^{^{\}rm 7}$ The 2015 Quality of Death Index, Economist Intelligence Unit

⁸ Global Atlas of Palliative Care at the End of Life published jointly by the WHO and the Worldwide Hospice Palliative Care

Alliance (WHPCA), January 2014

⁹ International Narcotics Control Board, World Health Organization by Pain & Policy Group, University of Wisconsin, WHO Collaborating Centre, 2016

Number of Lien Collaborative faculty members	8 doctors, nurses and medical social workers from Australia, Malaysia and Singapore
Number of Participants	28 from 12 institutions - 17 doctors, 7 nurses and 2 social workers Centralised training at Yangon General Hospital
Training of Trainers in Palliative Care program	6 in-country training sessions – total of 30 training days
Overseas Clinical Attachment program	Five doctor participants completed overseas training at the National Cancer Centre Singapore

Annex: Palliative Care in SRI LANKA

Global standing	
Ranking in the world – Quality of Death Index ¹⁰	65th out of 80 countries
	Did best in Community Engagement category
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Global Atlas of Palliative Care at the End of Life ¹¹	Isolated service provision: Access & availability of hospice and palliative care needs to be improved
	Palliative care activities need to be less donor dependent in order to be sustainable
Morphine usage	Generally low, annual average consumption of less than
 	5mg/capita, well below world average
	Availability of morphine is severely limited ²
Key Challenges	
Palliative care in Sri Lanka is just beginning	Largely charitably funded community services
	A few unofficial palliative care services at government hospitals and cancer centres
	No funding for palliative care in government health budget
Education and training needs to be boosted, largely run by charitable	Palliative care not included in undergraduate medical or nursing training
organisations	Severe lack of social workers & psychologists in health care

 $^{^{10}}$ The 2015 Quality of Death Index, Economist Intelligence Unit 11 Global Atlas of Palliative Care at the End of Life published jointly by the WHO and the Worldwide Hospice Palliative Care Alliance (WHPCA), January 2014

12 International Narcotics Control Board, World Health Organisation by Pain & Policy Group, University of Wisconsin, WHO

Collaborating Centre, 2016

Recent Milestones in Palliative Care	Development	
Policy	In 2015, outpatient prescriptions for oral morphine increased from 3 days to 30 days at government approved cancer clinics & palliative care & pain clinics	
	In July 2016, National Steering Committee on Palliative Care, chaired by the Director-General of Health Services, was formed & held its inaugural meeting.	
Services	New outpatient service started at the National Cancer Institute Maharagama in August 2015	
Education	Post-graduate Medical Institute has approved a postgraduate diploma in Palliative Medicine for doctors, to be rolled out in 2017	
	Nursing college discussing curriculum for basic nursing training	
About the Lien Collaborative in Sri Lanka - started in 2014		
Number of Lien Collaborative faculty members	16 doctors, nurses and medical social workers from Australia, India, Malaysia and Singapore	
Number of Participants	50 Participants from 20 institutions	
	- 17 consultant oncologists, 16 consultant physicians, 4 medical officers, 11 nurses/nurse educators, 1 psychologist, 1 social worker	
	Centralised training at National Cancer Institute Maharagama	
Training of Trainers in Palliative Care	5 in-country training sessions – total 25 training days	
program	A two-day training workshop was conducted for nursing leaders from government cancer units in 2016	
Overseas Clinical Attachment program	Upcoming	